

**FAMILY NEEDS AND INVOLVEMENT IN  
THE INTENSIVE CARE UNIT IN SAUDI  
ARABIA: MIXED METHODS STUDY**

Submitted by:

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## **Dedication**

When I was in Saudi Arabia for the study data collection, my father's health deteriorated and he was admitted to hospital. He was diagnosed with congestive heart failure, having had a history of hypertension and diabetes mellitus for many years. My father was admitted in the Intermediate Care Unit of the medical ward and was receiving medical treatment to lessen the pulmonary oedema and other treatments to control blood pressure and blood glucose levels. I accompanied him during his stay in the hospital to participate in the care to feed him, look after him and offer any help I could.

One day, my elder brother asked me to if he could stay to assist in the care. In the early morning of the next day, my elder brother rang me to say that our father had gone into cardiac arrest, CPR was performed, he was connected to a mechanical ventilator and had been transferred to the ICU. The hospital, to which my father was admitted, was two hundred bed capacity with only five beds in the ICU. The unit had a very restricted visiting time and family members were allowed to visit one hour a day, with only up to two family members visiting at once, for a maximum of five minutes. Additionally, the unit had no informational booklets or any kind of protocols for interacting between family members and the ICU staff.

As I was the only medical professional among the family, my siblings were asking me about every tube connected to my father, the use of the medications and the purpose of the procedures being undertaken. The reason for this was that because healthcare providers don't communicate well with family members. When any member asked the nurses about anything regarding my father, they replied "ask doctor" as they were not authorised to release any information. Due to visiting practices, family could not meet the treating doctor regularly to receive information, support is not provided and involvement in the care is not allowed.

I realised that the needs, rights and participation in care for which I was calling in the care of the families in my study, I was calling for myself and my family.

I dedicate this work to the soul and memory of my father, who raised me to love and value education, and to him and my mother who sacrificed a great deal to raise me and my siblings to be the best. This work is also dedicated to every family with a critically ill member.

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## **Abstract**

### **Aim**

The aim of this study was to identify the perceived needs of Saudi families with a critically ill family member admitted to the Intensive Care Unit as perceived by family members and healthcare providers. The study explains how family needs were being met and who were the most appropriate healthcare providers to meet their needs. The study also compares the families' perceptions of their needs being met to those of healthcare providers'. It also describes the healthcare providers' attitudes towards family involvement during routine care and family presence during resuscitation, or other invasive procedures.

### **Background**

Admission of a family member to an intensive care unit often occurs without any warning, leaving the family in a very stressful situation. Families of intensive care patients have specific needs that should be acknowledged and met during this time. If unmet, the stress for the patients' families may be increased and also produce stress for the healthcare providers. Further, the literature is virtually silent on the issue of recognizing the ICU family needs of Saudi or Muslim families in relation to religious beliefs and cultural values in intensive care settings. Knowledge about health professional's attitudes towards family involvement during routine care and family presence during resuscitation or other invasive procedures can inform intensive care practice for holistic family centred care.

## **Design**

A mixed method two phase sequential explanatory design was utilised for the study. In Phase One, a convenience sample of 644 participants (167 family members and 477 healthcare providers) was recruited and a closed-ended questionnaire was administered. Participants were invited from ICUs located in eight hospitals in six major cities in Saudi Arabia. Phase Two involved face-to-face semi-structured interviews with 12 close family members at the same participating hospitals.

## **Results**

Family members and ICU healthcare providers perceived assurance, information and cultural and spiritual needs as the most important needs, and proximity and support needs as least important. The findings indicated that family members considered their needs of assurance as being met but their needs for support as not being met. Moreover, they considered needs related to information, proximity and cultural and spiritual needs as not always met. Despite this, the healthcare providers identified all the families' needs as being successfully met. Family members recognized doctors as the most appropriate person to meet most of their needs, followed by nurses, then hospital administration. Healthcare providers perceived doctors as the most appropriate person to meet most of the family needs, followed by the hospital administration and then nurses. The healthcare providers had positive attitudes towards family involvement during routine care, but negative attitudes towards family presence during resuscitation or other invasive procedures.

A deeper understanding of Saudi family needs was obtained through the qualitative results. Family members described their experiences of having a critically ill relative

in the ICU. The analysis of the interview transcripts revealed six explicit themes. These themes were: 1) looking for information; 2) maintaining reassurance; 3) spiritual healing; 4) maintaining close proximity; 5) involvement in the care and 6) support not being facilitated.

## **Conclusion**

This study builds upon previous work and contributes important new nursing knowledge about the needs of Saudi families with a relative in the ICU. In Saudi Arabia, it is recommended that ICU nurses be prepared to recognize family needs, and support and facilitate family involvement and caregiving. An emphasis should be placed on the recognition of family needs in relation to the influence of cultural values and religion. In the 21<sup>st</sup> century, models of nursing care should not just focus on the patients' needs but should also be focused on of the needs of the families.

## Table of Contents

<b>Dedication</b> .....	<b>i</b>
<b>Acknowledgements</b> .....	<b>ii</b>
<b>Abstract</b> .....	<b>iii</b>
<b>Table of Contents</b> .....	<b>vi</b>
<b>List of Tables</b> .....	<b>xvii</b>
<b>List of Figures</b> .....	<b>xx</b>
<b>General Declaration</b> .....	<b>xxi</b>
<b>List of other Publications and Presentations Completed During</b>	
<b>Candidature</b> .....	<b>xxii</b>
<b>List of Acronyms</b> .....	<b>xxiii</b>
<b>Glossary of Terms</b> .....	<b>xxv</b>
<b>Chapter One: Introduction</b> .....	<b>1</b>
1.1 Introduction .....	1
1.2 Understanding the context of Saudi Arabia.....	2
1.2.1 Country background .....	2
1.2.2 Geography.....	3
1.2.3 An overview of the Saudi government .....	4
1.2.4 Demographics .....	5
1.2.5 Healthcare services in Saudi Arabia .....	6
1.2.6 Nursing workforce in Saudi Arabia .....	8
1.2.7 Physician workforce in Saudi Arabia .....	10
1.3 Research aims, objectives and questions.....	10
1.3.1 Aims of the study.....	11
1.3.2 Objectives of the study .....	11

1.3.3 Research questions.....	11
1.4 Significance of the study .....	12
1.5 Scope of the study .....	13
1.6 Methodology and data collection .....	14
1.7 Theoretical framework .....	15
1.7.1 Maslow's Hierarchy of Needs.....	15
1.7.2 Family-Centered Care.....	18
1.7.3 Implications of the theories for the proposed study.....	19
1.8 overview of the thesis .....	19
1.9 Conclusion.....	20
<b>Chapter Two: Integrative Literature Review .....</b>	<b>22</b>
2.1 Introduction .....	22
2.2 Search strategy.....	23
2.3 Family needs.....	27
2.3.1 The Critical Care Family Needs Inventory (CCFNI) .....	29
2.3.2 CCFNI dimensions .....	30
2.3.2.1 The need for information.....	30
2.3.2.2 The need for assurance .....	31
2.3.2.3 The need for proximity.....	32
2.3.2.4 The need for comfort.....	33
2.3.2.5 The need for support .....	34
2.4 Selected research on family needs.....	35
2.4.1 Families' perspectives .....	35
2.4.1.1 CCFNI studies .....	36
2.4.1.2 Qualitative approaches .....	43

2.4.2 Healthcare providers' perspectives.....	47
2.4.3 Comparison of family members' and healthcare providers' perspectives	
50	
2.5 Meeting family needs .....	56
2.6 Family involvement in routine care.....	59
2.6.1 Benefits of family involvement and factors affecting involvement .....	60
2.6.2 Family involvement in routine care as perceived by family members.	61
2.6.3 Family involvement in routine care as perceived by healthcare	
providers .....	65
2.6.4 Comparison of family members and healthcare providers' perspectives	
on family involvement in routine care.....	67
2.7 Family presence during resuscitation and other invasive procedures .....	69
2.7.1 Benefits of family presence .....	71
2.7.2 Family attitudes to family presence.....	71
2.7.3 Healthcare providers' attitudes to family presence. ....	76
2.8 Conclusion.....	91
<b>Chapter Three: Research Design.....</b>	<b>94</b>
3.1 Introduction .....	94
3.2 Development of the mixed method approach.....	95
3.3 The value of mixed methods research .....	98
3.4 The study design.....	99
3.4.1 The sequential voyage of the research.....	100
3.5 The study setting.....	102
3.5.1 King Saud Medical Complex-Riyadh (KSMC).....	103
3.5.2 King Fahad Medical City-Riyadh (KFMC).....	104

3.5.3 King-Fahad Specialist Hospital-Dammam (KFSH-D).....	105
3.5.4 Dammam Medical Complex (DMC).....	105
3.5.5 Qatif Central Hospital (QCH).....	106
3.5.6 King Fahad Hospital-Hofuf (KFHH).....	106
3.5.7 King Fahad Central Hospital-Jazan (KFCH-J).....	107
4.5.8 King Fahad Hospital-Medina (KFH-M).....	108
3.6 Ethical considerations.....	108
3.6.1 Anonymity, confidentiality and protection of human rights .....	109
3.6.2 Beneficence and level of risk of the research .....	110
3.6.3 The right of self-determination and full disclosure toward informed consent.....	112
3.7 Participant inclusion and exclusion criteria.....	114
3.8 The sample.....	115
3.8.1 The sample size.....	116
3.9 Recruitment .....	118
3.9.1 Phase 1: Recruitment of the family members.....	119
3.9.2 Phase 1: Recruitment of healthcare providers .....	121
3.9.3 Phase 2: Recruitment of family members.....	122
3.10 Strengths and weaknesses of data collection instruments in Phase 1 and 2.....	122
3.11 Phase 1: Data collection instruments.....	124
3.11.1 Family members' questionnaire .....	124
3.11.1.1 Part One: Socio-demographic information.....	124
3.11.1.2 Part Two: the modified Saudi version of CCFNI.....	125
3.11.2 Healthcare providers' questionnaire .....	127

3.11.2.1 Part One: Socio-demographic information.....	128
3.11.2.2 Part Two: the modified Saudi version of CCFNI.....	129
3.11.2.3 Part Three: Attitudes of healthcare providers regarding family involvement during routine care and family presence during resuscitation and other invasive procedures (FIDRRIP). .....	129
3.12 Back-translation procedure of data collection materials .....	131
3.13 Data quality of quantitative results.....	132
3.13.1 Validity .....	133
3.13.2 Reliability .....	135
3.13.3 Data screening and cleaning .....	136
3.14 Questionnaire data analysis .....	137
3.14.1 Descriptive statistics .....	137
3.14.2 Inferential statistics.....	138
3.14.3 Treatment of missing data .....	139
3.14.4 Thematic analysis of open-ended question.....	140
3.15 Phase 2: qualitative data collection with family members .....	141
3.16 Interview analysis: Phase Two .....	142
3.16.1 Establishing rigour and trustworthiness for qualitative data .....	144
3.17 Conclusion.....	146
<b>Chapter Four: Quantitative Results .....</b>	<b>148</b>
4.1 Introduction .....	148
4.2 Response rate.....	148
4.2.1 Family members' response rate .....	148
4.2.2 Healthcare providers' response rate.....	149
4.3 Sample characteristics .....	151

4.3.1 Family members' socio-demographics.....	151
4.3.2 Healthcare providers' socio-demographics .....	154
4.4 Family needs.....	156
4.4.1 Family members' perception of family needs .....	156
4.4.2 Healthcare providers' perceptions of family needs .....	159
4.5 Family needs as being met .....	162
4.5.1 Family members' perception of meeting family needs .....	162
4.5.2 Healthcare providers' perception of meeting family needs.....	164
4.6 Most appropriate person to meet each need .....	167
4.6.1 The most appropriate person as perceived by family members .....	167
4.6.2 The most appropriate person as perceived by healthcare providers ...	169
4.7 Attitudes of healthcare providers regarding family involvement during routine and resuscitation and other invasive procedures.....	172
4.8 Ancillary results of family member participants.....	174
4.8.1 Hospital.....	174
4.8.2 Age.....	175
4.8.3 Sex .....	175
4.8.4 Nationality .....	176
4.8.5 Level of education .....	177
4.8.6 Previous ICU experience .....	177
4.8.7 Relationship to critically ill patient.....	177
4.8.8 Length of patient stay in the ICU .....	178
4.8.9 Patients' age.....	178
4.8.10 Patients' sex .....	179
4.8.11 Visit preference.....	179

4.8.12 Relationship between family needs categories .....	180
4.9 Ancillary results of healthcare providers.....	182
4.9.1 Hospital.....	182
4.9.2 Age.....	183
4.9.3 Sex .....	183
4.9.4 Nationality .....	184
4.9.5 Level of education .....	186
4.9.6 Healthcare profession .....	187
4.9.7 Years of employment.....	189
4.9.8 Experience in Saudi Arabia .....	190
4.9.9 Relationship between families' needs categories .....	190
4.10 Conclusion.....	192
<b>Chapter Five: Qualitative results.....</b>	<b>194</b>
5.1 Introduction .....	194
5.2 Results of open-ended question Phase One.....	195
5.2.1 Themes in family members' further comments and suggestions .....	195
5.2.1.1 The need to know straightforward and honest information.....	196
5.2.1.2 The need to remain close to the patient .....	197
5.2.1.3 The need for psychological and spiritual support.....	198
5.2.1.4 The need for a caring and supportive environment .....	198
5.2.2 Themes in healthcare providers' further comments and suggestions.	199
5.2.2.1 The need to know versus communication difficulties .....	201
5.2.2.2 Involvement of families during routine nursing care .....	202
5.2.2.3 Fears of emotional disturbance from family presence.....	203
5.2.2.4 Decision-making regarding family involvement.....	204

5.3 Results of qualitative Phase 2 (interviews) .....	206
5.3.1 Overview of study participants .....	206
5.3.2 Interview findings .....	207
5.3.2.1 Looking for information .....	207
5.3.2.2 Maintaining reassurance .....	212
5.3.2.3 Spiritual healing.....	214
5.3.2.4 Maintaining close proximity.....	217
5.3.2.5 Involvement in care .....	218
5.3.2.6 Support not facilitated .....	221
5.4 Conclusion .....	222
<b>Chapter Six: Integrative Discussion .....</b>	<b>224</b>
6.1 Introduction .....	224
6.2 Theoretical framework forming findings .....	225
6.3 The sample.....	225
6.4 Needs of Saudi families.....	227
6.4.1 Assurance and information needs.....	228
6.4.2 Cultural and spiritual needs .....	231
6.4.3 Proximity and support needs .....	232
6.4.4 Responsibilities for meeting family needs.....	234
6.4.5 Factors influencing family needs.....	237
6.4.5.1 Study setting .....	237
6.4.5.2 Age and sex .....	239
6.4.5.3 Nationality and level of education.....	241
6.4.5.4 Length of stay and patient's sex .....	243
6.4.5.5 Profession and experience .....	244

6.4.6 Family needs interrelations.....	246
6.5 Healthcare providers’ attitudes towards family involvement during routine care .....	247
6.6 Healthcare providers’ attitude towards family presence during resuscitation and other invasive procedures. ....	249
6.7 Interpretative qualitative synthesis .....	253
6.7.1 Providing information.....	254
6.7.2 Spiritual comfort .....	255
6.7.3 Support and reassurance .....	256
6.7.4 Proximity needs .....	257
6.7.5 Involvement in care .....	257
6.8 Family-Focused Care framework .....	258
6.9 Conclusion.....	260
<b>Chapter Seven: Conclusion .....</b>	<b>262</b>
7.1 Introduction .....	262
7.2 Key findings of the research.....	263
7.2.1 Providing assurance, information, proximity, support and cultural and spiritual needs to families .....	263
7.2.2 Meeting family needs and responsibility towards them .....	265
7.2.3 Family involvement during routine care and family presence during resuscitation and other invasive procedures .....	266
7.3 Limitations of the study.....	266
7.4 Implications of the study findings .....	268
7.4.1 Clinical practice .....	268
7.4.2 Education .....	269

7.4.3 Future research.....	270
7.5 Conclusion.....	271
<b>References .....</b>	<b>273</b>
<b>Appendices .....</b>	<b>294</b>
<b>Appendix A: Monash University Human Research Ethics Committee approval.....</b>	<b>294</b>
<b>Appendix B: General Administration for Medical Research Approval....</b>	<b>295</b>
i.    KSMC and KFMC letter .....	295
ii.   KFSD-D, DMC, QCH and KFH-H letter.....	296
iii.  KFCH-J letter .....	297
iv.   KFH-M letter.....	298
<b>Appendix C: Explanatory statements.....</b>	<b>299</b>
i.    Explanatory statement for Family Members in Phase 1 .....	299
ii.   Explanatory statement for Family Members in Phase 1 in Arabic Language .....	301
iii.  Explanatory statement for Healthcare Providers in Phase 1 .....	303
iv.   Explanatory statement Healthcare Providers in Phase 1 in Arabic Language .....	305
v.    Explanatory statement for family members in Phase 2 (Interview)...	307
vi.   Explanatory statement for Family Members in Phase 2 (Interview) in Arabic Language .....	309
<b>Appendix D: Study Invitation Poster .....</b>	<b>311</b>
i.    Research Participants Invitation Letter “English Version” .....	311
ii.   Research Participants Invitation Letter “Arabic Version” .....	312
<b>Appendix E: Informed consent .....</b>	<b>313</b>

i.	Consent Form for Family Members “English version” .....	313
ii.	Consent Form for Family Members “Arabic version” .....	314
	<b>Appendix F: Family Members Questionnaire .....</b>	<b>315</b>
	<b>Appendix G: CCFNI Permission Letter .....</b>	<b>320</b>
	<b>Appendix H: Health Care Providers Questionnaire .....</b>	<b>321</b>
	<b>Appendix I: Letter of Translation Certification.....</b>	<b>327</b>
	<b>Appendix J: Interview Schedule .....</b>	<b>328</b>
	<b>Appendix K: Article I: Providing culturally congruent care for Saudi patients and their families.....</b>	<b>330</b>
	<b>Appendix L: Article II: Family needs and involvement in the intensive care unit: a literature review .....</b>	<b>333</b>
	<b>Appendix M: Article III: Needs and Experiences of Intensive Care Patients’ Families: A Saudi Qualitative Study .....</b>	<b>348</b>
	<b>Appendix N: Article IV: Families' needs of critical care patients in Saudi Arabia: a quantitative Study .....</b>	<b>358</b>
	<b>Appendix O: Article V: Attitudes of healthcare providers towards family involvement and presence in adult critical care units in Saudi Arabia: a quantitative study .....</b>	<b>369</b>

## List of Tables

Table	Title	Page No
<b>Table 1.1</b>	Total Saudi and expatriate population	5
<b>Table 1.2</b>	Age structure of the Saudi population in 2010	6
<b>Table 1.3</b>	Number of hospitals and beds provided by healthcare sectors in KSA	7
<b>Table 1.4</b>	Nursing workforce in Saudi Arabia	8
<b>Table 1.5</b>	Physician workforce in Saudi Arabia	10
<b>Table 2.1</b>	Polit and Beck guide to critique research articles	24
<b>Table 2.2</b>	Comparison of the five most important needs as identified by families	37
<b>Table 2.3</b>	Comparison of family members' rank order of the CCFNI of four studies	42
<b>Table 3.1</b>	Participants' inclusion and exclusion criteria for Phase 1 and 2	115
<b>Table 3.2</b>	Cronbach's alpha for internal consistency for each subscale and total for Saudi modified version of the CCFNI	136
<b>Table 4.1</b>	Family members' distributed, returned and excluded questionnaires	148
<b>Table 4.2</b>	Healthcare providers' questionnaire response rate	150
<b>Table 4.3</b>	Family members' socio-demographic details	151
<b>Table 4.4</b>	Healthcare providers' socio-demographic details	154
<b>Table 4.5</b>	The five most important needs as perceived by family members	156
<b>Table 4.6</b>	The five least important needs as perceived by family members	157
<b>Table 4.7</b>	Family members' rank order of CCFNI	157
<b>Table 4.8</b>	Saudi modified version of CCFNI items, means and standard deviations for family members and healthcare providers	158
<b>Table 4.9</b>	The five most important needs as perceived by healthcare providers	160

<b>Table</b>	<b>Title</b>	<b>Page No</b>
<b>Table 4.10</b>	The five least important needs as perceived by healthcare providers	160
<b>Table 4.11</b>	Healthcare providers' rank order of CCFNI	161
<b>Table 4.12</b>	CCFNI subscales, means and standard deviations for FM and HCP	162
<b>Table 4.13</b>	Family needs perceived by family members as being met or unmet	163
<b>Table 4.14</b>	Family needs perceived by healthcare providers as being met or unmet	165
<b>Table 4.15</b>	Family members and healthcare providers' comparison of family needs whether met or unmet	167
<b>Table 4.16</b>	Most appropriate person to meet each need by FM (%)	168
<b>Table 4.17</b>	Most appropriate person to meet each need by HCP (%)	170
<b>Table 4.18</b>	Most appropriate person to meet family needs by FM and HCP	172
<b>Table 4.19</b>	Attitudes of healthcare providers to family involvement during routine care and resuscitation and other invasive procedures	173
<b>Table 4.20</b>	Relationship between family needs categories as perceived by family members	181
<b>Table 4.21</b>	Relationship between HCPs' sex and family needs being met or unmet	183
<b>Table 4.22</b>	Relationship between nationality and family needs being met or unmet	185
<b>Table 4.23</b>	Relationship between healthcare profession and ranking of importance of family needs	187
<b>Table 4.24</b>	Respiratory therapists mean of family needs being met or unmet	188

<b>Table</b>	<b>Title</b>	<b>Page No</b>
<b>Table 4.25</b>	Relationship between family needs categories as perceived by healthcare providers	191
<b>Table 5.1</b>	Family members' response to the open-ended item	195
<b>Table 5.2</b>	Identified themes in families' further comments and suggestions	196
<b>Table 5.3</b>	Healthcare providers' response to the open-ended item	200
<b>Table 5.4</b>	Identified themes of healthcare providers' further comments and suggestions	201
<b>Table 5.5</b>	Profile of qualitative phase interviewees	205

## List of Figures

Figure	Title	Page No
<b>Figure 1.1</b>	Map of Saudi Arabia	4
<b>Figure 1.2</b>	Maslow’s Hierarchy of Needs five-level model (Maslow, 1970)	16
<b>Figure 2.1</b>	Literature review flow diagram	26
<b>Figure 3.1</b>	Sequential, Explanatory Mixed Methods Design based on Creswell and Plano-Clark (2007)	102
<b>Figure 4.1</b>	Comparison of response rate of family members and healthcare providers	150
<b>Figure 4.2</b>	Previous ICU experience	153
<b>Figure 4.3</b>	Healthcare providers’ education level	155
<b>Figure 4.4</b>	Rank order of family needs by family members and healthcare providers	161
<b>Figure 4.5</b>	Family needs being met or unmet according to family members	164
<b>Figure 4.6</b>	Family needs being met or unmet according to healthcare providers	166
<b>Figure 4.7</b>	Most appropriate person to meet family needs by family members	169
<b>Figure 4.8</b>	Most appropriate person to meet family needs by healthcare providers	171
<b>Figure 6.1</b>	Family-focused care model framework in adult intensive care	259

## General Declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis and appendices.

This thesis includes five papers published in peer-reviewed journals (refer to Appendices K – O).

Publication title	Journal
Providing culturally congruent care for Saudi patients and their families.	Contemporary Nurse Journal
Family needs and Involvement in the intensive care unit: a literature review.	Journal of Clinical Nursing
Family members needs of Muslim critical care patients in Saudi Arabia setting: a quantitative study.	Journal of Nursing in Critical Care
Attitudes of healthcare providers towards family involvement and presence in adult critical care units in Saudi Arabia.	Journal of Clinical Nursing
The needs and experiences of families of intensive care patients in Saudi Arabia: a qualitative study.	Journal of Nursing in Critical Care

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Abbas Saleh Al Mutair



26/11/2013

## **List of other Publications and Presentations Completed During Candidature**

1. The do's and don'ts of clinician's writing for publication, an abstract was presented for an oral presentation in the 1st International Congress on Medical Writing February 19-21, 2013 Dubai-UAE.
2. Saudi Families in Intensive Care Units: Needs and Involvement, an abstract was presented for an oral presentation in 5th EfCCNa & 5th UINARS Congress May 23-25, 2013 Belgrade-Serbia.
3. Needs and involvement of families of intensive care patients in Saudi Arabia: mixed method study, an abstract was presented for an oral presentation in Health Sciences College in Sharjah University May 28, 2013 UAE.
4. The needs and experiences of families of intensive care patients in Saudi Arabia: a mixed methods study, an abstract was presented for oral poster presentation in the 38th Australian and New Zealand Annual Scientific Meeting on Intensive Care and the 19th Annual Paediatric and Neonatal Intensive Care Conference October 17-19, 2013 Australia.

## List of Acronyms

<b>AAST</b>	American Association for the Surgery of Trauma
<b>A&amp;E</b>	Accident and Emergency
<b>ANOVA</b>	Analysis of Variance
<b>CCFNI</b>	Critical Care Family Needs Inventory
<b>CCU</b>	Coronary Care Unit
<b>COPD</b>	Chronic Obstetric Pulmonary Disease
<b>CPR</b>	Cardio Pulmonary Resuscitation
<b>CVA</b>	Cerebral Vascular Accident
<b>DMC</b>	Dammam Medical Complex
<b>DVT</b>	Deep Venous Thrombosis
<b>ED</b>	Emergency Department
<b>ENA</b>	Emergency Nurses Association
<b>FM</b>	Family Members
<b>FIDRRIP</b>	Family Involvement during Routine Care and Family presence during Resuscitation and other Invasive Procedures
<b>GAMR</b>	General Administration for Medical Research
<b>HCP</b>	Health Care Providers
<b>ICU</b>	Intensive Care Unit
<b>KFCH-J</b>	King Fahad Central Hospital-Jazan
<b>KFHH</b>	King Fahad Hospital-Hofuf
<b>KFH-M</b>	King Fahad Hospital-Medina
<b>KFMC</b>	King Fahad Medical City-Riyadh
<b>KFSH-D</b>	King-Fahad Specialist Hospital-Dammam
<b>KSA</b>	Kingdom of Saudi Arabia

<b>KSMC</b>	King Saud Medical Complex-Riyadh
<b>MOH</b>	Ministry of Health
<b>MUHREC</b>	Monash University Human Research Ethics Committee
<b>NMI</b>	Needs Met Inventory
<b>PHC</b>	Primary Healthcare Centre
<b>QCH</b>	Qatif Central Hospital
<b>RN</b>	Registered Nurse
<b>SA</b>	Saudi Arabia
<b>SD</b>	Standard Deviation
<b>SPSS</b>	Statistical Package for Social Science

## Glossary of Terms

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<b>Close Model Visit ICU</b>	In this study it is referred to ICU which has restricted visiting practices where visit is opened once a day only.
<b>Expatriates</b>	Foreign healthcare workers in in the healthcare facilities in Saudi Arabia.
<b>Family Needs</b>	Requirements of family members of ICU patients which if fulfilled, relieve or diminish family distress and if unmet, may produce distress in family members.
<b>Proximity</b>	Is the state of the family members being close or near to their critically ill relative admitted in the ICU.
<b>Qur'an</b>	The Islamic holy book, which Muslims believe to be a revelation from God to Prophet Muhammad by the archangel Gabriel and written down in Arabic.
<b>Qur'an Reader</b>	A person who was trained to read and memorise the verses of the Qur'an.
<b>Saudisation</b>	Known as Saudi nationalization program which encourages the employment of Saudi nationals in the public and private sectors.
<b>Shahadatain</b>	Testimony of faith which consists of saying: there is no God but Allah and Mohammad is the Messenger of Allah.

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## **Chapter One: Introduction**

### **1.1 Introduction**

Admission to an intensive care unit (ICU) is a stressful situation for both patients and the family members. The impact of a family member's admission to ICU may be higher for Muslims such as Saudi family which is characterized by strong ties, with family members sharing cultural, social and religious obligations towards each other. The majority of general hospitals ICUs in Saudi Arabia have restricted visitation policies. Families cannot sit for long periods by the bedside to support their loved one and they are not permitted for the visitor rules to participate in the caregiving process. Families seek for their needs to be met and if they are unmet, this may produce stress which can cause anxious, disorganized or even hysterical behaviours that may then impact on the patient's health (Leske, 1992b).

The needs of families in Saudi Arabia can be met by supporting and involving families in the caring process of their ill family member. Family involvement may include participation during daily routine care or even presence during resuscitation and other invasive procedures. The shift to involve family members in the care of their ICU patients creates the need for many changes in policy and medical staff behaviour. Intensive care unit healthcare providers should have positive attitudes toward family involvement in care in Saudi Arabia. Attitudes assessment can provide an indication of staff acceptance or rejection of families' needs and involvement and

also helps to identify key potential barriers that will need to be addressed during this transformative process (Verhaeghe et al, 2005; Davidson et al, 2007).

Using a mixed methods approach this study explores for the first time the perceived needs of Saudi families and the attitudes of healthcare professionals to family involvement during routine care and family presence during resuscitation and other invasive procedures. In this chapter the research proposal is outlined, the context and background to the study are discussed, the research methodology is introduced and the study's conceptual framework is described.

## **1.2 Understanding the context of Saudi Arabia**

This study was conducted in six major cities in Saudi Arabia: Riyadh, Dammam, Madinah, Al-Hassa, Qatif and Jizan. This section therefore, addresses the context of the country including the country background, geography and the healthcare system.

### **1.2.1 Country background**

The Kingdom of Saudi Arabia (KSA) is the conventional long form of the country name and Saudi Arabia (SA) is the conventional short form. Saudi Arabia is the homeland of Islam, the second largest religion in the world, where Prophet Mohammed founded Islam and is the location of the two holy pilgrimage cities of Mecca and Medina. Saudi Arabia was also the homeland of the Arab peoples, where the first Arabs originated on the Arabian Peninsula. The Kingdom of Saudi Arabia was established in 1932, by King Abdul-Aziz Bin Abdurrahman Al-Saud, known in

the West as Ibn Saud. It took King Abdul-Aziz thirty years to recover the rest of most parts of the Arabian Peninsula and to fulfill his vision and build the new and unified country (Harper & Gritzner, 2007).

### **1.2.2 Geography**

Saudi Arabia, with a total area of 2.24 million square kilometers, occupies 80% of the Arabia Peninsula, which makes it the third largest among all Arabian countries and the largest in the Middle East. Saudi Arabia, with a unique location lies at the crossroads of three continents: Europe, Asia, and Africa (Harper & Gritzner, 2007). It is bordered on three sides by water and is bounded by eight countries. To the north lies Jordan, Iraq and Kuwait and it has also borders with Yemen and Oman in the South. The Red Sea and the Gulf of Aqaba are to the west and the Persian Gulf lies to the east. Saudi Arabia also has borders with Bahrain, Qatar and the United Arab Emirates on the East. The Saudi Arabian topography is mostly desert and the country contains the world's largest continuous sand desert, the Rub Al-Khali, or Empty Quarter.



**Figure 1.1: Map of Saudi Arabia (Google Maps)**

### **1.2.3 An overview of the Saudi government**

The Kingdom of Saudi Arabia has a traditional monarchy. The King and Prime Minister, Custodian of the Two Holy Mosques, King Abdullah Bin Abdul-Aziz, ascended the throne on 1 August 2005 following the death of his brother King Fahad. The King is advised by the Consultative Shura Council and the Government's legislation is promulgated through the Council Ministers, regional governments and municipal councils (Al Sharqi, 2006). The legal system in Saudi Arabia is based on sharia Islamic law. The Kingdom of Saudi Arabia is divided into thirteen administrative regions: Riyadh, Mecca, Medinah, Qasim, Eastern Region, Asir,

Tabouk, Hail, Northern Border Region, Jizan, Najran, Al-Baha and Al Jouf Region (Al Sharqi, 2006).

#### 1.2.4 Demographics

The demographic characteristics of the Saudi population are set out in Table 1.1 below. The total Saudi population in 2010 was 27,163,977 and, of the total, 18,707,576(69%) were Saudi citizens and 8,429,401(31%) were expatriates. The males represent 50.9% of the total Saudi citizens and the females represent 49.1%. Of the expatriates the percentage of males was 70.4% and the percentage of females was 29.6%.

**Table 1.1: Total Saudi and expatriate population**

<b>Gender</b>	<b>Saudi citizens (%)</b>	<b>Expatriates (%)</b>	<b>Total * (%)</b>
<b>Male</b>	9,527,173 (50.9%)	5,932,974 (70.4%)	15,460,147 (57%)
<b>Female</b>	9,180,403 (49.1%)	2,496,427 (29.6%)	11,676,830 (43%)
<b>Total **</b>	18,707,576	8,429,401	27,163,977 (100%)

(Ministry of Economic and Planning, 2010), (Total \*: total population according to gender variable, Total \*\*: total population according to citizen variable).

According to the MOH report (2011), the population annual growth rate in Saudi Arabia in 2010 was 3.19%. The median age for males and females was 21.5 years and the life expectancy for men was 72.6 years and 74.9 years for women (United Nations, 2010; MOH, 2011). Table 1.2 shows the age distribution of the Saudi population in 2010.

**Table 1.2: Age distribution of the Saudi population in 2010**

Age category	Percentage
Under 5	11.39%
5 to 14	31.64%
15 to 64	65.48%
Over 65	2.8%

(Ministry of Health, 2011).

### **1.2.5 Healthcare services in Saudi Arabia**

The healthcare system in Saudi Arabia consists of three sectors providing health care services to different populations: the public sector which represents 59.1%, other governmental health sectors (18.9%) and private health sectors (22%) of the total healthcare system. The public health sector is managed by the Ministry of Health (MOH) which oversees a widespread network of healthcare facilities and services across the country, delivered through integrated regional health directorates. The MOH was founded in 1951, and is considered the largest financier and provider of health care in KSA. In 2011, the MOH budget accounted for 6.5% of the total general budget (MOH, 2011). There are eighteen health directorates across Saudi Arabia. Each one is responsible for managing the healthcare facilities in the same region and is attached directly to the Ministry of Health (Aboul-Enein, 2002). The MOH is the governing body in planning, managing, regulating and leading the health services in the country and provides free of charge medical services for the Saudi population. With 249 hospitals representing 60% of the country's hospitals and 34,370 hospital beds which represent 59.1% of all hospitals beds in SA, the MOH incorporates the vast majority of the health services in Saudi Arabia. At the community level the MOH

manages 2,094 Primary Health Centres (PHCs) distributed all over the country: on average each PHC provides health services to 12,959 people (Ministry of Health, 2011). Primary healthcare services are provided by PHCs while secondary and tertiary healthcare services are provided by hospitals.

**Table 1.3: Number of hospitals and beds provided by healthcare sectors in KSA**

<b>Health sector</b>	<b>No of Hospitals</b>	<b>No of Beds</b>
Ministry of Health	249 (60%)	34370 (59.1)
Other governmental health sectors	39 (9.4%)	10939 (18.9%)
Private Hospitals	127 (30.6%)	12817 (22%)
<b>Total</b>	<b>415 (100%)</b>	<b>58126 (100%)</b>

(Ministry of Health, 2011)

The other governmental health sectors provide healthcare services to certain populations: for instance, the National Guard and Armed Forces Hospital provide healthcare services to the armed forces and their dependants and to the civil defence and their dependants respectively. Other governmental hospitals serve as a referral centre for MOH such as King Faisal Specialist Hospital in Riyadh, King Fahad Specialist Hospital in Dammam and other university hospitals for example, King Faisal University Hospital in Al-Khobar city in the East Region. Those hospitals are managed independently and have separate budgets. As shown in Table 1.3 the other governmental health sectors represent 9.4% of the total hospitals, with 39 hospitals, and have 10,939 hospital beds, representing 18.9% of the total health services in Saudi Arabia.

In Saudi Arabia, there are 127 private hospitals (see also Table 1.3) which represents 30.6% of the total hospitals, with 12,817 hospital beds representing 22% of the healthcare services provided in the country. The private sector provides health services through private hospitals, clinics and diagnostic and allied medical services to the population with health insurance which allows them to be treated in the private sectors as well as those who pay to obtain treatment. The private sector hospitals are supervised by MOH, and work within health regulations set up by the MOH (Al Sharqi, 2006).

### 1.2.6 Nursing workforce in Saudi Arabia

The health workforce in Saudi Arabia is a mix of Saudi and a significant international expatriate workforce. As shown in Table 1.4, the number of Saudi nurses has dramatically increased from 22,590 which represented 44% in 2007, to 37,009 which represented 48.7% in 2011 of the total nursing workforce (Ministry of Health, 2007; Ministry of Health, 2011).

**Table 1.4: Nursing workforce in Saudi Arabia.**

Health Sector	Saudi Nurses	Expatriates	Total
Ministry of Health	37009 (48.7%)	38969 (51.3%)	75978 (100%)
Other governmental health sectors	2623 (10.1%)	23257 (89.9%)	25880 (100%)
Private Hospitals	1624 (5.8%)	26310 (94.2%)	27934 (100%)

(Ministry of Health, 2011)

The debate about whether to let women study nursing has limited the growth in the number of Saudi nurses in the past (Jannadi et al., 2008). The segregation of education between males and females and the small number of male nursing colleges has played a role in diminishing the overall number of Saudi nurses as well. Nevertheless, these obstacles appear to be in transition as the government is placing a high priority on implementation of the Saudisation policy which has placed emphasis on increasing the number of Saudi citizens in the workforce (Tumulty, 2001). It was further suggested by Tumulty that globalisation and modernization of nursing have played a significant role in lessening the cultural rejection of nursing as a profession in Saudi Arabia. However, recent research has demonstrated nurses in Saudi Arabia feel their work goes unrewarded and still stigmatised (Alhethlt, 2012).

Many nursing staff continue to be recruited from different dominions such as the Philippines, India and China and other Arab and Muslim countries as Jordan, Egypt, Pakistan and Indonesia. Nurses who work in the other governmental health sectors are mainly recruited from Western countries such as United States, Canada, United Kingdom and Australia. As presented in Table 1.4 there were 38,969 expatriates representing 51.3% nursing workforce in the MOH healthcare facilities in 2011. In turn, the number of Saudi nurses working in the other governmental health sectors and private hospitals is still limited. According to the Ministry of Health (2011) there are 23,257 (89.9%) expatriate nurses of the total nursing positions and only 2,623 (10.1%) Saudi nurses working in the other governmental health sectors. The same applies to the private hospital sector as there are 26,310 expatriate nurses, representing 94.2% and only 1,624 (5.8%) positions are filled by Saudi nurses.

### 1.2.7 Physician workforce in Saudi Arabia

The physician workforce in the Saudi Arabia healthcare system is similar to that of nurses in that the majority are expatriates. In the MOH sectors physicians are predominantly expatriates 24699 (78.4%) and only 6818 (21.6%) are Saudi. The same trend continues in the private hospitals, 95.6% of a total 21134 physicians are expatriates with the Saudi physicians representing only 4.4% of the total number. As illustrated in Table 1.5, the physicians' positions in the other governmental health sectors were equally filled by Saudi and non-Saudi (MOH, 2011).

**Table 1.5: Physician workforce in Saudi Arabia**

<b>Health Sector</b>	<b>Saudi physicians</b>	<b>Expatriate physicians</b>	<b>Total</b>
Ministry of Health	6818 (21.6%)	24699 (78.4%)	31517 (100%)
Other governmental health sectors	6488 (50%)	6480 (50%)	12968 (100%)
Private Hospitals	951 (4.4%)	20183 (95.6%)	21134 (100%)

(Ministry of Health, 2011)

The following section will present the research aims, objectives and questions.

### 1.3 Research aims, objectives and questions

Research aims, objectives and questions were formulated to direct the study and to plan for data collection and analysis.

### **1.3.1 Aims of the study**

This study aimed to:

1. Identify the needs of Saudi families with a critically ill family member in ICU in Saudi Arabia.
2. Investigate healthcare providers' attitudes regarding family involvement during routine care, and family presence during resuscitation or other invasive procedures.

### **1.3.2 Objectives of the study**

The objectives of this study were to:

1. Compare relatives' perceptions of how important their needs were with how important healthcare providers perceived them to be.
2. Compare how well the family needs were being met as perceived by family members and by healthcare providers.
3. Compare who family members perceived to be the most appropriate person to meet each of their needs with the person healthcare providers believed to be the most appropriate.

### **1.3.3 Research questions**

The research questions which guided the study were:

1. What are the needs of Saudi families of critically ill adults, as perceived by both the family members and the ICU health care providers?
2. How well are those needs being met and by whom?
3. What are the attitudes of healthcare providers' regarding family involvement during routine care?

4. What are the attitudes of healthcare providers' regarding family presence during resuscitation or other invasive procedures?

#### **1.4 Significance of the study**

This study is significant because it is the first empirical study focused on identifying the needs of families with a relative in intensive care in Saudi Arabia from both the family members' and healthcare professionals' perspectives. Much of the previous family needs research has focused on identifying the needs of families in different cultures using the Critical Care Family Needs Inventory (CCFNI), a questionnaire administered to family members (Rukholm, Bailey & Wakulezyk, 1992; Lee, MacKenzie & Chien, 1999; Omari, 2009; Bailey, Sabbagh, Loiselle, Boileau and McVey, 2009). While this work is important, only two studies (Al-hassan & Hweidi, 2004; Omari, 2009) have been conducted in Muslim societies and neither identified Muslim family cultural need concerns. The findings of this study are likely to contribute new nursing knowledge regarding the needs of Saudi family members of the hospitalised patient in the ICU. The study informs the care of family members more broadly, including the particular needs of Muslim families when a relative requires admission to the ICU.

The potential significance of this study in Saudi Arabia lies in the recognition of those practices that include family involvement during routine and family presence during resuscitation and other invasive procedures, and involving the family as an important resource to support patients. Knowing more about the nature of interaction between healthcare providers and family members during routine care and resuscitation and other invasive procedures through this work will fill a gap in research in clinical

practice. Therefore, the findings will help to inform the development of a unique Saudi model of care currently lacking in the country, to help families recognize their strengths and contribute to improving patient wellbeing.

The study findings may also contribute to the development of staff support education programs to actively involve family members in health care organizations by formally incorporating their input. It can contribute to the enhancements of nursing curricula in Saudi Arabia to document nursing care plans for family members to be active participants in the process of care. The 21<sup>st</sup> century nursing curriculum should emphasize not merely the physical and psychological needs of the patients but also those of their families.

### **1.5 Scope of the study**

This study explored the perceived needs of Saudi families from ICUs in a range of Ministry of Health (MOH) hospitals in Saudi Arabia, the largest healthcare provider in the Kingdom and where the researcher had worked for several years. Other types of hospitals such as other governmental and private hospitals were outside the scope of the study. This study explored the perceived needs of Saudi families from the perspective of family members and the three main groups of ICU healthcare providers (nurses, physicians and respiratory therapists). The study further investigated the healthcare providers' attitudes regarding family involvement during routine and family presence during resuscitation and other invasive procedures. The data was captured from family members during the visiting time and from healthcare providers who worked permanently in the ICU in a range of hospitals affiliated with the Saudi Arabian MOH but could not include the casual workforce. Vulnerable family

members and families of patients with unstable vital signs and major complications were not included in the study in recognition of the high levels of stress and potential grief for relatives in the first 24 hours.

## **1.6 Methodology and data collection**

A descriptive, explanatory, sequential mixed method design, a follow-up qualitative study after a quantitative study was used in two phases to identify the family needs from family members and healthcare providers' perspectives (Teddlie, & Tashakkori, 2009). The design was also employed to examine healthcare providers' attitudes towards family involvement during routine care and family presence during resuscitation and other invasive procedures. A decision was made to choose a mixed method approach to provide a broad perspective, as combining quantitative and qualitative approaches can enhance the findings, reduce bias and minimize the weaknesses, compared with selecting a qualitative or quantitative method (Creswell, 2009). For this study the combination of qualitative and quantitative will help provide an in-depth understanding of family members and healthcare providers. In the first phase, the quantitative method was employed through a self-administered questionnaire developed and adapted for the study to gather the data from family members and ICU healthcare providers. In the second phase a semi-structured interview was used to gather in-depth information from family members.

The following section discusses the conceptual framework this study used.

## **1.7 Theoretical framework**

The theoretical framework underpinning this study was drawn from Maslow's Hierarchy of Needs and Family Centered Care theory. Often the family operates as a unit with family members being socially and emotionally involved in all aspects of family life. Hospitalization of a family member can result in disruption in the emotional homeostasis of the family system contributing to psychological challenges and a state of disequilibrium involving the patient's family members (Horn & Tesh 2000). A discussion of Maslow's Hierarchy of Needs and Family Centered Care theory is detailed in the following sub-sections.

### **1.7.1 Maslow's Hierarchy of Needs**

Maslow's Hierarchy of Needs is a theory in psychology, proposed by Abraham Maslow which has influenced a number of different fields, including patients' health and social care, due to the high level of practicality of Maslow's theory (Krapp & Gengage, 2002). According to Maslow (1970) an individual's unmet basic needs interfere with holistic growth, whereas satisfied or met needs promote growth. In his theory Maslow developed his Hierarchy of Needs five-level model in which the needs are assumed to operate from lowest to highest level. Maslow represented the Hierarchy of Needs as a pyramid, with the larger, lower levels representing the lower level needs, and the upper level representing the need for self-actualization, as shown in Figure 1.2:



**Figure1.2:** Maslow's Hierarchy of Needs five-level model (Maslow, 1970).

Maslow postulated that each person has five categories of needs:

1. **Physiological needs:** the body needs for food, shelter, drink, rest.
2. **Safety needs:** the need for protection from danger, for security and safety.
3. **Social needs:** such as the need for acceptance, giving and receiving affection and belonging.
4. **Esteem needs:** need for achievement, self-esteem, self-confidence and respect.
5. **Self actualisation needs** - finally at the top of the Maslow's Hierarchy of needs is the need to become the person that feels capable of becoming and achieving what they consider to be an individual's very best.

Maslow (1970) suggests when the lower order of needs is satisfied, then the next level order needs are energized and this directs the individual's behaviour. Conversely, if the things that satisfy individual's lower order needs are not achieved, individuals then will not be able to move on to the next higher order needs.

The nature of the concepts underpinning the theory makes it valid and applicable in today's world (Krapp & Gengage, 2002). Maslow's Hierarchy of Needs provides a useful framework for understanding patients and families with a critically ill member (Krapp & Gengage, 2002). It emphasizes the healthcare providers' role in helping the patient to meet his or her physiological and psychosocial needs and look for the "big picture" of a given patient's situation (Krapp & Gengage, 2002). After physiological and safety needs are fulfilled, the third level order needs are social which involves feelings of belongingness, love and acceptance by social connections such as those of family members. The absence of this level of Maslow's hierarchy due to hospitalization may result in the deterioration of the patient's health status. In the critical care environment family members will not be able to assist their critically ill relative to move towards the higher level order needs if their perceived needs are not met and they are not involved in the caring process of their loved one.

Despite the advantages and the widely implications of Maslow's hierarchy of needs theory which integrates into a single framework both biological and social needs, researchers have found it difficult to verify whether this hierarchy of needs is accurate (Rutledge, 2011). Different people also give different priorities to their needs, for instance some may value psychological needs over safety needs or love over self-esteem and vice versa. However, despite the criticism of Maslow's Hierarchy of needs it remains a useful tool of human needs.

The needs of families have been well studied, demonstrating that family members have basic needs which have to be met for meeting the needs and satisfaction of patients (Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Kleinpell & Powers 1992;

Mi-Kuen, French & Kai-Kwong 1995; Lee, MacKenzie & Chien, 1995; Burr, 1998; Kosco & Warren, 2000; Holden, Harrison & Johnson, 2002; Al-Hassan & Hweidi, 2004; Omari, 2009).

### **1.7.2 Family-Centered Care**

In Family-Centered Care theory, Kerr and Bowen (1988) suggest that individual behaviour may be influenced and changed based on the presence of the family unit. The family presence and support then may affect the response of patients undergoing hospitalization or medical procedure. Based on Kerr and Bowen (1988), Family Centered Care was defined as “an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and healthcare providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting”.

The family is considered to be the greatest single social institution that can influence a patient’s health (Friedman, Bowden & Jones, 2003). In addition, patients' families, during a critical illness, fulfil an additional essential role for patients who may be unconscious or unable to communicate or make decisions (Mitchell, Chaboyer, Burmeister & Foster 2009). As a result, during a critical illness families not only provide vital support to patients but also become the voice of the patients (Granberg, Engberg & Lundberg, 1999). Therefore, caring for family is a component of caring for the critically ill patient.

The family can be involved to reduce the patient's anxiety and fear, increase reassurance, mutual understanding and empathy, enhance better cooperation, and

obtaining a timely medical and nursing history on admission, which assists in the provision of more holistic care (Gardner & Stewart, 1978; Robinson, Mackenzie-Ross, Campbell, Egleston & Prevost 1998; Holzhauser, Finucane & Vries, 2006). During critical care, families can be involved during routine care, including activities of daily living, or even be present during resuscitation and other invasive procedures. The notion of family involvement in the care of their loved one during routine nursing care and family presence during resuscitation and other invasive procedures has been widely studied in the literature. The literature has addressed the notion that family should be involved to physically and psychologically support the patient (Astedt-Kurki, Paunonen & Lehti, 1997; Liddle, 1988; Eldredge, 2004; Robinson, MacKenzie-Ross, Campbell, Egleston & Prevost 1998; Holzhauser, Finucane & Vries, 2006).

### **1.7.3 Implications of the theories for the proposed study.**

Understanding the family needs of critically ill patients is expected to inform healthcare providers in ICU of Saudi hospitals to support families. The findings of this study are expected to provide healthcare providers with a knowledge base regarding Saudi families' needs and recommendations regarding family involvement in the care of their critically ill family member. Those needs if met, should help family members to cope better with their situation and support their critically ill relative.

### **1.8 Overview of the thesis**

The thesis is composed of seven chapters: the introduction to the study, the literature review, the design, quantitative results, qualitative results, the discussion and the

conclusion. Chapter One has introduced the study. Chapter Two provides an overview of the literature on family needs and family involvement in routine and family presence during resuscitation and other invasive procedures of critically ill patients. The literature review is presented in three sections: family needs, family involvement in routine care and family presence in resuscitation and other invasive procedures, in the context of the critical care environment. Each section is divided into how the concept was perceived by family members and by healthcare providers. The available literature is investigated and critiqued in order to determine whether there is a gap. Chapter Three details the design approach and the identification of mixed methods explanatory sequential research design in two phases as the best method for this study. The Chapter also covers the setting of the study, ethical considerations, the sample, the inclusion and exclusion criteria, recruitment of participants, data collection strategies and the data collection tools used in Phase 1 and 2.

Chapter Four outlines the quantitative findings which emerged from the analysis of the quantitative phase of the study with respect to family members' questionnaire and the healthcare providers' questionnaire. The qualitative findings are presented and all linked to the literature in Chapter Five. These findings arose from the open-ended question in family members' and healthcare providers' questionnaires and from the second phase qualitative findings of the semi-structured interview with family members are presented in the form of themes. In Chapter Six the study findings in Phase 1 and 2 are interpreted, discussed in relation to the available literature. Chapter Seven concludes the thesis, providing a summary of the key findings, recommendations and clinical, educational and research implications and limitations of the study.

## **1.9 Conclusion**

Health care services in Saudi Arabia have been supporting families in the caring of their family member in ICU for approximately forty years. As for most health services worldwide, various policies and practices have been adopted involving family involvement in care, some have been derived from the evidence and others embedded in tradition. This study seeks to explore the empirical evidence that families' needs are being met and which will translate to practice, for the benefit of families, patients and health professionals. A critical review of the literature is undertaken in the next chapter to provide background to the study.

## **Chapter Two: Integrative Literature Review**

### **2.1 Introduction**

The admission of a patient to the ICU places a significant stress on the family. The critical illness of a family member often occurs without any warning and may leave the family in an anxious state. It can be a catastrophic time for the family, resulting in psychological upsets, anxiety, uncertainty and fear of losing a loved one (Horn & Tesh, 2000). The family also acts as a barrier for patient anxiety because when family anxiety is high they will be unable to support the patient and may subconsciously transfer their anxiety to the patient (Leske, 2002). Many healthcare providers tend to view their patients' families solely as an extension of the patient. This perception is becoming problematic as the profession moves towards more holistic and individualised care, for the reason that the family appear to have a strong impact on the patient's response to treatment (McLaughlin, 1993). Therefore, caring for the family is an important component of caring for the patient. This can be achieved when the family members are supported and involved in the care of the patient (Beeby, 2000).

The literature review is primarily aimed at identifying the landmark studies which inform the understanding of needs of the families of critically ill patients in the ICU; the second aim is to determine how these needs were being met or unmet, the third aim is to explore the patterns of involving family members during routine care and family presence during resuscitation and other invasive procedures.

## 2.2 Search strategy

The initial inclusion criteria that were established for this literature review were that the research was:

- published in English.
- conducted in an adult ICU.
- addressed some aspects of family needs and involvement during routine care and resuscitation and other invasive procedure.
- involved participants that were either family members or ICU healthcare providers such as nurses and doctors.

A comprehensive search was carried out on the following databases: CINAHL, Pubmed, Proquest, Google Scholar, Meditext, Ebsco and MedLine. A hand search of critical care journals was carried out for any recently published studies that have not been included in the electronic databases. Any useful grey literature, such as reports, unpublished dissertations or studies, booklets or discussion papers were also sought.

The search terms included: family, 'family in intensive care unit', 'family involvement in patient care', family involvement in nursing care', family needs', 'critical care nurse perceptions of family needs', 'nurses perceptions of family needs', 'attitude of healthcare providers', 'family presence in CPR', 'health professionals', 'nurses' with 'family witnesses resuscitation', and 'relatives'. The quality of the studies included in the review was appraised using Polit and Beck (2012) guide to critique research articles asking questions on the report of the research process to determine whether the findings are usable and of good quality (refer to Table 4.1). Questions were on study purpose, research design, literature review, research

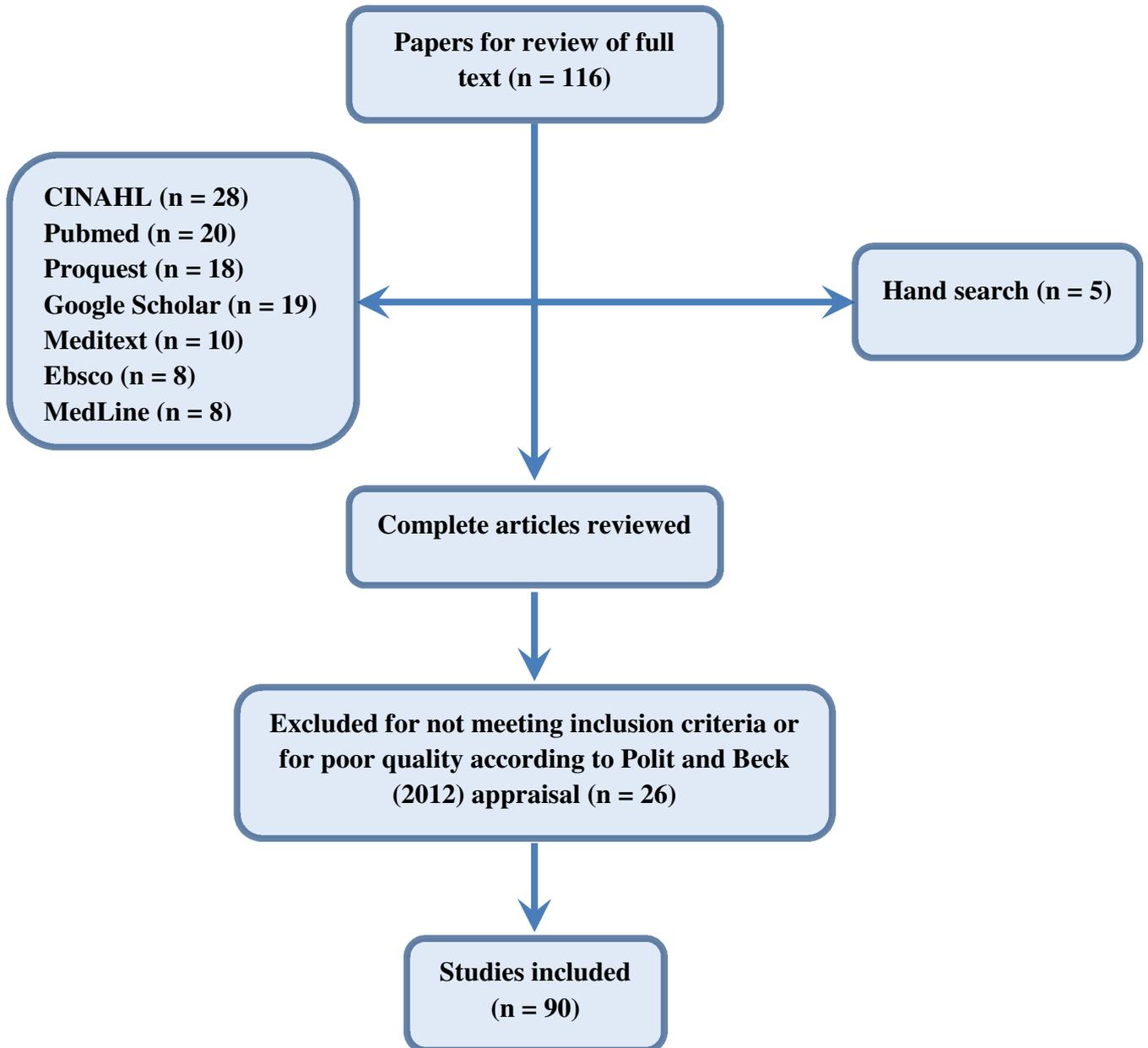
question/hypothesis, study sample, data collection, study results, and study recommendations.

**Table 2.1: Polit and Beck guide to critique research articles**

<b>Critique element</b>	<b>Questions to be asked</b>
Study purpose	Is the purpose clear? Is it relevant to your practice? Is there a need for the study? Will the study improve nursing practice and add to the body of the nursing?
Research design	Is there a framework /theory to guide the study? If there is no framework/theory, is it clear to identify how the data was collected? Who will be studied? What is the plan for conducting the study?
Literature review	Is the literature review comprehensive? Is the literature review current? Are the majority of sources primary or secondary? Is the literature review well organized?
Research question/hypothesis	Is the research question/hypothesis clearly stated? Does the question/hypothesis match the purpose of the study?
Study sample	How were the sample chosen? Who is included and excluded? How large is the sample?
Data collection	What steps taken to collect data? How often data was collected and for how long? What instruments or tools were used? Who designed the tool? Is the tool valid and reliable? Is the tool adequately described? Were data analysis procedure appropriate?
Study results	Is the research question/hypothesis answered? Were there limitations? Can generalization be made? Are the results supported in the literature? Were there any unexpected findings?
Study recommendations	Are recommendations for further use in practice? Is there identified need for further research? Can change be made in practice based on the results of the study? What are the benefits to using the information learned?

As a result of the search, 116 articles were retrieved that were published between 1978 and 2012. These publications were mainly research reports; however, discussion and review papers were included. Most of the studies were descriptive and mainly used a quantitative approach to identify family needs or family involvement during routine and other invasive procedures (Molter, 1979; Eldrege, 2004; Majasaari, Sarajarvi, Koskinen & Paavilainen, 2005; Mitchell, Chaboyer & Burmeister, 2009; Barrat & Wallis, 1998; Fulbrook, Albarran & Latour, 2005; Badir & Sepit, 2007). Fewer studies used an experimental design or qualitative approach. The majority of those studies were American in origin; however, some were Canadian, British, Swedish, Norwegian, Chinese, Icelandic, French, Australian, Turkish, Jordanian and German. In total, 90 English language publications were selected for this review. The excluded studies were either of poor quality or did not meet the inclusion criteria. This sample (n = 90) included twelve papers that were published following the definition and initial development of family needs. A larger sample of 78 more recently published papers between 1990 and 2012 was included to represent the current perspectives on family needs and involvement in routine care, resuscitation of the patient and other invasive procedures (Figure 2.1).

The identified studies differed somewhat in their use of the term "family", "family members", "relatives" or "significant others". Some studies have used the term "family" only; others were more flexible and used "family members" and "relatives" and a few studies used "significant others" in their sampling criteria. The terms family, family members, relatives and significant others will all be used throughout this review and other chapters to include all those of immediate significance to the patient.



**Figure 2.1: literature review flow diagram**

The research articles were critically analysed and divided into distinct but interrelated areas: family needs, family involvement in routine care, and family presence during resuscitation and other invasive procedures. All literature will be addressed from the earlier date to the later.

### **2.3 Family needs**

The family needs are identified as those requirements of family members which if fulfilled, relieve or diminish family distress and, if unmet, may produce distress in family members (Kosco & Warren, 2000). Three principal reasons have been identified for meeting the needs of family members:

- Holistic care and that, if it is to be practised effectively, should include consideration of the family in the planning of care (Woolley, 1990).
- Meeting the family needs reduces the stress of family members which ultimately benefits patient care (Dyre, 1991).
- Family members may be a source of stress for nurses and if family stress can be reduced this may serve to reduce stress on nurses and other healthcare providers (Wilkinson, 1995).

Verhaeghe, Defloor, Duihnstee and Grypdonck (2005) identified four major categories of family needs: cognitive, emotional, social and practical. Cognitive needs refer to the information regarding patient progress and treatment. Emotional needs relate to the need for hope and reassurance. Social needs consider all the needs that concern relationships between people such as support, and to be with the patient. Practical needs according to Verhaeghe et al. (2005) generally concerns the family members' feeling of comfort, such as having flexible visiting hours, being involved in the care and all other basic amenities including the waiting room, access to food and drink.

Dyre (1991) argued that, for healthcare providers to meet the needs of family members, they should firstly be aware of the family needs and secondly have a desire to meet these needs. Dyre (1991) maintained that each hospital has the facilities to meet the personal needs, but that the visitors of the admitted relative need to be made aware of these facilities. For cognitive needs, information about the patient's condition, treatment and patient progress must be provided to the relatives in simple understandable terms prior to and during the admission of their loved one to the hospital. Dyre (1991) recognized the emotional needs as the most difficult to satisfy since these may expose the healthcare provider to additional stress. However, meeting these needs is the essence of good care for the patient and family.

The issue of family needs in healthcare has been researched extensively because it is essential to meet the family needs in order to meet the needs of the patients. If healthcare providers truly believe in a family centred care system, then it is their responsibility to change policies, philosophies of care and physical structure that impede progress toward this vision. The needs of families have been well researched using quantitative and qualitative method approaches. Numerous studies have demonstrated that family members have basic needs which have to be met (Kleinpell & Powers 1992; Mi-kuen, French & Kai-Kwong 1995; Gelling & Prevost, 1999; Lee, MacKenzie & Chien, 1999; Burr, 1998; Kosco, & Warren, 2000; Holden, Harrison & Johnson, 2002; Al-Hassan & Hweidi, 2004; Takman & Severinsson, 2006; Omari, 2009).

### **2.3.1 The Critical Care Family Needs Inventory (CCFNI)**

In a landmark study, Molter (1979) constructed 45 needs statements through a literature review and a survey of 23 graduate nursing students. The instrument is a self-report questionnaire which lists the need statements to be rated on a 4-point Likert type scale as 1) not important, 2) slightly important, 3) important and 4) very important. Leske (1986) in her study entitled "Needs of relatives of critically ill patients: a follow-up", used the need statements developed by Molter (1979), although she changed the order of the statements and named the new instrument Critical Care Family Needs Inventory (CCFNI). Six years later Leske (1992a) divided the CCFNI into five sub-scales of assurance, information, proximity, comfort and support. Different versions of the CCFNI have been used internationally and have included from 14 to 48 items (Paul & Rattray, 2007). Numerous studies have used the CCFNI as a data collection tool to investigate the importance of family needs (Engli & Kirsivali-Farmer, 1993; Mi-Kuen, French & Kai-Kwong, 1995; Burr, 1998; Lee, Mackenzie & Chien, 1999; Al-hassan & Hweidi, 2004; Omari, 2009; Bailey, Sabbagh, Loiselle, Boileau & McVey, 2009; Kleinpell & Powers, 1992; Kinrade, Jackson, & Tomnay, 2009). This has added to the face validity of the instrument. The tool has been translated into different languages to study different populations; as a result modified Chinese and French versions of the CCFNI were developed.

The content validity of the CCFNI was determined by an expert panel consisting of 23 nurses with individual agreement ranging from 64.71% to 96.08%. The CCFNI has been used by many other researchers, which supports its content validity. Also, other researchers have used expert panels to support the content validity of the CCFNI

(Macey & Bouman, 1991). Over 50 studies have adopted the CCFNI and obtained very similar results, which supports the CCFNI's construct validity. Moreover, Leske (1991) examined the internal consistency, reliability and content validity of the tool over a period of nine years in 14 states of the United States with 677 subjects. The internal consistency measured by Cronbach's alpha coefficient was 0.92, which fits into excellent reliability range (Leske, 1991).

### **2.3.2 CCFNI dimensions**

As indicated in the previous section Leske (1992a) divided the CCFNI into five dimensions of information, assurance, proximity, comfort and support. To further understand each dimension, they will now be outlined based on the CCFNI studies.

#### **2.3.2.1 The need for information**

During critical illness, family members seek information and communication of knowledge in many different ways. Family members may use the internet to access information, stay with the patient to be involved in the care and gain information, ask healthcare providers, and attend education sessions (Leske, 1992b). The need for information dimension includes eight items (Leske, 1992a):

1. To know how the patient is being treated medically.
2. To know exactly what is being done for the patient.
3. To know why things were done for the patient.
4. To talk to the doctor every day.
5. To have a specific person to call in the hospital when unable to visit.
6. To know which staff members could give what type of information.

7. To know about types of staff members taking care of the patient.
8. To help with the patient's physical care.

In reviewing the CCFNI studies, several studies identified information as one of the highest priority needs (Leske, 1992a; Engli & Kirsivali-Farmer, 1993; Warren, 1993; Mi-Kuen, French & Kai-kwong, 1995; Quinn, Redmond & Begley, 1996; Gelling & Prevost, 1999; Bailey, Sabbagh, Loiselle, Al-hassan & Hweidi, 2004; Kinrade, Jackson, & Tomnay, 2009; Bailey *et al*, 2009; Omari, 2009). Those studies suggested that healthcare professionals must ensure that family members are delivered appropriate and sufficient information at the right time. Also, the information should be given in an understandable manner that can be absorbed by family members.

### **2.3.2.2 The need for assurance**

Family members of the critically ill patient need to be reassured by healthcare professionals about the health status of their family member and that their patient is receiving the best care. Seven items were included under this need dimension (Leske, 1992a):

1. To have questions answered honestly.
2. To be assured that the best care possible is being given to the patient.
3. To know the expected outcome.
4. To feel there is hope.
5. To know specific facts concerning the patient's progress.
6. To feel that staff care about the patient.
7. To have explanations that are understandable.

The need for the assurance dimension was ranked as one of the “most important” family need dimensions in a number of studies which were conducted in different contexts (Quinn, Redmond & Begley, 1996; Burr, 1998; Lee, Mackenzie & Chien, 1999; Gelling & Prevost, 1999; Al-Hassan & Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki, Klimathianaki, Anastasaki, *et al*, 2012).

### **2.3.2.3 The need for proximity**

The proximity need is understood as the state of being close or near to the patient. Family members are physically and emotionally distressed and they need to be near to their relative. According to Leske (1992a) nine need statements are defined in the proximity need dimension:

1. To be called at home about changes in the patients condition.
2. To receive information about the patient every day.
3. To see the patient frequently.
4. To be told about transfer plans while they are being made.
5. To have the waiting room near the patient.
6. To have visiting hours changed for special conditions.
7. To visit at any time.
8. To have visiting hours start on time.
9. To talk to the same nurse every day.

As indicated by the statements, the need for proximity dimension is related to the visiting time and to the desired changes in the healthcare facility structure such as having a waiting room near the patient. The literature has shown that the proximity need dimension was ranked as the second or third most important need (Mi-Kuen, French & Kai-kwong, 1995; Lee, Mackenzie & Chien, 1999; Warren, 2000; Al-

Hassan & Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki et al, 2012). In spite of the fact that the proximity need is important, these needs have not always been met (Warren, 1993). This might be considered as being due to the restrictions and inflexibility of the visiting hours which has limited family members access and having this need met by intensive care team.

#### **2.3.2.4 The need for comfort**

Comfort in CCFNI is a multidimensional need that includes physical, environmental, psycho-spiritual and personal needs such as access to food and a bathroom (Berry, 2010). There are six statements under the comfort dimension in the CCFNI (Leske, 1992a):

1. To feel accepted by the hospital staff.
2. To have a telephone near the waiting room.
3. To be assured it is alright to leave the hospital for a while.
4. To have a bathroom near the waiting room.
5. To have good food available in the hospital.
6. To have comfortable furniture in the waiting room.

Most studies reported that families ranked the need for comfort as fourth or fifth in importance (Al-Hassan & Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki *et al*, 2012) as families see it as less important than the need for assurance, information and proximity. Leske (1992a) found that the ranking of comfort differs as it is related to family relationship and age; parents and spouses ranked comfort higher than other relatives and the elderly gave a higher ranking than the younger population.

### **2.3.2.5 The need for support**

The support need dimension concerns the support needs to be met by healthcare professionals, family members, friends, religious groups and many others (Berry, 2010). The support need dimension is one third of the 45 statements in the CCFNI and has the largest number of need statements of 15 items (Leske, 1992a; Lee, MacKenzie & Chien, 1999). Those need statements under the support dimension according to (Leske, 1992a) are:

1. To have explanations of the environment before going into ICU for the first time.
2. To talk about the possibility of the patient's death.
3. To have friends nearby for support.
4. To have directions as to what to do at the bedside.
5. To have the pastor/chaplain visit.
6. To have concern for the relative's health.
7. To be told about others that could help.
8. To have someone help with financial problems.
9. To have a place to be alone while in the hospital.
10. To be told about chaplain services.
11. To be told about other people that could help with problems.
12. To talk about feelings.
13. To have a staff member with relative while visiting the ICU.
14. To be alone at any time.
15. To be encouraged to cry.

A number of studies ranked support as the “fourth” or “fifth” most important need dimension (Lee, MacKenzie & Chien, 1999; Omari, 2009; Chatzaki *et al*, 2012). Support needs of family members sometimes reflect cultural preferences. For instance, Chinese and Jordanian families have been shown to share culturally strong bonds and support between family members. Those family members will rely solely on each other for emotional support more than healthcare professionals (Lee, MacKenzie & Chien, 1999; Al-Hassan & Hweidi, 2004; Omari, 2009). Family members ranked support needs lowest and this related to families' desire for healthcare professionals to spend their time caring for the ill relative rather than spending their time caring for them (Berry, 2010). Other families may rely differently on the healthcare professional and other hospital support personal for support (for example, social workers); therefore a planned, comprehensive approach to family support is required.

## **2.4 Selected research on family needs**

The family needs studies in this review will be divided into four sections: families' perspectives, healthcare providers' perspectives, comparison of family members and healthcare providers' perspectives and meeting family needs. Studies will be discussed in chronological order from the earlier date to the later.

### **2.4.1 Families' perspectives**

The main focus of the family needs studies has been the identification of the importance of those needs (Leske, 1992a). This section identifies the family needs of critically ill patients from the perspective of family members and the differences in

needs in different populations, locations, languages and diagnoses. The studies of family needs as perceived by family members in this section are divided into two sub-sections: CCFNI studies and qualitative approaches.

#### **2.4.1.1 CCFNI studies**

Many studies have adopted a quantitative approach using the CCFNI in different locations, languages and cultures worldwide. For example, Burr (1998) used a mixed method triangulation design to contextualize the critical care family needs in four general ICUs of major teaching hospitals in Sydney, Australia. The quantitative data design to explore the needs and experiences using CCFNI were complemented by the qualitative data which provided more contextual representation of the needs and greater understanding of the whole construct. The sample population consisted of 131 family members: 105 participants completed the CCFNI and 26 different family members participated in the interviews. Two needs appeared to be the most important: "to feel that hospital personnel care about the patient" and "to be assured that patient is receiving the best care possible" (Burr, 1998, p. 168). The participants in both approaches prioritised the need for information and access to the patient; however the personal needs were accorded low priority. From the interviews emerged two major needs that were not represented in the CCFNI. These were to provide reassurance and support to the patient and the family need to protect the patient.

Lee, MacKenzie and Chien, (1999) conducted a study in Hong Kong to explore the family members' perceptions of their immediate needs following admission of a relative to the intensive care unit. A convenience sample of 30 families was invited to participate from those available during the first 96 hours of the hospitalisation of their

relative. Self-report questionnaires consisting of a demographic sheet and the modified Chinese version of the 45-item CCFNI and semi-structured interviews were the instruments used for this study. The domains of assurance and information were the most important needs categories, which were also identified by Burr (1998), Al-Hassan and Hweidi (2004) and Omari (2009). The least important as indicated by the study findings, were support and comfort needs. There was a statistically significant difference between sex and relationship to the patient: female family members rated the ten top family needs higher than male family members.

A comparison was conducted of six studies of family needs through the use of CCFNI to demonstrate how the needs remain the same over the time and different cultures and populations. The needs of family members identified by Engli and Kirsivali-Farmer (1993), Quinn, Redmond and Begley (1996), Al-Hassan and Hweidi (2004), Omari (2009), Kinrade, Jackson and Tomnay (2009) and Chatzaki et al. (2012) are shown below. The need for assurance and information were ranked as highest priorities (see Table 2.1).

**Table 2.2 Comparison of the five most important needs as identified by families.**

Engli and Kirsivali-Farmer (1993)	Quinn, Redmond and Begley (1996)
<ol style="list-style-type: none"> <li>1. To know the prognosis.</li> <li>2. To have questions answered honestly.</li> <li>3. To be assured that the best possible care is being given to the patient.</li> <li>4. To be called at home about changes in the patient's condition.</li> <li>5. To feel that the hospital personal care about the patient.</li> </ol>	<ol style="list-style-type: none"> <li>1. To know that they will be called at home, about any changes in the patient's condition.</li> <li>2. To have questions answered honestly.</li> <li>3. To be assured that the best care is being given to the patient.</li> <li>4. To feel that there is hope for the patient.</li> <li>5. To know the probable outcome of the patient's condition.</li> </ol>
Al-Hassan and Hweidi (2004)	Omari (2009)

<ol style="list-style-type: none"> <li>1. To talk to the doctor every day.</li> <li>2. To feel that hospital personnel care about the patient.</li> <li>3. To receive information about the patient once a day.</li> <li>4. To have questions answered honestly.</li> <li>5. To receive explanations in terms that are understandable.</li> </ol>	<ol style="list-style-type: none"> <li>1. To be assured that the best care possible is being given to the patient.</li> <li>2. To feel that the hospital personnel care about the patient.</li> <li>3. To feel there is hope.</li> <li>4. To have questions answered honestly.</li> <li>5. To have explanations given that are understandable</li> </ol>
<b>Kinrade, Jackson and Tomnay (2010)</b>	<b>Chatzaki, <i>et al</i> (2012)</b>
<ol style="list-style-type: none"> <li>1. To have questions answered honestly.</li> <li>2. To visit at any time.</li> <li>3. To feel that hospital personal care about the patient.</li> <li>4. To know specific facts concerning the patient's progress.</li> <li>5. To know the expected outcomes.</li> </ol>	<ol style="list-style-type: none"> <li>1. To have questions answered honestly.</li> <li>2. To feel that the hospital personnel care about the patient.</li> <li>3. To receive information about the patient once a day.</li> <li>4. To have explanations given that are understandable.</li> <li>5. To know the prognosis.</li> </ol>

Holden, Harrison and Johnson (2002) reviewed the literature published over 20 years related to family needs of critically ill patients. Twelve studies and six items from the grey literature were reviewed and critically analysed. The authors identified that families placed the need for information as a priority need, followed by the need for support and the need to have hope. Additionally, when nurses met these needs and built up a good relationship with the family members, they often helped families to cope more successfully during that difficult time. However, the review showed that the studies which used CCFNI failed to demonstrate the importance of interaction between nurses and family members. The predominantly small and convenience samples used in most of the studies limits the extrapolation of the findings, and caution should be exercised when applying the results to other clinical settings. Another limitation was that only a few studies considered the influence of culture, spirituality, gender, age or socio-economic variables of the participants.

Using a questionnaire adapted from CCFNI a descriptive cross-sectional study was carried out to identify the needs of Jordanian families of hospitalised critically ill patients (Al-Hassan & Hweidi, 2004). One hundred and fifty-eight family members who were visiting their hospitalised critically ill relatives completed the Arabic translated CCFNI. The study was conducted in CCUs of the four largest hospitals in the northern and middle areas of Jordan. The findings revealed that more than 80% of the family members perceived 16 need statements as important or very important. The participants ranked needs for assurance, information and proximity the highest and needs for support and comfort the lowest. As shown in Table 2.1 the most important needs of families were to receive information about the patients, to feel that the hospital personnel care about the patients and to have the information given in understandable terms. This study indicated that Jordanian families had specific and identifiable needs. Providing families of critically ill patients clear, simple and updated information about the patients and assuring them about the quality of care the patients receive should be essential components of the critical care nursing delivery system. The instrument's content validity and reliability were well tested; nevertheless, the study failed to assess and identify the spiritual and cultural needs of the Jordanian families.

The structured CCFNI instrument has been criticised because the nature of its perspectives inhibits families from expressing needs not included in the list and is constructed from the perspective of nurses which differs from the perspective of family members (Yang, 2008). To avoid this, Yang (2008) adopted a triangulation mixed methods design to achieve an understanding of the needs and experiences of Korean families in ICU. The researcher used the CCFNI survey to measure the needs

of ICU families and semi-structured interviews focusing on the process of hospitalisation in the ICU to identify difficulties experienced by families and their need to cope with critical situations. The study recruited 85 families for the quantitative inventory and 25 family members of the 85 voluntarily agreed to the interview. The quantitative results showed that the ICU Korean families ranked the most important needs as follows:

1. Assurance	M = 3.67	SD = 0.41
2. Information	M = 3.49	SD = 0.40
3. Proximity	M = 3.23	SD = 0.50
4. Comfort	M = 2.93	SD = 0.60
5. Support	M = 2.63	SD = 0.55

Those quantitative results were complemented and verified by the main themes derived from the qualitative data and demonstrated in what ways the needs identified quantitatively were met or unmet by hospital and family systems (Yang, 2008). Yang's findings indicated that healthcare professionals should maintain open communication and close contact with patients to meet the priority needs of Korean families. The authors suggested an educational program for nurses and to include a support group program for families. The educational program for nurses was recommended to highlight the needs of families, maintain effective communication and improve cultural competence levels. Additionally, the family support group programs were to be informative and supportive, where families could learn and be empowered. The small sample used in the inferential statistical analysis in the study means that caution is required in interpreting and generalising the results.

Another descriptive exploratory Jordanian study by Omari (2009) took place in adult ICUs of three hospitals in Jordan. The study purpose was to identify the self-perceived needs of adult Jordanian family members who have a family member admitted to the ICU and to explore whether these needs were being met and by whom. Data were collected from 139 relatives of 85 critically ill patients using a demographic data questionnaire and the CCFNI and the Needs Met Inventory (NMI) version 2 which was developed by Molter and Leske, (1983) and translated into the Arabic language. The 10 most important needs identified were under the assurance and information subscales, with a mean score of at least 3.59. Additionally, Table 2.1 shows that under the assurance subscale, the need to be assured that the best care possible was being given to the patient had the highest mean score (3.97). The results showed that the 10 least important needs were under the support and comfort subscales. Statistically significant differences were found between some demographic variables and subscales on the CCFNI, but with a small sample size which make the comparison underpowered. The findings of this study provide a basis for understanding the family needs of adult Jordanian family members of a critically ill patient. Like Al-Hassan and Hweidi (2004), the study used a convenience sample from only one geographical area in Jordan which may limit the generalisability of the findings to the whole country.

In another comparison conducted for the purpose of this review of four studies of family needs of critically ill patients through the use of CCFNI with different populations. As shown in Table 2.2 the rank order by mean scores on CCFNI as perceived by family members were assurance followed by information as the "most important" needs. Proximity, comfort and support dimensions had lowest subscales,

which demonstrate that family members perceived the needs under these dimensions as "least important".

**Table 2.3: Comparison of family members' rank order of the CCFNI of four studies**

Dimension	Ranking: (Mean)			
	Warren (1993)	Kosco & Warren (2000)	Yang (2008)	Omari (2009)
Assurance	2 (3.22)	1 (3.16)	1 (3.67)	1 (2.65)
Information	5 (2.85)	2 (2.99)	2 (3.49)	5 (2.15)
Proximity	4 (2.91)	3 (2.95)	3 (3.23)	2 (2.56)
Comfort	3 (3.12)	4 (2.94)	4 (2.93)	3 (2.22)
Support	1 (3.61)	5 (2.57)	5 (2.63)	4 (2.18)

The needs of families of ICU patients in Greece have also been addressed using a prospective cohort study by Chatzaki et al (2012). The data were drawn from a convenience sample of 230 family members of a mixed medical-surgical 11-bed ICU. The assurance dimension was ranked as the most important, as judged by the family members, followed by information, proximity and then support, whereas comfort was ranked the least important. Significant findings of this particular study were that educational level or socio-economic status of family members related to the importance of needs in the support dimension. Also, there was a significant relationship between older participants and the rank of importance for the need "to help with the patient's physical care". This was reasonable, as indicated by the author because in traditional societies and in the Greek Orthodox Church, the family is responsible for the care of the sick member.

#### **2.4.1.2 Qualitative approaches**

Qualitative approaches in family needs studies may enable family members to present their perspectives more clearly (Holden, Harrison & Johnson, 2002). Qualitative methods also allow exploration of in-depth data and rich themes are produced. For instance, Wilkinson (1995) studied the perspectives of the family members of a critically ill patient. The study took place in an eight-bed general ICU in Essex, United Kingdom, which had an open visiting policy. Through unstructured interview, six relatives were invited to discuss their experiences and needs related to visiting their critically ill family member.

Wilkinson's (1995) findings emerging out of the interviews revealed numerous concerns and needs. First, the shock of admission to ICU and the family members' awareness of the life and death of their loved one for some families may create anxiety, fears and worries. Second, the need for proximity was important as participants did not want to be far from their relative. Third, many relatives in the study required the positive caring environment within the ICU and this subsequently perhaps influenced their involvement in the care. The need for information and the need for hope are consistent with others, such as those of Engli and Kirsivali-Farmer (1993) and Burr (1998). Therefore, accurate information about the condition of a loved one should be delivered in understandable terms to the relatives. Also, nursing curricula should place an emphasis on the communication and counselling skills of nurses to facilitate the relatives' fears and anxiety.

In another study to identify the family needs using a qualitative approach, Bond, Draeger, Mandleco and Donnelly (2003) studied the needs of families of patients with severe traumatic brain injury during the families' experience in neurosurgical ICU. The authors used an exploratory qualitative descriptive design with a convenience sample of family members of patients admitted to an 11-bed neurological ICU in a level I trauma centre. Seven family members with severe traumatic brain injury (GCS score < 8) were interviewed: two mothers, a daughter, a father, a grandmother, a sister and an uncle. The analysis of the interviews revealed that four common needs were identified: 'need to know', 'need for consistent information', 'need for involvement in the care' and 'need to make sense of the experience'.

These findings suggest that family members wanted information about the diagnosis, the treatments and the rationale for those treatments. The relatives voiced the need for consistent information because with the second and third days of admission families began to receive inconsistent information regarding their relatives condition. Consistent with other studies (Leske, 1992; Al-Hassan & Hweidi, 2004; Omari, 2009) this study recognised the right of the family members to have information presented in terms they could understand. Perhaps the need for involvement in the care of the patient by the relatives reflects that they are prepared to spend long hours at the hospital to support the patient. In this study also, the family members felt frustrated when they were not allowed to help with patients' routine care. Following a close examination of the needs identified here, it can be argued that the family needs for information remained unmet. Based on this study's findings, nurses should recognise ways for the families to be involved in the patient's care to assist the patient and alleviate their own anxiety and stress.

In one qualitative study, Fry and Warren (2007) interviewed 15 participants and used Heideggerian hermeneutic contextual analysis to illuminate the perceived needs of the critical care patient's family members in the waiting room, viewed through their own words. Consistently with the other qualitative studies such as Wilkinson (1995) and Bond, Draeger, Mandleco and Donnelly (2003), the needs expressed by all participants in this study were seeking information, trusting the professionals, being a part of the care and maintaining a positive outlook. The authors concluded that a way to connect with the patient is being aware of the family member's need, thus further stimulating trust and positive outcomes. The design used in this study allowed the family members to freely express their perceived needs, and the rich descriptions supported explicit needs expressed by all participants.

More recently, following a qualitative approach, Keenan and Joseph, (2010) interviewed 25 family members to identify their needs in relation to a critically ill family member who sustained a severe traumatic brain injury, and to determine whether these needs change over time. The data were based on 44 interviews from a purposive sample conducted twice after discharge from the ICU, and after discharge from the acute care facility to home or rehabilitation. The family members demonstrated a need to express their experience of looking after their injured relative. The need to receive information and to understand the prognosis was identified as important. The family members required professional and community support to become increasingly involved in the patient's care. Thus it can be suggested that relevant and understandable information being delivered to the families develops trust and strengthens the links with healthcare professionals, which is consistent with Bond, Draeger, Mandleco and Donnelly, (2003). The need to maintain hope also remained

strong and significant by the family members, especially for brain injury patients and their families. Involvement in the care remained a need for the families as it gives them a sense of involvement and feeling close to their loved one. The study suggested for healthcare professionals to become more involved in the family's psychological health: for instance family conferences to provide an in-depth discussion of the patient's status and family needs. The ethical considerations were not provided in the article and in the sample female participants were overrepresented, so potentially those two issues would influence on the credibility of the findings.

A meta synthesis of 14 qualitative studies by Linnarsson, Budini and Perseius, (2010) helps to complete the contextual representation of the family needs and to provide a deeper understanding of what the family members experience during an ICU admission. According to the authors, five major themes with subthemes emerged from the analysis which are very like the themes of the previous qualitative studies (Holden, Harrison & Johnson, 2002; Bond, Draeger, Mandelco & Donnelly, 2003; Fry & Warren, 2007; Keenan & Joseph, 2010). The theme, “Uncertainty and emotional roller coaster” reveals that the significant others of the critically ill patient in this situation had feelings which were overwhelming and chaotic. The family members had general feelings of anxiety, distress, fear and having difficulties understanding the situation. The “Information – balancing hope and reality” theme embodied a strong need to receive honest, consistent and straightforward information regarding the patient situation. The significant others searched for any information, whether good or bad, and it was important that the information was clear and understandable.

In the third theme “To protect and guard the loved one” significant others indicated a strong need to be close to their family member, to see them and observe the care being provided. The families also wanted to be part of the care and offer whatever help they could. “Alliance with caregivers – crucial support” is a theme characterised by the need for social support by the caregivers and building a trusting and confident relationship. Honest and open communication was appreciated by the significant others and had a positive influence. The fifth theme was “Social network – support and disequilibrium”: families felt removed from their social network which disrupted social normality. This required a need for social support, such as from family, friends or colleagues, so that family members of the critically ill patient could find strength and be emotionally supported to cope (Linnarsson, Budini & Perseius, 2010).

In summary, findings from the reviewed studies in this literature showed that the family members in several CCFNI and qualitative studies identified the need for information and the need for assurance as the highest priority needs. The quantitative studies through the use of CCFNI shared many similarities in the importance of family needs identified by the families in different populations, locations and cultural background. Furthermore, the qualitative methods added an in-depth and rich understanding of the family needs issue and provided a deeper perspective to the CCFNI findings.

#### **2.4.2 Healthcare providers’ perspectives**

Healthcare providers were found to prioritise the family needs differently from the family members (Quinn, Redmond & Begley, 1996). O'Malley, Favaloro, Anderson,

Anderson, Siewe, Benson-Landau et al. (1991) used both a descriptive and an ex post facto research design to examine the intensive care nurses' perceptions of family needs. A questionnaire was distributed to 126 ICU nurses of a 700-bed teaching hospital (O'Malley et al. 1991). This revised tool examined the nurse perceptions of family needs, their perception of the time available to meet the needs in daily practice and the best professional to meet the family needs if the need was identified as best met by someone other than the nurse.

The majority of the nurses in this study perceived family needs as important or very important, and 85% of the nurses indicated that they were able to meet family needs and had time to do so. In contrast to the families perceptions' in studies such as Warren (1993), Lee, MacKenzie and Chien, (1999), Al-Hassan and Hweidi, (2004) and Omari, (2009), nurses in the O'Malley et al (1991) study ranked cognitive family needs higher than psychological or personal and physical needs. The results also revealed that nurses from the four intensive care units ranked family needs significantly different from families, a result that may be influenced by differing patient acuity and patient length of stay in the ICU. These perceptions of family needs held by nurses were influenced by the setting, length of nursing experience practicing in the intensive care, educational preparation and length of time in nursing. It could be said that the perception of family needs could differ greatly in relation to the factors of staffing, hospital size, organizational culture and climate, acuity, available resources and cultural values.

As part of a larger study Takman and Severinsson, (2006) investigated the healthcare providers' (registered nurses, physicians and enrolled nurses) perceptions of the needs

of critically ill adult patients' significant others based on the CCFNI. Twenty-one ICUs were surveyed, nine in Norway and twelve in Sweden. Two hundred and thirty two enrolled nurses, 292 registered nurses and 79 physicians from Sweden and 275 registered nurses and 36 physicians from Norway participated in the study. Significantly, the qualitative content analysis of handwritten responses to the open-ended items by the participating healthcare providers (48 from Norway and 49 from Sweden) identified the following needs in order of priority (Takman & Severinsson, 2006, P. 230-233).

1. The need to feel trust in the healthcare providers' ability.
2. The need to be prepared for the consequences of critical illness.
3. The need to be aware of patients' needs and reactions in relation to significant others.
4. The need for ICU and other hospital resources.

In contrast to the family members who ranked information and assurance as the highest priority needs in studies for instance, Engli and Kirsivali-Farmer, (1993), Wilkinson (1995), Burr (1998), Lee, MacKenzie and Chien, (1999), Bond, Draeger, Mandelco and Donnelly, (2003), Al-Hassan and Hweidi, (2004) and Omari, (2009). The healthcare providers in this study identified the need to feel trust in the healthcare providers' ability, and the need for ICU and other hospital resources had the highest response frequency. This, however, is consistent with O'Malley et al (1991) findings and confirms Quinn, Redmond and Begley's (1996) argument that healthcare providers prioritise the family needs differently from the family members. The findings can contribute to the development of interventions that could be tested to evaluate whether they improve the ICU experiences of patients and their significant

others. Also, this would protect the patients' rights needs to be evaluated in relation to current clinical practice for the purpose of ensuring high quality of care for both patients and their significant others. The study also identifies cultural or religious needs needed to be acknowledged by the healthcare providers.

### **2.4.3 Comparison of family members' and healthcare providers' perspectives**

It has been argued that family members and healthcare providers are required to develop connections and be flexible to be effective in meeting family needs (Berry, 2010). As discussed earlier, family needs are perceived differently by family members and healthcare providers. In this section the differences in the perceptions between family members and healthcare providers will be examined and family members' and healthcare providers' perspectives on the family needs compared, to assist in meeting these needs.

Jacono, et al. (1990) directed their study to compare the perceived psychosocial needs of family members of critically ill patients from two perspectives: the care givers and the family members. A convenience sample of 30 ICU registered nurses and 49 family members answered the Norris and Grove, (1986) needs questionnaire. The study was undertaken in two community hospitals in Ontario's mid-north. The results demonstrated that registered nurses had a positive appreciation of family needs. In addition, family members ranked their needs consistently higher and in some areas differently than did the registered nurses. These findings indicate that, if family needs are met, this has a positive effect on the patient and family; hence the nursing

intervention should be directed toward more family-focused and patient centred care and the nursing profession should dedicate time integrating psychosocial needs in the care of patients. The Norris and Grove needs questionnaire tool used in that study did not allow respondents to give their opinions as to whether their needs were generally satisfied.

Another comparative study, by Kleinpell and Powers, (1992) examined the perceived needs of the families of the critically ill patients from the family members' and the nurses' perspectives, and also the level of participant satisfaction with how these needs were met. The study took place in a university affiliated hospital in a midwestern city of the United States. The data were collected from 64 family members of 40 patients, and 58 nurses who were asked to complete a modified version of the CCFNI. Both family members and nurses shared similar important needs, such as "the need to have questions answered honestly", "to be called at home about the changes in the patient's condition" and "to know why things were done for the patient". Moreover, some needs were indicated by the families as more important and at the same time less met. Those needs were "to know the occupational identity of staff members", "directions as to what to do at the patient's bedside" and "having friends for support". The study recommended innovative nursing interventions to better meet the needs of family members such as an orientation-education program, pamphlets, nurse-family interaction sessions and open visiting policies. The report did not indicate that the study was reviewed by an ethics committee.

Mi-Kuen, French and Kai-Kwong, (1995) examined the differences in families' and nurses' perceptions of the importance of 45 items of the Chinese version of the

CCFNI. A survey was conducted using structured interview and questionnaire methods in three high-dependency neurosurgical special care units in three regional hospitals. A total of 52 family members and 36 nurses were recruited for the study. The data were collected from the family members by interview and from the nurses by questionnaire. The findings indicated that the majority of needs were related to assurance, while needs for support and comfort were much less important. The study also showed that nurses in neurosurgical units in Hong Kong had a particular perception of the needs of family members and that this did not always match the actual needs of family members in other areas. This study examined the differences and similarities in the need perceptions of nurses and family members within the Chinese context. The ethical approval to conduct the study in the targeted hospitals was not addressed in the report. Also, the authors failed to explore the cultural and spiritual needs of the Chinese families.

A comparative descriptive study also used the CCFNI to survey both relatives and nursing staff in 24 adult intensive care units in the Republic of Ireland (Quinn, Redmond & Begley, 1996). Compared with Kleinpell and Powers, (1992), the surveyed relatives (n=255) and intensive care nurses perceived the importance of family needs differently. Assurance and information profiles were ranked the highest by the family members. Nurses however ranked them as low priority indicating that nurses are not sufficiently aware of the needs of the family members. The authors further recommended nurses to assess family members who may need extra support through the use of a relatives' assessment form to ensure continuity and reliability of care not merely to the patients, but also to their relatives. As a result, total patient care

will be implemented when the whole family unit of both patient and family are considered.

A study by Gelling and Prevost, (1999) took place on an 8-bed neurosciences intensive care unit between December 1997 and April 1998 in UK. The study explored the needs of relatives of critically ill patients admitted to the unit from the relatives', nurses' and doctors' perspectives. Relatives who met the inclusion criteria (n=41) and nurses (n=38) as well as doctors (n=14) were asked to complete the same CCFNI. The CCFNI contained 30 items which were adapted from similar studies. The relatives' identified the need for information as the most important need, which was also found by Engli and Kirsivali-Farmer, (1993), Wilkinson, (1995), Burr, (1998), Lee, MacKenzie and Chien, (1999), Bond, Draeger, Mandleco and Donnelly, (2003), Al-Hassan and Hweidi, (2004). Additionally, these findings are consistent with Jacono, Hicks, Antonioni, Brien and Rasi's (1990) findings that intensive care units should continue to emphasize the importance of meeting the needs of relatives as integral to patient care. This study demonstrated different findings from earlier studies such as Mi-Kuen, French and Kai-Kwong, (1995) as they suggest that the needs of family members do not differ between general and specialist intensive care units. The small number of participants used means limited generalisation is possible; and the quantitative survey may not have identified all the needs of relatives of critically ill patients admitted to a neurosciences critical care unit.

Another comparative, descriptive, exploratory study was carried out by Kosco and Warren, (2000) to determine whether nurses' perceptions of meeting families' needs correlated with the families' perception of these needs being met. The data were

collected from 45 family members and 45 nurses in a large country hospital in the United States, designated as a level 3 trauma centre. The data were collected through the use of a structured interview schedule. The nurses and family members were asked to complete a 3 part questionnaire. Similarly to the early studies reviewed, the results indicated that the subscales of assurance, information and proximity were ranked the highest by the family members, whereas support and comfort were ranked the lowest. The subscales of assurance, proximity and information were ranked the highest according to the nurses' perceptions of the family needs, whereas support and comfort ranked the lowest. In contrast with Quinn, Redmond and Begley, (1996), the findings of this study showed some similarities in the perceived needs of family members and healthcare providers. The findings can be used extensively to direct assessing, planning, implementing and evaluating care toward those needs that the family perceives as unmet. The authors concluded that the intensive care nurses must know the expectations of the patients' families.

The family needs of a patient with a critical illness have also been highlighted by Hinkle, Fitzpatrick and Oskrochi, (2009). The authors conducted a study using a qualitative approach to describe the current family members' needs of patients with critical illness identified by family members and nurses. The study also sought to compare and identify the differences in the needs experienced by family members visiting patients with the critical illness and nurses working in ICUs. The data were collected prospectively using a convenience sample of 101 family members and nurses. The hierarchical cluster analysis identified the themes of: emotional resources and support, trust and facilitation of needs, treatment information and feelings.

The results above also reveal that the family members and nurses agreed on the order of importance with emotional resources and support first, trust second, treatment and information third and feelings last. They differed significantly, however, on three of the four themes of depth of importance. Family members considered the depth of emotion and trust to be more serious than did the nurses. Furthermore, family members considered the depth of feeling to be less serious than did the nurses. Similarly to the earlier reviewed studies this study neglected to identify the religious influences on the participants' perceptions.

More recently, the CCFNI tool was adapted by Kinrade, Jackson and Tomnay (2010) to study the needs of Australian relatives whose family member was unexpectedly admitted to the ICU, and compare them with perspectives of nurses. The study used a descriptive design and was conducted in a regional Victorian hospital. A total of 25 family members (3 male, 22 females) and 33 female nurses participated in the study. As with Kosco and Warren's (2000) findings, only minor differences of the need statements were identified among nurses and family members. Minor differences also were identified in both the rank order of individual need statements, as well as the five factor analysis categories established previously. An interesting point in this study was that relatives did not rank as highly as nurses "to be told the truth even if it is distressing", but the difference was not statistically significant ( $p = 0.36$ ). Furthermore, the results demonstrated that more years' experience in the case of the nurses did not necessarily result in a greater understanding of family needs. Three factors could have affected the generalisability of these study findings: the very small sample size, lack of power and all of the participants were sourced from one hospital only.

In brief, the research literature findings highlight many areas of convergence and divergence between family members and healthcare providers. Family members identified information and assurance needs as their highest priority, whereas healthcare providers mainly identified personal and cognitive needs as their highest priority. Generally speaking, the studies that used the CCFNI failed to identify the religious and cultural influences on the family members and healthcare providers' perceptions.

## **2.5 Meeting family needs**

One of the challenges that healthcare providers encounter in the critical care area is their ability to meet or "satisfy" the family needs of a critically ill patient. Molter, (1979), as cited in Berry, (2010), suggests that this may be because healthcare providers in intensive care areas focus solely on patient care and spend little time in meeting their family's needs. Several studies have examined the levels of family members satisfaction and explored how their needs have been met and who is the most appropriate healthcare provider to help them fulfil each need. Molter and Leske, (1983) developed the Needs Met Inventory (NMI) from the CCFNI to assess how well families perceived their needs being met and who would be the most likely person to meet each need. The NMI is a self-administered questionnaire consisted of the same 45 needs statements as the CCFNI, including a four-point Likert type scale: 1 = never met, 2 = sometimes met, 3 = usually met and 3 = always met.

Several previously mentioned studies have focused on the phenomenon of gaining better understanding of how well families' needs are being met and who meets them:

for example, those of Warren, (1993), Quinn, Redmond and Begley, (1996), Kosco & Warren, (2000), Lee, MacKenzie and Chien, (2000) and Omari, (2009). In their study Quinn, Redmond and Begley, (1996) reported that only 10 out of 30 needs were perceived as being met by at least 60% of families in study. Also, in this study families perceived only 19 of the 30 needs to be best met by a nurse.

O'Malley et al, (1991) using a convenience sample of 126 nurses studied the nurses' perception of family needs and who was the best to meet these needs from the perspectives of nurses. Significantly, in agreement with the early studies from the perspective of family members who identified nurses as the most appropriate person to meet their needs, the authors reported that 85% of the nurses indicated that they were able to meet family needs and had time to do so.

In her study Warren, (1993) used the NMI with 94 family members who were asked to complete the questionnaire 36 to 48 hours after their relative's admission to the CCU. The results demonstrated that families rated their important needs of "information", "assurance" and "proximity" as being unmet by the CCU team. However, comfort needs were the most frequently met needs and were rated as less important.

Lee, MacKenzie and Chien's (1999) study, aimed at determining who met the family needs, using the NMI and semi-structured interviews with 30 family members within 96 hours of the patient's admission to the ICU. Female family members in this study perceived their needs as unmet more than male family members. Doctors and nurses

were noted by the participants as the most appropriate persons to meet the family needs.

Another study reporting on family's needs being met and by whom, using NMI and comparing the perceptions of 45 family members and 45 nurses, was by Kosco and Warren, (2000). Three of the ten most important needs identified were perceived as being met and the other seven as not being met to some extent. This study results indicated that relatives, nurses and doctors differed in how well they perceived the needs were being met and who should meet them. This finding is in line with Gelling and Prevost's (1999) O'Malley et al's (1991) and Quinn, Redmond and Begley's (1996) findings.

In a later study, Omari, (2009) explored to what extent the family needs of 139 family members participants were being met and by whom. The results showed that none of the 10 most important needs identified by the family members were considered as being met. Seven of the 10 of those most important needs were under the assurance dimension and the other three were under information, consistent with Warren, (1993). Also, the ICU nurses were perceived as the most appropriate person to meet 12 out of 44 items on the NMI.

Family members and healthcare providers clearly have different viewpoints of how well the family needs are being met and by whom. The family members perceived their important needs as being unmet. They also identified the nurses as the best to meet these needs followed by the doctors. The key issues for healthcare providers meeting family needs were that they should firstly understand the experience and

encourage family members to express their feelings, reassure them, provide sufficient and consistent information, facilitate involvement in the care and build a trusting relationship with the families (Lee, MacKenzie & Chien, 1999). Molter (1979) also recommended that support groups facilitated by ICU staff should help meeting family needs. Furthermore, structured family meetings and conferences, providing information, flexible visiting times are interventions which can help in meeting relatives' needs (Paul & Rattray, 2007).

## **2.6 Family involvement in routine care**

The involvement of family in the care of hospitalised patients is an accepted and growing trend in today's care. Involvement of families theoretically and practically is essential components of the holistic approach (Hammond, 1995). Family involvement in some of the patient's personal care may serve to decrease the powerlessness and the anxiety the family may feel (Titler et al. 1995). This includes involvement of family members in routine care, the daily living activities such as feeding the patient, helping with baths or linen change, providing back care, turning the patient or giving fluids (Wahlin, Ek & Idvall, 2009). This development has implications for the working situation of nurses and other healthcare professionals and ultimately for the quality of care. Involving families in improving nursing care is vital to quality performance improvement. Angood et al, (2010) stated that family wishes must always be respected and everything possible must be done by healthcare providers to honour the wishes of the patient and their family. They suggest that if family input is emphatically built into a system of performance improvement and if families are taken seriously, then an organisation can continuously improve.

### **2.6.1 Benefits of family involvement and factors affecting involvement**

Gardner and Stewart, (1978) argue that family involvement benefits patients, families and staff members. Family involvement can lead to decreased anxiety, increased reassurance, better cooperation, mutual understanding and empathy and improved patient care (Gardner & Stewart, 1978). They addressed factors that may affect the staff-family involvement in the care. These factors include: workload, staff attitudes regarding visitation, age, religion, culture and behaviours of patients and family members. Family involvement patterns may include education and information to relieve their anxiety (Gardner & Stewart, 1978); for instance, the family can be taught how an intubated patient may communicate. Furthermore, the medical staff may encourage appropriate expression of feelings, make environmental interventions and provide physical and emotional care. As a result, family members can aid the staff with patient care by providing important historical data and actively encouraging the patient's efforts to recover.

Still, healthcare providers have a diversity of opinions about the role of family members in the patient care process. Family involvement in the routine care studies in this review will be divided into three sections as to how they were perceived by the family members, and by healthcare providers. The third section is a comparison of family members and healthcare providers regarding family involvement in routine care.

### **2.6.2 Family involvement in routine care as perceived by family members**

While there is limited research on perceptions of family involvement during routine care, there is some evidence suggesting that their inclusion in the care provides them with some satisfaction. Liddle, (1988), investigated some of the needs as perceived by family members of patients admitted in the ICUs. A total of 10 relatives filled in the questionnaire that was developed for the study: three husbands, one wife, five daughters and one mother. The majority of the family members wanted to be involved in the care of their loved one. However, none of the relatives was offered the opportunity by the nurses to do so: a daughter of a patient stated "If it had helped my mum I would've been glad to" (Liddle, 1988 p. 154). This study suggested a care plan and teaching plan to help alleviate relatives' fear and enable them to care for their family members in hospital if they and the patients wished to do so. The study concluded that family members should be taught how to give care that might be necessary at home.

Astedt-Kurki, Paunonen and Lehti, (1997) explored how family members experienced their visits to the hospital and what they expected from the nursing and other medical staff. The results showed that family members believed that, mostly, nursing staff were not seriously interested in the family's well-being. This was exemplified by the fact that only one quarter of the family members had been told what they could do in the hospital. Nurses were ranked highly important to support family members during hospitalisation than doctors. The majority of family members indicated that doctors were very hard to "get hold of" in the hospital. Over half of the participants said they were directly involved in the care of their loved one. Family members believed that their admitted relatives look forward to their visits and that they could be of help to

physically and psychologically support them. Accordingly, nurses and other healthcare providers should facilitate the involvement of families in the process of care.

Eldredge, (2004) used a repeated-measures design to assess relationships of closeness, helpfulness and optimism to emotional outcomes. The study aimed at describing the spouses' helping behaviours at the ICU bedside and to explore how well preferences for closeness and helpfulness explain variation in spouses' emotional condition during their partners' illness. The data were collected from a 16-bed Medical ICU/Coronary Care Unit in a tertiary care community hospital affiliated with a north-eastern university medical centre. Results indicate that closeness and helpfulness are integrated concepts, and that attachment dimensions of a relationship and optimism are useful for understanding spouses' emotional responses to critical illness. The findings also suggest that spouses of ICU patients who are high in what is described as compulsive caregiving or low in optimism are at substantial risk for poor emotional condition. Nurses are in a unique position to help spouses clarify and achieve goals. Because of their prolonged contact with patients, nurses may be able to suggest uncomplicated helping activities that would enable spouses to feel both necessary to, and capable of, participating in the care of their ill partners.

Vandall-Walker, Jensen and Oberle, (2007) developed a grounded theory of nursing support from the perspective of family members of critically ill adults within the context of two Western Canadian teaching hospitals to address a gap in the theoretical knowledge about how nurses help these individuals. Twenty families were recruited in the study through a convenience sample. The results highlighted that family

members were initiated into a cycle of work to meet perceived responsibilities to "get through" the experience. Supportive nurses engaged in the process of "lightening our load" to mitigate the negative effects of the critical care experience on family members by "engaging with us, sustaining us, and disengaging from us". This theory extends the understanding of nursing support beyond current knowledge of family needs, caring, comfort, supportive care and social support. It also constitutes one important step in the development of theoretical nursing knowledge about the process of nursing support for family members of critically ill adults. Because of the small sample size, the results can only be generalized with caution to develop theoretical nursing knowledge about the process of nursing support for family members of critically ill adults.

Similar findings were identified by Mitchell, Chaboyer and Burmeister (2009) in a clinical trial study with a non-equivalent control group pretest-posttest design. This study was to determine the effect of family-centred nursing intervention on the perceptions of family members of critical care patients as measured by respect, collaboration and support. At the control site, patients' families experienced usual care, and at the intervention site patients' families were invited to assist with some of their relatives' fundamental care with nurses' support. The family-centred care survey was used to measure families' perceptions of respect, collaboration, support and overall family care at baseline and 48 hours later. A total of 174 family members of patients participated (75 control, 99 intervention). The study outcome suggests that partnering with family members to provide fundamental care to patient significantly improved the respect, collaboration, support and overall scores on the family centred care survey at 48 hours. Authors concluded that for critical care nurses to provide

holistic care, this must involve patients' families in patient care and by doing so will better meet the needs of the patients' families.

There is evidence to suggest that family involvement in the care will empower them to further support the ICU patients. Wahlin, Ek and Idvall (2009), using a phenomenological method, found that participation in the care enhanced the next of kin's experiences of empowerment in an intensive care situation. All next of kin participants (spouses, siblings, parents or children of ICU patient) were empowered by the caring atmosphere where they received continuous, straightforward and honest information that encouraged hope and in which closeness to patient was facilitated and medical care was perceived as the best possible. More importantly, some of the participants were also strengthened by support from other family members and by being involved in caring for the patient. The findings of the study emphasise the importance of discussing attitudes and behaviours, as well as surveillance and treatment when trying to improve the care of next of kin in the intensive care unit, and also conducting staff development. The phenomenological approach used in the study allowed the participants to reveal their experiences freely. However, perhaps those family members, other than next of kin, may have other experiences to share and express. Therefore, limitation of the participants to the next of kin only may have constrained the findings.

In summary, the review of studies identifying the family involvement to provide the routine care to their critically ill patients highlights the families' desire to be involved in the care of their loved one. When families are involved this appears to lessen their anxiety and, in doing so, they are able to support their critically ill relative.

### **2.6.3 Family involvement in routine care as perceived by healthcare providers**

The function of critical care providers, the interaction and the relationship between the healthcare providers and family members of critically ill patients is discussed here. This section will also identify the attitudes of healthcare providers in relation to family involvement during routine care as a key priority. In a small Swedish research study (n = 10), Soderstrom, Benzein and Saveman (2003) attempted to describe nurses' experiences of interactions with family members in the ICU. The data collected came from interviews of nurses that lasted for one hour. The nurses were asked to describe positive and negative interactions with the family members in the ICU and about their thoughts and feelings in the interactions with family members.

The findings of this study revealed two categories of how nurses described their experiences. The two categories were inviting and non-inviting interactions between nurses and families. In inviting interactions, nurses considered family members as important in nursing care and important to create contact with and engage in the nursing care. Also, nurses believed that having a good relationship with families was a requisite for providing good care for both patient and family. On the other hand, in non-inviting interactions, nurses believed that medical and technical tasks were considered to be the most important nursing duties and saw themselves as technical experts, having little time for family members and having problems with creating relationships. Additionally, they did not want interference in their work by the family members, and felt disturbed by family members asking them questions. A limitation of this study was the small sample size; it was difficult to determine whether the interviews with just 10 participants were adequate to ensure theoretical saturation.

The article was silent about this point, perhaps more interviews with nurses (>10) from more than two hospitals would enrich the gathered data.

Similar results to those by Astedt-Kurki, Paunonen and Lehti, (1997) and Mitchell, Chaboyer and Burmeister, (2009) were found by Fisher, Lindhorst, Mathews, Munroe, Paulin and Scott (2008) who assessed the attitudes and values of nursing staff towards family presence during routine nursing care. This was a cross-sectional descriptive study using a survey technique and was conducted in a rural community hospital in the United States of America. The data collected from a convenience sample of 89 nursing staff, using an 18-item questionnaire developed by the authors. The results indicated that nurses' attitudes and behaviours towards family presence during routine nursing care were favourable. There was low agreement about family members being allowed to visit whenever the patient wished. Nursing staff attitudes were consistent with their self-reported behaviours supporting family presence. Nursing staff who believe family presence was important were more likely to include families in daily care. The study concluded that the organisation plays a key role in encouraging family-centred care by providing appropriate education and support to nursing staff. Also a systematic process is needed to assess nurse attitudes about family presence to guide in-service educational programs.

Another study was released in the same year by Benzein, Johansson, Arestet and Saveman (2008), which investigated the attitudes of registered nurses (RNs) about the importance of involving families in nursing care. A random selection of 634 Swedish RNs completed the questionnaire developed for the study. This large survey study reported that the Swedish RNs held a supportive attitude about families. As high

scores were found for the subscales: family as a resource in nursing care, family as conversational partner, family as burden and family as its own resource. Male nurses, newly graduated nurses and nurses who had no previous experience to the care of families at the place of work had less supportive attitudes about involving families in nursing care. Additionally, the authors indicated that when nurses have a supportive attitude, families will be invited to cooperate as partners in nursing care. If nurses and families work in partnership, satisfaction with the outcome of care is likely to increase. This study was unique in its design, as no other studies have used a random sample of RNs, which enhanced the rigour and trustworthiness of the findings.

#### **2.6.4 Comparison of family members and healthcare providers'**

##### **perspectives on family involvement in routine care**

Only two studies were found which compare both the family members' and healthcare providers' perceptions regarding family involvement during routine care. The first study was a mixed method design by Hammond (1995) to describe the positive and negative attitudes of intensive care nurses and relatives of critically ill patients towards the involvement of relatives in giving physical care. Methodological triangulation was used for the research approach to enhance reliability and validity. A total of 27 ICU nurses and 20 relatives completed a questionnaire developed for the study.

The results of this study highlighted issues of personal choice for individual lay involvement and adequate information for families to become involved. The major concerns emerging from the nurses' sample were the problems of role adaptation for

nurses, and the relationship with families and building that relationship. However, relatives were more concerned about adapting to the demanding ICU environment and identifying the parameters of their new caring role. The study has highlighted a number of issues relating to the involvement of relatives in the physical care of their critically ill loved one in the ICU. The involvement of relatives may provide the nurse with the opportunity to develop and build a professional caring relationship with each family and consequently enhance the care given to the patient and family as a whole unit.

The second study was by Schiller and Anderson (2003) and explored the family members and nurses' perceptions of family involvement in the daily work rounds with the trauma team. A 25 question survey was sent to selected family participants in order to obtain their retrospective opinions about the inclusion of family members in the daily work rounds. The ICU nursing staff also completed an abbreviated survey to document their perceptions as to how family rounds facilitated care. Consistent with Hammond (1995), the team reported that the rounds with family members resulted in a much improved relationship, the stress diminished, hostility reduced and system dysfunction was less frequent. Moreover, family members reported that the daily rounds allowed them to understand the patient's condition and plans for care. No areas of dissatisfaction were documented by the family members. Also, nurses indicated satisfaction with communication by the team and resultant facilitation of relations with the families. The presence of family members on rounds was a success, as judged by both the healthcare providers and family members. Also, there were no adverse events from the family's inclusion in the daily trauma rounds.

In summary, families in the reviewed studies endorsed the need to be involved in the routine care of their critically ill relative. Generally, healthcare providers had positive attitudes toward family involvement and considered family members as important in the care of their critically ill relative. The healthcare providers indicated that the inclusion and interaction with families improved communication and built relationships which ultimately resulted in providing good care for both patient and family. Further studies are needed to enhance knowledge of both family members and ICU healthcare providers of family involvement during routine care.

## **2.7 Family presence during resuscitation and other invasive procedures**

Family presence during resuscitation and other invasive procedures is an important topic of current debate among healthcare professionals. The literature has shown that attitudes of nurses, physicians and families toward family presence were found to be significantly different (Meyers, Eichborn, Guzzetta, Clark, & Taliaferro, 2004; Moreland & Manor, 2005). Some health care providers feared that family members may end up having traumatic memories of the practice (Redley & Hood, 1997) whereas many family members indicated they would prefer to remain with the patient (Meyers et al., 2004). Physicians were found to be more against family presence during resuscitation and other invasive procedures than were nurses (Meyers, Echhorn, Guzzetta, Clark, Klein, & Taliaferro, 2000; McClenathan, Torrington, & Uyehara, 2002; Maclean, Guzzetta, White, Fontaine, Eichhorn, Meyers, & Desy, 2003).

The idea of allowing family members to be present during resuscitation and other invasive procedures began at the Foote Hospital in Michigan in the United States of America in 1983 (Doyle, Post, Burney, Maino & Rhee, 1987; Hanson & Strawser, 1992). This was when two family members refused to leave their loved one during resuscitation and asked to be with them even for a few minutes to offer what they could during such a crisis event. The American Emergency Nurses Association in 1993 was the first professional organisation to develop evidence-based written guidelines endorsing the practice of family presence during resuscitation. Over the years the option for relatives to be present during resuscitation and other invasive procedures has been highly recommended by a number of medical organizations throughout the world.

Many healthcare organizations, including the American Association of Critical-Care Nurses, American Heart Association, Emergency Nurses Association, Canadian Association of Critical Care Nurses, Royal College of Nursing, British Association for Accident and Emergency Medicine, European Federation of Critical Care Nursing Associations, European Society of Paediatric and Neonatal Intensive Care and European Society of Cardiology Council on Cardiovascular Nursing and Allied Professions have issued statements that family members of patients undergoing resuscitation or other invasive procedure should be given the option to remain during the procedure (Emergency Nurses Associations, 1995; American Heart Association, 2000; Canadian Association of Critical Care Nursing, 2006; Fulbrook et al, 2007). The attitudes of family members during resuscitation and other invasive procedure as perceived by family members will be discussed, followed by the attitude of healthcare

providers toward the practice. However, before proceeding, the benefits of family presence during resuscitation and other invasive procedures are addressed.

### **2.7.1 Benefits of family presence**

According to Meyers et al. (2000), Robinson, Mackenzie-Ross, Campbell, Egleston and Prevost, (1998) and Holzhauser, Finucane and Vries (2006), the benefits of family presence during resuscitation and other invasive procedures include several factors. First, it assists in obtaining the patient's history quickly, thereby actively supporting the patient. Second, family presence helps nurses to provide more holistic care. Thirdly, family presence encourages more professional behaviour among staff during resuscitation. Fourth, it strengthens the link between nurses and families and alleviates many of the doubts. Fifth, it provides an opportunity to educate the family about the condition of the patient. Sixth, the family presence during resuscitation and other invasive procedures reduces family anxiety and fear. Seventh, it is easier to manage family members when they are present in the room with the patient. Eighth, it enables family members to recognise that everything possible is being done to save the patient. Finally, family presence allows the opportunity for family members to say goodbye to their loved one when death occurs.

### **2.7.2 Family attitudes to family presence.**

The presence of family members during resuscitation and other invasive procedures can help them to face the reality of the situation and support the critically ill patient. Much of the literature has examined the attitudes of the family members towards their presence during resuscitation and other invasive procedures, but has neglected to explore the psychological effects of the practice on the family members.

In 1998, a small retrospective survey study took place at an inner-city teaching hospital in London by Barratt and Wallis (1998). The study was to assess the family members' desire to be present and to determine their knowledge of what was involved in the resuscitation process. Thirty-five family members who were not present during the resuscitation were asked to complete a questionnaire three months after their loved one's death. The findings suggested that only four (11%) of the 35 family members were given the option to be present during the resuscitation. Interestingly, of the total sample, 62% of family members would have chosen to be present during the resuscitation attempt if they had been given the option. This study indicated that most of the participating family members did not have an accurate idea of what occurred during the procedure. Therefore, their inclusion may have had a positive impact by knowing that everything possible was done to save their loved one. Family members of patients who survived were not included in the study and their inclusion would have added depth and enriched the study findings.

In the same year, Meyers, Eichhorn and Guzzetta (1998) completed a retrospective survey study of 25 family members who were not present during resuscitation, regarding their attitudes toward the practice. The participants were interviewed via telephone within 8 weeks to 15 months after the patient's death; all patients had received resuscitation and died within 1 hour after admission to the hospital and 95% of the patients' deaths were caused by traumatic injury. The findings here revealed that 80% of family members who were surveyed indicated their desire to be with their loved one during resuscitation; 96% believed that they had the right to be present; 68% believed that their presence would have helped the patient and 64% felt their presence would have helped their sorrow following the death of their loved one.

Regardless of the long period between the death of the family member and the data collection, the family members in Barratt and Wallis (1998) and Myers et al. (1998) confirmed the benefit to the patient and family members and supported the option of being present.

The third study which was conducted in 1998 was a randomised controlled trial in an Emergency Department (ED) in Cambridge, United Kingdom by Robinson, MacKenzie-Ross, Campbell, Egleston, and Prevost (1998). The study concerned the psychological effect on 18 family members who witnessed the resuscitation of their family member. The family members of patients who required resuscitation were divided into two groups: the first was the family members who were given the option to remain during the resuscitation (n = 8). The second was the family members who were not given the option to remain during the resuscitation (n = 10). The relatives were asked to complete five standardised psychological questionnaires within one to six months after the resuscitation. The small sample size and the criteria for subjects which were not provided in the article, have constrained the study findings. The findings showed that relatives who witnessed the resuscitation had lower levels of anxiety, intrusive imagery, depression, and grief than did those who did not witness the resuscitation. No family members in the group reported being frightened or had to be asked to leave the room. The routine exclusion of family members from the resuscitation room may not be appropriate because family presence provides a means of expression for grieving family members.

Myers et al. (2004) using mixed methods surveyed family members, to investigate their attitudes toward family presence during resuscitation and other invasive

procedures. They surveyed 39 family members, following 19 instances of family presence during resuscitation and 24 invasive procedures. The study indicated that all participating family members ascribed benefits to attending resuscitation. They added that for the families of dying patients, family presence afforded the opportunity to say goodbye and come to closure on a shared life for people who believed being with the patient was their right. Family members involved in resuscitation viewed themselves as 'active participants' in the care process, which met their needs for knowing about providing comfort and support for their loved one. All the participating family members surveyed in this study believed that visitation was helpful to them and noted that they would do it again. Also, almost all participants said they thought it was their right to be present with their loved one, and most importantly follow-up did not show they suffered from traumatic effects. They added that other benefits for the family included knowing that everything possible had been done, reducing their anxiety and fear, and easing their bereavement. A strong bias can clearly be identified in the data collection, family members who accepted visitation during resuscitation or other invasive procedures were included in the study while those who refused it were excluded.

Differently from the previous studies, six family members whose loved ones underwent resuscitation and survived were interviewed by Wanger, Kent, Ohio and Ohio (2004) within 24 hours of the resuscitation. This study was conducted in the Coronary Care Unit in a 700-bed urban community hospital in north eastern Ohio. The participants were adult family members and they were asked to describe the experiences, thoughts and perceptions of their critically ill relative during resuscitation in the ICU. The interviews showed that the family members were barred

from the patients' room and asked to wait in another room. They struggled with the question of "should we go or should we stay". The author added that "families lose autonomy and do not gain ground when they attempt to negotiate their way into the resuscitation room" (Wanger et al. 2004, p. 417). The study concludes that when families are not provided information during resuscitation they cannot determine what is going on. Also, during the resuscitation of the loved one the family is in crisis and needs reassurance and informational support to cope effectively. The study had a small sample size due to the exclusion of families whose relative underwent resuscitation and died. Although this exclusion criteria is understandable, it had influence on the power of the study as those members may have opinions and concerns to share that could have enriched the study findings.

A randomised control trial design was chosen by Holzhauser, Finucane and Vries (2006) to study the attitudes of family members who were present during resuscitation. The study was carried out by the researchers in a major tertiary referral teaching hospital in Queensland. Family members meeting the inclusion criteria were randomised to either the control group or experimental group. The control group (n = 40) did not attend the procedure and remained out of the resuscitation room. The experimental group (n = 58) were invited to the resuscitation room during resuscitation. A questionnaire was developed to gather the data for the study based on clinical staff experience and review of literature. The findings showed that the majority of family members in both the control and experimental group were grateful to be present during the resuscitation of their loved one. None of the participants felt pressured or traumatised to be present and 43% preferred to be present. Sixty-seven per cent of control group participants preferred to be present.

Furthermore, in this study all of the family members who were present during resuscitation (experimental group) were glad they were present to support their relative. The vast majority of the experimental group participants agreed that their presence during resuscitation helped them to come to terms with the patient's outcomes. Of the control group, 71.2% thought their presence would have helped them to cope better with their loved one's outcome. Participants in the experimental group (85%) felt their presence was beneficial to the patient's recovery. The findings of this research strongly support the presence of family during resuscitation, and have several clinical implications.

In summary, the family members in those earlier reviewed studies indicated their desire and supported their presence during resuscitation and other invasive procedures. They also advocated further benefits including helping the patient, knowing everything possible was done to save their loved one and support provided to grieving family members. These findings highlight the importance of giving the healthcare providers the confidence in including the family during the care of the patient and considering them as part of the caring team.

### **2.7.3 Healthcare providers' attitudes to family presence.**

The healthcare providers' behaviours toward family members often affect the family members' decision to be present or leave during the resuscitation or any invasive procedures. In 2000, three studies of health professional attitudes toward family presence during resuscitation were released using a survey design which was conducted in three different contexts throughout the world. Meyers, et al. (2000)

conducted a retrospective study in a university-affiliated Level I trauma centre. The authors surveyed a total of 96 medical staff; 14 physicians, 22 residents and 60 nurses, who had participated in resuscitation or an invasive procedure with family members. The participants were asked to complete a 33-item questionnaire developed for the study within 17 days of the resuscitation or invasive procedure event.

Most of the medical staff (96% of nurses, 79% of physicians and 19% of the residents) favoured family presence during resuscitation. The vast majority (95% of the nurses, 77% of physicians and 64% of the residents) were comfortable with family presence during resuscitation or other invasive procedures. The study also evaluated the perceived stress of the 96 health care providers who had performed invasive procedures or resuscitation efforts with family members present. The majority (84%) believed their performance was unaffected by the family's presence. The study concluded that the provider discomfort and inexperience decreased the likelihood of a supportive family presence. Also, the authors claim that family members should be assessed for their coping abilities and emotional stability before the option of family presence during resuscitation is offered. The study resulted in the development of a policy for family presence during resuscitation. The accuracy of the recollections of the medical staff may be questioned in Meyers et al.'s (2000) study, because the survey was completed over two weeks after the actual event.

In the second study, Helmer, Shapiro, Dors and Karan (2000) surveyed 368 members of the American Association for the Surgery of Trauma (AAST) and 1261 Emergency Nurses Association (ENA) members. The study proposed to determine the healthcare providers' opinion regarding the phase of the trauma resuscitation in which family

members should be allowed to be present. The results indicated that only 3% of AAST members' participants, but 59% of ENA members, favoured family presence during resuscitation. The authors concede that the findings were biased by, first, the overrepresentation of ENA members, and secondly because the AAST members do not represent ED staff. Similarly to the previous study, Helmer et al. (2000) suggested the implementation of family presence may cause conflicts and thus impact on the performance of the trauma team.

In a third study, Boyd and White (2000), conducted a retrospective study in the Accident and Emergency (A&E) Department which took place at Hope Hospital Salford in the United Kingdom. The study included only non-traumatic adult cardio pulmonary resuscitation and was to determine whether the presence of relatives during resuscitation altered perceived symptoms of stress in medical staff. An anonymous structured questionnaire was used to survey 114 medical staff 24 hours after participating in resuscitation to obtain symptoms and acute stress reaction based on ICD-10 diagnostic criteria. The results indicated that 25 medical staff reported at least more than two symptoms of acute stress reaction. Of the 25 reporting more than two symptoms, 13 reported with the family being present during resuscitation and 12 without the family being present: there was thus no significant difference between the two groups. The study included only non-traumatic adult resuscitation and excluded the traumatic resuscitation which would have enriched the study findings. The findings here substantiate Meyers, et al.'s (2000) findings that the presence of relatives witnessing resuscitation did not affect self-reported stress symptoms.

In 2002, McClenathan, Torrington and Uyehara (2002) surveyed 592 healthcare professionals attending the International Meeting of the American College of Chest Physicians in San Francisco, using a quantitative method. The questionnaire distributed consisted of six questions about family presence practice and resuscitation experience with relatives. The study found that fewer physicians (20%) compared to nurses and allied health-care workers combined (39%), would allow family members presence during adult resuscitation. Thus study indicating that the majority of intensive care professionals did not support it. They added that the intensive care professionals' opposition was based on many reasons, which included the fear of psychological trauma to the witnessing family members, performance anxiety among the CPR team, and the distraction of the resuscitation team. However, others believed strongly that the presence of family members in the resuscitation bay would positively affect patient care. An interesting significant relationship of this study was found in that the healthcare professionals with previous experience of family presence opposed the practice more than those with no experience.

Maclean et al. (2003) undertook a quantitative descriptive research study using a 30-item survey on a random sample of 1500 members of the American Association of Critical-Care Nurses and 1500 members of the ENA. The study sought to identify policies, preferences and practices of critical care and emergency nurses toward family presence during resuscitation and invasive procedures. The survey consisted of 20 items on demographic data, 9 items on practice, preferences and policies and 1 item for comments and experiences of the nurse. Four hundred and seventy-three intensive care nurses, 465 emergency nurses and 55 nurses who either practised in both areas or did not provide detailed work information participated in the study. The

results indicate that nearly all of the 984 respondents had no written policies for family presence during resuscitation and other invasive procedures, and most preferred it to be allowed. Nearly half the participants indicated that they worked in units that allow family presence without written policies. Thirty-seven per cent of the respondents preferred written policies allowing family presence. Furthermore, most intensive care and emergency nurses supported the practice. These findings are consistent with Meyers et al.'s (2000) findings. The findings of this study also add to the evidence that healthcare providers who have experience with family presence tend to support the practice more than those who do not have experience, in contrast to the study by McClenathan, Torrington and Uyehara (2002).

These findings are important and have implications for conducting research on this issue in different settings because many nurses receive requests from patients' family members to be present during resuscitation and other invasive procedures and nurses are often the facilitators of the family presence. The study concluded that family presence during resuscitation lacked written policy. The study did not undergo reliability testing and appeared to have no construct validity, also the generalisability of the study is limited to nurses.

Ellison (2003) applied a descriptive correlational study with qualitative components to identify the relationship between demographic variables and nurses' attitudes and beliefs regarding family presence during resuscitation or invasive procedures. These demographic variables included educational preparation, specialty certification, experience, completion of a family presence educational offering, age, sex, and ethnicity. A total of 208 hospital nurses and New Jersey ENA members completed the

questionnaire. The study found a statistically significant difference between positive attitudes toward family presence and higher educational preparation ( $r = .216$ ,  $P < 0.01$ ), certification in emergency nursing ( $r = 0.216$ ,  $P < 0.01$ ), and emergency nurse specialisation ( $r = 0.234$ ,  $P < 0.01$ ). These findings support the Helmer et al. (2000) study that certified nurses had more favourable attitudes toward family presence than noncertified nurses.

Qualitative findings revealed that personal factors such as experience with crisis situations, ability to manage crisis situations, and cultural differences between patients/families and nurses were identified as variables influencing respondents' attitudes toward family presence (Ellison, 2003). Qualitative findings also revealed organisational and social factors that can have a negative impact on nurses' attitudes towards family presence. Working in an environment with supportive colleagues such as those with higher education and specialised training was more likely to bring a change in behaviour. Additionally, nurses in Ellison's (2003) study found family presence most acceptable when they or their families were patients. Those findings are limited as the data was collected from only one hospital and one professional nursing organisation.

Two years after the release of the studies by Maclean et al. (2003) and Ellison (2003) another descriptive qualitative study was carried out by Knott and Kee (2005). The study explored nurses' beliefs regarding family presence during resuscitation. The data were gathered from ten Registered Nurses (RNs), one male and nine female with a minimum of 4 years clinical experience working in diverse acute care units through a semi structured interview. The interview consisted of 16 open-ended questions and

lasted for 45 minutes. Certain findings in this study are similar to those in the study by Meyers et al. (2000). Both studies revealed that families should be assigned with staff due to the possibility of psychological harm to the families; staff feelings of being watched; and increased professional behaviour on the part of the resuscitation team when families are present. The issue of disruption by family members was also raised by Meyers et al. (2000) but they commented that nearly their entire healthcare provider sample of 60 RNs and 36 physicians responded that family behaviour toward resuscitation procedures was appropriate.

Findings in Knott and Kee (2005) and Maclean et al. (2003) differed with respect to participants' views about the need for policies. Participants in the Knott and Kee (2005) study were not asked to address the issue of having written policies regarding family presence. In contrast, findings from the Maclean et al. (2003) indicated that most intensive care nurses preferred having policies in place for resuscitation. The MacLean et al. (2003) study also noted that nurses, more than physicians, supported family presence. Family presence is not traditionally practised and it may not be considered, unless brought to the attention of administration by nursing staff committed to changing their policy. The study group in Knott and Kee (2005) was small (n = 10), the age group was limited to 31 to 41 years of age and those factors accordingly limited the generalisability of the study findings. Furthermore, the setting of the interview was different for all nurses and this did not allow consistency in the interview process.

Fulbrook, Albarran and Latour (2005) explored the experiences and attitudes of 124 European critical care nurses to the family presence during resuscitation of adult

patients. The nurses were invited to participate in the study during the first conference of the European Federation of Critical Care Nursing Associations which was held in Paris in May 2002. A self-administered questionnaire was used to capture the attitudes and experiences of nurses. It consisted of biographical data, six questions concerning nurses' experiences of the practice and 30 questions concerning nurses' attitudes of family presence during resuscitation. Generally, critical care nurses supported the presence of family members and the majority (n = 94, 76.4%) thought that allowing family members to be present would reassure them to see that everything possible was done to save the patient.

Further, a majority of the nurses (n = 71, 57.3%) believed that family might draw comfort from sharing the last moment with patient. Nurses from the UK, however, held significantly more positive attitudes toward the practice than their non-UK counterparts. A more important finding of this study was the strong agreement among nurses that there should be a member of the resuscitation team facilitating family members throughout the experience, including providing emotional support, explanations and interpretations of the procedure, to the attending families. The authors believed that cultural values varying from country to country in Europe may have affected the experiences and attitudes of nurses towards family presence during resuscitation. This study relied on convenience sampling of critical care nurses, so there are difficulties in generalising the results to other areas. Additionally, the questionnaire was based on a review of the existing literature rather than an already validated tool; thus its validity and reliability might be questioned. In spite of the study limitations, the authors propose that further policy be developed accordingly to guide clinical practice.

The concept of family presence during resuscitation has also been researched in the Turkish context by Badir and Sepit (2007). This descriptive study with a quantitative approach sought to explore experiences and opinions of critical care nurses regarding family presence during resuscitation in Turkey. The data were gathered using a 43 item questionnaire developed by Fulbrook, Albarran and Latour (2005). The questionnaire consisted of three main areas: demographic characteristics of nurses, experiences of family presence during resuscitation and nurses' opinions of family presence. The study took place at ten hospitals, four affiliated with the Turkish MOH, three affiliated with universities and three affiliated with Social Security Agency hospitals. According to Badir and Sepit (2007) a total of 409 eligible critical care nurses returned the self-report questionnaire.

The results of Badir and Sepit (2007) indicated that more than half of the nurses had no experience of family presence during resuscitation and none of them had ever invited family members to be present during resuscitation. The study indicated that the majority of the nurses did not agree that it was necessary for family members to be with the patient during resuscitation and they did not want family members to be present. In fact none of the Turkish hospitals that participated in this study had a protocol or policy allowing family members to be present during resuscitation. The findings reveal that critical care nurses in Turkey are not familiar with the concept of family presence during resuscitation; accordingly, the authors further recommended educational programs about this issue and policy changes within the hospitals to enhance critical care.

Mian, Warchal, Whitney, Fitzmaurice, and Tancredi (2007) designed and implemented a program of family presence during resuscitation at the Urban Academic Medical Centre. The study assessed the attitudes of all nurses and physicians regarding family presence during resuscitation, using a two group pre-test post-test design. The initial survey was completed by 86 nurses and 35 physicians and the follow-up survey was completed by 89 nurses and 14 physicians. The questionnaire included three parts, demographic information, professional attitudes and behaviours and personal and professional experience of the practice. Consistent with Meyers et al. (2000), McClenathan et al. (2002) and Maclean et al. (2003) the study found that nurses showed stronger support for the rights of patients to have their families present than did physicians on both surveys. The authors in this study failed to identify the psychological effects of family presence during resuscitation on medical staff; also a limitation that was highlighted by the authors was that anonymity of participants did not allow the authors to evaluate individual change in the practice. Despite the differing concerns of nurses and physicians, the implementation of a family presence program was successful and is now the standard practice at the hospital where the study was conducted.

At the same time that the study by Mian et al, (2007) was released, another two studies in different contexts have been published on family presence during resuscitation. The first was by Madden and Condon (2007) who examined the perception of 90 emergency nurses toward the family presence during resuscitation at Cork University Hospital in Ireland. The authors in this study used a descriptive quantitative design through a questionnaire utilized for the study which was developed by the ENA. The sample was a convenience sample of 90 nurses working

in a level 1 trauma ED with over six months' experience. The nurses were predominantly females (83.3%) in the 30 to 40 years age group and were employed as staff nurses (80%). Surprisingly, the study showed that 58.9% of the participants had invited family members to attend the resuscitation. Another 17.8% had not had the opportunity to do so, but would allow the family members to be present if the opportunity arose. However, 74.4% of the nurses preferred a written policy which gives the family members the option of being present during resuscitation. In spite of using a quantitative design which did not allow the nurses' perceptions to be explored in detail, the study has clinical implications. The study emphasised the need to develop educational programs for nurses on the safe implementation and practices of families witnessing resuscitations.

A descriptive study using survey methods was conducted by Holzhauser and Finucane (2008) who investigated the outcomes of family presence on staff attitude immediately post-resuscitation. The findings here are part of a larger project of family presence that was conducted at a tertiary referral hospital in Brisbane in Queensland, Australia. The participants of this study were any medical staff members present during resuscitation of patients who met the inclusion criteria for the study. The inclusion criteria for an eligible resuscitation were Australian patients presenting as Triage Categories 1 or 2, with or without an altered level of consciousness, hypotension, respiratory distress or the need for CPR. The majority of the informants were nurses, followed by registrars, residents, consultants then social workers. In this survey, the staff felt there were positive aspects and advantages for relatives being present during resuscitation. These advantages include being able to obtain a medical history quickly; the patients being comforted by having relatives present; and the

relatives benefiting by being present; thus the staff thought it was easier to manage while the relatives were present.

This study provided an Australian and international perspective to the existing research literature on staff attitudes to family members present during resuscitation, and a new perspective as well by examining staff attitudes immediately post-resuscitation. The findings of this study further support the presence during resuscitation within an environment that supports staff to undertake the care of the patients with their family being present

Nurses' opinions of family presence during resuscitation have been influenced by culture and religion, according to a study by Cunes and Zaybak (2009). This study replicated Fulbrook et al. (2005) and Badir and Sepit's (2007) survey to determine the experiences and attitudes of Turkish intensive care nurses concerning family presence during resuscitation. Using a descriptive design research study, Cunes and Zaybak (2009) surveyed 135 intensive care nurses from two university hospitals in Izmir by structured questionnaires developed by Fulbrook et al. (2005). The vast majority (88.1%) disagreed that family members should be given the option to remain with their loved one during resuscitation. Only 22.2% of the intensive care nurses participated in resuscitation where family members were present. Almost all nurses (91.1%) agreed that they did not want family members to be present.

In addition, all nurses indicated that they had no protocol on family presence during resuscitation. Nurses agreed (72.6%) that family members, if present, would interfere

with the resuscitation team performance and 86.6% of nurses believed that witnessing resuscitation by family members is a traumatic experience and a very stressful situation. The findings of this study are consistent with those of Badir and Sepit (2007) as to the lack of support of Turkish intensive care nurses which is a result of nurses having no knowledge, and neither policy nor protocol for family presence during resuscitation. The researchers concluded that educational programs, if implemented together with the developmental of protocols and guidelines, should both aid in the acceptance of the concept by the intensive care nurses in Turkey. The instrument used did not have any open ended questions to allow nurses to write their additional thoughts.

Koberich, Kaltwasser, Rothaug and Albarran (2010) conducted another descriptive survey study to explore the German intensive care nurses' experiences and attitudes toward family presence during resuscitation. The study used the questionnaire which was developed by Fulbrook et al. (2005); however, a fourth section was added to allow delegates to further write any additional concerns related to the issue. Unlike Fulbrook et al. (2005) this qualitative data enhanced both the depth and comprehensiveness of the participants' experiences. A total of 164 intensive care nurses were recruited who attended the 26<sup>th</sup> Reutlinger Fortbildungstage held in Reutlingen, Baden-Wurttemberg, Germany during September 2008. According to the researchers, most of the participants (68%) did not agree that family members should be given the option of being present during the resuscitation of their loved one. Also, over half (56%) were concerned that family presence would disturb the performance of the resuscitation team.

Consistent with Fulbrook et al.'s (2005) informants in this study, 73.5% agreed that there should be a dedicated member of the resuscitation team who should be available to meet the family needs, for instance to support and explain the resuscitation procedure to the family members. Moreover, 68% of nurses believed that family presence could help them to know that everything possible was done for their patient, which was also found by Fulbrook et al. (2005). Nurses in this study indicated that they rarely invited family to be present, which might be due to the lack of unit protocol or practice guideline. Researchers interpreted that the nurses' decision regarding practice might have been influenced by the German cultural values and societal traditions. The study encouraged simulation training techniques to assist practitioners to increase their confidence, overcome their fears and support the family during the situation: those topics are to be introduced within the nursing curricula.

In a Muslim community of Iran, a study was undertaken to determine the opinions of healthcare providers of family presence during resuscitation and other invasive procedures in four teaching hospitals in Tehran (Kianmehr, Mofidi, Rahmani & Shahin, 2010). A total of 200 healthcare providers were surveyed by a questionnaire developed for the study which asked about the demographic characteristics of the respondents, years of working experience, and opinions about relatives' presence during intubation and resuscitation. The participants' age, gender, experience and speciality did not correlate with the participants' attitudes toward family presence. However, participants with previous exposure to family presence were more in favour of family presence. Similar to a study previously sampled from nurses in another Muslim community in Turkey by Badir and Sepit (2007), the results of this study revealed that the majority (77.9%) opposed the practice. The most common reasons

for the participants' opposition, as indicated by the authors, were the healthcare providers' fear of psychological trauma to family members, possible interference with patient care as the Muslim families are potentially closer and more prone to display emotions which may distract the resuscitation team.

Further, on Muslim communities, Al-Mutair, Plummer and Copnell, (2012) surveyed 132 nurses using a self-administered questionnaire in two hospitals in Saudi Arabia. Al-Mutair et al. (2012) found that 75.6% of the participants did not support the family presence practice indicating the same reasons as Kianmehr et al. (2010) for opposition such as witnessing resuscitation is a traumatic experience and fearing that family members will negatively impact on the resuscitation team. An interesting finding of Al-Mutair et al. (2012) was a statistically significant relationship between nurses with previous experience of family presence and support for the practice. Nurses with previous experience of family presence opposed the practice more than nurses with no previous experience ( $p = 0.001$ ). However, this was not the case in a study by Leung and Chow, (2012) where ICU healthcare providers with previous experience of family presence during resuscitation were found to be more supportive of the practice, compared to the healthcare providers with no previous experience. Al-Mutair et al. (2012) maintained that the Islamic religion and the Saudi culture influenced the nurses' attitudes toward the practice of family presence.

In general, most of the reviewed studies were descriptive, using either quantitative or qualitative approaches. The studies demonstrated that healthcare providers have significantly different opinions regarding family presence during resuscitation and other invasive procedures. Some oppose family presence for many reasons including

that the practice would be offensive, produces stress in staff and that family members may interfere with the treatment. Other healthcare providers were comfortable with the family presence and believed that it would positively affect patient care, agreeing that their presence would reassure them that the best care is being provided. Regardless of the difference in healthcare providers' views, some endorsed the need for written policies to allow family presence and others suggested a "nurse facilitator" dedicated to evaluate readiness of the family members to attend the procedure and explain it to them when they attend.

## **2.8 Conclusion**

The review of literature in this chapter has described family concerns of hospitalised patients including three aspects: family needs, family involvement in routine care and family presence during resuscitation and other invasive procedures. The studies in each section were addressed as perceived by family members and as perceived by healthcare providers. The evidence highlights that the perceptions of family members and healthcare providers' of the three aspects were found to be incongruent.

Several studies have focused on the needs of family members within the critical care environment. Many of these studies have adopted a quantitative approach utilizing Molter's (1979) CCFNI and obtained very similar results which support the CCFNI construct validity; accordingly, it had strong validity. Most of those studies indicated that family members ranked the information and assurance need statements as highest in importance. On the other hand, healthcare providers were found to prioritize the family needs differently from the family members. This literature has also focused on

the phenomenon of gaining a better understanding of how well families' needs are being met and who is the most appropriate person to meet each need as identified by the family members or the healthcare providers. The review showed that the family members perceived their important needs as being unmet and identified the nurses as the best person to meet their needs followed by the doctors.

Furthermore, the literature has considered family involvement in routine care and demonstrated that their involvement offered potential benefits to patients and their families. Both family members and healthcare providers held positive attitudes toward family involvement during routine care; also the healthcare providers supported the families' desire to be involved in the care of their critically ill family members. The review revealed that the involvement of family members taking part in aspects of patient physical care should be empowering and supportive to both patient and family members. Additionally, studies on family presence during resuscitation and other invasive procedures showed that family members mostly had positive perceptions toward family presence and some healthcare providers agreed, while others opposed the practice. However, it was obvious that the research so far has failed to identify the psychological effects of family presence on the families during resuscitation and other invasive procedures on family members.

A significant finding of this literature review is that researchers have neglected to recognise family needs in relation to the influence of cultural and religious values held by the family members and the healthcare providers. To date, studies of family needs and family involvement in the care of their loved one have been conducted mainly in Western societies, without particular reference to culture or religion and only a few

studies have been conducted in Muslim societies. This raised questions for the researcher about the need to further identify the perceived family needs for Saudi families together with their involvement in routine care and resuscitation and other invasive procedures. Beside the family needs and involvement, this proposed study considered the Saudi culture's uniqueness which could contribute to the nursing knowledge and cultural competence. The diversity of family structure and relationships directed the use of a mixed method design which will be discussed in the next chapter.

## **Chapter Three: Research Design**

### **3.1 Introduction**

Triangulation afforded the opportunity to investigate the research question with greater confidence. Two complementary research methods were used to capture multiple forms of evidence in an integrated mixed methods approach, quantitative data was in the Phase 1 and qualitative data in Phase 2. In this study, in order to identify the family needs and the attitudes of healthcare providers to family involvement in care, the use of a mixed method design was employed in order to explore the phenomenon from different angles, using different types of data. The data collection strategies were then utilized to complement each other. Integration was important to consider at the earliest stage of design, conceptualization of the study (Fetters, Curry & Creswell, 2013).

This chapter begins by introducing the mixed method approach and the development of the method and its value, the design selected for this study, and the subsequent journey. In this chapter the study setting is discussed, also the ethical considerations which framed the study, sampling methods, recruitment process, data collection strategies, data quality and analysis in the quantitative phase. The qualitative phase includes discussion about the data collection instrument, data analysis and strategies undertaken to ensure rigour and trustworthiness of the findings.

### **3.2 Development of the mixed method approach**

Mixed method research was developed by the American psychologists Campbell and Fiske in 1959, who referred to it as multi-method or multi-trait research (Morse, 2003). Mixed method research has gained increasing popularity over the last two decades and has been identified as the third major research approach after the quantitative and qualitative approaches (Johnson & Onwuegbuzie, 2004; Creswell & Plano-Clark, 2007). Broadly speaking, mixed method research design refers to the combination of quantitative and qualitative research methods to provide depth exploration of the research problem in place of one approach by itself (Greene, Caracelli, & Graham, 1989; Creswell, 2005). Tashakkori and Teddlie (2003) describe mixed methods as a "research design in which qualitative and quantitative approaches are used in different types of questions, research methods, data collection and analysis procedures, and/or inferences" (p. 711). According to Creswell (2009), mixed method research is an approach to inquiry that combines or associates both qualitative and quantitative forms of research. This approach involves philosophical assumptions, the use of qualitative and quantitative approaches and combining them in a study. Johnson, Onwuegbuzie and Turner (2007) argue that combining method research is the third paradigm that can provide the most informative, balanced, complete and useful results and partners with the philosophy of pragmatism.

Creswell and Plano-Clark's (2007) four-design framework is built from mixed method literature and represents a "parsimonious typology" that is straightforward to apply (Plano-Clark, Huddleston-Casas, Churchill, Green & Garrett, 2008). They described the four major designs of mixed method as triangulation, explanatory, exploratory and embedded design. Triangulation design is the oldest form of mixed

methods research and is used to compare quantitative and qualitative forms of evidence to corroborate results or identify discrepancies between data sources (Creswell, Plano-Clark, et al., 2003; Plano-Clark, et al., 2008). Quantitative and qualitative data in the triangulation design are collected at the same time and often analysed in parallel (Creswell & Plano-Clark, 2007). The explanatory mixed method design is used when qualitative data explains or expands on initial quantitative findings or when quantitative findings are needed to direct the selection of participants for qualitative investigation (Morse, 1991; Morgan, 1998). Therefore, the data collection in the explanatory design takes place in two sequential phases. The quantitative data collection and analysis occurring in the first phase provide the overall emphasis of the study followed by the qualitative data collection and analysis in the second phase (Creswell, Plano-Clark, et al., 2003).

The third mixed method approach is the exploratory design, beginning with a qualitative data collection and data analysis building to a secondary quantitative phase (Creswell & Plano-Clark, 2007). According to Creswell and Plano-Clark (2007), this design is best suited when there is lack of a theoretical framework, instruments or variables, or when a phenomenon is needed to be explored qualitatively before measuring or testing it. The embedded mixed method design is the final design discussed in the Creswell and Plano-Clark (2007) typology. In this type scholars use one type of data source (quantitative or qualitative) to support the other method type (Creswell & Plano-Clark, 2007). The study is guided by either a quantitative or qualitative methodology that frames the direction of the study; this is so the supplemental data can be collected before, after or during the collection of the focal

data and is done to enhance the study findings overall (Greene & Caracelli, 1997; Creswell & Plano-Clark, 2007).

The mixed methods design is distinguished by the timing, weighting and mixing of quantitative and qualitative elements (Creswell & Plano-Clark, 2007). In mixed methods design, a decision must be made as to when the quantitative and qualitative methods will be implemented relative to each other (Greene, Caracelli & Graham, 1989). According to Morgan (1998) timing in mixed method studies refers to when the data are collected, analysed and interpreted. There are two timing options for quantitative and qualitative data collection and analysis in mixed methods research either "parallel or sequential phases" (Creswell, 2009; Teddlie & Tashakkori, 2009). A parallel phase is where the collection of qualitative and quantitative data occurs simultaneously in one phase. Sequential timing on the other hand involves sequencing of the two methods. In the sequential approach each method is implemented in one phase, therefore it is time-consuming because of the extensive data collection and analysis required (Creswell, 2005). In addition to the timing, weighting is very important for addressing the study's purpose in mixed methods (Morgan, 1998). Mixed method studies, depending on the research questions and philosophical assumptions, have either an equal or an unequal weight (Morse, 1991). The equally balanced weight places equal emphasis on both quantitative and qualitative aspects, and an unequal balance may prioritise quantitative or qualitative aspects (Plano-Clark et al., 2008).

When using a mixed method it is important to carefully mix quantitative and qualitative aspects of the study and how the quantitative data and results are related to

the qualitative data and results (O'Cathain, Murphy & Nicholl, 2007). Creswell and Plano-Clark (2007) argue that mixing occurs in one of the three ways that the two data sets are merged, connected or embedded. Merged research integrates the two data sets either during data analysis or during the final interpretation and discussion such as in a triangulation design (Plano-Clark et al., 2008). In connected studies such as explanatory and exploratory design, one type of data is linked to the results of the other type (Plano-Clark et al., 2008). Embedded designs use one type of data within the context of a design of the other type and this mixing occurs not just at the data level but at the design level (Greene & Caracelli, 1997; Plano-Clark et al., 2008).

### **3.3 The value of mixed methods research**

Perhaps the greatest value of mixed methods research is that it looks at a research problem from a number of different angles and can provide the most appropriate means to answer the research questions (Williamson, 2005; Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2003). Also, in mixed method research the strengths are heightened and the weaknesses are diminished within one particular single study (Johnson & Onwuegbuzie, 2004; Schnieder, Whitehead, Elliott, Lobiondo-Wood & Haber, 2007). In other words, the weaknesses in one method can be counterbalanced by the strengths in another. Greene (2006) maintains that the combination of both quantitative and qualitative data yields a more complete analysis and the two complement each other. Thus a mixed method design strengthens the reliability and validity of the research through corroboration and mutual assurance. Polit and Beck (2006) note that the judicious blending of qualitative and quantitative data can enrich and enhance the evidence base. Moreover, four advantages of integrated designs were identified by Polit and Beck (2006) which involve the following:

- Complementary: quantitative and qualitative data represents the two fundamental languages of human communication, numeric and narrative (Teddlie & Tashakkori, 2009). By using mixed methods in one study the limitations of a single approach of data collection can be avoided.
- Incrementality: this refers to the incremental progress of mixed method research (Polit & Beck, 2006). For instance, quantitative findings may need clarification through in-depth probing and qualitative findings may generate hypotheses that can be tested quantitatively.
- Enhanced validity: in mixed methods studies researchers can be more confident about the validity of their results because the hypothesis or model is strongly supported by the complementary types of data.
- Creating new frontiers: this may happen as sometimes quantitative and qualitative findings are incongruent with each other. This incongruence, if it happens in a single approach can lead to further inquiry and explorations, whilst mixed methods research can make a meaningful distinctions in such circumstances.

The following is an explanation of the research design used in this study.

### **3.4 The study design**

A decision was made to use a sequential, descriptive, explanatory mixed method design in two phases to answer the research questions. This mixed method design was considered the most appropriate for the proposed study to identify the perceived needs of the Saudi families' and healthcare providers' attitudes towards family involvement during routine care and family presence during resuscitation and other invasive procedures. Ganong (1995) argued that the mixed method design is viewed as the most suitable design for exploring the diversity of families' complexities. Those

complexities arise from the factors which influence and shape families such as social, political, cultural, gender and generational norms. According to Ganong (1995) the use of one method only will result in ignoring the family and cultural diversity issues.

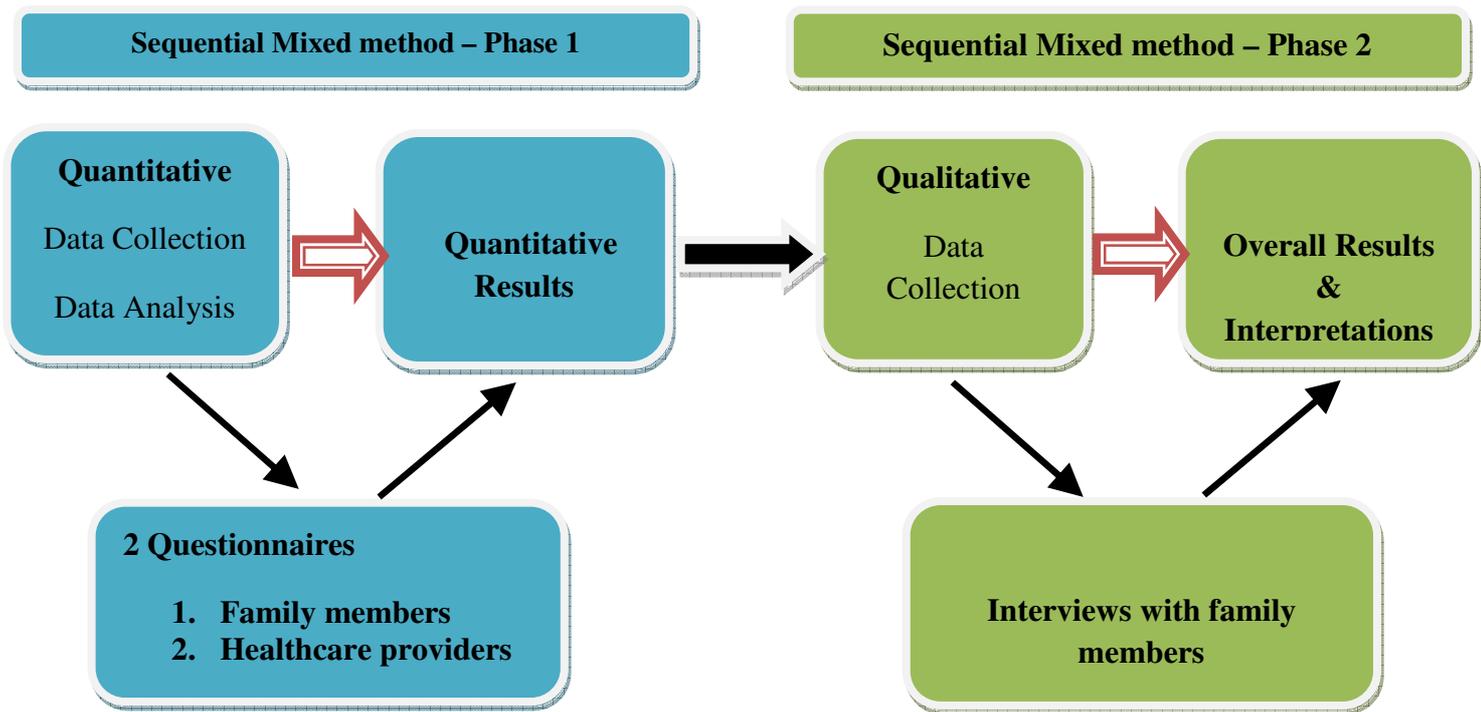
Little is known about how values of the family affect the needs of Saudi families of critically ill patient in the ICU. In addition, no mixed method study has examined the needs of Saudi families and only two studies were identified that used mixed method designs to achieve an understanding of the needs and experiences of Australian and Korean ICU patients' families (Burr, 1998; Yang, 2008). Therefore, it was timely and appropriate to identify the perceived needs of the Saudi families and the attitudes of healthcare providers regarding family involvement using mixed method design which would be able to contribute to nursing knowledge and cultural competence. Accordingly, the data collection methods were designed to complement each other in order to explore the phenomenon from various angles (Creswell & Plano-Clark, 2007). The qualitative research method was to give voice to Saudi families who had no voice in the current literature and to enhance the main data gathered from the questionnaires.

#### **3.4.1 The sequential voyage of the research**

The study adopted a sequential explanatory mixed method design with more emphasis and priority on the quantitative research method (Morgan, 1998; Creswell & Plano-Clark, 2007, Creswell, 2009). In sequential mixed methods, the quantitative and qualitative phases of the study occur in chronological order (Teddlie & Tashakkori, 2009). The data collection of the qualitative strand emerges and depends on the quantitative strand (Creswell & Plano-Clark, 2007). In other words, the qualitative

interviews with family members could bring out the missed elements and expand on what was learned from the analysis of the quantitative questionnaires (Morgan, 1998). The two approaches of data are separate but connected (Creswell, 2009). According to Morgan (1998) the implementation of sequential designs is considered the most practical strategy for mixed method studies. The adoption of sequential mixed method designs was guided by the straightforward nature of the design and its implication for the rigour or validity of the findings (Creswell, 2009). It is argued by Creswell (2009) that the use of different data sources in a sequenced order helps to confirm, cross-validate and corroborate findings. However, this design involves a long time in data collection and analysis, with two separate phases (Creswell, 2009).

The sequential mixed method design used in this study is outlined in Figure 3.1. This diagram shows the quantitative and qualitative strands, the tools and the data. Phase 1 was a descriptive, explanatory phase using a self-administered, close-ended questionnaire to collect data from family members and ICU healthcare providers. Phase 2 was a sequential explanatory phase using face-to-face semi-structured interviews with family members to address domains identified from the questionnaire.



**Figure 3.1:** Sequential, Explanatory Mixed Methods Design based on Creswell and Plano-Clark (2007).

### 3.5 The study setting

The setting of the research is an important feature to consider when designing a study. The researcher had worked for the MOH for several years prior to the commencement of the study. This facilitated access to hospitals under the management of MOH. A decision was made to select a number of major trauma hospitals with ICUs also operated by the Ministry from different areas in Saudi Arabia. The eight hospitals invited to participate in this study are located in Riyadh, the capital city in the Central Province of the country; Dammam, Qatif and Hofuf in the Eastern Province; Jizan in the Southern Province and Medina in the Western Province. This was to capture different views and opinions from family members and healthcare providers situated in different areas in the country.

The invited hospitals were as follows: King Saud Medical Complex-Riyadh, King Fahad Medical City-Riyadh, King Fahad Specialist Hospital-Dammam, Dammam Medical Complex, Qatif Central Hospital, King Fahad Hospital-Hofuf, King Fahad Central Hospital-Jizan and King Fahad Hospital-Medina. The selection of those hospitals was based on the hospital bed capacity, ICU bed capacity and the admission rate in the ICU.

- 1) The hospital bed capacity had to be at least 300 beds with and adult ICU not less than eight beds.
- 2) The ICU had at least an average of one patient admission rate every day.

The researcher obtained the approval Monash University Human Research Ethics Committee (MUHREC) to conduct the research from in the selected hospitals (see Appendix A). The approval was also obtained from the General Administration for Medical Research (GAMR) which is the principal governing body for conducting medical research in the MOH facilities in Saudi Arabia (see Appendices B, i-iv). The GAMR then informed the participating hospitals of the decision to undertake the research and facilitate the researcher's task.

### **3.5.1 King Saud Medical Complex-Riyadh (KSMC)**

King Saud Medical City is a large tertiary care hospital in Riyadh province, providing all healthcare services, with a capacity of 1500 beds. The hospital is operated by the MOH and provides all healthcare services free of charge to all patients from Riyadh province. KSMC had a closed-model, mixed medical-surgical 11-bed ICU, admitting an average of 1778 patients every year with a rate of 4 patients' admissions per day. There were two visiting periods available for family members-one hour each from

4:00 to 5:00 pm and 7:00 to 8:00 pm, and no more than two visitors could visit at a time. There was no waiting room for the family members in the ICU; nor was there any special protocol or even informational booklets used to liaise between healthcare providers and family members or to describe the ICU to them. Also, family members were not allowed to participate in the patient's physical care.

### **3.5.2 King Fahad Medical City-Riyadh (KFMC)**

King Fahad Medical City is a healthcare complex located in Riyadh, providing all healthcare services under the supervision of MOH. KFMC is one of the largest healthcare facilities in the Middle East countries with 1400 beds. The hospital provides a wide range of healthcare services including Oncology, Haematology, Cardiology and Obstetrics. KFMC is a teaching centre and established Faculty of Medicine for students who are being trained in the same city.

The adult ICU had a total bed capacity of 31 and was divided into four ICUs: A: 8 beds, B: 8 beds: C: 8 beds and D: 7 beds. The average number of patients cared for every year in the ICU was 1300, with an average of 3 patient admissions every day. The unit had two visiting periods during the day and night at 1:30 pm to 3:30 pm and from 7:30 pm to 9:00 pm, and two family members could visit at the same time. The unit in KFMC had also two big waiting areas with good furniture one area each for males and females.

A project entitled "Family Satisfaction in ICU" has been developed for the family members in the ICU. Part of that project was a survey to be distributed to the family

members during the visiting time to identify their satisfaction with the service being provided to them. In addition, the family members were provided with informational booklets before they entered the ICU which explained the ICU environment, how to interact with the ICU healthcare providers and how to get help during visiting time.

### **3.5.3 King-Fahad Specialist Hospital-Dammam (KFSH-D)**

KFSH-D is a tertiary referral hospital situated in Dammam to which patients in the eastern province are referred for specialist medical care in Oncology, Transplant, Neurosciences, and Genetics specialty. The hospital is supervised operationally by the MOH and has a 360 bed capacity. The adult ICU in KFSH-D had 16 beds which provided care for over 600 patients annually including post-surgical, oncology, and trauma patients.

The ICU had an average admission rate of about two patients' every day. The unit had restricted visiting hours from 11.00 am to 1200 pm and 5.00 pm to 6.00 pm and a maximum of two family members at a time. There was no waiting room for the family members in the ICU. Furthermore, the hospital had no special protocol or informational booklet used to connect between healthcare providers and family members in the ICU.

### **3.5.4 Dammam Medical Complex (DMC)**

Dammam Medical Complex is one of the MOH hospitals in the Eastern Province. The hospital is one of the oldest hospitals in the eastern region and is located in the centre of Dammam city. There is a total of 423 beds in DMC is 423 with 34 beds dedicated for adult ICU. All types of critical patients are treated in the ICU including medical, surgical, neuro and trauma patients. The ICU had an average of two patients

admission every day and cared for an average of 720 patients annually. The visiting hours in the ICU of DMC were from 4.30 pm to 5.30 pm and only one family member could visit at a time for five minutes and no more than six visitors were allowed for each patient every day. The ICU had a humble waiting room for visitors with a limited number of chairs and had a policy developed for interacting with family members during the visiting time which included also how to get help during the visiting time.

### **3.5.5 Qatif Central Hospital (QCH)**

QCH is one of the MOH hospitals in the Eastern Province and the only major trauma centre hospital in Qatif city. The total bed capacity of Qatif Central Hospital was 385 beds with an eight bed general medical surgical ICU which cared for over 800 patients annually on an average of two admissions a day. The type of patients admitted in the ICU required all aspects of critical treatments including cardiothoracic, obstetric, neurosurgical, Chronic Obstructive Pulmonary Disease COPD and trauma. The ICU had a restricted visiting time for one hour a day and usually only two family members could visit their critically ill relative at a time for 3 to 5 minutes. The unit had no waiting room to accommodate family members during visiting time as well as no special protocol or even informational booklet used to liaise between healthcare providers in the ICU and family members.

### **3.5.6 King Fahad Hospital-Hofuf (KFHH)**

King Fahad hospital-Hofuf is a major referral trauma centre and is the most highly equipped diagnostic, treating and teaching centre in the Al-Hassa region. It was established in 1980, serving a population of 1,250,000, and is located at the crossroads

for most of the Gulf countries. The hospital total bed capacity is 502, with 25 beds dedicated for adult ICUs, 12 in ICU1 and 13 in ICU2. The two adult ICUs are one medical ICU and another surgical ICU, they care for over 1,164 patients every year with an average admission rate of three patients' every day including critical medical, surgical and trauma patients. The visiting time in the ICU was restricted for only one hour a day from 6:00 to 7:00 pm and only two family members could visit at a time for a maximum of 5 minutes. The two ICUs had no waiting rooms as well as having no special protocol to mediate between ICU staff and family members, so the ICU visitors waited in the ICU corridor to be allowed to visit their relative.

### **3.5.7 King Fahad Central Hospital-Jazan (KFCH-J)**

The study also took place in the 20-bed general adult ICU in King Fahad Hospital in Jazan. KFCH-J is a tertiary, referral and teaching facility affiliated with Jazan University in the Jazan region. The unit received an average of two admissions a day and cared for an average of 600 to 700 patients a year; all of these admissions were emergency in nature, related to medical or surgical specialities. As in the case with most Saudi hospitals involved in the study, this ICU exercised restricted visitation policy hours, and family members could access the patients one hour a day only from 4:00 pm to 5:00 pm. Also, as with most of the participants ICUs, the unit had no waiting room nor protocol or informational booklet used to liaise between healthcare providers and family members of ICU patients.

#### **4.5.8 King Fahad Hospital-Medina (KFH-M)**

King Fahad Hospital-Medina is the largest referral centre in Medina region, the city of the Prophet Mohammed. Al-Medina is the second holiest city in Islam after Mecca and where the Prophet Mohammed is buried. Hundreds of thousands of Muslims come to Medina every year to visit the Prophet's Tomb. This is a > 500-bed teaching hospital and has two ICUs, medical-ICU with 16 beds and another surgical-ICU with 16 beds. The ICUs had a total average number of patients cared for every year of 1200 patients, of which there were 600 in medical-ICU and 600 in the surgical-ICU, with an average of 3 patients admitted every day. The ICUs had restricted visitation; therefore families had access to one hour a day from 4:00 pm to 5:00 pm. There were no waiting areas in the ICUs for the visitors; neither were there protocol or informational booklets used to liaise between ICU healthcare providers and family members. Therefore families were seen visiting the ICU patient in groups with no limited number.

#### **3.6 Ethical considerations**

The National Statement on Ethical Conduct in Human Research of Australian Government applied to Monash University Human Research Ethics Committee (MUHREC) guidelines formed the ethical framework of this study (National Health and Medical Research Council, 2007). Ethical approvals to conduct the research project, including the methodology used to collect the data, were received from MUHREC and from the General Administration of Medical Research (GAMR) in the Saudi Arabian Ministry of Health to undertake the study (see Appendices A & B). The MOH is the principal governing body of the participant hospitals in Saudi Arabia. In accordance with MUHREC guidelines many ethical issues were relevant to the

conduct of the study including: anonymity, confidentiality and protection of human rights, level of risk, benefits of the study and the right of self determination and full disclosure.

### **3.6.1 Anonymity, confidentiality and protection of human rights**

In this research the participants had the right to anonymity and the right that the data collected would be kept confidential (Burns & Grove, 2007). The anonymity and confidentiality of participants' responses were ensured. The participants were not required to write their names on the questionnaire and the surveys did not record any identifying information. The type of questions that were asked in the socio-demographic part would not identify the participants and cannot be linked to them or their location or organisation. The maintenance of anonymity was fully explained to the participants in the explanatory statements. The questionnaire was coded; participants were assured that this was for registering the number of the distributed questionnaires and for data entry purposes only. Participants were not required to sign the completed questionnaire to ensure confidentiality. To maintain confidentiality also the participants' names were coded during the interviews which were conducted in the eight hospitals.

An assurance of confidentiality was given to the participants by the researcher as detailed in the explanatory statements (see Appendices C, i-vi). Only the researcher and the researcher's supervisors had access to the raw data obtained from the participants. During the study time the raw data which were obtained from participants for the purpose of the present study were kept in a locked filing cabinet at

the researcher's house and the computer data were password protected. On the completion of the study all the written data, including questionnaires, interviews audio-record, interviews transcription and consent forms, were then stored in a locked filing cabinet at Monash University, Peninsula Campus, in the School of Nursing and Midwifery. The research data are securely kept at Monash University for the required five year period (National Health and Medical Research Council, 2007). The material will then be shredded, in accordance with university policy (National Health and Medical Research Council, 2007).

It was made clear to the participants that the findings of the study would be presented at intensive care conferences and several articles are anticipated to be written and published in nursing journals. However, the reports will contain only aggregated data and individual participants or their organizations will not be identifiable.

### **3.6.2 Beneficence and level of risk of the research**

Beneficence is one of the fundamental ethical principles in conducting research, which obliges the researcher to maximise benefits and minimise harm (Polit & Beck, 2006). The informants' participation in research must be essential for achieving scientifically and socially important aims which cannot be otherwise realised and participants must not be subject to unnecessary risks of harm and discomfort (Polit & Beck, 2006). Harm and discomfort can be physical, emotional, social or financial, according to Polit and Beck (2006). The harm and discomfort consequences may be even greater in qualitative studies which involve in-depth exploration into highly personal areas (Polit & Beck, 2006). The National Health and Medical Research Council (2007) identified three levels of risk for human research including harm,

discomfort, and inconvenience. In low risk studies the only anticipated discomfort can occur as a result of anxiety that may be induced by engaging participants in an interview (NHMRC, 2007). In the current study the participating family members were assessed by MUHREC as being a "low risk" as they may have experienced some difficulties and be emotionally vulnerable because of their critically ill family member while they were engaged in the interview. Therefore, the researcher developed several strategies to minimise all types of harms and discomforts and family members' vulnerability.

A private room was made available to the researcher to conduct the interview in each hospital. In cooperation with the ICU Charge Nurse the researcher identified patients who met the sample selection criteria. After that the nurses who were caring for the patients were asked to assess the family members' situations and their readiness to talk about their experience and then inform the researcher. The researchers informed the family members through the explanatory statement as well as verbally during the interview of the support system available at the time of conducting the study within the hospital, specifically the social worker, and were provided with the contact numbers. It was arranged that at the time of conducting the interview if hospital staff requested the researcher to stop the interview so they could speak to the family members this would be done; however, this was not required.

The researcher is Saudi and is aware of the sensitive cultural issues that may arise during the conduct of the research. A highly sensitive cultural and legal issue for the researcher was to consider that the male researcher would not be able to interview female family members on most occasions in Saudi Arabia. To enable female participants of

family members to be involved in the research a female Saudi research assistant was trained to conduct semi-structured interviews with family members. By following the measure of Islamic law and Saudi culture, a private and culturally safe room was made available which is the preferred place for interviewing Saudi female participants. Furthermore, it was possible that the questionnaire and the interview were may cause distress or anxiety to the family members or may remind them of the difficulties that they experienced when coping with the situation of their critically ill member while involved in the research. If this was noticed either in answering the questionnaire or during interview, it was planned to advise them to withdraw and seek support from another family member or the researcher or to contact the social worker of the hospital to assist through this challenging process. However, no participants decided to withdraw from the interview and none appeared distressed or anxious during participation.

### **3.6.3 The right of self-determination and full disclosure toward informed consent**

Respect for the participants' dignity, for their right to self-determination and full disclosure is the second ethical principle after beneficence (Polit & Beck, 2006). This means participants have the right to voluntarily participate in the study without adverse consequences and have a full description of the nature of the study. The explanatory statement of this study informed the participants that they were under no obligation to participate in the study. The participants were fully informed about the nature of the research, the demands it would make on them, and potential risks and benefits, in order for them to be in a position to make thoughtful decisions regarding participation in the study (Polit & Hungler, 1999). In addition, the participants had the

right to withdraw from the research at any time and this was indicated in the explanatory statement. The family member participants were assured that their decision whether to take part in the study or not would not affect their family member's treatment, relationship with those treating their family member or even relationship with the hospital. The participants also had the right to ask questions or clarification at any time during the research. Participants were informed in the explanatory statement that they would not be paid for their engagement in the research. Nevertheless, many family members and healthcare providers stated that it was good to be able to express their opinions and experiences.

The participants' right to self-determination and full disclosure are the two major elements on which informed consent is based. Informed consent means that participants have sufficient information about the research that enables them to consent voluntarily in the research or refuse participation (Polit & Beck, 2006). The return of the completed self-administered questionnaires in the current study was treated as implied consent. Informed consent was obtained from family members who voluntarily participated in Phase 2 interviews (see Appendices E, i & ii). One female family member denied permission to have her interview audio-recorded, as this is culturally inappropriate for some Saudis. In this case the researcher took notes throughout the interview and immediately after the interview. As suggested by Holloway and Wheeler (2002) these notes reflected the words of the participant as accurately as possible. The family members received a copy of their signed consent and the researcher kept the original.

### **3.7 Participant inclusion and exclusion criteria**

Participation in the study was based on several inclusion and exclusion criteria. The inclusion criteria for healthcare professionals were that permanent healthcare providers working in adult ICU were eligible to participate in the study. The permanency criterion reflects the desire to ensure that the healthcare professionals could express their experience and comment on the environment in which they worked regularly. The inclusion criteria for family members were that they:

- 1) were aged 18 years or above which is considered to be the legal age in Saudi Arabia
- 2) were available in the hospital during the visiting time
- 3) were able to read and write Arabic, and
- 4) Had a family member in the ICU for 24 hours or more to ensure that family members had had sufficient time to experience the ICU environment.

The exclusion criteria for family members was their potential vulnerability as study participants, as they were relatives of unstable patients. Unstable patients are those with unstable vital signs, major complications or whose death was considered to be imminent. Collecting data at this stage of the patients admission would be intrusive and would ignore the needs of grieving relatives (see Table 3.1).

**Table 3.1: Participants' inclusion and exclusion criteria for Phase 1 and 2.**

<b>Inclusion Criteria</b>	
<b>Healthcare Professionals</b>	<b>Family Members</b>
A healthcare provider who works permanently in adult ICU including: <ol style="list-style-type: none"> <li>1) Physicians.</li> <li>2) Nurses.</li> <li>3) Respiratory therapists.</li> </ol>	A family member: <ul style="list-style-type: none"> <li>• Age 18 years or above.</li> <li>• Available in the hospital during visiting time.</li> <li>• Able to read and write Arabic.</li> <li>• Had a family member in the ICU for 24 hours or more.</li> </ul>
<b>Exclusion Criteria</b>	
<b>Healthcare Providers</b>	<b>Family members</b>
Healthcare providers not regularly working in the ICU.	A family member deemed by the assigned ICU nurse as too vulnerable to participate in the study.

### **3.8 The sample**

Adhering to the view that the same participants could not be recruited for both quantitative and qualitative components of this current mixed methods study due to the gap in data collection between Phase 1 and Phase 2, different samples of family members were recruited for each method. The sequential mixed methods procedures should involve different types of sampling techniques using a probability convenience sample in the quantitative phase to reach more population and a purposive sample in the qualitative phase for a smaller population (Teddlie & Tashakkori, 2009; Bazeley, 2004).

The overall sample used in the quantitative method was a convenience sample to recruit healthcare providers and family members. Convenience sampling enables the researcher to acquire information in unexplored areas of study (Burns & Grove, 2009). Caution however was taken to control biases by the sample criteria used to determine the target population. In Phase 1 healthcare providers who were working in the adult ICU and the visiting family members who met the selection criteria were invited to participate in the study by completing the questionnaires developed for the study. In Phase 2 a purposive sampling strategy was used to increase the credibility of the study findings to gain insight into the new area of the study and to obtain in-depth understanding of the family needs during the qualitative phase (Patton, 1990; Burns & Grove, 2009). The sample of interview participants comprised the closest family member available during the visiting time who met the selection criteria (see Section 3.7). The closest family member was identified as being the closest to the patient among the family members available during the visiting time and at the same time had experience of the phenomenon of interest.

### **3.8.1 The sample size**

Two different types of sample sizes were combined: larger convenience quantitative samples of family members and healthcare providers in Phase 1 and carefully selected smaller purposive qualitative samples of family members in Phase 2. In quantitative research the sample size ideally should generate a representative sample of the population (Teddlie & Tashakkori, 2009). A general recommendation by Polit and Beck (2012) is to use the largest sample possible: the larger the sample the more representative the sample is likely to be. Quantitative studies with inadequate sample sizes run the risk of gathering data that will not support the research hypotheses

(Burns & Grove, 2009; Polit & Beck, 2012). Consequently, the larger the sample, the smaller the sampling error (Polit & Beck, 2012).

Determining the adequate sample size for the quantitative approach was based on several factors including power, level of significance and effect size (Munro, 2005). Power is the capacity of the study to reject the null hypothesis (Burns & Grove, 2009). Expressed another way, it is the probability of the statistical tests to detect differences or relationships in the population: 0.80 (80%) is the best acceptable power for a study (Cohen, 1988). Level of significance is the probability of making a Type I error in a statistical analysis, which occurs when the researcher rejects the null hypothesis when it is true (Burns & Grove, 2009; Polit & Beck, 2012). Significance level (alpha) is often set at 0.05 which means that there is a probability of 5% of the researcher getting a Type I error (Burns & Grove, 2009).

In addition, effect size is the degree to which the null hypothesis is false or, in other words, is the degree of the presence of the phenomenon in the population (Munro, 2005; Burns & Grove, 2009). The effect size can be small  $< 0.3$ , medium, between 0.3 to 0.5 and large  $> 0.5$  (Munro, 2005; Burns & Grove, 2009). A medium effect size is more suitable for studies with a defined theoretical framework and with many relevant studies which have been conducted in the same area of interest (Burns & Grove, 2009). A medium effect size of 0.4 was considered to be the most appropriate for the recent study.

The power calculation has been undertaken using the G Power computer program to determine the sample size of family members and healthcare providers for this study based on the following parameters: a power of 0.80, a level of significance of 0.05 and a medium effect size of 0.4. The minimum required sample size was a total of 250 participants; a minimum of 125 family members and 125 healthcare providers. The same sample size of 250, 125 each family members and healthcare providers was the minimum when comparing between the two proportions. The actual sample size in Phase 1 in this present study was a total of 477 participants, 167 family members and 477 healthcare providers.

In qualitative research, the sample size used is typically small. Patton (2002) has stated "there are no rules for sample size in qualitative inquiry" (p. 244). He maintained this as the size may be influenced by a number of factors such as "what you want to know" and "what will have credibility" (Patton, 2002, p.244). By and large, the sample size in qualitative research is considered adequate when the data collection is continued until saturation is achieved, according to Creswell (2009). Saturation in purposive sampling occurs when the addition of more subjects provides no new information, only redundancy of previously collected data (Teddlie & Tashakkori, 2009). Therefore, saturation was the general rule used for the purposive sampling of family members in Phase 2.

### **3.9 Recruitment**

Recruitment of family members and healthcare providers was commenced in November 2011 and concluded in February 2012 for the quantitative data, and then

the qualitative, semi-structured interviews. Prior to the commencement of recruiting from the participating hospitals, the researcher conducted a meeting in each ICU with the social worker, the ICU general director, the ICU head nurse, and any other staff considered to have responsibility and commitment to the safety of healthcare providers and family members. The meetings were held to discuss the data recruitment plan and the implementation of the study.

Recruitment took place in two phases and with two groups of participants. In Phase 1, family members and healthcare providers were recruited for participation for the questionnaire. In Phase 2, family members were recruited for participation in semi-structured interviews. The details of the recruitment procedures follow.

### **3.9.1 Phase 1: Recruitment of the family members**

In cooperation with the charge nurse of the ICU, the researcher identified the patients who met the selection criteria: those patients with stable vital signs, without major complications and who had been in the ICU for 24 hours or more. During the visiting time the nurses who were caring for patients identified as stable and who had been in the unit for at least 24 hours were asked to assess the family members' situations and their readiness to participate in the study by completing the questionnaire. Family members who were acutely distressed were not approached to participate. The researcher then contacted the family members who met the criteria for participation in the study either in the waiting room or ICU corridor or at the patient's bedside when there were no waiting rooms in the ICU. The researcher contacted only one member of each patient's family to participate in the study.

An explanatory statement along with the questionnaire was distributed to the participants. The explanatory statement detailed the project title, researcher and supervisors' names, the time required to complete the questionnaire and the contact details as well as a statement of assurance of anonymity and voluntary participation (see Appendices C, i & ii). The researcher also provided written and verbal explanation of the purpose of the study and potential benefits and risks of family members' participation in the study. The family members were requested to answer all questions independently. On some occasions, the researcher was available at the time of answering the questionnaire for any questions and clarifications the participants may have needed. This facilitated an increased understanding of the questionnaire by the family members and gave the researcher an opportunity to gain greater insight into relatives' specific needs. The collection of the completed questionnaires was either carried out by the researcher on the same day or they were placed in the attached envelope and returned to the study box near the intensive care unit or, alternatively, were sent to the researcher's mail box.

In addition, family members were given instructions to keep the explanatory statement sheet for further information in line with the conduct of ethical research. The explanatory statement included the name and contact details of a Saudi bilingual who was independent of the research and the researcher and who agreed to take any complaints that may arise during the study and pass them on to the Ethics Committee at Monash University. This was thought to be the most appropriate way of facilitating transborder communications, as most of the family member participants were not expected to speak and understand English and therefore providing them with the

complaints clause in English would not be helpful. The local contact also dealt with the issue of international calls to contact MUHREC, no complaints were received.

### **3.9.2 Phase 1: Recruitment of healthcare providers**

In preparation for recruitment of healthcare providers, the researcher contacted the ICU head nurse regarding advertising for the study. Informational sessions were held in the eight ICUs to advertise and recruit healthcare providers. All Saudi and non-Saudi healthcare providers working in the ICU were invited to complete the questionnaire developed for the study (Appendix H). Distribution and collection of the questionnaire was carried out by the researcher. An explanatory statement sheet was attached to the front page of the questionnaire. The explanatory statement detailed the project title, the researcher's and supervisor's names, assurance of anonymity and confidentiality of participants, the voluntary participation, the timeframe required to complete the questionnaire and contact details. Participants were given instructions to keep the explanatory statement sheet with them for future reference and if they were interested in the results of the study (see Appendices C, iii & iv). Adhering to the MUHREC recommendations, the explanatory statement of the healthcare providers included the name and contact details of the local person to take any complaints that may arise during the study and pass them on to the Committee. Participants were also instructed to place the questionnaire in the provided envelope and return it to the secure study box inside the ICU or hand it to the head nurse within two weeks of receiving the questionnaires.

### **3.9.3 Phase 2: Recruitment of family members**

The recruitment of family members for semi-structured interviews took place in the eight ICUs of the participants' hospitals. The same processes used for recruiting family members in Phase 1 were employed in Phase 2 (refer to 3.9.1). A private room was made available for the researcher or the researcher's female assistant to conduct the interview. An invitation poster was placed on the notice board of each participant ICU introducing the "Critical Care Family Study" and the voluntary participation (Appendices D, i & ii). During the visiting time the closest family member who met the selection criteria was first asked to participate in the study by the assigned nurse. If they agreed to participate, the researcher or the researcher, assistant was then introduced to the family member by the assigned nurse. After a full written and verbal explanation of the project by the researcher the written consent was obtained from the participating family member (see Appendices E, i & ii). As with Phase 1, family members were provided with further information and instructed to keep the explanatory statement for future reference. The explanatory statement also included the name and contact details of the local person to take any complaints that may arise during the study and pass them on to MUHREC.

### **3.10 Strengths and weaknesses of data collection instruments in Phase 1 and 2**

A decision was made to use close ended questionnaire in Phase 1 and semi-structure interview in Phase 2. Both close ended questions and semi-structured interviews have strengths and weaknesses. Good close ended questions are difficult to construct but easy to administer and analyse (Polit & Beck, 2012). They maintain that close ended

questions are more efficient because respondents can complete more close ended questions in a given amount of time as participants in close ended questions are only required to circle or check appropriate response. Schneider et al, (2003) states that close ended questions have the advantage of having a limited number of responses, simplifying the respondent's task and researcher's analysis. However, the close ended items can be superficial which may cause the researcher miss some important information about the subject. They also prevent respondents to express themselves well verbally (Polit & Beck, 2006). Tashakkori and Teddlie (2003) have also identified a number of strengths and weaknesses of close ended items including quick turnaround, perceived anonymity, low drop rate, considered to be inexpensive and moderately high measurement validity. Weakness include possibility of missing data, need validation, respondents may not answer all questions.

Face-to-face semi-structure interview was appropriate with family members where depth of meaning is important and the research is primarily focused in gaining insight and understanding (Gillham 2000). Face-to-face interview can provide the opportunity to generate rich data, language use by participants is considered essential in gaining insight into their perceptions and values; data generated can be analysed in different ways (Streubert & Carpenter, 2011). It is important to recognise and address the weaknesses of the semi-structured interview. The researcher is considered the main data collection in qualitative studies. Therefore, in qualitative research using face-to-face interview, participants will respond differently depending on how they perceive the interviewer. The interviewer effect "In particular, the sex the age, and the ethnic origins of the interviewer have a bearing on the amount of information people are willing to divulge and their honesty about what they

reveal” (Denscombe, 2007; p.184). This weakness is very dependent on the nature of the topics being studied which necessitates to make clear at the beginning of an interview what the purpose and topics are and seek to put the interviewee at ease.

The researcher has taken in full consideration the strengths and weaknesses of the close-ended questionnaire and semi-structured interview and appropriate plans were taken to avoid the weaknesses and strengthen the study data collection tools.

### **3.11 Phase 1: Data collection instruments**

Phase 1 involved the collection of quantitative data using closed-ended self-administered questionnaires. The quantitative data were gathered from family members of critically ill patients admitted in the ICU and healthcare providers who worked permanently in the adult ICU. The Saudi modified version of the CCFNI tool was used as the foundation for each questionnaire involved in the study – one for family members and one for healthcare providers.

#### **3.11.1 Family members’ questionnaire**

In Phase 1 family members were invited to participate in the study by completing a questionnaire in Arabic language incorporating the socio-demographic information and the modified Saudi version of CCFNI (see Appendix F).

##### **3.11.1.1 Part One: Socio-demographic information**

This part contained 10 items developed by the researcher to identify the socio-demographic background of the respondents and to obtain information to describe the

sample. It was the self-administered closed-ended questionnaire that contained data including the family member's age, sex, nationality, educational background, previous ICU experience, relationship to the patient, length of patient stay in the ICU, age of the patient, sex of the patient and how often the family wished to visit the patient in the ICU.

The structure of questions in this part was guided by the literature reviewed for the study. The demographic details were sought to identify the relationship between the perceived needs of family members and the background of the participants (Polit & Hungler, 1999). It was also to determine whether any of the demographic information correlated, or were associated with the perceived needs of family members.

#### **3.11.1.2 Part Two: the modified Saudi version of CCFNI**

The Critical Care Family Needs Inventory is a closed-end self-administered questionnaire developed to assess the degree of importance of various aspects of needs of families of critically ill patients. The CCFNI was chosen as it includes family members' needs statements identified in previous research as most appropriate (Leske, 1991). The CCFNI consists of 46 items and has five major dimensions: assurance, information, support, proximity and comfort (Leske, 1992).

The Saudi modified version of the CCFNI consists of 35 needs statements (see Appendix F). Some needs statements were adapted from Leske (1992a) to be used to develop the Saudi version with her permission. Permission from the author was also obtained to translate it into Arabic (see Appendix G). The rest of the statements were

adapted from a wide range of literature and personal experience. As the researcher is a Saudi who has experience in the critical care areas and is interested in family and cultural issues, he added eight particular statements relevant to Saudi family religious, cultural and spiritual needs. This was to identify the various aspects of the cultural and spiritual needs of Saudi family. The majority of the literature reviewed neglected to recognize the family needs in relation to the influence of cultural values and religious views and beliefs held by the family members and the organisational climate and culture of the working area of the healthcare providers. Moreover, the Saudi version of CCFNI was developed to explore the uniqueness of the Saudi culture in relation to the research questions.

The Saudi version of CCFNI measures five dimensions: assurance, information, proximity, support and spiritual and cultural needs. Each needs statement was allocated to a needs dimension. The description and items included in each dimensions are as follows:

1. The assurance dimension contains 7 items representing the need of family to be reassured by the healthcare provider about the health condition of their critically ill patient.
2. The information dimension contains 10 items reflecting information and knowledge required by the family members.
3. The proximity dimension contains 5 items which is reflective of a state of being close or near to the patient and being respected by the healthcare professionals.
4. The support dimension contains 5 items identifying the resources and assistance needed by family members.

5. The spiritual and cultural dimension contains 8 items concerning the cultural and religious needs believed to be held by the Saudi families which, if met by the healthcare providers, should provide relief from distress.

The items were then mixed and listed randomly and a four-point Likert-type scale was used in order for the respondents to rate the items in order of importance as follows:

- Not important,
- Slightly important,
- Important,
- Very important.

The four point Likert-type scale enables the direction of responses to be measured without a confusing range (De Vaus, 1999). Another two columns were added to the CCFNI to identify whether the perceived needs were being met or unmet, and who was the most likely person to be meeting each need. The respondents were given three selections of the person who met, or should meet each need most of the time as follows: doctor, nurse or administration. Furthermore, an open-ended item was provided to the family member respondents at the end of the questionnaire for any further comments about family's needs which may have not been covered by the questionnaire (see Appendix F).

### **3.11.2 Healthcare providers' questionnaire**

In Phase 1 healthcare providers were invited to participate in the study by completing the questionnaire in the English language incorporating the socio-demographic

information, the Saudi modified version of the CCFNI and Attitudes of Healthcare Providers of Family Involvement during Routine Care and Family presence during Resuscitation and other Invasive Procedures (FIDRRIP) (see Appendix H). These types of data were gathered to assist the researcher in determining the following:

- The healthcare providers' perceptions of the perceived needs of Saudi families of hospitalised critically ill adults: whether those needs were being met or unmet and the most appropriate person who could meet each need.
- A comparative platform of the perceived needs between ICU healthcare providers and family members.
- The attitudes of healthcare providers' towards family presence during routine care and resuscitation and other procedures.

### **3.11.2.1 Part One: Socio-demographic information**

This part of the questionnaire included questions eliciting some demographic details (see Appendix H). The demographic details help to interpret data and understand the background of the participants in the study and allow findings to be generalised (Polit & Hungler, 1999). The socio-demographic part includes questions related to the healthcare provider's age, gender, nationality, level of education, job title, years of employment and years of working experience in Saudi Arabia. These data were sought to determine any statistically significant differences in healthcare providers' perceptions of the family needs in relation to their demographic information. Likewise they were sought to determine whether the healthcare providers' attitudes to family involvement during routine and resuscitation and other invasive procedures were

related to their age, gender, nationality, level of education and years of work experience.

### **3.11.2.2 Part Two: the modified Saudi version of CCFNI**

The same tool used to gather data from family members was employed with healthcare providers to investigate the perceived needs of family members of the critically ill patient in the ICU from healthcare providers' perspectives. Only a few wording modifications were made on the healthcare providers' questionnaire to make it fit for them, for example changing "To request to stay during the care of my family member" to "To request to stay during the care of the patient" (see Appendix H, Part 2). The use of the same tool was to seek data so a comparison could be made of the perceived family needs from two perspectives: the family members and healthcare providers. The use of this method can add depth and richness to the gathered data and explored the phenomena from various aspects. Furthermore, this type of comparative platform has been used previously in different contexts in the world (Jacono, et al, 1990; Kleinpell & Powers, 1992; Mi-Kuen, French & Kai-Kwong, 1995; Gelling & Prevost, 1999; Hinkle, Fitzpatrick & Oskrochi, 2009).

### **3.11.2.3 Part Three: Attitudes of healthcare providers regarding family involvement during routine care and family presence during resuscitation and other invasive procedures (FIDRRIP).**

The third part of the questionnaire was designed to identify the healthcare providers' attitudes of family involvement during routine care and resuscitation and other invasive procedures. Routine care is the involvement of families in activities of daily

living such as feeding the patient, helping with baths or linen change, giving back care, turning the patient or giving fluids. This part consists of nineteen statements regarding family involvement. The statements were adapted from a wide range of literature and professional nursing experience. The statements of family involvement during routine care were listed first, then the family presence during resuscitation and other invasive procedures statements. This was intended to introduce the practices gradually in order for the questionnaire to elicit factors of family involvement during routine care and resuscitation and other invasive procedures (see Appendix H, Part 3).

Responses to these items were recorded on a four point Likert-type scale where respondents indicated to what extent they agreed or disagreed with each statement as follows:

- Strongly disagree (1),
- Disagree (2),
- Agree (3),
- Strongly agree (4).

Polit and Beck (2004) state that a Likert-type scale response format is employed to place respondents on a continuum with respect to an attribute or content domain. Also, this method of rating is fairly simple to construct, it is very reliable and amenable to measuring many types of abstract qualities (Polit & Beck, 2004). Free comments were sought at the end of the questionnaire and participants were invited to add further comments which were thought to be not covered by the questions.

### **3.12 Back-translation procedure of data collection materials**

The use of quantitative instrument tools in cross-cultural studies sometimes requires the researcher to translate the instrument tools and the other data collection documents into the language of the target cultural group (Jones, 1987). Proper translation procedures must be employed; otherwise the results of study might suffer due to the mistakes in translation (Chapman & Carter, 1979). Maneesriwongul and Dixon (2004) maintain that there is no single perfect translation technique to be used in cross-cultural studies. However, according to Brislin (1970) and Chapman and Carter (1979), back translation is the most common, appropriate and recommended procedure for verifying translation from the source language to the targeted language. In the back translation procedure, the instrument tool is translated from the source language into the targeted language and then another translator translates that version back into the source language (Chapman & Carter, 1979).

This study was conducted in Saudi Arabia and the participants were family members who could read, write and speak Arabic. Therefore, the data collection instruments for family members were translated into Arabic including: the family members' questionnaire, the explanatory statements for the two phases, the informed consent and family members' invitation letter. Also, Arabic versions of the healthcare providers' questionnaire and explanatory statement were made available as some healthcare providers are not fluent in English and may have found it difficult reading and interpreting the English version.

The data collection documents were firstly written in English by the researcher. As the researcher is bilingual, he translated the documents into Arabic. After they were translated into Arabic, the Arabic version was given to a competent bilingual person to back-translate into English. As a result, there were two versions in English, the original and the back-translated version and one in the target language, Arabic. Afterwards, the English and Arabic versions were both given to a professional translator who was specifically recruited for the task to read, check and confirm the Arabic translation of the documents and to check the equivalent versions of English and Arabic to see whether they measured the same construct (refer to Appendix I).

### **3.13 Data quality of quantitative results**

Assessing data quality is an analytic task which should be undertaken early in quantitative research when questionnaires are used. Researchers must demonstrate that findings are believable and dependable (Schneider et al., 2007). Two important concepts, validity and reliability in research will ultimately influence the outcomes of the findings (Brink & Wood, 2001). They refer to the measurement of data as they will be used to answer the research questions (Brink & Wood, 2001). Validity in quantitative research is known as the extent to which an instrument measures what it is supposed to measure (Burns & Grove, 2009). Reliability represents the degree of consistency or dependability of the measure obtained (Polit & Beck, 2012). This exists when the researcher can depend on the consistency of the data collection instrument. In other words, it is the confidence that, when the same data collection instrument is applied to measure the same variable in the same person again, the results would be the same (Brink & Wood, 2001).

Distinct procedures were undertaken to ensure the data quality of the study. These include determining the reliability and validity of the data, which will be discussed next.

### **3.13.1 Validity**

The issue of validity of the quantitative instruments used for this study was ensured in two dimensions: content validity and construct validity. Content validity refers to the degree to which the instrument's items sufficiently represent the concepts being studied (Polit & Beck, 2012). Researchers look for evidence of content validity through experts to assess whether the items are representative of the concept being measured (Creswell & Plano-Clark, 2011). Construct validity is the degree to which an instrument actually measures the theoretical construct under investigation (Burns & Grove, 2009). Teddlie and Tashakkori, (2009) state note that an indicator of construct validity is called a criterion. To assess the construct validity of an instrument researchers consider the total test score as a criterion for evaluating the degree of construct validity of each individual item (Hoskins, 2004).

In order to determine the content validity of the family members and healthcare providers questionnaire for this study in the context of Saudi Arabia the questionnaires were reviewed with a panel of experts which consisted of 12 members (6 Australians and 6 Saudis), to obtain content validity and clarity. The experts were nurse academics, critical care nurses, nurse managers and a statistics consultant. They were asked to judge the degree to which the questionnaire items were suitable for the aims and questions of the study. The experts were also asked to respond to the

questionnaires and to write their comments. This was to determine whether the questions were accessible and measured what they were supposed to measure. Based on feedback, changes were made as necessary, then the questionnaires were reviewed. According to Teddlie and Tashakkori (2009) this validation method with a group is useful because experts may disagree with one another.

After that, a pre-test of the instruments was carried out in Qatif Central Hospital in Saudi Arabia over a period of three weeks. The pre-test yielded seven family members of adult patients admitted in the ICU who met the initial inclusion criteria for the study. Family members were asked to complete the study questionnaire in Arabic language. The pre-test also yielded seven Saudi and non-Saudi healthcare providers who regularly worked in the ICU of Qatif Central Hospital in Saudi Arabia who were invited to complete the questionnaire in the English language.

The participants were asked to write their comments as the rationale for pre-testing the questionnaires was to determine whether the items were accessible and clear to understand and to consider the participants' comments in revising the questions from the context of Saudi Arabia. In addition, the pre-test provided the opportunity to assess how long it would take the family members and healthcare providers to complete the questionnaires. The approximate time to complete the questionnaires for family members and healthcare providers was 10 and 15 minutes respectively. This pre-testing revealed that family members and healthcare providers' feedback was positive and indicated that the questionnaires were clear and accessible to understand and no changes needed to be made on the two questionnaires. Furthermore, in order to validate the questionnaires for the Saudi context, an open-ended question was added

in family members' as well as healthcare providers' questionnaires for any further comments which were not been covered by the questionnaire.

### **3.13.2 Reliability**

Reliability of a quantitative instrument is a major criterion for assessing its quality, ensuring that the instrument provides consistent, stable and repeatable results (Brink & Wood, 2001; Polit & Beck, 2012). There are three key methods of testing the reliability of a quantitative instrument: checking for stability, equivalence and internal consistency (Burns & Grove, 2009). Brink and Wood (2001) define stability as how stable the instrument is over time; equivalence as the "consistency of the results by different investigators or similar tests" (p. 184); and internal consistency as the extent to which an instrument's items measure the concept consistently in all parts of the test. Brink and Wood (2001) maintain that researchers need to use only one or more of these tests to establish the level of reliability of the instrument. Internal consistency is the most widely used and most useful method for evaluating reliability (Polit & Beck, 2012). Cronbach's Alpha Coefficient is the most frequently used and most accurate and sophisticated statistical test to establish internal consistency (Brink & Wood, 2001; Polit & Beck, 2006).

The internal consistency of the Saudi modified version of the CCFNI and FIDRRIP was evaluated by using Cronbach's Alpha Coefficient. The total alpha coefficients of the CCFNI was 0.88 for the overall scale and from 0.85 to 0.87 for the five subscales (Table 3.2). The overall Cronbach's alpha for the FIDRRIP was 0.80. The Cronbach's alpha coefficient ranges from 0-1 with a reliability coefficient of < 0.60 considered insufficient, 0.60-0.69 marginal, 0.70-0.79 acceptable, 0.80-0.89 good and  $\geq 0.90$

excellent (Barker, Pistrang & Elliott, 1994). According to these criteria the Saudi modified version of CCFNI and FIDRRIP's alpha coefficient of 0.88-0.98 fits into the good to excellent reliability range.

**Table 3.2: Cronbach's alpha for internal consistency for each subscale and total for Saudi modified version of the CCFNI**

Subscales	Alpha Coefficient
Assurance	0.85
Information	0.85
Proximity	0.87
Support	0.86
Cultural and spiritual	0.85
Total	0.88

### 3.13.3 Data screening and cleaning

Before analysis was commenced, the data set was screened and checked for errors. The data were first entered into an Excel spreadsheet then imported into an SPSS spreadsheet. The data screening in this study followed two steps which were suggested by Pallant (2011):

1. Ensuring that each dependent and independent variable scores are not out of range.
2. Finding any data error and correcting or deleting the value.

In addition, the sample size was checked to make sure that it did not exceed the number of participants: 167 for family members and 477 for healthcare providers. The frequency and rank of each item and category were also rechecked.

### **3.14 Questionnaire data analysis**

Family members' and healthcare providers' questionnaire responses were coded and entered into an Excel spreadsheet as coded for analysis. The quantitative data were analysed using the Statistical Package for Social Sciences (SPSS) complex program (Version 20 for Windows) for the personal computer. A descriptive and inferential statistics were employed to analyse data from the demographics, the CCFNI and FIDRRIP of family members' and healthcare providers' questionnaires. Descriptive statistics were employed to describe the data by summarizing them into more understandable terms (Munro, 2005). Inferential statistics involved testing the differences or relationships between groups or variables (Teddlie & Tashakkori, 2009).

#### **3.14.1 Descriptive statistics**

Descriptive statistics were employed on the CCFNI, and the mean and standard deviation for each need statement were computed to determine which needs were perceived as most important based on mean scores. The mean score of each item could range from 1 to 4, an item with a lower mean score reflecting that participants perceived the needs as less important, and items with higher mean scores reflecting that participants perceived them as more important. The mean scores were also calculated for each subscale of assurance, information, proximity, support and spiritual and cultural needs, to determine which of these subscales was most important based on mean scores. The means were computed and divided by the number of items in each subscale for easy interpretation (Pallant, 2011).

Descriptive statistics were used which included percentages to identify the family needs as being met or unmet by family members and healthcare providers. Descriptive statistics were also used with percentages to determine the most likely persons who met or should meet the family members' needs as perceived by families and healthcare providers. Other descriptive statistics were employed to analyse the FIDRRIP to determine healthcare providers' attitudes towards family presence during routine care and resuscitation and other invasive procedures: these included percentages, means and standard deviations.

### **3.14.2 Inferential statistics**

Parametric and non-parametric tests were performed as appropriate. Thus an independent sample *t*-test, and a series of one-way between-groups analysis of variance with post-hoc test and Mann-Whitney tests were used to determine any statistically significant differences between participants' demographic characteristics and family needs as perceived by family members and healthcare providers. Also, the independent sample *t*-test was undertaken to determine if a relationship existed between the participants' demographics and the perceived needs as being met or unmet. All statistical analyses were considered significant at the 0.05 level (Munro, 2005).

An independent sample *t*-test, or a series of one-way between-groups analysis of variance (one-way ANOVA) with a post-hoc test was also performed to detect any statistically significance relationship between demographic details and the most appropriate person to meet most of the family needs. Inferential statistics were

implemented to check any statistically significant relationship between healthcare providers' participants and family involvement during routine and resuscitation and other invasive procedures. The relationship between family needs dimensions as perceived by both family members and healthcare providers was also investigated using the Pearson product-moment correlation coefficient (Pallant, 2011).

### **3.14.3 Treatment of missing data**

Despite the fact that the questionnaire is considered a major method of data collection, it has a number of limitations which should be avoided by appropriately constructing the questionnaire (Tashakkori & Teddlie, 2003). Possibility of missing data is one of the most frequent weaknesses of the questionnaire tool (Tashakkori & Teddlie, 2003). Missing data in a research study is when there is missing information of variables for one or more respondents (Knapp, 1998). Preventing missing data happening is the preferred and satisfactory approach to addressing missing data (Fleming, 2011). However, the systematic missing data may influence the generalisability, making the findings limited and reducing the integrity and interpretability of the results (Munro, 2005; Fleming, 2011).

To meaningfully reduce the missing data, the researcher consulted with a Monash University expert panel and statistical experts to recognize and address factors that commonly lead to missing data. After data analysis, missing data were evaluated for patterns and disruption and were replaced with the group mean value if they had no influence in the generalisability of the findings. The missing data which had the

possibility of impacting on generalisability and reducing the integrity and interpretability of results were trimmed from the data analysis.

#### **3.14.4 Thematic analysis of open-ended question**

A theme is "an abstract entity that brings meaning and identity to recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experiences into meaningful manifestations" (DeSantis & Ugarriza, 2000, p.362). Thematic analysis refers to dealing with qualitative data by creation and application of coding categories to qualitative data that recur through being similar or connected to each other in a patterned way (Buetow, 2010). It can, however, tend to conflate the recurrence of data and importance of data. The thematic analysis was applied to the open-ended question addressed to the participants for their further comments and suggestions. This item at the end of the questionnaire invited further comments by family members and healthcare providers which was thought not to be covered by the questions.

Common patterns and categories were sought from written comments made by family members and healthcare providers. A total of 44 family members respondents out of the original sample of 167 respondents and a total of 46 healthcare providers out of 477 offered written comments for this analysis. The emergent themes were repetitively reviewed including levels and lenses of interpretation to detect inconsistencies, contradictions and researcher bias (Baptiste, 1995, cited in Saunders & Byrne, 2002).

### **3.15 Phase 2: qualitative data collection with family members**

A decision was made to use the semi-structured interview as a data collection technique in Phase 2 for a range of reasons. This technique gives participants the freedom to voice their experience, illustrations and explanations as they wish (Streubert & Carpenter, 2011). Polit and Beck (2012) note that the semi-structured interview gives the participants an opportunity to provide rich and detailed information about the phenomenon under study.

Data was collected by the researcher, who is a critical care nurse and was not an employee in any of the hospitals or related to any of the participants. The researcher is an indigenous Muslim Saudi and aware of the sensitive cultural issues that potentially could have arisen during the conduct of the research. The semi-structured interviews were conducted in Arabic language lasting 30–45min, to give participants the freedom to voice their experience, illustrations and explanations of being a family member of a critical care patient in the ICU (Streubert and Carpenter, 2011). Data was collected between November 2011 and February 2012.

Preparation of the semi-structured interview questions was directed by the findings of the quantitative research in Phase 1 and previous literature (Teddlie & Tashakkori, 2009). In preparing the semi-structured interview guide, questions were ordered chronologically from the general to the specific. A definition of family needs was provided to the participants at the beginning of the interview to allow the interviewee to fully understand the meaning. After that, the interviewer started asking general questions such as the demographic information of the participants as ice-breaking then moving toward the core questions of the topic. However, this sequencing of the

questions was not the same for every participant as it depended on the process of the interview and the responses of each participant (Holloway & Wheeler, 2002). This was considered to allow the participant to express themselves freely in the description of his/her experience of having a critically ill relative admitted in the ICU. The main job of the interviewer was to encourage participants to talk freely about the topics in the interview guide. Throughout the interview the interviewer took field notes and noted the participant's facial expressions and important responses and comments for each question (refer to Appendix J).

### **3.16 Interview analysis: Phase 2**

The process of interview analysis went through five stages according to Holloway and Wheeler's (2010) process of analysis of qualitative data as follows:

- Transcribing interviews and sorting field notes.
- Organizing and ordering the data.
- Listening to and reading the material over and over again.
- Coding and categorizing.
- Building themes.

The analysis commenced by the researcher transcribing the interviews to become fully aware of the important issues in the data. Pages were numbered and the front sheet of each transcript consisted of the interviewer name, interview location, date, time, specific comments by the interviewee and the important demographic information of the participants and the critically ill relative. In order to find the data quickly during analysis the researcher numbered each line of the interview transcript (Holloway &

Wheeler, 2010). In addition, the verbatim interview transcripts were crosschecked, labeled and stored in appropriate files. The organisation and management of the data was carried out to help in future retrieval of the interview analysis. This structuring of unstructured data is called "content analysis" (Brink & Wood, 2001).

From the very beginning listening to the recording, reading transcripts, field notes and other documents as well as through organising and managing the data materials, significant ideas, categories and common themes began to generate naturally out of the data themselves. Categories were developed to fit the answers of the questions under phenomenon. Different responses came from the same person were placed in different categories. Increasingly, individual participants' responses that presented some similarities, and were different from others, and so were grouped together in the same categories.

Line-by-line coding was performed to identify information that both participant and researcher considered important. The coding was achieved through singling out words or phrases that were used by the participants (Holloway & Wheeler, 2010). The result was six major mutually exclusive themes around central themes. Themes in qualitative data are the "groupings of similar data that fall into mutually exclusive categories" (Brink & Wood, 2001, p. 220). The final themes generated provided answers that explained the perceived needs of family members of a critically ill member admitted in the ICU. This process of analysing qualitative data in mixed methods study enables the researcher to compare qualitative data with the quantitative results and relate them to the characteristics of the participants (Brink & Wood, 2001; Creswell, 2009).

During the data analysis and throughout the entire study the researcher stayed as close to the data as possible, as recommended by Holloway and Wheeler (2010). This helped the researcher to examine everything connected with the phenomenon under study. Strategies undertaken to ensure the qualitative findings trustworthiness and rigour will be discussed in the following section.

### **3.16.1 Establishing rigour and trustworthiness for qualitative data**

The researcher undertook several strategies to ensure rigour and trustworthiness of the findings (Sandelowski, 1986). Aroni, Goeman, Stewart, et al. (1999) defined rigour as the means by which the qualitative researcher shows integrity and competence. Rigour is ensured via establishing dependability, validity, generalisability and confirmability. Reliability refers to the degree of consistency or dependability in which the study is repeatable and produces the same results when the methodology is replicated in similar circumstances and conditions (Polit & Beck, 2012). However, the researcher is the main research instrument in qualitative inquiry and the researcher's characteristics and background will definitely influence the research and accordingly the research can never be wholly replicable (Holloway & Wheeler, 2002). Validity of the study is the credibility of its findings and Maxwell (1996) asserts that in qualitative research, it is "the credibility of description, conclusion, explanation interpretation or other sort of account" (p. 87). A number of threats can impact on the validity that must be dealt with, including collecting incorrect or incomplete data (Maxwell, 1996). Holloway and Wheeler (2002) maintain that awareness of those threats by the researcher helps to produce a valid piece of research. There are two types of validity, internal and external validity. Internal validity refers to the degree to

which the findings of the study are true and accurately reflect the aim of the study (Holloway & Wheeler, 2002). External validity, also called generalisability, is the degree to which study findings and conclusion can be generalised to other or similar settings or populations (Polit & Beck, 2012). Holloway and Wheeler (2002) insist that generalisability is difficult to achieve in qualitative research; however, the qualitative researchers should attempt to achieve some generalisability beyond their study. Increasingly, researchers refer to confirmability as the objectivity or neutrality of the data and interpretations and for the research to be free of biases (Holloway & Wheeler, 2002; Polit & Beck, 2006). Until recently, other researchers have thought confirmability is difficult to achieve and in fact the researcher and participants must openly acknowledge their own subjectivity and become an integral part of the research (Holloway & Wheeler, 2002).

The rigour and trustworthiness of this study was ensured through the following strategies. First, the time frame of four months of data collection developed a trusting relationship between the researcher and participants allowing in-depth data to be gathered. Second, the inclusion criteria for family members was carefully planned and restricted to those who were capable of describing their experience while having a critically ill relative admitted in the ICU. Third, the interview questions and the other data collection documents were written in English and then translated to Arabic by the researcher and a professional translator was asked to confirm the translation prior to conducting the interviews. Fourth, validity was promoted by letting the participants speak and listen to their voices. Fifth, the researcher noted the important responses and took notes and suggestions for each question in the interview guide which added to the validity when conducting the data analysis.

Sixth, the researcher analysed the interviews independently and generated a list of categories out of the analysis. Then a peer review was performed with colleagues to confirm that the themes emerging from content analysis accurately reflected the subjective data. Finally, a decision trail was included by documenting the details of how the data were analysed for future research.

### **3.17 Conclusion**

A sequential, descriptive, explanatory mixed method design in two phases was employed to answer the research questions. This design was the most suitable and appropriate in identifying the perceived needs of the Saudi families' and healthcare providers' attitudes regarding family involvement patterns. The study was carried out in two phases using a self-administered, closed-ended questionnaire to collect quantitative data from family members and ICU healthcare providers in Phase 1. In Phase 2 qualitative data were collected using face-to-face semi-structured interviews with family members to address domains identified from the questionnaire and to enrich the main data gathered in Phase 1.

In this chapter, the study sites, ethical considerations, sampling methods, recruitment, data collection strategies, data quality strategies undertaken to ensure trustworthiness of findings and data analysis in Phase 1 and 2 were presented. Sampling methods, recruitment, data collection and data analysis in the quantitative and qualitative phases were designed to complement each other. This provided knowledge of the Saudi families' needs and involvement in the care of the critically ill family member. The

results are reported over two chapters due to the volume and characteristics of the data. In the next chapter, Chapter 4 the quantitative findings of the study will be reported. This will be followed in Chapter 5 with the reporting of the qualitative findings.

## **Chapter Four: Quantitative Results**

### **4.1 Introduction**

In this chapter the quantitative results arising from questionnaires in Phase 1 of the study are reported. The response rate of the sample, family members and ICU healthcare providers are described first. This is followed by the soci-demographic profile of the participants and then the reports of the rank of importance of family needs as perceived by family members and healthcare providers. This is followed by views of the family needs being met or unmet and views on the most appropriate person who can meet each family needs as identified by family members and healthcare providers. The attitudes of healthcare providers regarding family involvement during routine care and resuscitation and other invasive procedures are reported next and the responses of family members and healthcare providers participants are compared. Finally the ancillary results of the family members and healthcare provider participants are reported respectively.

### **4.2 Response rate**

The following two sections report the response rate among family members and healthcare providers during Phase 1 (quantitative phase).

#### **4.2.1 Family members' response rate**

The family members of all adult ICU patients admitted between November 2011 to February 2012 in the participating hospitals were considered for this study. The family members of 24 patients were not approached because they did not meet the inclusion criteria (Section 3.7). The questionnaires were distributed to the families of

294 patients who were admitted in the ICUs of the eight participant hospitals and met the inclusion criteria. A total of 176 questionnaires were returned, which gives a 59.8% response rate among family members. Of the returned questionnaires, nine were regarded as inconclusive because family members completed only the socio-demographic information and therefore were trimmed from the analysis. The number of distributed, returned and excluded questionnaires to the families in the participating hospital as well as the response rate is reported in Table 4.1.

**Table 4.1: Family members’ distributed, returned and excluded questionnaires**

<b>Hospital</b>	<b>Distributed</b>	<b>Returned</b>	<b>%</b>	<b>Excluded</b>
<b>KFHH</b>	20	13	65	0
<b>DMC</b>	29	19	65.5	2
<b>QCH</b>	20	13	65	0
<b>KFSH</b>	30	18	60	0
<b>KFMC</b>	50	31	62	2
<b>KSMC</b>	80	51	63.7	3
<b>KFCH-J</b>	30	19	63.3	0
<b>KFH-M</b>	35	12	34.2	2
<b>Total</b>	294	176	59.8	9

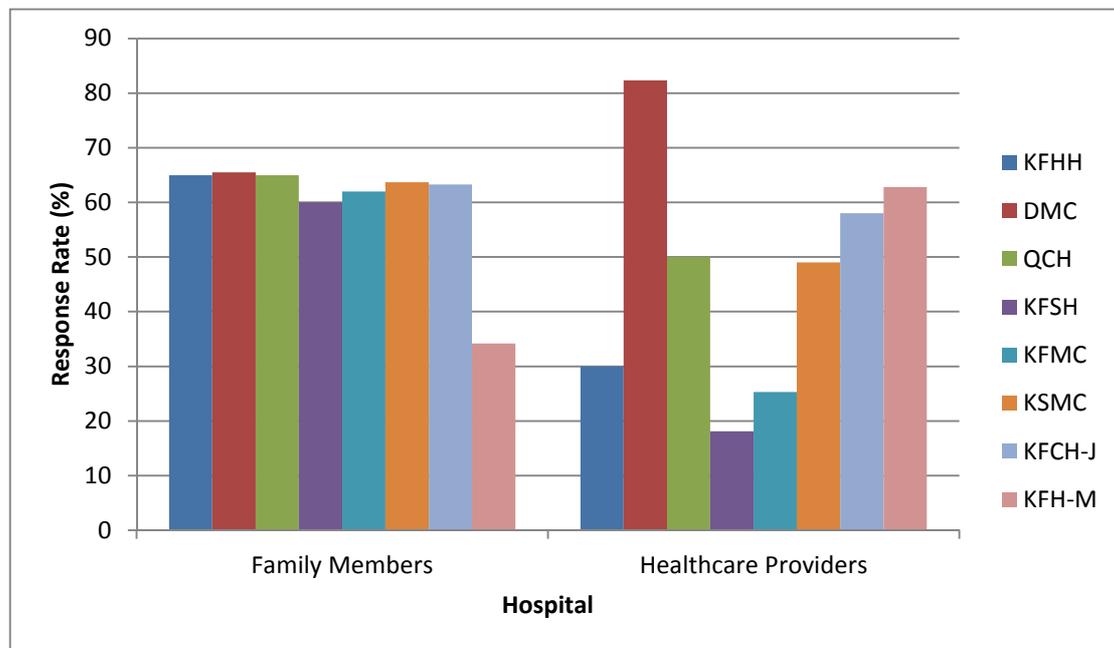
#### **4.2.2 Healthcare providers’ response rate**

Healthcare providers’ questionnaires were distributed to all categories of ICU patient care givers in the eight participating hospitals. This included physicians, nurses and respiratory therapists. As detailed in Table 4.2, a total of 1100 healthcare providers who permanently work in the ICU of the participant hospitals were approached to participate in the study by completing the questionnaires. The participation rate for ICU healthcare providers was 45.1% (497) and of those, 20 questionnaires were excluded from the analysis as the participants completed only the socio-demographic part and did not complete the rest of the questionnaire. In total, 477 healthcare providers’ questionnaires were collated.

**Table 4.2: Healthcare providers' questionnaire response rate**

Hospital	Distributed	Returned	%	Excluded
KFHH	100	30	30	3
DMC	130	107	82.3	3
QCH	60	30	50	0
KFSH	88	16	18.1	1
KFMC	280	71	25.3	2
KSMC	320	157	49	8
KFCH-J	62	36	58	1
KFH-M	70	44	62.8	2
<b>Total</b>	<b>1100</b>	<b>497</b>	<b>45.1</b>	<b>20</b>

Figure 4.1 compares the response rate between family members and healthcare providers in the eight participants hospitals.



**Figure 4.1: Comparison of response rate of family members and healthcare providers.**

An overall response rate of 60% for family members and 45.1% for ICU healthcare providers was obtained by the study. This percent falls within a satisfactory to acceptable range according to Teddlie and Tashakkori, (2009).

### 4.3 Sample characteristics

The family members' and healthcare providers' socio-demographic characteristics will be presented here.

#### 4.3.1 Family members' socio-demographics

The profile of the family members' participants is shown in Table 4.3. The age range of family participants was 18 to 75 years, but older participants were in the minority and the mean age was 33.16 years (*SD* 11.21). Age was not provided by 30 participants. There was an uneven sex spread: 110 (65.9%) were males and 57 (34.1%) were females.

**Table 4.3: Family members socio-demographic details (N=167)**

Scio-demographic item	Subgroups	Frequency	Percentage
<b>Age</b>	18 - 24	33	24.1
	25 – 27	25	18.2
	28 – 33	25	18.2
	34 – 42	29	21.2
	43+	25	18.2
	Missing	30	
<b>Sex</b>	Male	110	65.9
	Female	57	34.1
<b>Nationality</b>	Saudi	151	91
	Non-Saudi	15	9
	Missing	1	
<b>Level of education</b>	Less than high school	31	18.6
	High school	47	28.1
	Diploma	26	15.6
	Bachelor	59	35.3
	Master	4	2.4
<b>Relationship to patient</b>	Spouse/partner	5	3.1
	Sibling	32	19.9
	Parent	45	28
	Son/daughter	24	14.9
	Other relative	44	27.3
	Friend	11	6.8
	Missing	6	
<b>Length of patient stay in the ICU in days</b>	1 - 2	25	16.8
	3 – 7	46	30.9
	8 – 9	6	4
	10 – 17	23	15.4
	18 - 45	30	20.1

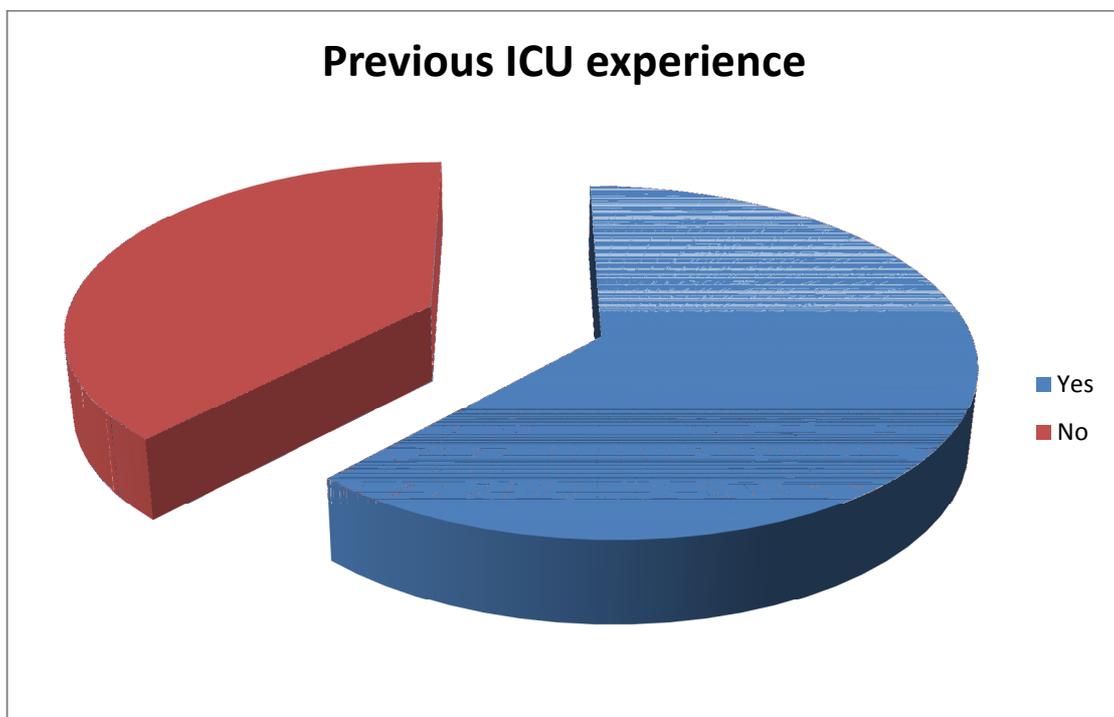
	46+	19	12.8
	Missing	18	
<b>Patient's age</b>	17 – 21	36	23.4
	22 – 30	26	16.9
	31 – 53	31	20.1
	54 – 68	31	20.1
	69 +	30	19.5
	Missing	13	
<b>Patients sex</b>	Male	100	62.1
	Female	61	37.9
	Missing	6	
<b>Visit preference</b>	Once a day	39	23.8
	Twice a day	65	39.6
	Three times a day	42	25.6
	Every other day	11	6.7
	Every two days	1	0.6
	Open	6	3.7
	Missing	3	

The families were predominantly Saudi 151 (91%): only 15 (9%) were non-Saudi and one participant did not respond to the nationality item. Of the total sample 59 (35.3%) held a bachelor's degree, 47 (28.1%) had attained at least high school education, and 31 (18.6%) had less than high school education. Additionally, family members who had a diploma numbered 26 (15.6%) and four participants (2.4%) held a masters qualification. The largest proportion of the participants identified themselves as parents of the patients (45 or 28%) or other relatives of the patient (44 or 27.3%). Siblings accounted for 32 (19.9%); 24 (14.9%) were sons or daughters; 11 (6%) were friends; and 6 responses were missing. With regard to the length of patient stay in the ICU, the period ranged between 1 day to 3 years with mean days of 40.1 (119.16). The participants mostly 46 (30.9%) reported that their relative had been in the ICU for 3 to 7 days, 30 (20.1%) for 18 to 45 days, 25 (16.8%) for 1 to 2 days, 23 (15.4%) for 10 to 17 days, 19 (12.8%), 6 (4%) for 8 to 9 days and 18 responses were missing.

The patients were mainly males 100 (62.1%), with 61 (37.9%) female and 6 responses missing. The patient age ranged from 17 to 102 years old, with a mean age of 44.6 years (*SD* 22.86). Patients aged 17 to 21 represented 23.4% of the sample. Those aged

31 to 53 and 54 to 68 years each accounted for 20.1%, 19.5% were 69 years or above 16.9% were 22 to 30 years and 13 were missing. The families mostly preferred to visit their relative in the ICU twice a day (39.6%) or even three times a day (25.6%), compared with, 23.8%, who preferred one visit per a day. A smaller proportion (6.7%) preferred one visit every other day while (3.7%) asked for an open visiting policy. Only one participant (0.6%) preferred every two days and 6 did not express any opinion regarding this issue.

Figure 4.2 presents the family members' response concerning their previous experience in caring for patients while they have been in the intensive care unit. The results indicated that more than half of the sample (62%) had previous experience in the ICU, whereas 38% had no experience.



**Figure 4.2: Previous ICU experience**

### 4.3.2 Healthcare providers' socio-demographics

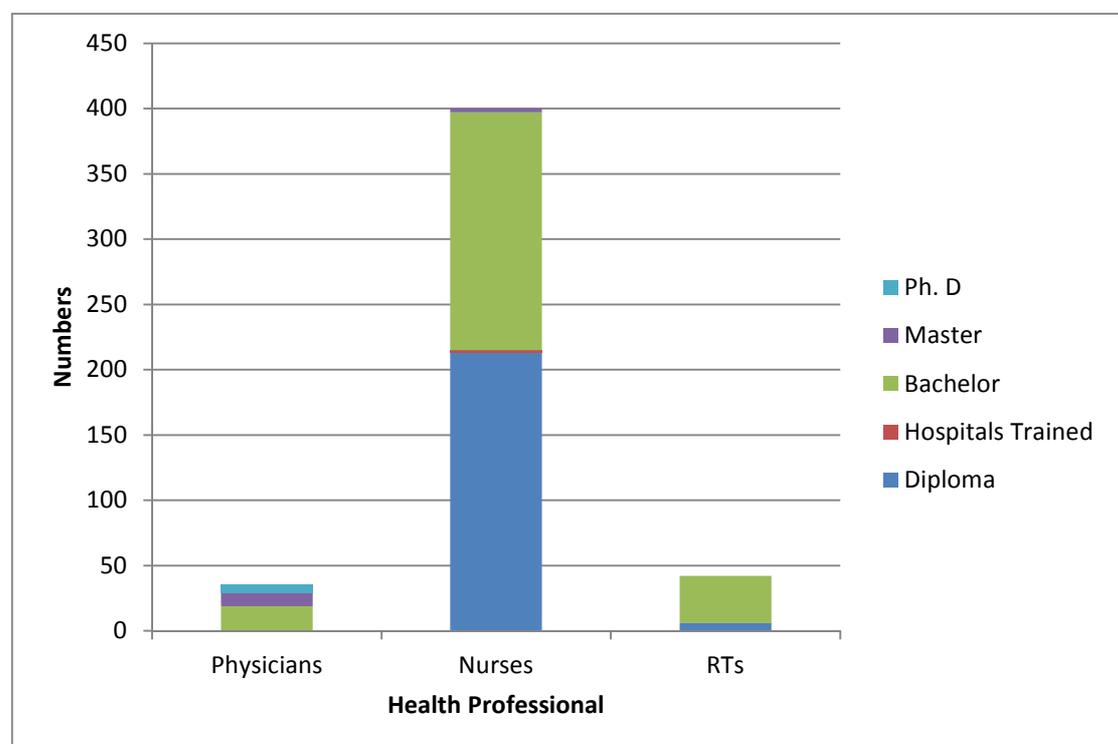
The healthcare providers profile is illustrated in Table 4.4. The table details the age, sex, nationality, level of education, job title, years of employment and years of experience in Saudi Arabia health service. The age range of the healthcare provider participants was from 22 to 60 years with a mean of 30.7 years ( $SD = 6.93$ ). More than 84% of the sample was female and only 15.2% were male. Healthcare providers of 13 nationalities participated in the study: the largest national group was from India 232 (49.7%), the second largest nationality was from Philippines 112 (24%) whereas Saudis healthcare providers were the third largest with 59 (12.6%) of the total sample.

**Table 4.4: Healthcare providers' socio-demographic details (N=477)**

Socio-demographic item	Subgroups	Frequency	Percentage
<b>Age</b>	22 – 25	82	17.9
	26 – 27	115	25.2
	28 – 28	44	9.6
	29 – 31	66	14.4
	32 – 36	74	16.2
	37+	76	16.6
	Missing	20	
<b>Sex</b>	Male	72	15.2
	Female	403	84.8
	Missing	2	
<b>Nationality</b>	Saudi	59	12.6
	Indian	232	49.7
	Filipino	112	24
	British	1	0.2
	Jordanian	5	1.1
	Egyptian	13	2.8
	Syrian	1	0.2
	Sudanese	8	1.7
	Pakistani	17	3.6
	Indonesian	12	2.6
	South African	5	1.1
	Malaysian	1	0.2
	Tanzanian	1	0.2
	Missing	10	
<b>Level of education</b>	Diploma	219	45.9
	Hospital Training	2	0.4
	Bachelor	237	49.7
	Masters	13	2.7
	PhD.	6	1.3
<b>Healthcare profession</b>	Nurse	400	83.9
	Physician	35	7.3
	Respiratory Therapist	42	8.8

	Missing	2	
<b>Years of employment</b>	Less than one year	16	3.4
	1 to 5 years	219	46.2
	6 to 10 years	130	27.4
	More than 10 years	109	23
	Missing	3	
<b>Years of experience in Saudi Arabia</b>	Less than one year	56	11.8
	1 to 5 years	301	63.6
	6 to 10 years	65	13.7
	More than 10 years	51	10.8
	Missing	4	

The largest proportion of the participant healthcare providers were nurses who represented 83.9%, while respiratory therapists and physicians were 8.8% and 7.3% of the total. Figure 4.3 reports the level of education by profession. A total of 49.7% reported that they held a bachelor degree and 45.9% reported having a diploma in either nursing or respiratory therapy. Only 4% reported having postgraduate qualification: ten physicians and three nurses had a Masters qualification and another six physicians had a Ph.D.



**Figure 4.3: Healthcare providers' education level**

Most of the respondents 219 (46.2%) had one to five years of working experience, whereas 130 (27.4%) had working experience of between six to ten years; 109 (23%) had worked for more than 10 years, and only 16 (3.4%) had less than one year's experience. Similarly with the healthcare providers experience in Saudi Arabia, the majority 301 (63.6%) had worked for one to five years in Saudi Arabia, 13.7% for six to ten years, 10.8% had more than ten years' experience in Saudi Arabia and 11.8% had less than one year's experience in the Kingdom.

#### 4.4 Family needs

Participants were asked to rank each needs statement on the Saudi modified version of the CCFNI on a 4 point Likert-type scale, with 1 = not important, 2 = slightly important, 3 = important and 4 = very important.

##### 4.4.1 Family members' perception of family needs

Families perceived 31 needs (88.6%) of the total needs statement as either important or very important and the other 4 (11.4%) were ranked as slightly important. The five most important needs identified by family members in this study are presented in Table 4.5.

**Table 4.5: The five most important needs as perceived by family members**

Item No	Need statement	Dimension	Mean (SD)
29	To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect	Cultural and spiritual	3.80 (0.51)
16	To have an explanation in detail about the condition of the patient when it becomes worse.	Information	3.75 (0.54)
12	To have questions answered honestly.	Assurance	3.72 (0.54)
1	To know specific facts concerning the patient's progress.	Assurance	3.70 (0.55)
30	To be told of the reason for the chosen treatment of my relative.	Information	3.70 (0.54)
17	To understand everything that occurs with the condition of the patient.	Assurance	3.68 (0.61)

Of these very important needs, three were related to the assurance subscale, two to the information subscale and one to the cultural and spiritual subscale. The five least important needs are shown in Table 4.6. Two of the least important needs on the CCFNI were listed regarding proximity, another two were from the cultural and spiritual subscale, and one related to support.

**Table 4.6: The five least important needs as perceived by family members**

Item No	Need statement	Dimension	Mean (SD)
7	To be allowed to visit whenever we wish.	Proximity	2.81 (1.13)
18	To have another person accompany me while visiting the intensive care unit.	Support	2.82 (1.14)
31	To ensure that healthcare providers never attempt to interview or examine a female patient alone.	Cultural and spiritual	2.88 (1.16)
14	To ensure the healthcare providers who are the opposite sex from the deceased Muslim have no physical contact with the body.	Cultural and spiritual	2.99 (1.16)
10	To request to stay during the care of my family member.	Proximity	3.06 (1.00)

As reported in Table 4.7, assurance and information dimensions had the highest mean score, which indicated that family members perceived these needs as most important. Proximity and support dimensions had the lowest mean scores, which revealed that family members perceived the needs under these dimensions as least important.

**Table 4.7: Family members' rank order of CCFNI**

Dimension	No of items	Possible range	Actual range	Mean (SD)	Rank
Assurance	7	7 to 28	14 to 28	3.66 (0.43)	1
Information	10	10 to 40	15 to 40	3.52 (0.68)	2
Cultural and spiritual needs	8	8 to 32	9 to 20	3.33 (0.88)	3
Proximity	5	5 to 20	7 to 20	3.23 (0.86)	4
Support	5	5 to 20	11 to 32	3.19 (0.92)	5
Total	35	35 to 140	56 to 140		

When the scores of family members are compared to the scores of healthcare providers, a new picture emerges. Table 4.8 displays statistically significant differences in mean scores to items on the Saudi modified version of the CCFNI between family members and healthcare providers. There were significant differences in the mean values assigned by family members and healthcare providers for 25 of the needs ( $p = 0.04$  to  $p = 0.0005$ ). However, there were no significant differences in the mean values between the two groups for 10 of the needs and both groups had similar perceptions of these needs ( $p = 0.1$  to  $p = 0.9$ ).

**Table 4.8: Saudi modified version of CCFNI items, Means and standard deviations for family members (FM) and healthcare providers (HCP).**

Need	FM (167) Mean [SD]	HCP (477) Mean [SD]	Difference in mean [95% C.I]	P Value
To know specific facts concerning the patient's progress.	3.70 [0.55]	3.58 [.61]	0.12 [.016, .218]	0.04
To educate the family about the condition of the patient	3.60 [0.59]	3.65 [0.55]	0.05 [-.152, .048]	0.3
To feel accepted by the hospital staff.	3.36 [0.73]	3.34 [0.69]	0.02 [-.101, .153]	0.6
To relieve our families' anxiety by exploring the medical facts with them in a nonjudgmental manner.	3.53 [0.67]	3.36 [0.78]	0.17 [.043, .297]	0.009
To feel that healthcare providers care about my relative.	3.64 [0.60]	3.40 [0.75]	0.24 [.127, .359]	< .0005
To communicate effectively with healthcare providers to improve families ability to make care decisions	3.48 [0.67]	3.48 [0.66]	0.005 [-.115, .125]	0.9
To be allowed to visit whenever we wish.	2.81 [1.13]	1.85 [0.93]	0.96 [.781, 1.137]	<0 .0005
To have waiting room with comfortable furniture available for us in the intensive care unit.	3.08 [1.02]	2.52 [1.12]	0.56 [.375, .751]	< 0.0005
To have explanations given in terms that are understandable.	3.66 [0.62]	3.30 [0.79]	0.35 [.237, .477]	< 0.0005
To request to stay during the care of my family member.	3.06 [1.00]	1.71 [0.96]	1.34 [1.169, 1.520]	< 0.0005
To face the patient's bed towards the Holy Mosque in Mecca.	3.29 [0.98]	2.69 [1.07]	0.60 [.417, .785]	< 0.0005
To have questions answered honestly.	3.72 [0.54]	3.46 [0.66]	0.26 [.160, .368]	< 0.0005
To know exactly what is being done for the patient.	3.65 [0.62]	3.58 [0.63]	0.06 [-.048, .180]	0.25
To ensure the healthcare providers who are the opposite sex from the deceased Muslim have no physical contact with the body.	2.99 [1.16]	2.77 [1.07]	0.22 [.026, .430]	0.02
To be assured that the best care is being given to the patient.	3.65 [0.61]	3.71 [0.52]	0.06 [-.167, .045]	0.25
To have an explanation in detail about the condition of the patient when it becomes worse.	3.75 [0.54]	3.69 [0.54]	0.06 [-.037, .157]	0.22

To understand everything that occurs with the condition of the patient.	3.68 [0.61]	3.50 [0.67]	0.18 [-.069, .295]	0.002
To have another person accompany me while visiting the intensive care unit.	2.82 [1.14]	2.00 [0.99]	0.82 [.618, 1.014]	< 0.0005
To ensure that the Saudi culture is fully understood by the healthcare providers caring for Saudis.	3.31 [0.94]	3.42 [0.75]	0.11 [-.266, .053]	0.18
To talk to the doctor every day	3.52 [0.75]	3.20 [0.88]	0.32 [-.180, .463]	< 0.0005
To know the expected outcomes	3.63 [0.60]	3.41 [0.72]	0.22 [-.108, .336]	< 0.0005
To have someone providing psychosocial support to families during daily patient care.	3.40 [0.83]	3.18 [0.86]	0.22 [-.071, .378]	0.004
To ensure that healthcare providers respect the spiritual healing practices of the Saudi patients and families.	3.42 [0.81]	3.34 [0.75]	0.07 [-.062, .216]	0.27
To let the Saudi family know first about the bad news, not the patient.	3.45 [0.79]	2.65 [1.05]	0.79 [-.639, .950]	< 0.0005
To help with the patient's physical care.	3.12 [0.98]	3.30 [0.86]	0.18 [-.346, -.020]	0.02
To have explanations of the critical care environment before going to the critical care area for the first time.	3.37 [0.85]	3.37 [0.75]	0.007 [-.148, .133]	0.9
To have healthcare providers discuss with the family members what helps the patient deal with events during hospitalization.	3.52 [0.70]	3.33 [0.71]	0.19 [-.072, .325]	0.002
To have healthcare providers respect relatives' opinions.	3.30 [0.84]	3.13 [0.77]	0.17 [-.017, .316]	0.02
To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect	3.80 [0.51]	3.56 [0.65]	0.24 [-.137, .336]	< 0.0005
To be told of the reason for the chosen treatment of their relative.	3.70 [0.545]	3.23 [0.78]	0.47 [-.366, .586]	< 0.0005
To ensure that healthcare providers never attempt to interview or examine a female patient alone.	2.88 [1.16]	3.40 [0.82]	0.52 [-.723, -.332]	< 0.0005
To be told about other healthcare professionals that could help.	3.31 [0.77]	3.12 [0.75]	0.19 [-.053, .328]	0.007
To communicate information to help families understand each aspect of care.	3.41 [0.71]	3.26 [0.75]	0.14 [-.007, .274]	0.04
To develop trust with healthcare providers	3.65 [0.59]	3.54 [0.61]	0.11 [-.003, .219]	0.04
To know how the patient is being treated medically	3.51 [0.70]	3.43 [0.68]	0.08 [-.040, .207]	0.1

Significant at 0.05 level

#### 4.4.2 Healthcare providers' perceptions of family needs

Healthcare providers perceived 28 (80%) of the total family needs as very important or important; 5 (14.2%) were identified as slightly important (2.00) and two needs (5.7%) were perceived as not important (refer to Table 4.8). The five most important needs identified by the healthcare providers are listed in Table 4.9: three needs were related to information, two to assurance and one is related to cultural and spiritual subscale.

**Table 4.9: The five most important needs as perceived by healthcare providers**

Item No	Need statement	Dimension	Mean (SD)
15	To be assured that the best care is being given to the patient.	Assurance	3.71 (0.52)
16	To have an explanation in detail about the condition of the patient when it becomes worse.	Information	3.69 (0.54)
2	To educate the family about the condition of the patient	Information	3.65 (0.55)
1	To know specific facts concerning the patient's progress.	Assurance	3.58 (0.61)
13	To know exactly what is being done for the patient.	Information	3.58 (0.63)
29	To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect	Cultural and spiritual	3.56 (0.65)

Of the least important five needs, two relate to proximity, another two to the support subscale and the fifth least important need is under the cultural and spiritual dimension (see Table 4.10).

**Table 4.10: The five least important needs as perceived by healthcare providers.**

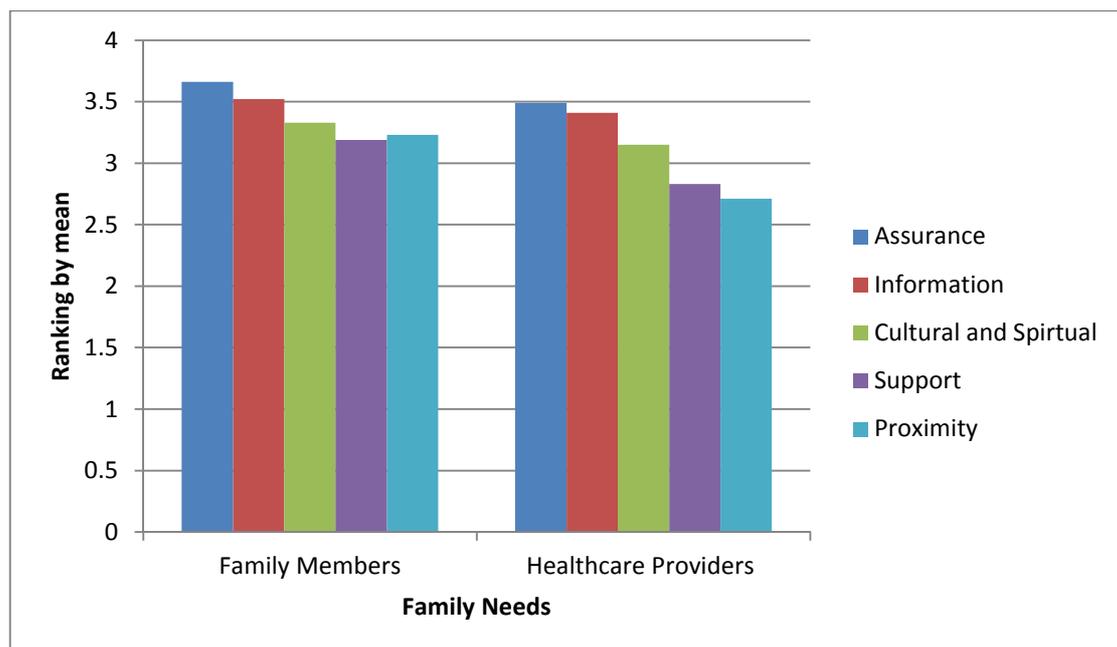
Item No	Need statement	Dimension	Mean (SD)
10	To request to stay during the care of my family member.	Proximity	1.71 (0.96)
7	To be allowed to visit whenever we wish.	Proximity	1.85 (0.93)
18	To have another person accompany me while visiting the intensive care unit.	Support	2.00 (0.99)
8	To have waiting room with comfortable furniture available for us in the intensive care unit.	Support	2.52 (1.12)
24	To let the Saudi family know first about the bad news, not the patient.	Cultural and spiritual	2.65 (1.05)

The analysis of the results revealed that the assurance subscale received the highest ranking by healthcare providers with a mean score 3.49, followed by information at 3.41. Cultural and spiritual needs were perceived as the third most important needs with a mean score of 3.15. In addition, support and proximity were perceived as least important as identified by the healthcare providers refer to Table 4.11.

**Table 4.11: Healthcare providers' rank order of CCFNI**

Dimension	No of items	Possible range	Actual range	Mean (SD)	Rank
Assurance	7	7 to 28	11 to 28	3.49 (0.678)	1
Information	10	10 to 40	18 to 40	3.41 (0.706)	2
Cultural and spiritual needs	8	8 to 32	8 to 20	3.15 (0.871)	3
Support	5	5 to 20	7 to 20	2.83 (0.900)	4
Proximity	5	5 to 20	12 to 32	2.71 (0.796)	5
<b>Total</b>	<b>35</b>	<b>35 to 140</b>	<b>58 to 140</b>		

Figure 4.4 reveals how the needs of assurance, information, proximity, support and spiritual and cultural needs were perceived by family members and healthcare providers. It is statistically significant that family needs were perceived differently between family members and healthcare providers as shown in Table 4.12.



**Figure 4.4: Rank order of family needs by family members and healthcare providers.**

The means, standard deviations and difference in means and *p* value between family members and healthcare providers for each subscale can be seen in Table 4.12. The

comparison of ranked means is important as it demonstrates the compatibility of ranking in terms of importance across both groups. There were highly significant differences ( $p < 0.0005$ ) between family members and healthcare providers in the ranking of importance of assurance, proximity, support and cultural and spiritual needs. There was also a significant difference in the mean values of information subscales between family members and healthcare providers ( $p = 0.01$ ).

**Table 4.12: CCFNI subscales, means and standard deviations for FM and HCP**

<b>Subscale</b>	<b>Family members (N = 167) Mean [SD]</b>	<b>HCP (N = 477) Mean [SD]</b>	<b>Difference in mean [95% C.I]</b>	<b>P Value</b>
<b>Assurance</b>	3.66 [0.43]	3.49 [0.67]	0.16 [0.582, 1.681]	< 0.0005
<b>Information</b>	3.52 [0.68]	3.41[(0.70)]	0.12 [0.283, 2.041]	0.01
<b>Proximity</b>	3.23 [0.86]	2.71[(0.796)]	0.30 [2.038, 3.027]	< 0.0005
<b>Support</b>	3.19 [0.92]	2.83 [0.900]	0.38 [1.360, 2.460]	< 0.0005
<b>Cultural and spiritual</b>	3.33 [0.88]	3.15 [0.871]	0.19 [0.788, 2.299]	< 0.0005

Significant at 0.05 level

#### **4.5 Family needs as being met**

Family members and healthcare providers highlighted the needs in the Saudi modified version of the CCFNI which they perceived as being or not being met (Table 4.13 & Table 4.14).

##### **4.5.1 Family members' perception of meeting family needs**

The need which was perceived as most frequently met, by 74.5% of the family members, was the need “to have the healthcare providers handle the body of the dead Muslim with extreme caution and respect”. The most important individual need was

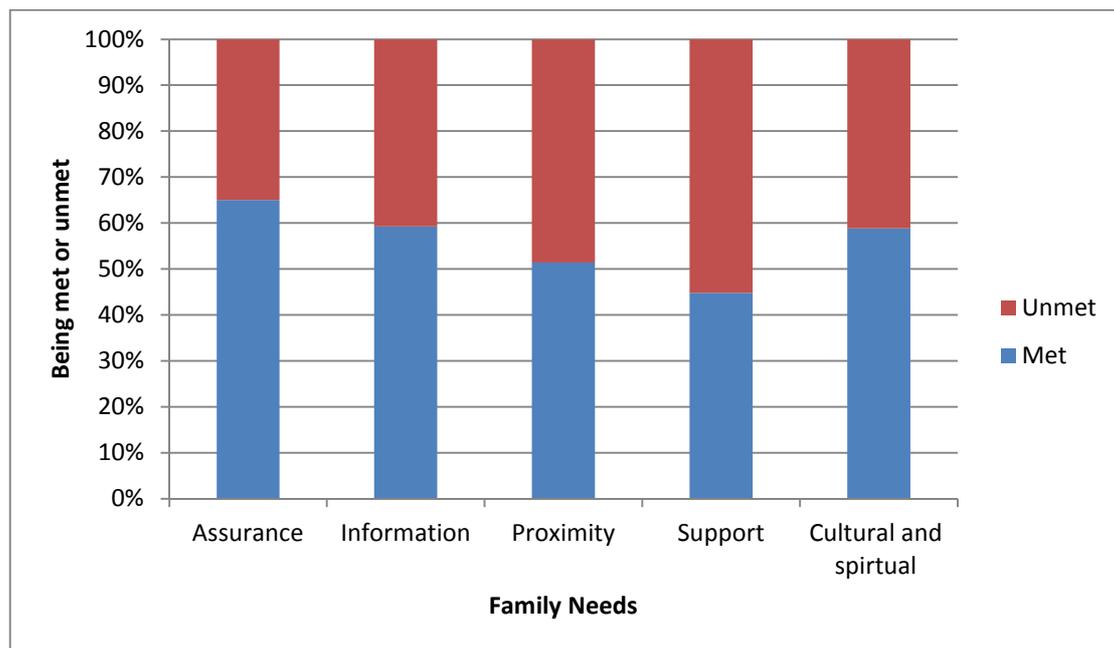
also identified by the family members as the most frequently met need “to have someone providing psychosocial support to families during daily patient care” was perceived as the most frequently unmet need by 72.7% of the family members.

**Table 4.13: Family needs perceived by family members as being met or unmet.**

Need statement	%	
	Met	Unmet
To know specific facts concerning the patient's progress.	69	31
To educate the family about the condition of the patient	62.7	37.3
To feel accepted by the hospital staff.	66.9	33.1
To relieve our families' anxiety by exploring the medical facts with them in a nonjudgmental manner.	62.0	38.0
To feel that healthcare providers care about my relative.	72.7	27.3
To communicate effectively with healthcare providers to improve families ability to make care decisions	56.6	43.4
To be allowed to visit whenever we wish.	29.2	70.8
To have waiting room with comfortable furniture available for us in the intensive care unit.	30.5	69.5
To have explanations given in terms that are understandable.	63.4	36.6
To request to stay during the care of my family member.	36.7	63.3
To face the patient's bed towards the Holy Mosque in Mecca.	34.2	65.8
To have questions answered honestly.	60.3	39.7
To know exactly what is being done for the patient.	64.3	35.7
To ensure the healthcare providers who are the opposite sex from the deceased Muslim have no physical contact with the body.	50	50
To be assured that the best care is being given to the patient.	70.2	29.8
To have an explanation in detail about the condition of the patient when it becomes worse.	61.8	38.2
To understand everything that occurs with the condition of the patient.	63.7	36.3
To have another person accompany me while visiting the intensive care unit.	63.2	36.8
To ensure that the Saudi culture is fully understood by the healthcare providers caring for Saudis.	65.9	34.1
To talk to the doctor every day	52.8	47.2
To know the expected outcomes	55.9	44.1
To have someone providing psychosocial support to families during daily patient care.	27.3	72.7
To ensure that healthcare providers respect the spiritual healing practices of the Saudi patients and families.	61.7	38.3
To let the Saudi family know first about the bad news, not the patient.	62.6	37.4
To help with the patient's physical care.	46.5	53.5
To have explanations of the critical care environment before going to the critical care area for the first time.	37.6	62.4

To have healthcare providers discuss with the family members what helps the patient deal with events during hospitalization.	53.3	46.7
To have healthcare providers respect relatives' opinions.	56.4	43.6
To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect	74.5	25.5
To be told of the reason for the chosen treatment of their relative.	74	26
To ensure that healthcare providers never attempt to interview or examine a female patient alone.	61.5	38.5
To be told about other healthcare professionals that could help.	65.5	34.5
To communicate information to help families understand each aspect of care.	60.8	39.2
To develop trust with healthcare providers	68	32
To know how the patient is being treated medically	59.7	40.3

When the needs were divided into subgroups (Figure 4.5) family members perceived the need for assurance as the most met need (65%), and unmet for only 35% of the family members. The least met need was for support, for only 44.8% of the relatives indicating the need was met and 55.2% of the relatives said it was unmet.



**Figure 4.5: Family needs being met or unmet according to family members.**

#### 4.5.2 Healthcare providers’ perception of meeting family needs

The healthcare providers identified most of the needs as being mainly successfully met. As indicated in Table 4.14, the need “to have the healthcare providers handle the

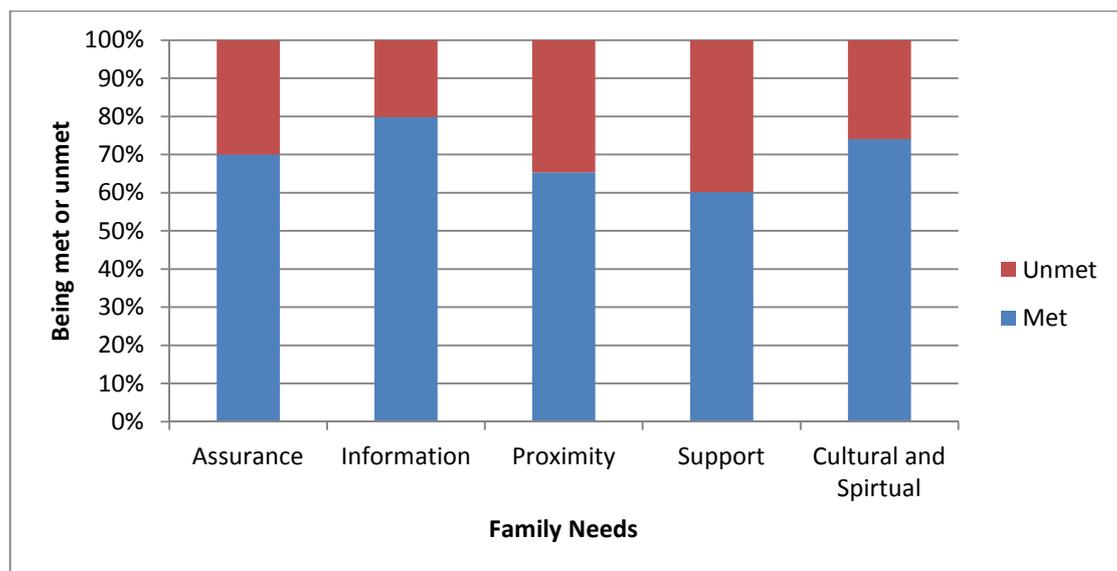
body of the dead Muslim with extreme caution and respect” was recognised as the most frequent met need by 88.8% of the healthcare providers. This need was identified as the most important need by family members and the fifth most important need by healthcare providers. It was also perceived as the most met need by the family members. The most unmet need identified by the healthcare providers was the need “to have waiting room with comfortable furniture available for family members in the intensive care unit” as the most unmet need (66%) of participants.

**Table 4.14: Family needs perceived by healthcare providers as being met or unmet (N=477).**

Need statement	%	
	Met	Unmet
To know specific facts concerning the patient's progress.	88.7	11.3
To educate the family about the condition of the patient	78.1	21.9
To feel accepted by the hospital staff.	79.6	20.4
To relieve our families' anxiety by exploring the medical facts with them in a nonjudgmental manner.	69	31
To feel that healthcare providers care about my relative.	84.4	15.6
To communicate effectively with healthcare providers to improve families ability to make care decisions	74.1	25.9
To be allowed to visit whenever we wish.	41	59
To have waiting room with comfortable furniture available for family members in the intensive care unit.	34	66
To have explanations given in terms that are understandable.	73.5	26.5
To request to stay during the care of my family member.	39.5	60.5
To face the patient's bed towards the Holy Mosque in Mecca.	44	56
To have questions answered honestly.	78.5	21.5
To know exactly what is being done for the patient.	85.5	14.5
To ensure the healthcare providers who are the opposite sex from the deceased Muslim have no physical contact with the body.	74.3	25.7
To be assured that the best care is being given to the patient.	85.5	14.5
To have an explanation in detail about the condition of the patient when it becomes worse.	81.8	18.2
To understand everything that occurs with the condition of the patient.	76.4	23.6
To have another person accompany me while visiting the intensive care unit.	53.8	46.2
To ensure that the Saudi culture is fully understood by the healthcare providers caring for Saudis.	81.4	18.6
To talk to the doctor every day	74.6	25.4

To know the expected outcomes	75.9	24.1
To have someone providing psychosocial support to families during daily patient care.	58.3	41.7
To ensure that healthcare providers respect the spiritual healing practices of the Saudi patients and families.	81	19
To let the Saudi family know first about the bad news, not the patient.	66.7	33.3
To help with the patient's physical care.	85.1	14.9
To have explanations of the critical care environment before going to the critical care area for the first time.	70.9	29.1
To have healthcare providers discuss with the family members what helps the patient deal with events during hospitalization.	69.6	30.4
To have healthcare providers respect relatives' opinions.	84.2	15.8
To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect	88.8	11.2
To be told of the reason for the chosen treatment of their relative.	84.7	15.3
To ensure that healthcare providers never attempt to interview or examine a female patient alone.	87.1	12.9
To be told about other healthcare professionals that could help.	83.2	16.8
To communicate information to help families understand each aspect of care.	78.4	21.6
To develop trust with healthcare providers	82.5	17.5
To know how the patient is being treated medically	82.5	17.5

Family needs of assurance, information, proximity, support and cultural and spiritual were mostly perceived as successfully being met by healthcare providers as illustrated in Figure 4.6.



**Figure 4.6: Family needs being met or unmet according to healthcare providers.**

Overall, the family members perceived that all needs were being met for at least 55.8% and unmet for 44.2% of the families (Table 4.15). This was higher for healthcare providers who perceived the needs being met (69.8%) and only 30.2% who perceived them as unmet.

**Table 4.15: Family member and healthcare provider comparison of family needs whether being met or unmet**

Subscale	Met %		Unmet %	
	FM	HCP	FM	HCP
<b>Assurance</b>	65	70	35	30
<b>Information</b>	59.25	79.8	40.75	20.2
<b>Proximity</b>	51.4	65.3	48.6	34.6
<b>Support</b>	44.82	60.1	55.18	39.9
<b>Cultural and spiritual</b>	58.8	74	41.2	26
<b>Total</b>	55.8	69.8	44.2	30.2

#### **4.6 Most appropriate person to meet each need**

Participants were given three selections of the person who met, or should meet each need most of the time as follows: doctor, nurse and administration.

##### **4.6.1 The most appropriate person as perceived by family members**

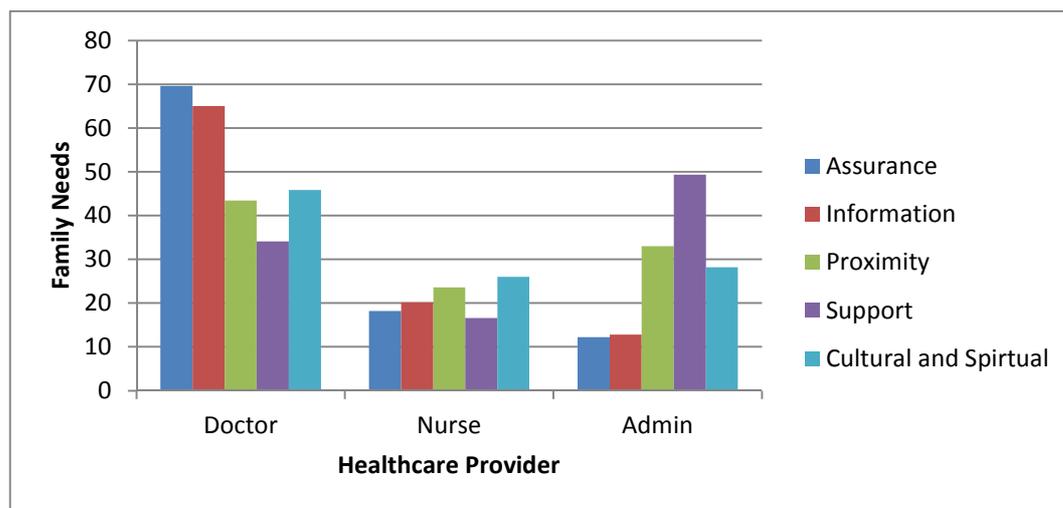
Family members considered most of their needs to be best met by doctors, followed by nurses, and then the hospital administration. They perceived 17 out of their 35 needs to be best met by doctors (Table 4.16). Assurance and information needs were perceived as a role more evenly shared between doctors and nurses (Figure 4.7). However, support was considered to be best met by the hospital administration followed by doctors then nurses. In addition, proximity and cultural and spiritual needs were perceived as evenly met by all three groups.

**Table 4.16: Most appropriate person to meet each need by FM (%)**

Need statements	Doctor	Nurse	Admin
To know specific facts concerning the patient's progress.	83	13	4
To educate the family about the condition of the patient	64.5	26	9.5
To feel accepted by the hospital staff.	43.3	26.5	30.2
To relieve our families' anxiety by exploring the medical facts with them in a nonjudgmental manner.	61.6	28.1	9.3
To feel that healthcare providers care about my relative.	43.5	41	15.5
To communicate effectively with healthcare providers to improve families ability to make care decisions	63.5	23	13.5
To be allowed to visit whenever we wish.	33	13.5	53.5
To have waiting room with comfortable furniture available for us in the intensive care unit.	23.8	17.2	59
To have explanations given in terms that are understandable.	72.5	17.5	10
To request to stay during the care of my family member.	44.5	29.5	26
To face the patient's bed towards the Holy Mosque in Mecca.	26.5	18	54.5
To have questions answered honestly.	72	18.8	10
To know exactly what is being done for the patient.	73.3	18	10.7
To ensure the healthcare providers who are the opposite sex from the deceased Muslim have no physical contact with the body.	39	30	31
To be assured that the best care is being given to the patient.	63.4	22.8	13.8
To have an explanation in detail about the condition of the patient when it becomes worse.	77	22	1
To understand everything that occurs with the condition of the patient.	74.5	16	8.5
To have another person accompany me while visiting the intensive care unit.	36.1	17	45.9
To ensure that the Saudi culture is fully understood by the healthcare providers caring for Saudis.	35.4	36.7	27.7
To talk to the doctor every day	75.5	12.1	16.4
To know the expected outcomes	75.8	14.2	10
To have someone providing psychosocial support to families during daily patient care.	33.5	11.5	54.5
To ensure that healthcare providers respect the spiritual healing practices of the Saudi patients and families.	40.05	31.9	27.9
To let the Saudi family know first about the bad news, not the patient.	73.4	13.2	13.1
To help with the patient's physical care.	43	39	18
To have explanations of the critical care environment before going to the critical care area for the first time.	40.9	18.7	39.4
To have healthcare providers discuss with the family members what helps the patient deal with events during hospitalization.	45.4	16.2	38.4
To have healthcare providers respect relatives' opinions.	47.4	26.45	25.95
To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect	37.7	28.3	34
To be told of the reason for the chosen treatment of their relative.	78.3	16	5.7
To ensure that healthcare providers never attempt to interview or examine a female patient alone.	53.1	22.4	24.5
To be told about other healthcare professionals that could help.	36.2	18.4	45.4

To communicate information to help families understand each aspect of care.	54.8	19.2	25.9
To develop trust with healthcare providers	49.3	21.3	29.4
To know how the patient is being treated medically	74.2	9.4	16.4

Figure 4.7 illustrates the most appropriate person to meet the family needs of assurance, information, proximity, support and cultural and spiritual needs as perceived by family members.



**Figure 4.7: most appropriate person to meet family needs by family members**

#### **4.6.2 The most appropriate person as perceived by healthcare providers**

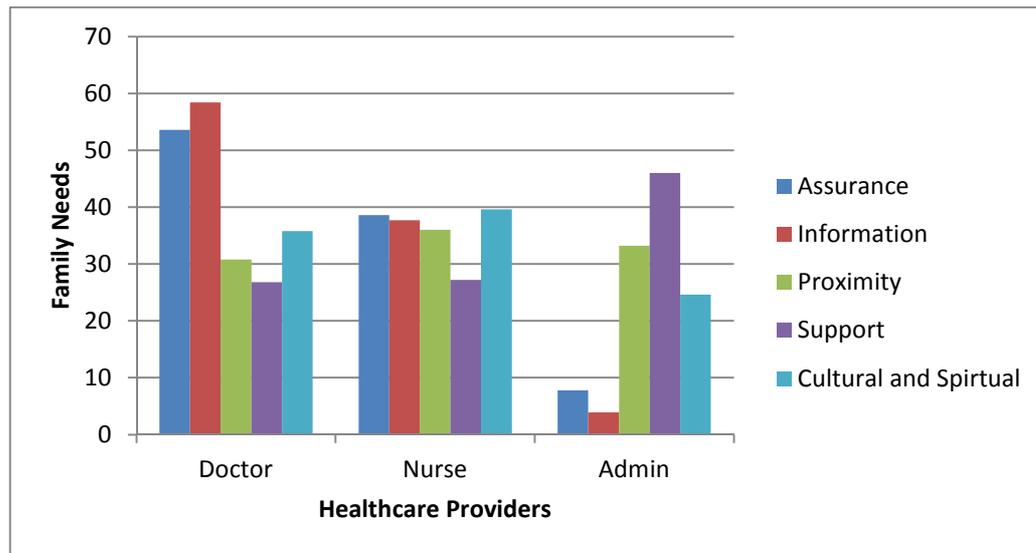
The healthcare providers perceived doctors as primarily responsible for meeting families’ needs, followed by hospital administration, then nurses. As indicated in Table 4.17 a total of 11 needs were considered to be best met by doctors compared to seven which were considered to be best met by nurses. The need for assurance and information were identified as the best to be met by doctors and nurses (refer to Figure 4.8). Support needs were recognized as the duty of the hospital administration. The healthcare providers considered proximity and cultural and spiritual needs as a shared duty between them.

**Table 4.17: Most appropriate person to meet each need by HCP (%)**

Need statements	Doctor	Nurse	Admin
To know specific facts concerning the patient's progress.	63.7	33.7	2.3
To educate the family about the condition of the patient	68.6	27.7	3.7
To feel accepted by the hospital staff.	28.1	54	17.9
To relieve our families' anxiety by exploring the medical facts with them in a nonjudgmental manner.	64.6	28.9	6.5
To feel that healthcare providers care about my relative.	19.5	74.5	6
To communicate effectively with healthcare providers to improve families ability to make care decisions	48.5	40	11.5
To be allowed to visit whenever we wish.	16.3	14.7	69
To have waiting room with comfortable furniture available for us in the intensive care unit.	8	11.4	80.6
To have explanations given in terms that are understandable.	63	23.7	13.3
To request to stay during the care of my family member.	26	25	49
To face the patient's bed towards the Holy Mosque in Mecca.	12.8	21.6	65.6
To have questions answered honestly.	59	31.3	9.7
To know exactly what is being done for the patient.	63.4	30.4	6.2
To ensure the healthcare providers who are the opposite sex from the deceased Muslim have no physical contact with the body.	24.5	59	16.5
To be assured that the best care is being given to the patient.	35.2	55.3	9.5
To have an explanation in detail about the condition of the patient when it becomes worse.	78	17	5
To understand everything that occurs with the condition of the patient.	67	27	6
To have another person accompany me while visiting the intensive care unit.	18.5	23.5	55
To ensure that the Saudi culture is fully understood by the healthcare providers caring for Saudis.	24.8	44.4	30.8
To talk to the doctor every day	65.5	27.5	7
To know the expected outcomes	68.2	24.8	7
To have someone providing psychosocial support to families during daily patient care.	25.4	37.3	37.3
To ensure that healthcare providers respect the spiritual healing practices of the Saudi patients and families.	30.8	40.7	28.6
To let the Saudi family know first about the bad news, not the patient.	58	20	22
To help with the patient's physical care.	25.8	65	9.2
To have explanations of the critical care environment before going to the critical care area for the first time.	38.8	33.5	27.7
To have healthcare providers discuss with the family members what helps the patient deal with events during hospitalization.	46.4	33.4	20.2
To have healthcare providers respect relatives' opinions.	44.6	40.7	14.7
To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect	24.5	59.5	16
To be told of the reason for the chosen treatment of their relative.	71.8	75.8	4.5
To ensure that healthcare providers never attempt to interview or examine a female patient alone.	46.5	43	10.5
To be told about other healthcare professionals that could help.	43.5	30	26.5

To communicate information to help families understand each aspect of care.	48.5	34.5	17
To develop trust with healthcare providers	39	45.7	15.3
To know how the patient is being treated medically	67.8	25.8	6.4

Figure 4.8 shows in percentage how the healthcare providers perceived the most appropriate person who can meet each need dimension for the family members.



**Figure 4.8: Most appropriate person to meet family needs by healthcare providers**

The family members and healthcare providers had almost the same perception that doctors are primarily responsible for meeting the family needs followed by nurses and administration. Table 4.18 compares in percentage who was assessed to be the most appropriate person to fulfil each need dimension as identified by family members and healthcare providers. It also demonstrates the total percentage for doctor, nurse and hospital administration according to both family members and healthcare providers

**Table 4.18: Most appropriate person to meet family needs by FM and HCP.**

Subscale	FM (%)			HCP (%)		
	Doctor	Nurse	Admin	Doctor	Nurse	Admin
<b>Assurance</b>	53.6	38.6	7.8	69.6	18.2	12.2
<b>Information</b>	58.4	37.7	3.9	65	20.2	12.8
<b>Proximity</b>	30.8	36	33.2	43.4	23.6	33
<b>Support</b>	26.8	27.2	46	34.1	16.58	49.32
<b>Cultural and spiritual</b>	35.8	39.6	24.6	45.8	26	28.2
<b>Total</b>	41	35.9	23.1	51.6	21	27.4

#### **4.7 Attitudes of healthcare providers regarding family involvement during routine and resuscitation and other invasive procedures.**

In total, 468 out of 477 healthcare providers completed Part 3, family presence during routine and resuscitation and other invasive procedures (FPRRIP). As seen in Table 4.19 the healthcare providers revealed positive attitudes toward family involvement during routine care; however they showed opposition to family presence and a resistance to the suggestion of allowing family members during resuscitation and other invasive procedures. Healthcare providers who opposed the practice expressed a variety of reasons. Of the participants 63.2% stated “agree” or “strongly agree” that “my performance will be affected by relatives presence”; 55.9% that “the presence of family members makes me feel stressed”; 79.2% “agreed” and “strongly agreed” that “family presence during invasive procedures or resuscitation is a traumatic experience for the family members”. On the other hand, 57.9% believed that “the presence of family members impacts positively on the patient's treatment progress”; 60% of the healthcare providers “agreed” and “strongly agreed” that “if present, family members will be able to recognise that everything possible was done to save the patient” and 63.3% believed they were not “too busy to be able to involve the family in the care process”.

In addition, the majority (64.5%) expressed that they “had sufficient training to meet the family needs”. They also suggested (64.2%) that “If relatives would like to be present during resuscitation and other invasive procedures they should be well informed and sign consent”. Almost half (49.4%) stated that “the hospital should develop guidelines to support family involvement and give family the option to attend invasive procedures and resuscitation”; and 64.2% expressed the view that “the hospital should develop a training program for nurses to support family when they attend invasive procedure or resuscitation”.

**Table 4.19: Attitudes of healthcare providers to family involvement during routine care and resuscitation and other invasive procedures (N = 468).**

Statement	Strongly disagree %	Disagree %	Agree %	Strongly Agree %
If requested by the family they should be allowed to provide activities of daily living.	14.4	41	41	3.9
I support patient wishes for family members to be present during daily patient care.	21.6	46.3	27	5.1
Family presence during patient care would help family to gain spiritual comfort.	16.3	39.9	38	5.9
Allowing family presence during patient care will reduce the family anxiety and fear	15.6	40.7	38.5	5.2
The presence of family members impacts positively on the patient's treatment progress	7.7	34.9	48.7	9.2
If present, family members will be able to recognize that everything possible was done to save the patient	9.4	30.7	50.8	9.2
It is easier to manage critical family members' issues when they are present in the room with the patient	27.4	48.4	21.4	2.8
My clinical performance will be affected by relatives' presence	8.8	28	43	20.2
The presence of family members makes me feel stressed.	7.5	36.6	43.9	12
I believe I have had sufficient training to involve the family.	6.9	29.9	54	9.1
I am too busy to be able to involve the family in the care process.	11.6	51.7	31	5.6
I believe I have had sufficient training to meet the family needs.	6.5	29	54.1	10.4
The presence of family during invasive procedure or CPR would assist the staff to get the history quickly	43.5	36.4	17.3	2.8
Relatives have the right to request to stay during resuscitation or any other invasive procedure	45	33.8	18.8	2.4
If relatives would like to be present during resuscitation and other invasive procedures they should be well informed and sign consent	16.7	19	45.2	19
Family presence during invasive procedure or resuscitation is a traumatic experience for the family members	7.6	13.3	45.9	33.3

The hospital should develop guidelines to support family involvement and give family the option to attend invasive procedures and resuscitation.	21.7	29	35.2	14.2
The hospital should develop training program for nurses to support family when they attend invasive procedure or resuscitation.	11.9	23.9	45.7	18.5
I support the practice of allowing family members to be present during invasive procedures and resuscitation	35.3	43.6	17.1	4.1

#### **4.8 Ancillary results of family member participants.**

In this section, statistically significant and non-significant results are demonstrated for family needs, met/unmet needs and the most appropriate person to meet these needs. These were with the following demographic variables: hospital, age, gender, nationality, level of education, previous ICU experience, relationship to patient, length of patient stay in the ICU, patient's age, patient's gender and visit preference. An independent sample t-test, a series of one-way between-groups analysis of variance with post-hoc test and Mann Whitney test procedures were used to detect any statistically significant differences between variables. The level of significance was set at  $p < 0.05$ .

##### **4.8.1 Hospital**

There were no statistically significant differences among hospitals and rankings of importance for assurance and cultural and spiritual needs ( $p = 0.07$ ). Family members from Qatif Central Hospital (QCH) rated needs for information (mean 32.5  $SD \pm 3.26$ ,  $p = 0.01$ ), proximity (mean 14.08,  $SD \pm 2.46$ ,  $p = 0.04$ ) and support (mean 12.83  $SD \pm 2.44$ ,  $p = 0.001$ ) less important than other hospitals. There were no statistically significant differences between hospital and met/unmet family needs for information and proximity ( $p = 0.06$  and  $0.3$ ). However, family members from different hospitals identified family needs for assurance, support and cultural and spiritual family needs differently ( $p = 0.002$ ,  $0.04$  &  $0.02$  respectively). Participants from King Fahad

Central Hospital-Jazan (KFCH-J) identified their need for assurance as less met than those at other hospitals (mean 3.67 *SD*  $\pm$ 0.10). Participants from QCH considered their needs for support to be less met than at other hospitals (mean 1.36 *SD*  $\pm$ 0.92). Also, participants from King Fahad Hospital-Hofuf KFHH identified their needs for cultural and spiritual to be less met (mean 2.71 *SD*  $\pm$ 1.25). Participants who were recruited from KFHH and Dammam Medical Complex (DMC) identified the administration as the best to fulfil their needs more than did participants from other hospitals ( $p < 0.0005$ , mean 2.69 & 2.33, *SD*  $\pm$ 0.7 &  $\pm$ 0.71 respectively).

#### **4.8.2 Age**

Participants were divided into four groups according to their age but there were no statistically significant differences between family members' age ( $p = 0.07$ ) and the rating of importance of assurance, information, proximity, support and cultural and spiritual family needs. There were also no statistically significant differences between participants' age group and family needs being met and unmet as well as the most appropriate person to meet family needs ( $p = 0.09$ ).

#### **4.8.3 Sex**

There were no statistically significant differences between males and females and ratings of importance of assurance, information, support, proximity and cultural and spiritual family needs ( $p = 0.10$ ). A test of statistical significance was conducted to compare family needs of assurance, information, proximity, support and cultural and spiritual needs being met or unmet for males and females. There was a statistically significant difference in mean scores of assurance for males (mean = 4.00, *SD*  $\pm$  2.55)

and females (mean = 5.48,  $SD \pm 1.57$ ;  $t(133) = -2.72$ ,  $p = 0.009$ ). There was a statistically significant difference in scores of information needs for males (mean = 4.82,  $SD \pm 3.40$ ) and females (mean = 7.30,  $SD \pm 2.38$ ;  $t(133) = -3.14$ ,  $p = 0.003$ ). There was a statistically significant difference in mean scores of cultural and spiritual needs between males (mean = 3.97,  $SD \pm 2.41$ ) and females (mean = 5.63,  $SD \pm 1.59$ ;  $t(133) = -3.05$ ,  $p = .003$ ). Nevertheless, there were no statistically significant differences between sex and needs of proximity and support being met or unmet ( $p = .06$ ).

An inferential statistical test was performed to detect the relationship between family members' sex and the best person to meet their needs. There were no statistically significant differences between sex and doctor meeting the family needs. Hence, there were statistically significant differences between participants' sex and nurse or administration as the most appropriate to meet each need ( $p < 0.0005$ ). Females family members recognised nurses as the best to meet their needs (mean 1.81  $SD \pm 1.3$ ), while male family members recognised administration as the best to meet their needs (mean 1.71  $SD \pm 1.24$ ).

#### **4.8.4 Nationality**

There were no statistically significant differences between Saudi and non-Saudi family members and ratings of importance for assurance, information, support, proximity and cultural and spiritual needs ( $p = 0.05$ ). There were also no significant differences between nationality and family needs of being met or unmet as well as between nationality and the most appropriate person to fulfil each need ( $p = 0.15$ ).

#### **4.8.5 Level of education**

There were no statistically significant differences between level of education (less than high school, high school, diploma, bachelor and masters) and ratings of importance for assurance, information, support, proximity and cultural and spiritual needs ( $p > 0.05$ ). Also, there were no statistically significant differences between level of education of family members and family needs as being met and unmet or even the most appropriate to meet each need ( $p = 0.20$ ).

#### **4.8.6 Previous ICU experience**

There were no significant differences between ratings of importance for assurance, information, proximity, support and cultural and spiritual needs and family members with or without previous ICU experience ( $p = 0.05$ ). There were also no significant differences between family members with or without ICU experience and family needs being met or unmet ( $p = 0.07$ ). The recognition of the nurse as the most appropriate healthcare provider to meet family needs was rated significantly more often by family members who had previous ICU experience ( $p = 0.03$ , mean  $1.5 \text{ SD} \pm 1.18$ ). However, there were no significant differences between family members with or without previous ICU experience and doctor and administration as the best to meet family needs.

#### **4.8.7 Relationship to critically ill patient**

Participants were divided into six groups according to their relationship to the patient. There were no statistically significant differences between spouses, siblings, parents, and sons/daughters, other relatives and friends in their ratings of importance for

assurance, information, proximity, support and cultural and spiritual needs ( $p = 0.08$ ). Moreover, there were no statistically significant differences between relationship to the patient and family needs being met or unmet, or preference for doctor, nurse or administration meeting their needs ( $p = 0.08$ ).

#### **4.8.8 Length of patient stay in the ICU**

There were no statistically significant differences between length of patient stay in the ICU and ratings of importance for information, support, proximity and cultural and spiritual needs ( $p = 0.09$ ). The length of patient stay in the ICU was divided into four groups. There was however, a significant difference between assurance needs and length of patient stay in the ICU. Families of patients admitted in the ICU for 10 to 30 days rated assurance needs as less important (mean 24.62,  $SD \pm 3.34$ ,  $p = 0.02$ ). There were also no statistically significant differences between length of patient stay and family needs being met or unmet and whether doctor, nurse or administration were the best to meet family needs ( $p = 0.05$ ).

#### **4.8.9 Patients' age**

Participants were divided into four groups according to their ill relative's age. There were no statistically significant differences between patient's age group and the family's perceived needs ( $p = 0.30$ ). There were no statistically significant differences between patient's age and family needs of assurance, information and support being met/unmet. Family members of patients aged between 23 and 38 years identified their needs of proximity (mean 1.83  $SD \pm 1.42$   $p = 0.03$ ) and cultural and spiritual (mean 3.67  $SD \pm 2.14$   $P = 0.01$ ) as being less met than families of patients in other age

groups. There were no statistically significant differences between patients' age and the doctor, nurse or administration meeting the family's needs ( $p = 0.05$ ).

#### **4.8.10 Patients' sex**

There were no statistically significant differences in family members' views of male and female patients' and rating of importance of family needs of assurance, information, proximity and cultural and spiritual needs ( $p = 0.10$ ). However, there were statistically significant differences in scores of family's views of support for male patients ( $M = 15.69$ ,  $SD = 3.24$ ) and female patients ( $M = 17.03$ ,  $SD = 3.04$ ;  $t(133) = -2.11$ ,  $p = 0.03$ ; family members of female patients ranked support as more important than family members of male patients.

There were no statistically significant differences among male and female patients and family needs of assurance, information, proximity, support and cultural and spiritual, as perceived by family members being met or unmet ( $p = 0.10$ ). There were also no significant differences in patients' sex and family views of the best person to fulfil each family need ( $p = 0.07$ ).

#### **4.8.11 Visit preference**

There were no statistically significant differences between participants who preferred to visit once, twice or three times a day, every other day, every two days, or to have an open visitation policy and the rating of importance of assurance, information, proximity, support and cultural and spiritual family needs ( $p = 0.05$ ). Additionally, there were no statistically significant differences between visit preference and family

needs being met and unmet  $p = 0.05$ . However, there appeared to be statistically significant differences between visit preference and administration meeting the family needs ( $p = 0.01$ ). Participants who preferred one visit a day indicated that administration was the best to meet their needs (mean 2.08  $SD \pm 0.94$ ).

#### **4.8.12 Relationship between family needs categories**

The relationship between the assurance dimension and information, proximity, support and cultural and spiritual dimension as perceived by family members was investigated using Pearson product-moment correlation coefficient. Preliminary analysis was performed to ensure no violation of assumptions of normality, linearity and homoscedasticity (Pallant, 2011). As illustrated in Table 4.21, there was a strong, positive correlation between assurance and information, ( $r = .75, n = 127, p < 0.0005$ ) with high levels of information perceived associated with high levels of assurance. There was also a medium, positive correlation between assurance and proximity ( $r = .47, n = 141, p < 0.0005$ ), a medium, positive correlation between assurance and support ( $r = .44, n = 143, p < 0.0005$ ), and a strong, positive correlation between assurance and cultural and spiritual needs ( $r = .56, n = 133, p < 0.0005$ ).

**Table 4.20: Relationship between family needs categories as perceived by family members N = 167.**

Dimension		Assurance	Information	Proximity	Support	Cultural and spiritual
Assurance	R		0.758**	0.477**	0.447**	0.560**
	Sig		0.0005	0.0005	0.0005	0.0005
Information	R	0.758**		0.631**	0.662**	0.709**
	Sig	0.0005		0.0005	0.0005	0.0005
Proximity	R	0.477**	0.631**		0.572**	0.640**
	Sig	0.0005	0.0005		0.0005	0.0005
Support	R	0.447**	0.662**	0.572**		0.734**
	Sig	0.0005	0.0005	0.0005		0.0005
Cultural and spiritual	R	0.560**	0.709**	0.640**	0.734**	
	Sig	0.0005	0.0005	0.0005	0.0005	

Significant at 0.05 level

There was also a strong, positive correlation between information and proximity, ( $r = 0.63$ ,  $n = 126$ ,  $p < 0.0005$ ). Additionally, there was a strong, positive correlation between information and support ( $r = 0.66$ ,  $n = 128$ ,  $p < 0.0005$ ) and a strong, positive correlation between information and the cultural and spiritual subscale, ( $r = 0.70$ ,  $n = 123$ ,  $p < .0005$ ) and a strong, positive correlation between proximity and support, ( $r = .57$ ,  $n = 139$ ,  $p < 0.0005$ ). There was also a strong, positive correlation between proximity and cultural and spiritual subscale ( $r = 0.64$ ,  $n = 123$ ,  $p < 0.0005$ ). There was a strong, positive correlation between the two variables ( $r = 0.73$ ,  $n = 150$ ,  $p < 0.0005$ ) (see Table 4.21).

## **4.9 Ancillary results of healthcare providers**

In this section, statistically significant and non-significant results are presented for family needs and family presence during resuscitation and other invasive procedures with the following healthcare provider variables: hospital, age, sex, nationality, level of education, healthcare profession, years of employment and years of experience in Saudi Arabia. An independent sample t-test, a series of one-way between-groups analysis of variance with post-hoc test and Mann Whitney procedures were performed to detect any statistically significant differences between variables. The level of significance was set at  $p < 0.05$ .

### **4.9.1 Hospital**

There were no statistically significant differences between hospitals and ratings of importance for assurance, information, proximity, support and cultural and spiritual needs ( $p = 0.07$ ). Also, there were no statistically significant differences between hospitals and family needs of assurance, information and proximity being met or unmet ( $p = 0.09$ ). The need for support however, was rated as met more in King Fahad Central Hospital-Jazan (KFCH-J) (mean 6.64,  $SD \pm 1.36$ ,  $p = 0.001$ ) and King Fahad Medical City (KFMC) (mean 6.21,  $SD \pm 1.36$ ,  $p = 0.001$ ) than other hospitals. Additionally, cultural and spiritual needs were identified by the healthcare providers to be met less in King Fahad Hospital-Medina (KFH-M) than other hospitals (mean 11.00  $SD \pm 2.06$ ,  $p = 0.04$ ). There were no significant differences between hospitals and doctor, nurse or administration as the most appropriate to meet family needs. The results revealed no statistically significant relationship between hospital and family presence during routine and resuscitation and other invasive procedures.

### 4.9.2 Age

There were no statistically significant differences between the ranking of importance of assurance, information, proximity support and cultural and spiritual needs and participants' age ( $p = 0.05$ ). There were also no statistically significant differences between healthcare providers' age and met/unmet family needs of assurance, information, proximity, support and cultural and spiritual needs or even the most appropriate person to meet each need ( $p = 0.10$ ). The results indicated also that there were no significant differences between healthcare providers' age and family presence during routine and resuscitation and other invasive procedures ( $p = 0.09$ ).

### 4.9.3 Sex

There were no statistically significant differences between male and female healthcare providers and ratings of importance for assurance, information, support, proximity and cultural and spiritual family needs ( $p = 0.10$ ). However, there was a statistically significant difference in scores of assurance, information, proximity support and cultural and spiritual family needs being met or unmet and the sex of the healthcare providers as tabulated in Table 4.21.

**Table 4.21: Relationship between HCPs' sex and family needs being met or unmet.**

Need	N	Mean		SD		t	P
		M	F	M	F		
<b>Assurance</b>	420	9.00	8.21	1.64	1.685	3.072	0.002
<b>Information</b>	420	13.38	11.88	4.35	2.529	2.405	0.01
<b>Proximity</b>	420	7.24	6.56	1.41	1.280	3.465	0.001
<b>Support</b>	420	7.85	6.86	1.19	1.521	4.479	0.0005
<b>Cultural and spiritual needs</b>	420	11.52	9.94	2.60	1.970	4.919	0.0005

Significant at 0.05 level

In addition, male healthcare providers indicated that doctors were the most appropriate to meet family needs (mean 3.35 *SD*  $\pm$  1.16,  $p < 0.0005$ ); however female healthcare providers indicated that nurses were the best to meet family needs (mean 2.21, *SD*  $\pm$  1.03,  $p = 0.002$ ). There was a statistically significant relationship between sex and healthcare providers' attitudes to family presence during resuscitation or other invasive procedures. Male healthcare providers opposed family presence during resuscitation and other invasive procedures significantly more than females with a mean difference of 1.69,  $t(464) = 3.78$ ,  $p = 0.0005$ . Male healthcare providers opposed family presence during resuscitation and other invasive procedures significantly more than females 1.69,  $t(464) = 3.78$ ,  $p = 0.0005$ . Males scored less mean (18.00 *SD*, 3.97) than females healthcare providers (19.69 *SD*, 3.48). However, there were no significant differences between male and female healthcare providers in relation to family presence during routine care ( $p = 0.08$ ).

#### **4.9.4 Nationality**

The healthcare providers' nationality was divided into two nationalities Saudi and non-Saudi to explore the impact of nationality on the ranking of importance of the family needs and family presence during routine and resuscitation and other invasive procedures. There was a significant relationship between nationality and assurance ( $p = 0.03$ ); the expatriate healthcare providers ranked the assurance needs slightly higher than Saudi healthcare providers (mean 24.74 *SD*  $\pm$  2.84). There was also a significantly relationship between nationality and information needs ( $p < 0.0005$ ): the expatriates rated the information needs higher than Saudi healthcare providers (mean 34.61 *SD* 4.33). However, there was no significant relationship between healthcare

providers' nationality and support, proximity and cultural and spiritual needs ( $p = 0.07$ ).

The table below shows the significant differences between nationality and the family needs of assurance, information, support, proximity and cultural and spiritual needs being met or unmet. As demonstrated in Table 4.22, there was a significant relationship between family needs being met or unmet and nationality. The Saudi healthcare providers had significantly higher mean scores of family needs. This indicates that assurance, information, proximity, support and cultural and spiritual needs were rated as being met more by Saudi than non-Saudi healthcare providers. The Saudi healthcare providers also identified doctors as the best to fulfil family needs more than did non-Saudis (mean 3.17 SD 0.91  $p = 0.007$ ).

**Table 4.22: Relationship between nationality and family needs being met or unmet.**

Need	N	Mean		SD		P
		S	NS	S	NS	
<b>Assurance</b>	477	9.19	8.21	1.86	1.63	< 0.0005
<b>Information</b>	477	13.76	11.85	4.54	2.49	0.008
<b>Proximity</b>	477	7.22	6.59	1.21	1.33	0.002
<b>Support</b>	477	8.14	6.81	1.22	1.47	< 0.0005
<b>Cultural and spiritual needs</b>	477	11.71	9.95	2.74	1.94	< 0.0005

Significant at 0.05 level

There was a statistically significant difference between Saudi and non-Saudi healthcare providers and their attitudes towards family involvement. Saudi healthcare

providers agreed with family involvement during routine care more than did the non-Saudis. With a mean difference of 2.50,  $t(453) = 3.81, p = 0.006$ , Saudi scored higher (mean 30.76,  $SD$  3.885) than did non-Saudi healthcare providers. The results also indicated a statistically significant relationship between Saudi and non-Saudi healthcare providers and attitudes towards the family presence during resuscitation and other invasive procedures. The Saudi healthcare providers indicated more agreement than did non-Saudis (mean 17.91,  $SD$  3.93) with a mean difference of 1.89,  $t(72.75) = 3.62, p = 0.001$ .

#### **4.9.5 Level of education**

There were no statistically significant differences between diploma, hospital trained, Bachelor, Masters and Ph.D holders on ratings of importance for assurance, information, support and cultural and spiritual needs ( $p = 0.05$ ). However, proximity was rated significantly more important by healthcare provider Ph.D holders ( $p = .04$ , mean 17.00  $SD \pm 2.16$ ).

There was a statistically significant difference between healthcare providers' level of education and family needs being met or unmet of assurance ( $p = 0.004$ ), information ( $p < 0.0005$ ), support ( $p = 0.005$ ) and cultural and spiritual needs ( $p = 0.01$ ). Ph.D qualified healthcare providers ranked assurance needs (mean 10.50  $SD \pm 3.53$ ), information (mean 16.50  $SD \pm 3.53$ ), support (mean 9.00  $SD \pm 1.41$ ) and cultural and spiritual needs (mean 13.50  $SD \pm 3.53$ ) higher than those with other qualifications. There was no statistically significant difference between the level of healthcare providers' education and proximity category being met or unmet ( $p = 0.056$ ). Additionally, there were no significant differences between level of education and the

most appropriate person who can meet family needs ( $p = 0.059$ ). There were no statistically significant relationship between healthcare providers' level of education and family presence during routine and resuscitation and other invasive procedures ( $p = 0.07$ ).

#### 4.9.6 Healthcare profession

Healthcare providers were divided into three groups according to their profession, physicians, nurses and respiratory therapists (Table 4.23). There was a statistically significant difference between healthcare providers profession and the rating of importance of information and support needs ( $p = 0.01$ ); whereas there were no significant differences between healthcare providers profession and rating of importance of assurance ( $p = 0.1$ ), proximity ( $p = 0.051$ ) and cultural and spiritual needs ( $p = 0.2$ ). Nurses rated the family need for information more important than physicians and respiratory therapists (mean 3.44,  $SD \pm .44$ ). In addition, respiratory therapists rated support as less important than physicians and nurses (mean 2.59,  $SD \pm .54$ ).

**Table 4.23: Relationship between healthcare profession and ranking of importance of family needs.**

Need	Physicians	Nurses	RTs
Assurance	---	---	---
Information	**	---	---
Proximity	---	---	---
Support	---	---	**
Cultural and spiritual needs	---	---	---

--- No significant difference, \*\* Significant difference, Significant at 0.05 level

Furthermore, there was a statistically significant difference between healthcare providers profession and their perception of family needs being met or unmet in relation to assurance ( $p = 0.004$ ), information ( $p = 0.02$ ), support ( $p < 0.0005$ ) and cultural and spiritual subscales ( $p < 0.0005$ ). Nevertheless, there were no statistically significant differences between healthcare profession and family needs of assurance ( $p = 0.4$ ). As shown in Table 4.24, the respiratory therapists identified the need for assurance, information, support and spiritual and cultural needs as significantly less met compared to physicians and nurses.

**Table 4.24: Respiratory therapists mean of family needs being met or unmet**

Need	Mean	SD
Assurance	9.61	2.062
Information	13.61	3.013
Support	8.33	.907
Cultural and spiritual needs	11.89	2.324

Significant at 0.05 level

There were statistically significant differences between healthcare providers' profession and the best person who can meet family needs. Doctors identified themselves as the most appropriate to meet most of the family needs (mean 3.77,  $SD$  0.99,  $p < 0.0005$ ). However, nurses also identified themselves as the most appropriate to meet most of the family needs (mean 2.29,  $SD$  1.07,  $p < 0.0005$ ). There were statistically significant differences between physicians, nurses and respiratory therapists and family presence during routine and resuscitation and other invasive procedures. Physicians expressed more opposition to family involvement during routine care than did nurses and respiratory therapists  $F(2, 465) = 3.20$ ,  $p = 0.04$ ,

physicians scored less mean (31.00, *SD* 4.16) than did nurses and respiratory therapists. Physicians also expressed more opposition to family presence during resuscitation and other invasive procedures than did nurses and respiratory therapists  $F(2, 465) = 5.63, p = 0.0005$ .

#### **4.9.7 Years of employment**

Participants were divided into four groups according to their years of employment. There was no statistically significant difference between healthcare providers' years of employment and the rating of importance of assurance, information, proximity and cultural and spiritual needs ( $p = 0.059$ ). However, there was a statistically significant difference between healthcare providers' years of employment and support needs ( $p = .03$ ). Healthcare providers with less than one year employment ranked support slightly higher than the other groups (mean 3.06, *SD*  $\pm$  0.39).

Additionally, there was a statistically significant difference between years of employment and family needs of proximity being met or unmet ( $p = 0.01$ ). Healthcare providers with less than one year employment ranked proximity less met than other groups (mean 8.00 *SD*  $\pm$  1.73). There was no statistically significant difference between healthcare providers' years of employment and assurance, information, support and cultural and spiritual needs being met or unmet ( $p = 0.06$ ). There were no statistically significant differences between years of experience and doctor, nurse or administration meeting family needs ( $p = 0.57$ ). Also, there were no statistically significant differences between healthcare providers' years of employment and family presence during routine and resuscitation and other invasive procedures.

#### **4.9.8 Experience in Saudi Arabia**

Participants were divided into four groups according to their years of employment in Saudi Arabia to explore the impact of healthcare providers' years of experience in SA. There were no statistically significant differences among healthcare providers experience in Saudi Arabia and the ranking of importance of family needs ( $p = 0.40$ ). There was a statistically significant difference between years of experience in Saudi Arabia and family needs of support being met or unmet ( $p = 0.02$ ). Healthcare providers with more than 10 years' experience in Saudi Arabia rated support needs as less met than other groups (mean  $8.17$   $SD \pm 1.52$ ). However, there was no statistically significant difference between healthcare providers' years of experience in Saudi Arabia and assurance, information, proximity and cultural and spiritual needs being met or unmet ( $p = 0.06$ ). Additionally, there were no statistically significant differences between experience in Saudi Arabia and doctor, nurse or administration meeting family needs need ( $p = 0.056$ ). There were also no statistically significant differences between healthcare providers experience in Saudi Arabia and their views on family presence during routine and resuscitation and other invasive procedures ( $p = 0.07$ ).

#### **4.9.9 Relationship between families' needs categories**

The relationship between the assurance dimension and information, proximity, support and cultural and spiritual dimension as perceived by healthcare providers was investigated using Pearson product-moment correlation coefficient. There was a strong, positive correlation between the two variables, ( $r = 0.76$ ,  $n = 477$ ,  $p < .0005$ ), with high levels of information perceived associated with high levels of assurance (see Table 4.25). There was also a strong, positive correlation between assurance and

proximity ( $r = 0.52$ ,  $n = 477$ ,  $p < 0.0005$ ), a medium, positive correlation between assurance and support, ( $r = 0.48$ ,  $n = 477$ ,  $p < 0.0005$ ) and a strong, positive correlation between assurance and cultural and spiritual needs ( $r = 0.60$ ,  $n = 477$ ,  $p < 0.0005$ ).

**Table 4.25: Relationship between family needs categories as perceived by healthcare providers N = 477.**

Dimension		Assurance	Information	Proximity	Support	Cultural and spiritual
Assurance	<b>R</b>		0.765**	0.523**	0.480**	0.602**
	<b>Sig</b>		0.0005	0.0005	0.0005	0.0005
Information	<b>R</b>	0.765**		-.547**	0.581**	0.660**
	<b>Sig</b>	0.0005		0.0005	0.0005	0.0005
Proximity	<b>R</b>	0.523**	0.547**		0.647**	0.581**
	<b>Sig</b>	0.0005	0.0005		0.0005	0.0005
Support	<b>R</b>	0.480**	0.581**	0.647**		0.555**
	<b>Sig</b>	0.0005	0.0005	0.0005		0.0005
Cultural and spiritual	<b>R</b>	0.602**	0.660**	0.581**	0.555**	
	<b>Sig</b>	0.0005	0.0005	0.0005	0.0005	

Significant at 0.05 level

The relationship between the information dimension and the proximity, support and cultural and spiritual dimension indicated a strong, positive correlation between information and proximity, ( $r = 0.54$ ,  $n = 477$ ,  $p < 0.0005$ ). There was also a strong, positive correlation between information and support ( $r = 0.58$ ,  $n = 477$ ,  $p < 0.0005$ ) and a strong, positive correlation between information and cultural and spiritual subscale,  $r = 0.66$ ,  $n = 477$ ,  $p < .0005$ . The relationship between proximity dimension and support and cultural and spiritual dimension as perceived by family members revealed a strong positive correlation between proximity and support, ( $r = 0.64$ ,  $n =$

477,  $p < 0.0005$ ) and a strong, positive correlation between proximity and the cultural and spiritual subscale ( $r = 0.58$ ,  $n = 477$ ,  $p < 0.0005$ ). Moreover, the relationship between the support dimension and the cultural and spiritual dimension showed a strong, positive correlation between the two variables, ( $r = 0.55$ ,  $n = 477$ ,  $p < 0.0005$ ).

#### **4.10 Conclusion**

In this chapter the quantitative results arising from questionnaires have been reported. The quantitative results revealed that family members and ICU healthcare providers had similar perceptions that assurance and information were the most important needs. In contrast, proximity and support needs were of the least importance to both groups. Three needs “To know specific facts concerning the patient's progress”, “To have an explanation in detail about the condition of the patient when it becomes worse” and “To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect” were perceived as most important to family members and healthcare providers. Three needs, “To be allowed to visit whenever we wish”, “To request to stay during the care of my family member” and “To have another person accompany me while visiting the intensive care unit”, were perceived as least important to both groups.

The results indicated that family members identified their needs of assurance as being met and their needs for support as unmet, with needs of information and proximity and cultural and spiritual needs as not always met. On the other hand, ICU healthcare providers identified all needs as being met. Family members recognised doctors as the most appropriate person who could meet most of their needs, followed by nurses then

hospital administration. Likewise healthcare providers perceived doctors as the most appropriate person to meet most of their needs, but followed by the hospital administration then nurses.

Ancillary results showed that there was a variety of significant findings between family needs as perceived by family members and healthcare providers. Moreover, there was a variety of significant findings between some selected demographic information and family needs, family needs being met or unmet and the most appropriate person to meet each need for both groups. Also, some significant findings were detected between the healthcare providers' demographic details and their attitudes regarding family involvement during routine care and resuscitation and other invasive procedures. Furthermore, a Pearson correlations result indicated medium to strong positive correlations between assurance, information, proximity, support and cultural and spiritual subscale as perceived by family members and healthcare providers. Those findings further led to understanding the phenomenon of the needs of Saudi families of critically ill patients. The qualitative results of the study will be reported in Chapter Five.

## Chapter Five: Qualitative results

### 5.1 Introduction

In this study the experiences of family members of having a seriously ill critical care patient have strongly affected participants. The family member vowed “*the Ministry of Health needs to be further developed not in every day but in every single minute*” (Saeed). The ICU period was felt as a terrible time by most participants. The Saudi families of ICU patients in this study recognized that they had needs that should be met and not neglected. It can safely be said that those needs, if unmet, would increase stress on families and ICU healthcare providers. Families in this study sought a caring atmosphere in the ICU where they could receive honest and straightforward information, remain positive and hold on to hope, feel closeness to their loved one, be reassured of the best care and be a part of the care process.

This picture provides the context for this chapter, which reports the qualitative results of the study. In Section 5.2 the results of the open-ended questions are reported. This is divided into two parts to present the findings of family members and healthcare providers further comments and suggestions for Phase 1 of the study. In Section 5.3 the findings of interviews of Phase 2 of the study are reported. The newly generated categories will be examined in relation to the literature, comparing the findings with those of other studies.

## 5.2 Results of open-ended question Phase One

An open-ended question was provided at the end of the questionnaire for any further comments about family's needs which may have not been covered by the questionnaire.

### 5.2.1 Themes in family members' further comments and suggestions

Of the 167 participants included in the study, 44 (26.3%) added further comments. The majority of the participants were recruited from KSMC (12), ten were from KFMC, six from DMC and five were from KFHH. As can be seen in Table 5.1, three family members were from KFSH, KFH-M and KFCH-J respectively and only two family members participated from QCH. The comments of family member respondents (n = 45) varied in length from one line to one page of smooth handwritten Arabic. The comments were translated into English and read several times and categorised by the researcher.

**Table 5.1: Family members' response to the open-ended item.**

<b>Hospital</b>	<b>No of responses to open-ended item</b>
KSMC	12
KFMC	10
DMC	6
KFSH	3
QCH	2
KFHH	5
KFH-M	3
KFCH-J	3
Total	44

Family responses to provide further comments and suggestions generated four categories (Table 5.2):

- A. The need to know straightforward and honest information.
- B. The need to remain close to the patient.
- C. The need for psychological and spiritual support
- D. The need for a caring and supportive environment

**Table 5.2: Identified themes in families' further comments and suggestions.**

No	Categories	Example
A	The need to know, straightforward and honest information.	<i>We need competent staff in the ICU to explain to us the nature of the disease of the patient and the treatment that is being given and the degree of improvement.</i>
B	The need to remain close to the patient.	<i>“Increase visit time” and “making available the required facilities for the family in the ICU”</i>
C	The need for psychological and spiritual support	<i>Providing psychological and spiritual support to the patient and family</i>
D	The need for caring and supportive environment	<i>I prefer ICU staff attention focus more on the patient care and treatment.</i>

The emergent categories are described in the following section and each of the categories is examined in the context of the literature.

### **5.2.1.1 The need to know straightforward and honest information**

The most frequent comment was that the family members needed to access straightforward and honest information about their critically ill relative. The need for information was ranked by family members as their most important need in Engli and Kirsivali-Farmer's (1993), Warren's (1993) and Mi-Kuen, French and Kai-Kwong's (1995) quantitative studies and this was also clearly identified in wider qualitative studies (Wilkinson, 1995, Burr, 1998). In this study the need to receive honest information was considered significant by the family members to be reassured about their loved one. This need was hindered by the bureaucratic structure of the ICU working environment. Many family members stated that they hardly met the doctor

due to “*visiting time limit*”, “*ICU medical team do not answer the phone calls*” and “*we need translator to be able to communicate effectively with the care team*”(ID: 68). The following illustrates this “*we hardly can get single information about our patient, when we requested meeting the treating doctor, they [healthcare providers] advised us to come in the morning; however when we came, the security did not allow us to access the ICU and said it is not visiting time*”(ID: 20). While the overall need for information was considered very important by both doctors and nurses, family members indicated in their comments that their needs remained unmet.

### **5.2.1.2 The need to remain close to the patient**

The family members expressed a strong need to remain close to the patient. They perceived the visiting time as inappropriate and inadequate for them to remain close to their relative. Wilkinson (1995) and Burr (1998) reported that one of the most important needs is to see the patient frequently. In Fry and Warren (2007), remaining close to the patient was regarded as a way to show the patients are loved and missed. Saudi families believed that facilitating visitation policy such as “*open visiting policy*”, “*more than one visit a day*” or “*allowing close relatives such as parents to visit whenever they wish*” would enable them to remain close to the patient and therefore offer any assistance they could. This was demonstrated by a family member in the following comment: “*the presence of a patient in the ICU requires the presence of the family nearby for a longer period*” (ID: 108). Equally it was acknowledged that “*many of the essential facilities*” were not available in the ICU to ease family proximity such as a “*waiting room*” or even “*visitors’ chairs*”. Being restricted from seeing the loved one in ICU can cause sometimes frustration. Accordingly, flexible

visiting time and waiting rooms with comfortable furniture was seen as necessary by family members.

#### **5.2.1.3 The need for psychological and spiritual support**

Supporting families of critically ill patients psychologically and spiritually could help reassure them, relieve their anxiety and make them satisfied with the care. Support needs have similarly been identified in previous studies (Burr, 1998; Verhaeghe et al, 2005). These qualitative studies have indicated that support is important and should be of major concern to ICU healthcare providers. The family members in the study wanted a social worker to be assigned in the ICU. The “*social worker*” was perceived as a complement to the ICU healthcare providers in terms of “*supporting, reassuring families and providing hope for survival*”. The role of the social worker was described by a family member as someone “*to provide psychological support and to explain the bad news in an honest and merciful matter without hiding anything and preparing the family for the treatment whichever within or outside the hospital*” (ID: 134). In terms of spiritual support participants suggested “*Quran Readers*” or “*Quran audio recordings*” to cite Quran phrases to the ICU patients as this would support and meet the “*families’ spiritual needs*”. A family member indicated that “*Quran recitations should be provided for each ICU patient*”. Such a need, if met, would reassure and support the family of the ICU patient and may help them to accept with patience any adverse consequences or bad news.

#### **5.2.1.4 The need for a caring and supportive environment**

Many families commented upon the care provided and the supportive services within the ICU. Families wanted ICU healthcare providers to focus on patient care and were

more concerned with the quality of care delivered to the critically ill patient in ICU. This finding in this section of the study is consistent with a qualitative study by Wilkinson (1995) and a quantitative study by Al-Hassan and Hweidi (2004). The relatives here are looking for “a *high standard of care*”, “*highly competent staff*”, “*nurses treat patients with respect and kindness*” (ID: 98) and “*quiet and happy atmosphere*”. The importance of infection control standards to prevent spread of infection from a family’s perspective was well documented. A relative indicated that “*each ICU patient must be placed in a single closed room, not all in together, to prevent spread of infection between patients*” (ID: 151) and another commented “*some nurses touch patients without even washing their hands in between*” (ID: 68). This need also included practical and supportive services, such as someone to “*help with the treatment expenses*” or in event of discharge and the patient needing medical equipment. They should be directed to the “*right person*” who can help them in this regard. The need to help with the treatment expenses was also reported by the Jordanian family members responding to the open-ended question in a study by Omari (2009). This need is only related to non-Saudi citizens, as Saudis receive free of charge healthcare services. Additionally, the social worker can be the “*right person*” who can help in the financial or any other issues of families with a critically ill patient.

### **5.2.2 Themes in healthcare providers’ further comments and suggestions**

A total of 46 (9.6%) healthcare providers offered further comments. As illustrated in Table 5.3, the majority of the questionnaires (17) were from DMC, while eight participants were from KSMC, six from QCH and five participants from KFHM. Four were from KFMC and two worked in KFSH, KFHH and KFCH-J respectively.

There were 35 (76%) nurses, 7(15.3%) physicians and 4 (8.7%) respiratory therapists. The comments of healthcare providers (n = 46) varied in length from one line to one page. It was noted whether the comment originated from a physician, nurse or respiratory therapist. The comments were read several times then categorised into themes.

**Table 5.3: Healthcare providers’ response to the open-ended item.**

<b>Hospital</b>	<b>No of responses to open-ended item</b>
KSMC	8
KFMC	4
DMC	17
KFSH	2
QCH	6
KFHH	2
KFH-M	5
KFCH-J	2
<b>Total</b>	<b>46</b>

The open-ended item provided data that brought deeper meaning to the survey results.

The thematic analysis led to four main themes in the written data (Table 5.4).

- A. The need to know versus communication difficulties.
- B. Involvement of family during routine nursing care.
- C. Fears of emotional disturbance from family presence.
- D. Decision making regarding family involvement.

**Table 5.4: Identified themes of healthcare providers further comments and suggestions.**

No	Theme	Example
A	The need to know versus communication difficulties	<i>Families should get full explanation about the patient condition in their language; however language is a barrier which hinders the communication.</i>
B	Involvement of family during routine nursing care	<i>Family involvement during routine care can be integrated in spiritual and mental development and decreases family stress.</i>
C	Fears of emotional disturbance from family presence.	<i>In my view family presence during resuscitation and invasive procedures may worsen the patient's condition and upset the family.</i>
D	Decision-making regarding family involvement	<i>Relatives' presence and involvement in the care is important but there should be a guideline to be followed.</i>

### 5.2.2.1 The need to know versus communication difficulties

Healthcare providers concurred with family members that families needed to receive information in understandable language using simple and clear terms. In their comments healthcare providers believed that providing updated information to the families of ICU patients should decrease their anxiety, stress and fear and enable them to have more trust in the patient care being provided. A nurse stated that:

*Families have the right to know about the disease and its management of their critically ill patient; some patients were discharged and their families knew nothing of their illness (ID: 175).*

They again indicated agreement that all aspects of care must be fully explained to the families in their own language as language differences may hinder the communication between healthcare providers and family members. One participant indicated:

*Families should get full explanation of the condition of their patient in their own language (ID: 403).*

The need for information has been found by ICU healthcare professionals to be of prime importance to families of ICU patients (O'Malley et al, 1991; Quinn, Redmond & Begley, 1996; Gelling & Prevost, 1999). The flow of information may be hindered in the ICU environment in Saudi Arabia due to the language barrier. For instance, the non-Arabic speakers of the healthcare provider sample in this study numbered 381, representing 79.8% of the total sample. As English is the language of communication in the hospital environment, a possible solution to overcome this problem is recruiting translators to ease the communication between healthcare providers and family members.

#### **5.2.2.2 Involvement of families during routine nursing care**

The healthcare providers indicated that families could be involved during routine nursing care in activities such as “*feeding the patient*” or “*applying lotion to their loved one’s body*”. It was perceived that the family members, if involved, can give “*physical, psychological and emotional support*” to their loved one. This validates the previous findings and supports the issue that both patients and families may benefit psychologically and emotionally from involvement in the care of their loved one (Hammond, 1995). Moreover, healthcare providers can help by

*including families on the patient’s care and explaining to them honestly, can prepare them for any further development of the patient condition”*  
(ID: 55).

Accordingly, families can “*support the patient physically, mentally and spiritually*”. Finally, the issue of the resources needed to involve the family was raised by the healthcare providers. Thus, the “*hospital administration*” should prepare “*a specific room/area intended for family members in the ICU*” to “*ease their access and*

*involvement*” (ID: 59). This finding is consistent with Takman and Severinsson (2005) who suggested that the hospital or ICU have to provide resources to help families with issues connected to the patient’s stay in the ICU. The need to stay overnight could arise also because some families may travel a long distance to visit a patient. Some of the participant hospitals have hotels nearby that families can be advised to stay in, whereas others have no hotels nearby, so it is important that relatives should have access to sleeping accommodation.

### **5.2.2.3 Fears of emotional disturbance from family presence**

Healthcare providers expressed fear that family presence during resuscitation and other invasive procedures would be traumatic and hazardous. They also believed that it might worsen the patient’s condition, upset the family and interfere with the staff performance. These attitudes were supported by personal experiences of healthcare providers that Saudi families “*come to visit in groups most of the time and cry in groups*” (ID: 140). However, participants suggested that family presence during resuscitation can be implemented if key environmental conditions were met such as “*families do not interfere or affect performance*” and were “*well educated before attending any invasive procedure or resuscitation*”. This concern was reported by healthcare providers in studies by Meyers et al. (2000) and Knott and Kee (2005), in which they argued that the implementation of family presence should be a well-prepared decision at hospital and healthcare provider levels. Furthermore, healthcare providers endorsed the need for public education regarding family presence. Al-Mutair et al. (2012) noted that family assessment for coping abilities, the absence of emotional disturbance and ensuring the safe implementation of family presence

during resuscitation are fundamental elements of implementation of educational programs. ICU healthcare providers claimed that:

*There should be extensive family education, so they understand the procedures, why these procedures are being done for the patient” (ID: 356).*

Another healthcare provider summarised how safe implementation of ICU family presence in Saudi Arabia would play:

*a significant role to recognize that everything possible was done to save their loved one and more easily accept any further development (139).*

#### **5.2.2.4 Decision-making regarding family involvement**

In this theme the data suggests that the healthcare providers advocated that involving family during routine care and resuscitation and other invasive procedures is the hospital administration’s responsibility through developing guidelines, protocols and “*written policies*”. One participant said:

*it is the responsibility of the hospital administration to shift the rules and regulations (ID: 206).*

They similarly confirmed that, for safe implementation of the practice, “*Clear well established protocols and guidelines*” should be implemented in advance and in consultation with patients’, families’ and staff’s preference. These results suggest that healthcare providers agreed that families should be given the option to be with their patient during resuscitation and other invasive procedures; however, they expressed some concerns regarding the implementation. A number of authors in earlier studies emphasised that the decision to implement the practice should be a well-prepared team decision with hospital-level support (Fulbrook et al. 2005; Gunes & Zaybak, 2009; Leung & Chow, 2012).

**Table 5.5: Profile of qualitative phase interviewees**

No	Pseudonym	M/F	Age	Education	Relationship to patient	Pt. M/F	Pt. Age	Admission period	Patient diagnosis	Perceived condition
1	Mossa	M	41	Less than high school	Father	M	18	11 days	Trauma	Critical
2	Waleed	M	29	High school	Nephew	M	21	3 days	Trauma	Critical
3	Badriah	F	45	University	Daughter	F	72	42 days	Pneumonia	Critical
4	Muhana	M	53	Less than high school	Son	M	83	4 months	COPD	Stable
5	Rabie'	M	55	Less than high school	Son	F	70	5 days	Trauma/ Dyspnoea	Stable
6	Aisha	F	50	University	Daughter	M	90	5 days	Aspiration pneumonia	Critical
7	Latif	M	43	Master degree	Son	M	78	43 days	Pneumonia	Critical
8	Abdullah	M	32	University	Husband	F	32	6 weeks	Hypoxia	Critical
9	Kahild	M	61	Less than high school	Son	F	88	33 days	Pneumonia	Critical
10	Awda	M	53	University	Cousin	M	18	1 month	Trauma	Stable
11	Mammdooh	M	23	High school	Brother	F	26	2 weeks	DVT	Critical
12	Saeed	M	46	University	Grandson	F	95	3 weeks	CVA	Critical

## **5.3 Results of qualitative Phase 2 (interviews)**

### **5.3.1 Overview of study participants**

Participants in Phase 2 of the study were from the same hospitals which participated in Phase 1. Interviewees were the closest family members who were available during the visiting time and met the selection criteria (Section 3.7). A total of 15 participants were approached by the researcher in the first instance to participate in the study and 12 agreed. Their ages ranged from 23 to 61 years, with a mean age of 44.25 years. Pseudonyms were given to informants to ensure anonymity and privacy. The interview participants were similar to Phase 1 in that the majority were male (10 or 83.3%), two (16.7%) were females, with half (50%) being the son/daughter of the patients (see Table 5.5). Half of the participants achieved at least a university degree, two achieved high school education and four less than high school.

Family members were associated with 12 patients who were admitted in the ICU for periods of three days to four months, with a mean of 30.75 days. Half the patients were male and half female, and ages ranged from 18 to 95 with the mean age of 57.5 years. Nearly all family members (9) perceived their loved one's condition as critical and only three (25%) perceived their condition as stable. The patients were diagnosed with trauma (4), pneumonia (4), with individualised patients having Chronic Obstructive Pulmonary Disorder (COPD), hypoxia, Deep Venous Thrombosis (DVT) and Cerebral Vascular Accident (CVA).

A purposive sample was used to increase the credibility of the study findings and to obtain a comprehensive understanding of the phenomenon of the family needs during

the qualitative phase (Burns & Grove, 2009). The interviews were conducted in the Arabic language, then transcribed and translated by the researcher into the English language.

### **5.3.2 Interview findings**

The data were analysed in the manner outlined in Section 3.15. Several major themes relating to the Saudi family of critically ill patients in this study have emerged in the analysis of the interviews,

- A. Looking for information.
- B. Maintaining reassurance.
- C. Spiritual healing.
- D. Maintaining close proximity.
- E. Involvement in care.
- F. Support is not facilitated.

Each of the themes is discussed individually in the following sections:

#### **5.3.2.1 Looking for information**

Almost all family participants indicated that not knowing the prognosis of their ill relative contributes to their experiencing intense feelings and deep anxiety. Information was the first and the most frequent need recognised by the participating family members in the interviews. Families sought to receive consistent and understandable information in their speaking language using simple and clear terms. They sought honest information regardless of whether it was good news or bad news, a finding also reported by Linnarsson, Budini and Perseius, (2010). A family member vowed:

*Every time I ask about the prognosis of my father they are just brushing you off, they give very brief and not depth explanation, just a word or two... for four days I haven't talked to the doctor, today I intended to talk to him and see what he says [doctor], he gave me a very short explanation that I couldn't understand very well. Nurses also, when asked, would reply that they were unauthorized to communicate any information with relatives and they leave us uncertain and scared (Muhana).*

The clearly identified need for information corresponds with earlier literature (Kleinpell, 1991; Fry & Warren, 2007; Yang, 2008; Keenan & Joseph, 2010). The participants wanted to receive honest information about what was going on and what would be done to the patient. They wanted to access information through meeting the doctor or by telephone:

*They don't give honest information; they (doctors) told me something and wrote something else in the report... they said that my son was in a stable condition whereas they wrote in the report that my son's status was critical (Mossa).*

Congruent with Draeger, Mandleco and Donnelly's (2003) findings, family members needed information about the medications, vital signs, surgical procedures or any tests or procedures that were performed on their ill family member. Questions were asked and some families would not leave until their questions were answered. However, family members were not always welcomed; in some situations they were treated in an unprofessional or even an impolite manner. It appeared that healthcare providers regarded families as uninterested, unpleasant and neglectful. One member stated:

*Some healthcare providers treat us as heavy-going... I will ask many questions and this is anticipated... because I have a family member between life and death (Waleed).*

Another shared the following:

*The doctor refused to talk to us and regarded us as ignorant, saying we know about the patient's condition but you don't (Awda).*

Families desired information from the critical care area as well as about the technical equipment, wires and tubes attached to their critically ill loved one. Family members wanted to know about the meaning of the numbers and waves on the digital display of the monitor screens. One member claimed:

*No one has even explained about the ICU environment to us or even the equipment attached to my sister... we have no idea what is their function or reasons for using them (Mammdooh).*

Through family education, conversation and communication with the healthcare providers, the family gain more knowledge of the patient's condition. This knowledge can prevent complications when caring for the patient at home. The significance of this was emphasised during interview. A participant shared his experience:

*My grandmother was discharged from the hospital without educating us about her condition; she stayed with us in the house for five days and then relapsed... we then brought her back to the hospital again (Saeed).*

Similarly to relatives' comments in Phase 1, participants in the interviews indicated that the family need for information was not always fulfilled and many times was hindered by the ICU's inflexible working style due to the "inability to meet the treating doctor", "restricted visiting time" or "unanswered phone calls". As a result families referred to their relationship or a contact (in Arabic "Wasta") in the hospital to access enough information or to ease their communication with the ICU healthcare providers. Waleed revealed:

*Honestly, I know somebody who works in the hospital that eased my communication with the ICU staff... I'm sure without this*

*person [backer] my communication and accessing ICU wouldn't be as easy (Waleed).*

Abdullatif agreed with Waleed's view and developed a further relationship with the security personnel to provide him with some information and diminish his stress and sense of disorganisation.

*I call three times a day, sometimes I get Mahdi [ICU security personnel] to reassure me about my father, as they don't [healthcare providers] answer my phone calls, I know Mahdi is not a medical professional but at least he can tell me whether my father is dead or still alive (Latif).*

Muhana shared his experience and suffering in trying to meet the treating doctor and access the ICU:

*I cannot meet the treating doctor during visiting time as he is only available in the morning shift; also when I come to see him in the morning the security won't allow me... it happened one day they [ICU staff] rang me to come to the hospital and consent to them transferring blood to my father but, when I came the ICU security didn't let me in, accidentally I met staff I know who assisted me to access ICU (Muhana).*

While honest and understandable information about the patient's progress was not always delivered to the families, some families were able to obtain consistent and sufficient information. These family members appeared satisfied with the care and were coping with the situation as a result of the information received which allowed them to anticipate and accept whatever might happen in future. A participant said:

*Excellent, yes our questions were always answered in an honest and consistent manner... Dr X called me to deliver some information regarding my father's condition; a day later my older brother met Doctor X and he gave him the same information that was given to me earlier (Aisha).*

The participants believed that family access to quality information was highly important and could ease their stress. However, they suggested that information should not be released to every family member; instead a very close, adult family member should be nominated by the family to receive information and liaise with the rest of the family:

*The hospital administration must ensure that the ICU staff do not release information to every and each family member and I suggest nominating one member to obtain information, and he/she in turn delivers to the rest of the family (Waleed).*

He continued:

*You know the problem here in Saudi Arabia; everyone asks and distributes the information to the rest of the family; during the last three days I received so many calls, a member says X has a fracture in the head, another a rupture in the spinal cord and another says he has paralysis... we should take into consideration that information should be delivered on a one person basis.*

This suggestion was also considered by Badriah, as well as Mahmmod who said:

*I wouldn't allow anyone [family] to come and see her [his sister], seeing her in this situation is very hard for the family, it is only me and her husband who visit her... for this reason I recommend naming one member only to communicate information to (Mahmmod).*

In their study, Titler et al. (1995) suggested a family spokesperson so the flow of information could be facilitated, particularly with large families. They maintained the family spokesperson has to accept the responsibility to receive the information and communicate with the rest of the family members.

### 5.3.2.2 Maintaining reassurance

During the immediate phase of critical illness, sufficient and honest information, as well as open communication between healthcare providers and family members, led in many circumstances to families being reassured regarding the care provided. In other studies too, using CCFNI and conducted in different contexts, relatives of a critically ill patient ranked the need for assurance as one of the most important family needs (Quinn, Redmond & Begley, 1996; Lee, MacKenzie & Chien, 1999; Gelling & Prevost, 1999; Al-Hassan & Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki et al. 2012).

Family members in Saudi Arabia relied on the healthcare providers to be optimistic, use encouraging words and maintain a smiling face. They valued nonverbal actions such as maintaining eye contact and varied facial expression by ICU healthcare providers to reassure them. Similarly, to Yang (2008) physicians in the current study were regarded as being more pessimistic and pragmatic:

*Doctors speak to us in a very harsh manner. Put a smile on your face, be hopeful, reassure me and, if you're not ready to talk, ask me to come in the following day... I talked to Doctor X, he is so conceited, he speaks from a sense of superiority, I'm honestly worried about the patients under his supervision (Waleed).*

Latif shared his opinion of the importance of healthcare providers being positive, hopeful and optimistic:

*As a second patient (he called the family member second patient) we need care, hope, optimism, use of encouraging words and we need the care givers to take into account the humanitarian aspect... sometimes the information made us tense and prevents us from sleep... you can give honest information with a bit of optimism.*

*Don't lie or deceive, the doctor knows that all ICU patients are critical but how to offer suitable words? I think they [healthcare providers] need courses to do this (Latif).*

Families realised the severity of their loved one's condition, although they maintained a hold on hope and reassurance:

*Oh, we are dying to hear happy news, but the physicians' discouraging words increase our stress and suffering; you know, they should be more positive (Mammdooh).*

Badriah shared this:

*Three times when I approached the physicians to reassure me about my mother's condition, they replied that they were busy... they are very tough in their words (Badriah).*

A quantitative study by Molter (1979) and qualitative studies by Wilkinson (1995) and Keenan and Joseph (2010) identified the need for families to feel there is hope and to hold on to it. Hope as described by Molter (1979) and cited in Holden et al. (2002) can be gained from several sources. These include God as well as nurses, doctors, other family members or any other hospital personnel. The family members in the current study revealed that meeting with the families, encouraging them to ask questions, acknowledging them and avoiding negligence would reassure them and maintain hope.

*I believe that being positive to the patient and family is half of the treatment while the other half is the presence of the family beside their loved one (Rabie).*

### 5.3.2.3 Spiritual healing

All twelve participants held a strong belief that the illness of their relative was a test of their faith in God and that God is the ultimate healer. The illness of their loved one enhanced their spiritual connections and meditation. Family members were behaving with stoicism and were found to be more engaged in reading the Qur'an, prayer, and charity. Families' faith in God, and being supported by spiritual practices, connected them to hold on to hope and to be convinced that things were going to change.

*The illness is a test of patient's faith in Allah (God) almighty; the patient and relatives should be always reminded of this thing to be more positive and hold on to hope (Rabie).*

Also, by remembering God's word, families were behaving with quiet strength.

Waleed shared that:

*We believe in Allah's (God) predestined will; therefore, if anything happens to the patient that's a reflection of Allah's will and we'll accept it (Waleed).*

Participants believed that illness and cure are God's will and that treatments came only after God's will, and believed that God was the best healer of any physical and spiritual illnesses.

*We [as Muslims] say that all available treatments are only after Allah's will; Allah is the ultimate healer (Saeed).*

Reading the Qur'an was an everyday practice; all families stated that they read the Qur'an at the patient's bedside during visiting time. Families also believed that this

action facilitated some meditation and comfort, maintaining hope, patience, remembrance of God and calmness of heart.

*Thank God I read Qur'an to my wife every day, I believe she has been improving because of the Qur'an not because of me or the doctor (Abdullah).*

Reading the Qur'an on a daily basis was perceived as spiritual healing for the patients as well as the family, having a therapeutic calming effect.

*I don't feel reassured unless I read the Qur'an every day I visit her [grandmother]; you know the Qur'an heals and reassures hearts "By remembering God, the hearts rejoice" (Saeed).*

Reading the Qur'an was highly valued for ICU patients to heal physically and spiritually. Family members suggested a Qur'an reader to ensure reciting verses from Qur'an to the patients all the time.

*We always recite Qur'an to her [sister], either me or her husband and sometimes we bring an external Qur'an reader. I suppose there is a Qur'an reader in the hospital for the ICU patients' to treat them by the Qur'an. I'm ready to pay the cost if required (Mammdooh).*

Family members during the critical illness were more engaged in prayer and supplications remembering God and asking for forgiveness.

*Definitely, this is the crucial element for patient cure and it is the practice of every day and every time, we ask Allah (God) for forgiveness and we pray to Allah (God) to cure her [mother] quickly, this is highly important (Rabie').*

In other instances family members may gather to pray for the cure of their patient:

*We gather in the house [family members] to pray to Allah (God) and read supplications asking him for a cure (Abdullah).*

Saudi families' cultural and spiritual practices also include paying charity on behalf of their critically ill relative. This action includes giving money to the poor, the charity organizations or can be spent in the cause of God for the sake of their loved one. It is believed by Muslims that this action may cure their patient.

*We pay charity on behalf of my father every day, it holds off disaster (Muhana).*

Also another member commented:

*We give money to charity on behalf of her, [mother] for the sake of her cure (Abdullah).*

Some families were realistic and knew that all efforts and outcomes may not end in their relatives recovering. Therefore, they desired to ensure that their ill family member be reminded to deliver Shahadatain or the testimony of faith before the commencement of intubation. The Shahadatain consists of saying: there is no God but Allah and Mohammad is the Messenger of Allah. One family member stated:

*I hope the respiratory therapists remind the patients to deliver Shahadatain before starting intubation; this is very important (Badriah).*

Family members fully understood that healthcare providers were only there to assist their critically loved one. Maintaining a positive outlook, holding on to hope, belief in God and spirituality impacted on how they tolerated the situation. Overall, the Saudi family's spiritual healing needs are not reflected in items on the CCFNI; however through the interviews, it did emerge as a unique and very important finding which contributes to the care of Saudi and Muslim ICU patients.

#### 5.3.2.4 Maintaining close proximity

Remaining close to the critically ill patient in the ICU as long as the family wanted was perceived to be of greatest importance. Some family members wanted to remain in the ICU close to their loved one, to see the patient frequently and be able to visit the patient whenever they desired. Families said that the restricted visiting time decreased the flow of information, they were not able to spend more time with their family member and feel more informed about their condition and progress:

*The visiting time was neither sufficient nor appropriate; we come from a very far place. Due to the traffic sometimes we arrive towards the end of the visit, we stay for only five to ten minutes then the security asks us to leave... when visiting time is flexible we can at least meet the treating doctor and have more information about the patient's condition (Awda).*

Participants reported that a family visit “*encourages the patients, raises their spirits and gives a sense of love and belongingness*” (Rabie). Wilkinson (1995) stated that it is paradoxical, at a time when the patient and family need each other, they may find themselves isolated by the restricted visiting practices. In contrast, restricted visiting time decreases interaction between family and patient which may result in adverse consequences for the patient's condition:

*Absolutely, an hour visiting time isn't enough; the patient needs his/her family close during such a crisis situation, which is not facilitated with such inflexible visiting practices. My wife was distressed that nobody visited her in spite of the fact that I visit her every day; however due to the sedation sometimes she does not realize this. I suggest increasing the visiting time, the ICU patient needs the family to be nearby, one hour is not enough, in this hour I may talk to the doctor, sign consents or I may arrive late because of the traffic or even finding somewhere to park the car (Majed).*

The interview results revealed also that both patients and families benefit emotionally from visiting family members in the ICU:

*Every time we [family] visit, my father says do not go, stay longer, I need you to be with me, he feels good when we visit and we feel the same too, but unfortunately this is not allowed here with such restricted visiting policy (Muhana).*

In order to offer proximity for the family members to be with their loved one there are additional physical prerequisites such as having a waiting room with comfortable furniture, which was not available in most of the participants' hospitals. This issue was raised by a participant who said:

*I prefer flexible, the least rigid, visiting protocols as this will have its positive impact on the family and the patient. Also, more flexible visiting practices require a visitor's waiting room with good amenities (Saeed).*

Proximity and flexible visiting practices may ease the communication interaction between families and ICU healthcare providers. It may also provide the opportunity for the family to know specific facts concerning the patient's condition and be well educated about the ICU environment. However it could also be tiring and draining being close to the patient all the time (Wilkinson, 1995).

### **5.3.2.5 Involvement in care**

As a consequence of not being informed about the further developments concerning the patient's condition, lack of communication, restricted visiting practices and families never being asked their opinion regarding the treatment, family members did not feel involved in the care process. Most of the participants' family members were

willing to assist with the care and thought that while they were present they would be able to support and calm their critically ill loved one. All family members indicated they were not involved in the caring of their family member.

*If I'm given the choice, I would sit in front of him [father] all the time, feed him, take care of him, talk to him, read Qur'an for him, I would stay beside him even if he is sleeping; at least this will reassure me and reduces my anxiety but unfortunately this is not allowed (Muhana).*

Those participants' wishes are consistent with several participants who expressed frustration at being restricted from helping with the care the patient requires, as also reported by Bond et al. (2003), Fry and Warren (2007) and Keenan and Joseph (2010). In some cases when family members tried to assist they were not welcomed and were asked to leave the bedside:

*I always want to participate in the care of my mother. You know this makes me feel good, but nurses never let me do this, and when I stay during bed bathing they shout at me and ask me to leave the bedside (Badriah).*

All members of the family expected to participate in the care process of their ill member to varying degrees as this is culturally highly appreciated. Close relatives are expected to look after their ill relative, especially if the patient is a parent as this considered as honouring in Islamic culture:

*If I'm offered the opportunity to look after her, I will certainly do it; you know this is my mother the reason for my being in this world; whatever I do will never pay her back (Abdullah).*

Some Saudi family members desired to be more involved in the care, but were uncomfortable caring for patients in such a critical situation, and were concerned that

they did not “harm” the patient. In their study also Keenan and Joseph (2010) revealed that relatives were concerned that they “do the right thing” (p. 31).

*Well, if I'm offered the opportunity I'll be very happy to assist in the care, but I'm concerned to do the right thing, I don't want to harm her [wife] instead of helping, otherwise it'll be my happiest moment taking care of her (Majed).*

Involving family members in direct patient care activities decreased their feeling of powerlessness and was most meaningful to them. Despite the fact that they wanted to be part of the care of their critically ill loved one, they were concerned about the ICU environment and healthcare providers' behaviours. Families wanted, first for the ICU to be well prepared and equipped and the healthcare providers to accept them being involved in the care:

*Certainly, by doing so you participate in the care of your parents when they are sick, this is honouring them and the least thing we can do for them; however, to involve us, the ICU should be well-prepared and the healthcare providers should accept the practice and allow us to participate in the care; this is important (Aisha).*

The trend is not to allow family presence during resuscitation and other invasive procedures. Some healthcare professionals believe that the practice is too traumatic for family members and influence in the performance of the critical team. Several advantages and disadvantages exist with family presence (Fry & Warren, 2007). However, allowing family presence in Saudi Arabia would be the height of family involvement in the care. A participant stated:

*You see brother, it is not easy attending a resuscitation being performed on a loved one, but as a Muslim we must be there, during those precious last moments of life, to face him in the direction of prayer in Mecca and to remind him to deliver Shahadatain (Aisha).*

### **5.3.2.6 Support not facilitated**

This theme embraced the need for support, a finding also reported by Keenan and Joseph (2010). Family members regarded support to be a crucial factor that can assist them in coping during such a time of high stress. However, interview results have shown that family needs for support were not always being met which placed them in a stressful critical care situation. ICU Healthcare providers did not initiate meaningful interactions or engagement with family members. There was also “*a lack of communication*” between the two groups; this in turn, may obstruct the healthcare providers from knowing the families’ support needs, ending in support not been facilitated. In addition, family members were not informed of the “*social services*” available in the hospital so the family coping patterns could be supported.

*The patient’s mother is very anxious, she needs to be supported and reassured that her son is receiving the best care to cope during this critical time (Awda).*

In spite of the fact that it was absent, support provided by the social services in the hospital was described as a necessary part of this challenging period.

*I think this is the social services duty; it should take action in helping families to cope, supporting them either psychologically or financially, and in some cases, if needed, maybe seeking for help outside of the hospital (Majed).*

Healthcare professionals were identified as giving “*very bad*” support during this phase of acute care of ICU hospitalization. A family member “*wondered about the reason for this lack of emotional support to the families by the ICU healthcare providers*” (Saeed). Accordingly, in order for the healthcare providers to be able to meet the family support needs, participants suggested:

*Training for the healthcare providers to improve family knowledge of patient condition and meeting the support needs of family members (Waleed).*

In crisis, support has to come to families because they do not have spare emotional capacity to look for support (Wilkinson, 1995). Therefore, families would appreciate any initiatives and support from ICU healthcare providers (Fry & Warren, 2007). This kind of support orients the family members to the new environment and gives them someone to share their burden and a feeling of being cared for (Linnarsson *et al*, 2010).

#### **5.4 Conclusion**

The qualitative results of the study in Phase 1 and 2 have been reported in this chapter. An analysis of the open-ended questions gathered from family members was presented and four themes identified: “the need to know, straightforward and honest information”, “the need to remain close to the patient”, “the need for psychological and spiritual support”, and “the need for a caring and supportive environment”. The analysis of the open-ended question gathered from healthcare providers generated four themes: “the need to know versus communication difficulties”, “involvement of family during routine nursing care”, “emotional and violent threats to family” and “decision making”.

Both family members and ICU healthcare providers agreed that they should have active communication and family members should receive clear, complete and honest explanations about their critically ill patient. Family members wanted to have a caring

ICU atmosphere in which they were supported socially and spiritually. Healthcare providers in turn thought that families should be involved during routine nursing care; however, they expressed fear of family presence during resuscitation and other invasive procedures in that they could have a traumatic experience.

In this chapter also, the analysis of the interviews conducted with twelve key close family members was presented and six main themes were identified: looking for information, maintaining reassurance, spiritual healing, maintaining close proximity, involvement in the care and support not being facilitated. Following the same trend in Phase One, the family members sought to access information easily to diminish their anxiety. The results indicated that the families need to be reassured that the best care is being delivered to their loved one, and be supported during this critical time. Saudi families have cultural and spiritual healing beliefs and practices including faith in God and that God is the ultimate healer, reading the Qur'an, prayer, and charity. This spiritual faith lessens their stress and connects them to hold on to hope. In addition, maintaining proximity was considered to be of the greatest importance to the families. This need remained unmet as families wanted to see the patient frequently whenever they desired, and to be with the patient. Families sought to be part of the care as this helped to reduce their anxiety and their feelings of powerlessness. In Chapter Six, further interpretations of the quantitative and qualitative results together will be offered, discussing them in relation to the literature.

## **Chapter Six: Integrative Discussion**

### **6.1 Introduction**

The previous chapter has presented a preliminary discussion of the qualitative findings drawn from Phase 1 and Phase 2 in relation to the literature. In order to meet the study aims and objectives and to answer the research questions, the approach has shed light on the needs of Saudi families and the healthcare providers' attitudes towards family involvement during routine care and family presence during resuscitation and other invasive procedures. In this chapter the themes arising from the quantitative data analysis are discussed and this gives rise to further interpretation of the qualitative findings. The mixed method approach enables an enriched understanding of the study phenomena from the both family members and healthcare providers. Fetters, Curry and Cresswell (2013) refer to the process of data integration, connecting the quantitative and qualitative results thematically, including intra-group comparisons as 'weaving' because there is a connectedness.

The first section of this chapter begins with a discussion of the theoretical frameworks which provided the interpretation of the study findings. The chapter then discusses the response rate and the participants' demographic profile. The family needs are then discussed; family needs as being met or unmet and the most appropriate person to meet family needs. The demographic and social profile of the study participants in the eight selected hospitals will also be interpreted in relation to the family needs of the wider population they represent. The attitudes of ICU healthcare providers towards family involvement during routine care and family presence during resuscitation or

other invasive procedures will be discussed. The family-focused care framework generated from the study findings is described.

## **6.2 Theoretical framework informing the findings**

Maslow's Hierarchy of Needs and Family Centered Care Theory provided the framework for this research. Maslow's Hierarchy of Needs assisted in understanding and identifying the family needs perceived by family members and ICU healthcare providers and Family Centered Care Theory helped to recognise the attitudes of healthcare providers towards family involvement during routine care and family presence during resuscitation or other invasive procedures. Family needs for assurance, information, proximity, support and cultural and spiritual needs should always be met by the physicians, nurses and hospital administration. The healthcare providers should also have positive attitudes towards family involvement during routine care and family presence during resuscitation or other invasive procedures. As a consequence, the family can supported while experiencing a critically ill patient admitted in the ICU and further support the patient. Maslow's Hierarchy of Needs and Family Centered Care Theory acted as a map that gave coherence to the empirical inquiry which connected all aspects, including articulating the research problem, purpose, literature review, methodology, data collection, analysis and findings.

## **6.3 The sample**

This is the first prospective study on the needs of families of ICU patients in Saudi Arabia. Additionally, the current study is one of the first to recognize the family's

needs, in relation to the influence of religious and cultural values held by Saudi families, through use of the CCFNI.

The overall response rate was 59.8% (n = 176) for family members and 45.1% (n = 497) for ICU healthcare providers. Nine questionnaires from family members and twenty questionnaires from healthcare providers respectively were excluded because of missing responses to too many items. This may have occurred because those excluded participants were less interested in the topic, lack of time or understanding or finding it too long.

The family members' demographic characteristics indicate that they comprised a relatively homogeneous sample of Saudi indigenous nationals (91%). The mean sample age of 33.16 years reflected a young population, predominately male (65.9%), and educated across the range from the lowest qualified (primary) to university education. The majority of family member participants (62%) had had previous experience with the ICU. This experience may have affected some family members' perceptions of the importance of their needs, or where their needs were met or unmet. Family members with previous ICU experience may be more knowledgeable about medical practices and have some expectation regarding process (Kosco & Warren, 2000). Although, religion was not specifically assessed in the demographic part of the questionnaire, the fact is that 100% of the general Saudi population is estimated as belonging to Islam (Ministry of Economic and Planning, 2010). It is safe to assume that the majority of the participants in this project practiced the Islamic religion. The variety in the sample, recruited from six different cities in Saudi Arabia, and the large size of the sample and their individual and group demographic characteristics in

relation to the national population of Saudi Arabia supports the assumption that the results may be generalisable to the Saudi ICU populations.

This study found that most of the healthcare provider participants were female (84.8%) in their 20s and 30s, which reflects the healthcare workforce in the MOH facilities. In the ICUs where the study was conducted, the Saudi healthcare providers were the smallest group, representing only 12.6%, compared to the expatriate healthcare providers who filled the majority of the ICU positions. The importance of this finding is that communication with patients and families may be hindered by the language differences and other cultural understandings of a Saudi population, growing up and being part of the Saudi education and cultural system.

#### **6.4 Needs of Saudi families**

The results of this study show that family members and ICU healthcare provider perceptions had areas of convergence and divergence regarding how important needs are for families, how those needs are being met or not met and the most appropriate person to meet each need. Such findings, however, are generally inconsistent with those of Quinn et al. (1996), Mi-Kuen et al (1999) and Kosco and Warren (2000) who claim that relatives and intensive care nurses generally differed in their perceptions of family needs. An explanation of this is that the similarity in answers between the groups in the current study occurred because ICU healthcare providers in Saudi Arabia had an understanding of the family needs. The differences in the perceptions may be explained due to the fact that ICU healthcare providers are patient focused and have minimal concern for the family needs and care.

#### **6.4.1 Assurance and information needs**

As perceived by both family members and healthcare providers, the assurance and information subscales were ranked as the first and second most important dimensions on the CCFNI. Three of the most important needs identified by family members and two identified by healthcare providers were related to assurance. Similarly, two and three of the most important needs as perceived by family members and healthcare providers respectively were related to the information subscale. Previous studies conducted in both Western and Asian countries also indicated that assurance and information needs were the most important (Kleinpell & Powers, 1992; Kosco & Warren, 2000; Al-Hassan & Hweidi, 2004; Omari, 2009; Chatzaki, et al, 2012). This finding reveals that during the immediate phase of the patient's stay in the ICU when the family's anxiety is high the major concern of Saudi families is to be reassured that the patient is receiving the best care, and to receive straightforward, realistic and consistent information.

Saudi families expressed a need to be reassured by the doctors and nurses. The need for assurance is important as it can alleviate stress and reduce uncertainty and increase families' hope of better outcome expectations (Leske, 1992a). The admission of a member in the ICU results in a strong impact on families and sometimes may feel stressed, frustrated and helpless and therefore, need to be reassured. However, in a closed-model ICU where family members can rarely access the treating doctors and where nurses are not authorised to release any information, there is a need to reassure families to prevent this from occurring.

In this study assurance needs were perceived to have been met by 65% of relatives and 70% of healthcare providers. This finding conflicts with Omari (2009) who found that items in the assurance subscale was perceived as being unmet, however, McHale and Bellinger (1988) cited in Quinn et al. (1996) suggest that a moderate lack of satisfaction with the most important needs requires attention. Researchers have suggested interventions to assist meeting assurance needs and reducing family anxiety. These suggestions have included individual counselling, support groups, caring and positive attitudes, understanding, reassurance and friendliness from ICU healthcare providers (Verhaeghe et al, 2005; Paul & Rattray, 2007).

The results show that families of ICU patients perceived receiving information and knowledge of greatest importance. They needed detailed information about the condition of the patient and about what was being done for the patient. It is reasonable that the family of a critically ill member will want to seek information and knowledge about their loved one's condition. Saudi Arabia has a young population in general with a median age of 21.5 years (MOH, 2011), resulting in families being more aware of and more vocal about their needs and thus seeking more information. It is important that information is accurate, realistic and provided in understandable terms. In addition, information, if communicated effectively, should help families in making the appropriate decision and alleviate their anxiety and stress.

The information subscale on the Saudi modified version of CCFNI was rated by an overall percentage of 59.25 of family members, and 79.8% of healthcare providers as being successfully met. The need for information is important, but is not always met which may be due to the fact that ICU healthcare providers do not always appreciate

the families' informational needs (Verhaeghe et al, 2005). The difference in perception between family members and healthcare providers may indicate that healthcare providers are not aware of the families' information needs or lack of education. It could, however, be said this diversity of opinions indicates that family members and healthcare providers differed in how well they perceived the needs were being met or unmet. This was similar to previous studies reported by Gelling and Prevost (1999) O'Malley et al. (1991) and Quinn, Redmond and Begley (1996) and Kosco and Warren (2000). This may highlight the need to increase interaction between relatives and healthcare providers.

In previous studies families have identified information needs as a priority which, if met, allows families to cope and influence the other needs being met (O'Malley et al, 1991). There are several interventions which have been offered in meeting families' information needs. These include communication boards, family conferences and flexible visitation practices to facilitate families in meeting the treating doctor (Titler, 1995). A variety of instructional materials should be made available to help families gather information about their ICU patient and critical care environment: for instance, providing information in the form of pamphlets or planned telephone calls and information websites (Paul & Rattray, 2007). In the case of large families such as in Saudi Arabia, communication of information can be facilitated by a family spokesperson who accepts the responsibility to undertake the task of receiving the information and liaising with the rest of the family.

#### **6.4.2 Cultural and spiritual needs**

Cultural and spiritual needs in the Saudi modified version of the CCFNI was perceived by both family members and ICU healthcare providers as the third most important needs, not identified in previous studies. An interesting and significant finding of this study also concerned the need item “To have the healthcare providers handle the body of the deceased Muslim with extreme caution and respect” a need which is important culturally and spiritually. Of the top five most important needs, this need item was perceived as the most important by family members but only the fifth most important need by the healthcare providers. Muslims believe that the dead feel pain and pressure and therefore should be handled minimally and with great gentleness (Wehbe-Alamah, 2008). In addition, the Saudi families might be concerned to minimise touching the body of the deceased Muslim as much as possible by the healthcare providers and want to discourage them from touching the body if they were not of the same sex. In fact, these findings support the understanding that the Islamic religion and the Saudi culture guide the ways of living for many Saudis. The healthcare providers in this regard shared the same general perception with family members despite the fact that healthcare providers in this study were of 13 different nationalities. These findings suggest that beliefs of the Saudi culture were adopted and learned by the expatriate healthcare providers. Although religion was not assessed in the healthcare providers’ demographic questionnaire, the fact is that most of the participant healthcare providers in this study were recruited from Muslim countries. Such results indicate that cultural and spiritual needs are important and should be of major concern to the hospital administration and ICU staff.

In this study the results showed that a large proportion (41.2%) of family members considered their cultural and spiritual needs as unmet; however, only 26% of ICU staff said the needs under the cultural and spiritual subscale were unmet. Healthcare providers' perceptions are sometimes incongruent with the perceptions of families (Titler, 1995). Therefore, it is crucial that healthcare providers understand the family needs from the perspective of families. Non-Muslim healthcare providers when caring for Saudi patients and families should be aware of the Islamic religion and Saudi culture. This should assist Saudi families to receive more holistic and family-centred care.

#### **6.4.3 Proximity and support needs**

In this study, proximity was ranked fourth and support fifth in importance by family members, whereas healthcare providers ranked support fourth and proximity fifth most important. Of the five least important needs that were identified by family members, two were listed in the proximity, and one was listed in the support subscale. On the five least important needs identified by healthcare providers, two were listed in the proximity and two in the support subscale. This is applied to findings of other studies that were conducted in Western and Muslim cultures (Lee, MacKenzie & Chien, 1999; Kosco & Warren, 2000; Al-Hassan & Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki et al, 2012). An important comment to be made here is that families and healthcare providers do not consider the needs of support and proximity unimportant but they scored them lower than the assurance, information and cultural and spiritual needs (Verhaeghe et al, 2005).

According to Paul and Rattray (2007), proximity concerns being physically and emotionally near the patient, and support concerns the resources and support system available to the family members in the ICU. The Saudi family has strong ties which reflect a mutual commitment between the family members. This includes visiting family members, especially at such a hard time of a critical illness, as this is highly encouraged in the Islamic teachings and Saudi culture. Visiting the sick person is also considered as providing emotional, psychological and financial support to the patient and to the whole family. Participants in this study regarded proximity and support as least important because they wanted ICU staff to focus on the health condition and preserve the patient's life, and as a result families sacrificed their needs for proximity and support. This finding also can be explained from the perspective of Saudi culture as this type of support can be provided by the extended family to the patient and to the close relatives.

Consistent with Omari's (2009) findings, the proximity and support needs were perceived as being unmet by 48.6% and 55.2% respectively for family members and by 34.6% and 39.9% of healthcare providers. Those findings were contrary to Warren (1993) who found that needs under proximity and support subscales were usually or always met. It can be argued that healthcare providers in Saudi are not prepared to meet the family needs. This may also be partly explained as the main concern of the ICU healthcare providers during this crisis time being to save the patient's life, rather than meeting the family needs of support. Additionally, lack of communication between healthcare providers and family members may result in healthcare providers being uncomfortable meeting family members to discuss their needs. According to Holden et al. (2002) the effective communication of information is vital if any of the

needs are to be met. Most hospital facilities in Saudi Arabia lack waiting rooms in the ICUs and have rigid inflexible visiting practices. Clearly, families prefer less restricted visiting policies which if practised, can increase the information flow, and family can spend more time with their loved one and be better informed of their condition.

#### **6.4.4 Responsibilities for meeting family needs**

This study identified who was the most appropriate person to meet family needs from the perspectives of family members and healthcare providers. The results demonstrated that family members (41%) and healthcare providers (51.6%) perceived doctors as primarily responsible for meeting most of the family needs. The results showed that family members and ICU healthcare providers had similar perceptions, for instance, doctors followed by nurses then hospital administration were considered the best to fulfil family needs of assurance and information. However, in previous studies by Quinn, Redmond and Begley (1996), Lee et al. (1999) and Omari (2009), participants perceived nurses as the best to meet most of the family needs. This finding may indicate that the family members and healthcare providers' image of nurses' role in Saudi Arabia is only to focus on patient care rather than provide information or reassure the family members. This also suggests that intensive care nurses have a lack of education, lack of knowledge and lack of time to meet family needs.

Family members had a perception that their needs for proximity were a shared responsibility mainly between nurses and hospital administration whereas healthcare providers perceived them to be best met by doctors and the hospital administration.

Proximity needs including: “to feel accepted by the hospital staff”, “to be allowed to visit whenever we wish, “to request to stay during the care of my family member”, “to have healthcare providers respect relatives' opinions, “to develop trust with healthcare providers”. As indicated earlier, healthcare providers may think that the nurses' role is only to give patient care. Another explanation for the family members' and healthcare providers' view is that the hospital administration has the principal responsibility for facilitating more flexible visiting policies to increase interaction between families and patients and between families and ICU healthcare providers.

An important finding is that the majority of family members (46%) and healthcare providers (49.32%) perceived the family needs for support as most appropriately to be met by hospital administration. This included the need to: “have a waiting room with comfortable furniture available for the family in the intensive care unit”, “have staff accompany the family while visiting the intensive care unit”, “have staff providing psychosocial support to families during daily patient care”, “have explanations of the critical care environment before going to the critical care area for the first time” and “to be told about other healthcare professionals that could help”. The participants may want to direct the family needs for support to be met mainly by the administration due to the fact that none of the participating ICU had a social worker; although this was proposed by many participants in the open-ended item. The social worker would be assigned in the ICU to support and reassure families and to enhance their ability to cope during such a stressful critical care experience. Assigning a social worker in the ICU and creating a waiting room with comfortable furniture are thought to be the duties of the hospital administration.

The results demonstrated that both family members and healthcare providers perceived meeting the family's cultural and spiritual needs as best to be a shared responsibility between doctor, nurse and hospital administration. It could be argued that providing culturally congruent care to the patients and their families is the duty of each healthcare provider. Also, the administration should ensure that Saudi patients and families receive culturally congruent care and that the Saudi cultural values and beliefs are learned and respected by the non-Saudi healthcare workers. The findings also indicate that the Saudi cultural need "to relieve the families anxiety" by exploring the medical facts with them in a nonjudgmental manner" was identified by both ICU healthcare providers and family members to be best met by the doctor. This is reasonable as the doctor was primarily perceived as the best to meet family informational needs. This need particularly concerns relieving the family anxiety through exploring and explaining the medical facts in a merciful manner. They similarly perceived the need "to face the patient's bed towards the Holy Mosque in Mecca" is to be best met by the administration. The beds in the participating ICUs were not all directed toward the Holy Mosque in Mecca; therefore, to meet such a need, the hospital administration should take on the responsibility.

### **6.4.5 Factors influencing family needs**

The underlying rationale of the demographic profile was found to have a statistically significant association with family members' and healthcare providers' perceptions of family needs, how those needs are being met or remaining unmet and the most appropriate person to meet the family needs.

#### **6.4.5.1 Study setting**

The results of this study demonstrate that family members from QCH rated needs for information ( $p = 0.01$ ), proximity ( $p = 0.04$ ) and support ( $p = 0.001$ ) as slightly less important than other hospitals, which is difficult to explain. QCH has a closed-model ICU with a restricted visiting policy where families can visit their patients only one hour a day, and it has no support system for ICU patients and families. The results further revealed that family members from KFCH-J, QCH and KFHH identified assurance ( $p = 0.002$ ), support ( $p = 0.04$ ) and cultural and spiritual needs ( $p = 0.02$ ) respectively as less met. By and large, Jazan, Qatif and Hofuf where the three hospitals are located, are remote cities and characterised by conservative and, at the same time, well-educated residents. It is a reasonable assumption that families in those hospitals are aware of their needs and, rights and therefore, identified them as being less met. Furthermore, families from KFHH and DMC identified the administration as the best to meet their needs significantly more than did participants from other hospitals ( $p < 0.0005$ ). It is assumed that these participants grasped that the hospital administration was responsible for meeting most of their needs. This is obvious in Saudi Arabia because hospitals have centralised authority and power planning, so decision-making is in the hands of the top management only. Generally speaking, those findings suggest that needs vary across sites in Saudi Arabia and yet

are culturally different due to variables that cannot be controlled for. For instance, a dominant administration may be perceived as controlling everything, including flow of medical information.

Contrary to family members, healthcare providers in KFCH-J and KFMC identified the need for support as met more than other hospitals ( $p = 0.001$ ). Family members in KFCH-J identified their needs for support as less met than family members in the other hospitals and also less met than the KFCH-J healthcare providers. Indeed KFCH-J does not have a support system for families of critically ill patients. KFMC has less restricted visiting practices and clear interactive policies between healthcare providers and families in ICU. Healthcare providers may have received insufficient training to meet the needs of families. This inverse relationship between family members and healthcare providers may be due to lack of healthcare providers' knowledge, lack of time and lack of understanding between family needs and patients' outcomes (Mi-Kuen et al, 1999). This highlights the need to increase interaction between families and healthcare providers.

The cultural and spiritual needs were identified by the healthcare providers to be less met in KFH-M than other hospitals ( $p = 0.04$ ). KFH-M is located in Al-Medina which is the second holiest city in Islam after Mecca and where the Prophet Mohammed is buried. The majority of healthcare providers working in this hospital are Muslims, as non-Muslims are not permitted to stay in Al-Medina. This may explain the reason that healthcare providers identified the cultural and spiritual needs as less met compared to healthcare providers in other settings as they all share the same religion.

#### **6.4.5.2 Age and sex**

A recent study conducted by Chatzaki et al. (2012) reported a statistically significant relationship between older respondents and ranking of family needs. For instance, older family members ranked as more important the need “to help with the patient’s physical care. Contrary to the previous study by Chatzaki et al. (2012) in the current study, age of family members as well as healthcare providers was found to have no influence on family needs.

Differently from previous studies (Leske, 1992a; Lee et al., 1999), the sex of family members was found to have no influence on the ranking of importance of family needs. However, female family members perceived assurance, information and cultural and spiritual needs as less met than male family members. It is possible that female family members may identify their needs as less met because they usually have higher stress than males (McDonough & Walters, 2001). Therefore, female family members should remain an important area of clinical concern and interventions. An interesting statistically significant difference ( $p < 0.0005$ ) was found between family members and the most appropriate person they feel who could meet their needs. Female family members recognized nurses as the best to meet most of their needs, while male family members recognized the administration as the best to meet most of their needs.

Two explanations for the contradictory views are possible. Firstly, the majority of ICU healthcare providers in Saudi Arabia are female nurses which was reflected in the healthcare providers’ sample (84.8%). Nurses are more appropriate to meet the needs of female family members as they share the same sex. Additionally, with respect to

Saudi culture, it might be inappropriate culturally for a female family member to meet and talk to male healthcare providers. Increasing interaction between nurses and female relatives may contribute to meeting the family needs. Secondly, the administration controls most of the authorities and any change is made at the top management. Perhaps this was recognized by the male family members; hence, the administration was perceived as the best to meet their needs. This finding evidently demonstrates that male and female family members differ in how they perceived the most appropriate person to meet their needs.

The vast majority of the healthcare providers in this sample were females (84.8%) and female healthcare providers perceived all needs categories as less met than did male healthcare providers. Previous investigators noted no differences between male and female healthcare providers' perception of family needs being met or unmet (Mi-kuen et al, 1999; Gelling & Prevost, 1999). This finding may be partly explained by female healthcare providers demonstrating greater understanding of family needs. Furthermore, male healthcare providers indicated that doctors were the most appropriate to meet family needs and female healthcare providers indicated that nurses were the best to meet family needs ( $p < 0.0005$ ). In the healthcare providers' sample, females mainly comprised nurses whereas males comprised doctors. Nurses identified themselves as the group responsible for meeting family needs and doctors in turn identified themselves as responsible for meeting the needs of families. Both doctors and nurses however share the responsibility for meeting most of the family needs. For instance, it could be considered that doctors are responsible for specific information and nurses are responsible for general information (Gelling & Prevost, 1999). This is further supported by the fact that doctors believed they were the most

appropriate to meet most of the family needs ( $p < 0.0005$ ) and nurses also believed that they are the most appropriate to meet most of the family needs ( $p < 0.0005$ ).

#### **6.4.5.3 Nationality and level of education**

Nationality of family members, level of education and relationship to the critically ill patient in the present study do not give rise to differences either in the importance of family needs, needs being met or unmet needs, or the most appropriate person to meet family needs. This is again in contrast to research where those variables have been associated with these family needs. Leske (1992a), for example reported that adult children rated the family needs for comfort less important than spouses. Furthermore, Chatzaki et al. (2012) reported that family members' education level greatly influenced the families' ranking of importance of needs for support.

More than half (62%) of the family members in this sample had some previous ICU experience. Some researchers have suggested that the family members' previous ICU experience influences the family members' rating of needs importance. However, in this sample this did not appear to influence the ranking of importance of family needs and how those needs were being met or unmet. This was similarly reported by Al-Hassan and Hweidi (2004) and Omari (2009), and suggests that all family needs were important to families in Saudi Arabia, whether or not they had previous ICU experience. Relatives with previous ICU experience recognised nurses as the most appropriate healthcare provider to meet their needs ( $p = 0.03$ ). A reason for this may be that relatives with previous experience realised that nurses work in closer association with the patients and families than other healthcare providers; hence, they were identified as the best to meet their needs.

The results show that expatriate healthcare providers demonstrated better understanding of assurance and information needs than did Saudi healthcare providers. The expatriate healthcare providers ranked the needs under categories of assurance ( $p = 0.03$ ) and information ( $p < 0.0005$ ) needs higher than Saudi healthcare providers. This raises questions about the curricula in Saudi Arabia and whether or not they place emphasis on the needs of families. This was further supported by the fact that the Saudi healthcare providers perceived significantly higher assurance ( $p < 0.0005$ ), information ( $p = 0.008$ ), proximity ( $p = 0.008$ ), support ( $p < 0.0005$ ) and cultural and spiritual needs ( $p < 0.0005$ ) as being met more by Saudis than non-Saudis. These data suggest placing more emphasis in nursing and medical curricula in Saudi Arabia to include family needs and building collaborative partnership with families of ICU patients. The finding also suggests developing a continuing educational program for ICU healthcare providers to highlight the priority needs of ICU families. Another significant relationship ( $p = 0.007$ ) was that the Saudi healthcare providers identified doctors as the best to meet family needs more than did the non-Saudis. This is again an indication that healthcare providers in Saudi Arabia believe that nurses have minimal concern for meeting family needs and their main focus should be patient care. Considering this, educational programs should effectively include interaction with families and act to change such view toward the nursing profession.

Statistically, there was a significant difference ( $p = 0.04$ ) in perceptions between healthcare providers with a PhD level of education and proximity needs. PhD qualified healthcare providers ( $n = 6$ ) also ranked assurance needs ( $p = 0.004$ ), information ( $p < 0.0005$ ), support ( $p = 0.005$ ) and cultural and spiritual needs ( $p =$

0.01) as more met than those with other qualifications. This difference is of clinical interest since those six PhD holders were ICU physicians and mainly had administrative tasks but since it is the highest educational level, there is an indication that there is a relationship between education and the meeting of family needs. In two previous studies conducted in UK and United States, it was noted that the perceptions of the intensive care team were influenced by their education level (Gelling & Prevost, 1999; Kosco & Warren, 2000)

#### **6.4.5.4 Length of stay and patient's sex**

In this study, length of patient stay in the ICU was not found to influence relatives rating of importance of information, proximity, support and cultural and spiritual needs, being met or unmet needs and the best person to fulfil the family needs. Assurance needs were rated significantly less important ( $p = 0.02$ ) by families of patients admitted in the ICU for 10 to 30 days. This statistically significant relationship is not surprising however, as relatives need to be more assured of the best care provided and about the condition of their loved one during the immediate phase of critical illness within the first 72 hours (Titler et al, 1995). After that, relatives need for information, support and remaining close to their patient was considered more important and prioritised than assurance needs.

Although not consistent with Al-Hassan and Hweidi's (2004) research, an interesting association in the present study was that relatives of patients aged between 23 and 38 years significantly identified their proximity ( $p = 0.03$ ) and cultural and spiritual needs ( $P = 0.01$ ) as less met than families of patients in other age groups. This is

reasonable because young patients are commonly aware of their needs than young or even older patients. Thus, patients have the right to see the family frequently which is not currently facilitated by the restricted visitation policies, and to be reassured that the Saudi cultural values and spiritual healing needs are fully understood and adopted by the healthcare providers. This perception influenced their families to recognize that their proximity and cultural and spiritual needs were not usually met. Another interesting association was that family members of female patients ranked support significantly more important ( $p = 0.03$ ) than did family members of male patients. This contradicts the findings of Omari (2009) who detected no influence of family members of male and female patients' on rating of importance of family needs. Almost 38% of the patients were females with sibling, parent son or daughter family members. Women in Islam are regarded as more vulnerable than men and accorded special support and protection especially during such crisis situation. This vulnerability of women necessitates the protection and support from men which was highly reflected in the Islamic teachings. The Prophet Mohammed has said "I command you to be kind to women. The best of you is the best to his family/wife".

#### **6.4.5.5 Profession and experience**

Nurses in this study rated the family need for information more important ( $p = 0.01$ ) than did physicians and respiratory therapists, and respiratory therapists rated support needs ( $p = 0.01$ ) as less important than physicians and nurses. This finding is similar to the results of an earlier study by Gelling and Prevost (1999) which demonstrated that nurses and doctors do not share the same perception of family needs. In addition, the respiratory therapists identified the need for assurance ( $p = 0.004$ ), information ( $p = 0.02$ ), support ( $p < 0.0005$ ) and spiritual and cultural needs ( $p$

< 0.0005) as less met than did physicians and nurses. These discrepancies of opinions are due to several causes: firstly the perception of the intensive care team was influenced by their profession. Secondly, the difference may demonstrate how the role of each profession affected their respective perceptions that meeting family needs was an important part of their role. Thirdly, the care of families of ICU patients in Saudi Arabia is currently based on the perceptions of healthcare providers. This study however, has clearly demonstrated that family members, doctors, nurses and respiratory therapists do not always share the same perception. It is important that ICU staff assess each family individually and plan to identify and meet their needs. Gelling and Prevost (1999) suggested that relatives were answering the questionnaire for their single relative. Healthcare providers however, were answering the same questionnaire based on many past experiences with patients and their families. This may have made it difficult for healthcare providers to give comparable responses.

In this study, it was found that ICU healthcare providers with less than one year's working experience ranked support needs more important ( $p = 0.03$ ) and also recognized proximity needs ( $p = 0.01$ ) as less met than did the more experienced healthcare providers. This result reveals that the novice ICU healthcare providers demonstrated more conscious awareness and understanding of support and proximity needs than did the more experienced staff. The expert intensive care team may perceive meeting family needs as non-influential on the basis of experience and accordingly ranked the needs lower (O'Malley et al, 1991). Furthermore, healthcare providers with more than ten years of experience in Saudi Arabia rated support needs as less met than other groups ( $p = 0.02$ ). Regarding support needs perhaps the more experienced staff in Saudi Arabia are aware of the Saudi cultural norms and values

and the need for family to be supported during such a critical time which is infrequently available for families in Saudi healthcare facilities and therefore, identified support as less met.

#### **6.4.6 Family needs interrelations**

Consistent with previous study findings by Leske (1991), Warren (1993) and Al-Hassan and Hweidi (2004), a positive relationship between assurance, information, proximity, support and cultural and spiritual needs was found in this study. This medium to strong relationship suggest a complex interaction among needs of Saudi families with a critically ill patient in the ICU. It was demonstrated in this study by family members and healthcare providers that the provision of information, support and proximity enhanced reassurance of the family members and cultural and spiritual needs. Information and knowledge are needed to flow in an understandable and consistent manner to help the family cope with the situation and leave room for hope. The family sought to see the patient frequently, be near the patient, and desired unrestricted visiting. Support during ICU hospitalisation is highly important including a caring and positive attitude, reassurance, friendliness and concerns (Titler et al., 1995). Also, cultural and spiritual healing believes has a therapeutic calming and reassuring effect on families. Based on this finding information, proximity and support needs should be met by taking into consideration Saudi cultural values and norms in order for the family to achieve reassurance.

## **6.5 Healthcare providers' attitudes towards family involvement during routine care**

Healthcare providers had a positive attitude toward family involvement during routine patient care. The healthcare providers reported agreement with most of the 12 items of family involvement during routine care. These healthcare providers indicated that “the presence of family members impacts positively on the patient's treatment progress” and family members “if present, will be able to recognize that everything possible was done to save the patient”. This finding is consistent with current literature (Fisher et al, 2008; Benzein et al, 2008). The ICU staff also reported agreement that their clinical performance would not be affected by relatives' presence. Healthcare providers who had positive attitudes toward family involvement acknowledged families as a resource, believed that family members were important and a prerequisite for good care, and were regarded as a natural part of the caring process. They also did not appear to complain about lack of time to look after families. Further, ICU healthcare providers believed that they had sufficient training to involve the family and to meet the family needs. This perception should ease the integration of family into the critical care environment, highlighting the implementation of family-centred care by including the patients' significant others.

Participants who did not support patients' wishes for family presence during daily care to participate in the daily caring activities agreed that the presence of family members made them feel stressed. They expressed concern that they could barely manage critical care issues when family members were present in the ICU. It seems that those healthcare providers felt threatened by family involvement and, therefore, opposed the practice by hiding behind stress caused by family presence or lack of

time or even impacts on clinical performance. Soderstrom, Benzein and Saveman (2003) indicated that some nurses believed that patient care, medical and technical tasks were considered to be most important nursing duties and that they considered themselves as experts, having little time for family members. Nurses also did not want interference in their work by the family members and felt disturbed by the presence of family members.

Healthcare providers' setting, age, sex, level of education, years of profession experience and experience in Saudi Arabia did not appear to influence healthcare providers' attitudes towards family involvement during routine care. This is in contrast to previous research where ICU staff attitudes were influenced by the length of working experience (Schiller & Anderson, 2003). They found in their study that the nurses with less experience held more positive attitudes than the more experienced nurses toward family involvement. In the current study there was a statistically significant difference in attitude in relation to nationality ( $p = 0.006$ ). Saudi healthcare providers agreed with family involvement during routine care more than did expatriate healthcare providers. This finding suggests that the Saudi medical team appreciate the need for family members of the critically ill adult to be involved in the care of their loved one. The Saudi healthcare workers would better understand the needs of Saudi families as they share with them the same culture, religion, spiritual values and social norms.

Another statistically significant difference was found in this study where physicians expressed opposition to family involvement during routine care ( $p = 0.04$ ) more than did nurses and respiratory therapists. Perhaps physicians have a narrow view of

holistic patient care and therefore, place less emphasis on family involvement to support the patient physically and psychologically. Nurses and respiratory therapists in turn have a more holistic view of the patient care and so acknowledge the needs of families; accordingly, they may engage family members to provide some fundamental care for the patient.

### **6.6 Healthcare providers' attitude towards family presence during resuscitation and other invasive procedures.**

The mean score for the multidisciplinary ICU staff who participated in this study indicated a negative attitude towards family presence during resuscitation and other invasive procedures. Nearly 80% of the sample in this study, which incorporated physicians, nurses and respiratory therapists, did not favour the practice, which is similar to studies sampled from Turkey, Iran, Germany and Hong Kong that also indicate a high percentage of opposition by healthcare providers (Cunes & Zaybak, 2009; Kianmehr et al, 2010; Koberich et al, 2010; Leung & Chow, 2012). In these studies medical staff displayed negative attitudes towards the practice and disagreed that family members should be present during resuscitation or other invasive procedures. Whether or not to allow family during resuscitation and other invasive procedures, family presence remains a matter of current controversy among healthcare providers in many communities including Saudi Arabia (Al-Mutair et al., 2012).

The results indicated that the majority of healthcare providers (78.8%) denied the relatives' right to request to stay during resuscitation or any other invasive procedure. They also did not believe that family presence would assist the staff to get the history quickly. In a recent study (Al Mutair et al., 2012) it was reported that 74.9% of nurses

denied the relatives' right to stay during resuscitation. Al-Mutair et al. (2012) observed that healthcare providers may fear emotional disturbance and traumatic experience when families witness the procedures. Healthcare providers may fear also that their performance will be affected by family presence.

Similar to McClenathan, Torrington and Uyehara (2002), Knott and Kee (2005) and Badir and Sepit (2007), the most common reason for opposing the practice was healthcare providers fear of traumatic experience for the family members. However, in Meyers et al. (2004), which surveyed family members to investigate their attitudes toward family presence during resuscitation and other invasive procedures, it was found that family members thought it was their right to be present with their loved one and follow-up did not show they suffered from traumatic effects. Similarly, Holzhauser, Finucane and Vries (2006) showed that none of the participating family members felt pressured or traumatised by being present and the majority preferred to be there. Meyers, et al. (2000) encountered very similar findings where they surveyed a total of 96 medical staff 14 physicians, 22 residents and 60 nurses who had participated in resuscitation or an invasive procedure with family members. The majority (95% of nurses, 77% of physicians and 64% of residents) were comfortable with family presence and 84% believed that their performance was not affected by the family's presence.

Notably, the current study demonstrates that staff had positive attitudes if family members were well informed and had signed a consent form. Leung and Chow (2012) argue that there was an agreement by healthcare providers to allow family presence only if the family was well informed and was accompanied by a facilitator. The

facilitator should assess the families for coping abilities and for the absence of any psychological and emotional disturbance. According to Leung and Chow (2012), the facilitator member is to be selected from the resuscitation team and has an important role to follow up and explain to the family throughout the procedure. The need for signed consent was also endorsed by ICU healthcare providers for safe implementation of family presence during resuscitation or other invasive procedures. Al-Mutair et al. (2012) noted that the practice constitutes a breach of confidentiality without prior consent by patient and family.

In the present study, no real differences in terms of positive or negative attitudes were evident among healthcare providers in relation to hospital, age, level of education, years of working experience and experience in Saudi Arabia. Similarly, in Kianmehr et al. (2010), staff participants' age did not correlate with staff attitudes. For family presence and level of education, in contrast, Ellison (2003) found a statistically significant relationship between education level and positive attitudes ( $P < 0.01$ ).

An interesting and significant finding in the present study ( $p < 0.0005$ ) was found between healthcare providers' sex and attitudes. Male healthcare providers opposed family presence more than females. Most of the nurse respondents were women and most of the physician respondents were men. This was surprising as women may be thought to have high sensitivity to stressors and to be more likely than men to develop emotional disorders when exposed to traumatic experiences (McDonough & Walters, 2001). Possibly one might argue that the attitudes of male healthcare providers were dominated by their professional role, and for women by the emotional element in care. This emotional element might help female healthcare providers to understand the

distressing impact on relatives if they were not present during resuscitation or other invasive procedures, and thus may explain why female healthcare providers were more positive about family presence.

One statistically significant finding inconsistent with the literature was detected between nationality and attitudes ( $p = 0.001$ ). The results showed that Saudi healthcare providers agreed that family members should have the option to be with the patient during resuscitation or other invasive procedures more than did the non-Saudi. It is possible that Saudi healthcare providers are more liberal in their viewpoints in that they share strong cultural values with family members. Although healthcare providers often work as a team in the ICU environment, they develop different beliefs about family presence during resuscitation or other invasive procedures. Physicians were found to oppose the rights of patients to have their families present during resuscitation or other invasive procedures more than their nurses and respiratory therapists colleagues ( $p < 0.0005$ ). As reported in Meyers et al. (2000), McClenathan et al. (2002), Maclean et al (2003) and Moreland and Manor (2005), this difference of opinions may be related to nurses' holistic view of patients. According to Moreland and Manor (2005) physicians are patient focused; however, nursing places more emphasis on the patient's role with the family system, recognising the importance of the family to the physical and emotional well-being of the patient. It can be said also that physicians spend less time at the bedside, less time engaging with families and have less time to observe the benefits to patient and family than nurses and respiratory therapists.

Despite the fact that healthcare providers held negative attitudes toward family presence, they reported a need for training programs to support the family when they attend resuscitation or other invasive procedures a finding congruent with previous research (Al-Mutair et al. 2012). A number of studies including Fulbrook et al (2005), Mian et al. (2007) and Koberich et al. (2010) also emphasised the need to develop educational programs for medical staff on the safe implementation and practice of family presence. According to Koberich et al. (2010), the training program is to assist staff to increase their confidence, overcome their fears and support the family during the situation; such topics are also to be introduced within the nursing curricula and other healthcare programs.

In addition, almost half (49.4%) of the healthcare providers expressed the need to develop guidelines to support family involvement and give family the option to attend resuscitation or other invasive procedures. This concern seems to be consistent with Maclean et al. (2003), Meyers et al. (2004), Mian et al. (2007) and Al-Mutair et al. (2012). This should alert the attention of the healthcare authorities in Saudi Arabia to develop guidelines and policies which give the family the opportunity to remain with their loved relative during such crisis time. The policies also should stress the facilitator responsibilities and interventions to follow up and explain to the family throughout the resuscitation or other invasive procedures.

## **6.7 Interpretative qualitative synthesis**

The major descriptive categories from both family members and healthcare providers' sampled in Phase 1 highlighted further issues regarding the phenomena under study.

The interviews in Phase 2 also shed light on the experience of being a family member of a critically ill patient in ICU. The interpretative synthesis of the family members sample gave four overarching themes from the open-ended question in Phase 1 and six themes from the semi-structured interviews in Phase 2 of the study. These themes described the families experience in the critical care setting and their needs. The qualitative approach of this study provides new insights into the participants' experience, a deeper understanding and gives their experiences voice. It helped also to refine variables which were missing in the Saudi modified version of CCFNI to be used in further research.

### **6.7.1 Providing information**

The family members responses showed that providing adequate and honest information to families is of great importance especially in the early stages of the patient's stay in ICU. Families seek to know information about the patient's prognosis, treatment, vital signs, surgical procedures or any tests or procedures to be performed. Computer and information technology systems can assist families in gathering information. The use of communication boards, family meetings and rounds, a family spokesperson, a family translator, and flexible visiting practices can also facilitate information dissemination to families as discussed in the information themes (Section 6.4.1). Instructional materials including education brochures and websites with pictures which describe the nature of the ICU, equipment families are likely to encounter and suggestions for interacting with their critically ill member can help meeting families' information needs. Fry and Warren (2007) also noted that encouraging relatives to ask questions and acknowledging their statements can make them feel part of the caring team. During admission families should be given the

telephone number of the ICU and the names of physician and nurse caring for their member and should be instructed about the best time the family can call.

### **6.7.2 Spiritual comfort**

In this study, a significant finding that broadens the understanding of the Saudi family needs was that various religious and cultural values and norms practised by Saudis were seen as essential when caring for ICU patients. The Saudi healthcare providers may remind families that illness is a test of their faith in God and that God is the ultimate healer. This can facilitate some meditation and comfort, hope to hold on to, quiet strength and calmness of heart. Reading the Qur'an is extremely important and valued by Saudi patients and families and believed to have therapeutic effects. When the Qur'an is being recited in a loud voice, ICU team should be quiet as possible and minimise interrupting the reader. It would be highly appreciated by families if the hospital authorities in Saudi Arabia considered a Qur'an reader to ensure reciting Qur'an to the ICU patients. It might be appropriate to suggest placing a charity box in the ICU for those families who would like to give money on behalf of their ICU patient to hold off disaster. Reminding the dying patient to deliver Shahadatain or testimony of faith is an additional practice surrounding death for Muslims. The Shahadatain consists of saying: there is no God but Allah and Mohammad is the Messenger of Allah. The recitation of Shahadatain in front of a dying Muslim is believed to facilitate admittance to heaven (Wehbe-Alamah, 2008). Before the commencement of intubation ICU staff may also remind the patient to deliver Shahadatain.

### **6.7.3 Support and reassurance**

During the immediate phase of critical illness the shock of admission to ICU necessitates the family to be supported and assured that the patient is receiving the best care and that the healthcare providers care about the patient. Several strategies and interventions can be implemented to meet the family needs for the assurance and support. Recruiting a social worker for the ICU, as suggested by the family members can assist to enhance the family ability to cope with the critical care situation. The social worker can also help in presenting information in terms the family can understand. ICU healthcare providers should have a caring attitude and be friendly to give support to families. The use of group support in which families can share their feelings and concerns is another intervention that provides support and assurance to the families (Vandall-Walker, Jensen & Oberle, 2007).

Titler et al. (1995) maintained that the group support strategy has been shown to reduce anxiety, improve the family knowledge of the patient's condition and ICU environment, and enhance the family's coping ability. Culturally, in Saudi Arabia, the critical illness event has the effect of strengthening family ties. The healthcare providers should encourage having family and friends around to provide different types of support. Furthermore, the analysis of interviews identified the need to hold on to hope, being positive and optimistic in the context of the ICU can be another supportive coping mechanism.

#### **6.7.4 Proximity needs**

Restricted visitation policies prevent families from seeing their patient as frequently as they wish and, spending time with them as well as obstructing them from obtaining information about the patient's condition. It can be argued that restricted visitation practices in ICU in Saudi Arabia are based on tradition rather than evidence. The Qualitative findings clearly revealed that family members prefer flexible visiting practices. This research emphasises that both patients and families benefited emotionally from being close to each other. Based on this emphasis, hospital authorities in Saudi Arabia should be advised to revise the ICU visiting policies. The patients' and families' contribution should be taken into consideration when revising the policies. For instance, patients and family may be asked, at admission time and thereafter, of their visit preference, length of visit, frequency and time of visit. Policies should also consider any special circumstances, such as those relatives who travel for long distances to visit their loved one. Families must have waiting rooms with comfortable furniture close to the ICU. Helping families meeting these needs will enhance their wellbeing and coping abilities.

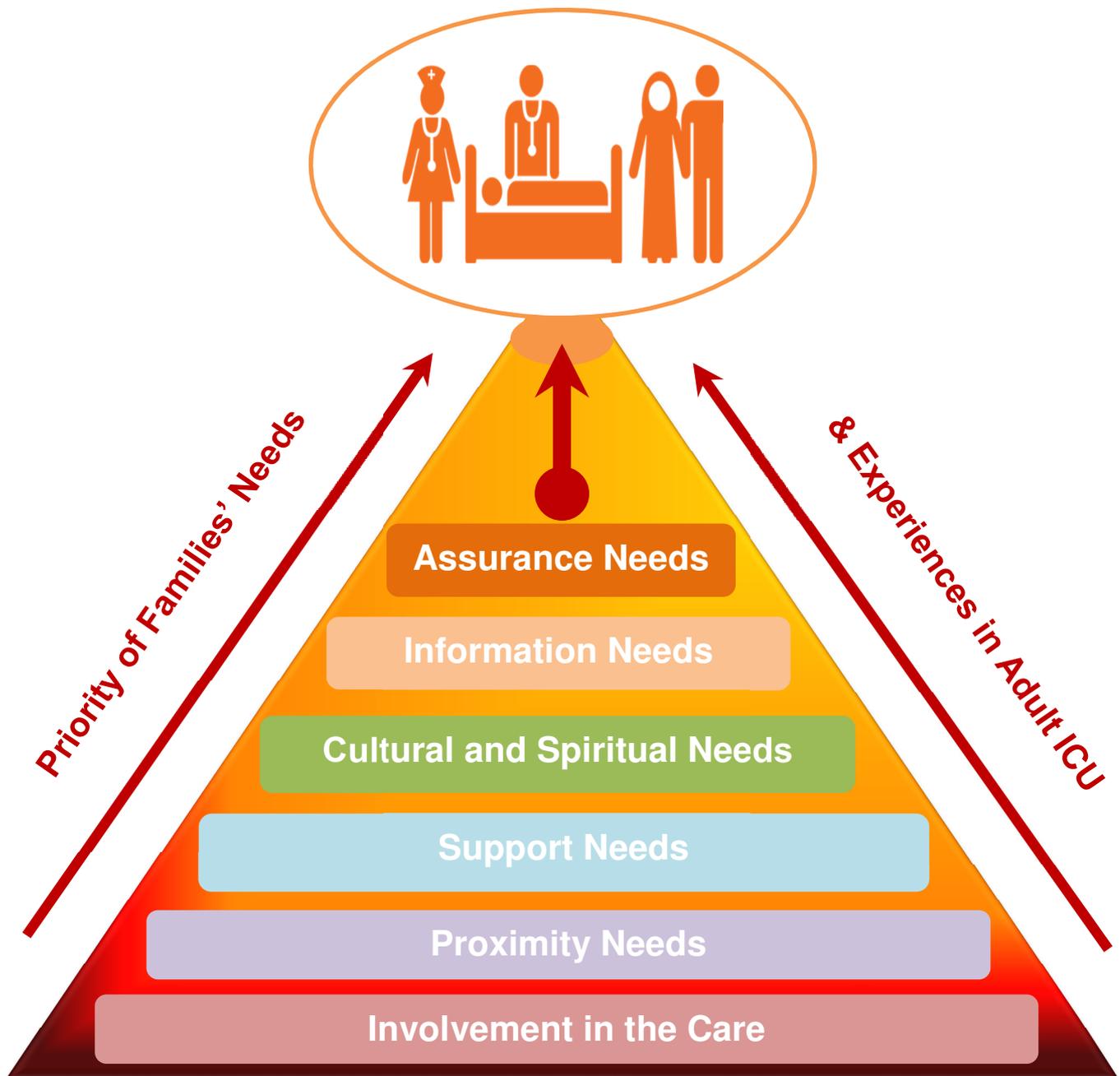
#### **6.7.5 Involvement in care**

It was further identified by family members that family involvement in patient care activities decreased the family anxiety and feeling of powerlessness and, more importantly, was culturally appreciated. Being involved in assisting with the daily task for the patient has evolved as a coping mechanism (Fry & Warren, 2007). Involvement may elicit the benefit of deepening the ICU healthcare professionals' understanding of the patient and strengthening the relationship with the families. Because patients often give important information to relatives that they do not share

with the ICU team (Titler et al, 1995). Family is an important resource in care of the patient and alleviates the patient's stress and improve the patient's outcomes (Fry & Warren, 2007). Relatives can be given the opportunity to assist in basic patient care such as bed bathing, feeding, linen changing or mouth care if possible. Bond et al. (2003) pointed out that including family members can increase their understanding of the gravity of the patient's situation and prepare them for the upcoming care-giving role if needed, when the patient is discharged from the hospital. It is important to note that not all family members desire to participate in the care; therefore if they do not want to participate it should not be assumed.

### **6.8 Family-Focused Care framework**

Adult intensive care staff in Saudi Arabia should be provided with opportunities and encouraged to take the initiative to change their approaches to care, gaining an in-depth understanding of the family needs and experiences and acting upon meeting those needs. Although the intensive care settings in Saudi Arabia use a predominately patient-focused care model, the 21<sup>st</sup> century care model should take into consideration meeting the needs of both the patient and family. Based on the findings of this study, the researcher has developed a family-focused care framework for application in the adult intensive care (see Figure 6.1).



**Figure 6.1:** Family-focused care framework in adult intensive care.

The framework shown in Figure 6.1 locates family centred patient care as the main focus of intensive care, at the pinnacle of the six domains of family needs and experiences, the family being an essential element of the care team along with health professionals, if the family wish to participate. As with Maslow's theory, when needs are met over time, other needs are prioritized. Of the six domains, assurance and

information needs are the most important needs to be met during patient admission in the ICU, followed by cultural and spiritual needs, and after that support and proximity needs, then involvement in the care. Those needs if unmet may produce stress, anxiety, disorganized or complete loss of control behaviours in the family and that in turn may impact on the patient's health. The family-focused care model focuses on reaching partnership between ICU healthcare providers and family members.

The framework may necessitate that ICUs allow open communication, a flow of information, provide flexible visiting hours, an efficient support system and family participation in the care and family presence during resuscitation and other invasive procedures. The framework also requires the ICU healthcare professionals to be aware of the spiritual and cultural needs of the family. The family-focused care framework involves building up relationships and supporting family members of critically ill patients to meet the family needs. The concept of family-focused care is not new worldwide, but there is clearly room for a new approach in the intensive care setting. Knowledge about the perceived family needs and involvement in the care is vital to achieve this improvement (Latour, Goudoever & Hazelzet, 2008).

## **6.9 Conclusion**

In this chapter the findings drawn from data analysis in Phase 1 and Phase 2 of the study have been discussed. Families of ICU patients in Saudi Arabia seek extensively for their needs to be satisfied which, if unmet, may produce stress on family members as well as ICU healthcare providers and may adversely affect the patient's well-being. These family needs can be addressed by supporting and involving families in the care. The concept of ICU families' needs and involvement has helped to identify the key

potential factors which will need to be addressed in the planning, development, implementation and evaluation of any new intervention.

The final chapter brings together the key findings emanating from this study. The chapter will outline a number of limitations encountered, recommendations regarding clinical implications, nursing education, and further research into family needs and involvement in care.

## **Chapter Seven: Conclusion**

### **7.1 Introduction**

This study aimed to identify the needs and experiences of families of critically ill adult patients in Saudi Arabia and to explore healthcare providers' attitudes to family involvement in routine care and family presence during resuscitation and other invasive procedures. Needs and experiences are two interrelated concepts that required different strategies to explore and identify them. The research questions which guided the study were: What are the needs of Saudi families of critically ill adults, as perceived by both the family members and the ICU health care providers, and how well are those needs being met and by whom? And what are the attitudes of healthcare providers' regarding family involvement during routine care and family presence during resuscitation or other invasive procedures? The research employed a descriptive, explanatory mixed methods sequential design in two phases. A questionnaire was used to collect data from family members and ICU healthcare providers in Phase 1, and interviews were used to collect data from family members in Phase 2.

The study was conducted in eight closed-model, mixed medical-surgical adult ICUs of eight major trauma hospitals situated in different areas in Saudi Arabia. The theoretical framework that shaped this study was drawn from Maslow's Hierarchy of Needs and Family Centered Care theory. Maslow's Hierarchy of Needs helped to identify the family needs and Family Centered Care theory assisted in recognizing the attitudes of healthcare providers towards family participation in the care.

The findings of the study revealed the “most” and “least” important family needs during the critical phase of patient admission to the ICU. The research results have provided a greater depth understanding of family experiences while having a loved one admitted in the ICU. The study provides a new and deeper perspective on Saudi healthcare professionals’ attitudes towards family participation during routine care and invasive procedures including resuscitation. In this final chapter a synthesis of the major findings is outlined in relation to family needs and experiences and family involvement during routine care and family presence during resuscitation and other invasive procedures. The implications of these findings for clinical practice, education and future research are outlined. The limitations of the study are also reviewed.

## **7.2 Key findings of the research**

The findings indicate that family members and ICU healthcare providers had similar perceptions in most areas including the importance of family needs, needs being met or unmet and the most appropriate person to meet and provide family needs.

The findings are now summarized under the following headings which reflect the study design and research questions.

### **7.2.1 Providing assurance, information, proximity, support and cultural and spiritual needs to families**

Quantitative results in Phase 1 demonstrate that both family members and ICU healthcare providers perceived the subscales of assurance, information and cultural and spiritual needs as the most important, with proximity and support as the least important needs. A key cultural and spiritual needs finding of this doctoral study has

been highlighted in the item “To have the healthcare providers handle the body of the deceased Muslim with extreme caution and respect”. This item was perceived as the most important need by family members and the fifth most important need by the healthcare providers (refer to Tables 4.6 and 4.9).

Of the five least important item needs that were identified by family members two were listed in the proximity, and one was listed in the support subscale. Similarly of the five least important needs identified by healthcare providers two were listed in the proximity and two in the support subscale (refer to Tables 4.7 and 4.10). A positive medium to strong relationship between assurance and information, proximity, support and cultural and spiritual family needs was detected in the current study as perceived by both family members and healthcare providers. Information and knowledge about the patient condition, if provided in an understandable manner as well as support and being near to the patient, can enhance assurance and addresses the cultural and spiritual needs of the family members. The study has also demonstrated that Islamic cultural values and spiritual healing are believed to have therapeutic calming and assurance effects on families.

The qualitative findings from the open-ended question and from interviews enriched and confirmed the quantitative findings of the study. The study provides a deeper understanding of the needs, wishes, lived experiences and challenges faced by families who have a relative admitted in the ICU. The results show that families wanted to access honest and straightforward information, be reassured that the best care is being delivered to their loved one, and be supported during an ICU admission. Families wanted to see the patient frequently whenever they desired and to remain close, hold

on to hope and be a part of the care process. The Saudi families in this study had cultural and spiritual healing beliefs and practices that can lessen their stress and connect them to hold on to hope. Those beliefs and practices include faith in God and that God is the ultimate healer, reading the Qur'an, prayer, and charity. The qualitative findings also revealed that family members sought a social worker in the ICU to support the family and to enhance their ability to cope with the critical care situation and to help in providing information in terms the family can understand.

### **7.2.2 Meeting family needs and responsibility towards them**

The quantitative findings in Phase 1 demonstrated that family members identified their needs of assurance as being met and their needs for support as unmet. Needs of information, proximity and cultural and spiritual needs were found to be not always met. The Saudi families of ICU patients interviewed in Phase 2 of this study believed that they had their needs neglected and unmet while they had their relative admitted in the ICU which increased their stress and feelings of powerlessness. ICU healthcare providers, in turn and by extraordinary contrast identified all family needs as being successfully met. This highlights that healthcare providers have little insight into what families truly need. Family members identified doctors as the most appropriate person to fulfil most of their needs, followed by nurses, then hospital administration. Healthcare providers perceived doctors as the most appropriate person to fulfil most of the relatives' needs, followed by the hospital administration, then nurses. This is disappointing considering the professional preparation of this specialised sector of the critical care workforce and may suggest that the public are not aware of the education, knowledge and preparation to meet family needs of critical care nurses in Saudi Arabia. In this climate nurses themselves may lack confidence.

### **7.2.3 Family involvement during routine care and family presence during resuscitation and other invasive procedures**

Healthcare providers expressed positive attitudes towards family involvement during routine care, but negative attitudes towards family presence during resuscitation or other invasive procedures. Healthcare providers who opposed the practice expressed a variety of reasons that their performance would be affected by the relatives' presence; the presence of family members made them feel stressed and fearful of traumatic experience for the family members. Physicians expressed more opposition to the family presence than did nurses and respiratory therapists. On the other hand, healthcare providers believed that family were an important resource in patient care in the ICU. This indicates a need for written guidelines and policies, as well as educational programs for the public and healthcare providers, to support family involvement and give the family the option and the needed support to attend resuscitation and invasive procedures.

### **7.3 Limitations of the study**

The study findings provide an important contribution to understanding Saudi Arabian family needs and experiences when having a family member admitted in the ICU. The study also acknowledges the attitudes of ICU healthcare providers towards family involvement during routine care and family presence during resuscitation or other invasive procedures. In this research, a number of limitations in design and data collection are to be considered which may have an effect on the generalisability of the study findings.

In Phase 1, the met/unmet needs on the CCFNI were identified through asking the participants to choose whether those needs were being met or unmet. Perhaps the use of a 4-point Likert type scale on the perceived family needs statements as follows: 1 = never met, 2 = sometimes met, 3 = usually met, 4 = always met. This would give the respondents the freedom to rate how well they perceived their needs were being met rather than just choosing between met or unmet as the Likert type scale has the benefit of spreading the distribution. A limitation in the data collection process related to the inclusion of family members within 24 hours of their family members' admission to the ICU, because family members are highly stressed during such times. The use of a non-probability convenience sample with family members and ICU healthcare providers limits the generalisability of the findings. Also, the low response rate and lower numbers of doctors and respiratory therapists could result in skewed doctor-nurse and respiratory therapist-nurse comparisons. Only those who were interested in the topic completed the questionnaire which may have resulted in non-respondent bias.

In Phase 2, a limitation of the study was that only family members who were present at the ICU at the time of conducting interviews were asked to participate in the study. It is possible that those other family members who did not visit their critically ill relative during the data collection period had other experiences to be shared. The interview methods conducted in the qualitative phase were with a small number of respondents (n = 12), making it hard to draw detailed recommendations for practice due to the generalisability being limited by the small sample size. Therefore, these qualitative results need to be treated with caution.

## **7.4 Implications of the study findings**

A deeper appreciation of the needs, wishes, lived experience and challenges faced by families who have a relative admitted to the ICU in Saudi Arabia has been realised. The study findings have three major areas of implication for clinical practice, education and future research. The findings indicate that the families in Saudi Arabia need to be seen, heard, and worked with collaboratively, by the ICU care team for patient as well as family well-being.

### **7.4.1 Clinical practice**

The study provides a new body of knowledge concerning intervention in the field of family needs and involvement of ICU patients. Knowledge about family needs can help the ICU team structure responses to the variety of family needs in order to plan appropriate interventions to meet them. Meeting family needs will serve to provide holistic care to the family which will in turn decrease the stress, powerlessness and anxiety experienced during the patients' admission to the ICU. Such structural developments to support families in their time of need will ultimately mean improving patient care. The family members might be a source of stress for the ICU team, but through meeting family needs, family stress can be reduced, and this in turn may serve to reduce pressure on the medical team. The recognition and meeting of family needs can also improve the communication between families and the ICU team.

The results highlight the importance of shifting the care model from the conventional medical approach to a family-focused model of care that respects all needs of the patient and their families. Moreover, this study is likely to inform healthcare providers caring for Muslim patients and families in Saudi Arabia and internationally. The

involvement of family in the care of hospitalised patients in the ICU has implications for the working situation and the quality of care delivered to the patient. It can also help the hospital authorities in Saudi Arabia to develop policies and guidelines to introduce safe implementation of family involvement policy during routine care and family presence during resuscitation and other invasive procedures. Those policies can include flexible visiting practices and waiting rooms with comfortable furniture in the ICU for the family members.

#### **7.4.2 Education**

The study has raised important questions about nursing and other health professional curricula standards in Saudi Arabia requiring greater emphasis on family needs, involvement and effective communication with a family of a critically ill family member in the ICU. The development of education guidelines for the provision of information, providing support needs and communicating verbally and non-verbally with families in every day care is of great importance, and must become a priority. Both undergraduate health professional education and professional development sessions should enhance ICU healthcare providers' skills in the recognition of families' anxiety and providing possible interventions. The study findings could also contribute to the development of nursing curricula and staff support training programs in Saudi Arabia to identify and meet family needs through a more empathetic model of patient centred care. Furthermore, the findings can help to produce integrated and consistent education for the public regarding their contributions during the care of their loved one in the ICU in routine care of the patient's activities, and also during resuscitation and other invasive procedures.

### **7.4.3 Future research**

This was the first empirical study to investigate the family needs and involvement of adult intensive care patients in Saudi Arabia. The study provides both baseline repository information and stimulus for building upon the research with critically ill patients and families and health care providers. It is clear from this research involving eight separate hospitals in Saudi Arabia that there is a need for further research on families' needs and involvement. It is recommended that those studies are to be from a broader range of hospitals of all health sectors in different areas in Saudi Arabia in order to enhance the evidence for practice in, for example, private hospitals, military hospitals, paediatric ICU, Medical ICU, High Dependency Units, Trauma Units, Infectious Diseases ICUs and Obstetrics ICUs. Future research could determine the families' requirements while having a critically ill relative admitted in the ICU. Additionally, it should highlight the Saudi cultural practices of a diverse patient population. The study found that family members preferred flexible visiting practices in the ICU. Therefore, further research into visitation policies may explore the ICU patients' attitudes and satisfaction with visiting practices, which may enhance the hospitals authorities' confidence in their practice. There is a need for more qualitative investigations into the lived experience of ICU patients and family members. Alternative research methods could be employed in the follow-up of this study under different paradigms of study.

Further research could also clarify the patients' attitudes to family involvement during routine care and family presence during resuscitation and other invasive procedures after discharge. With emerging trends in the Kingdom for home care of ventilated patients, it is not surprising that family members are embracing opportunities to be

part of the care, including complex care, when their loved one is critically ill. Research on the needs of the home ventilated patient and their families will also inform health services and health professionals

Finally research into the views and needs of those family members who do not wish to participate will be very important work and is highly recommended to follow this study.

## **7.5 Conclusion**

This study is unique in the fact that it was the first empirical study focused on exploring the needs of families of ICU patients in Saudi Arabia. It has also produced the first results in relation to clarifying families and healthcare providers' needs in Saudi Arabian intensive care environments. Families are in need of support by the ICU healthcare team in a more patient and family centred way. The study findings provide a new body of knowledge concerning intervention in this field. In this study, it has been demonstrated that families have significant needs and developing interventions to meet these needs must become a priority to enhance the care from the ICU healthcare providers.

The study revealed that access to understandable, consistent information; assurance that the best care is being delivered to the patient; support; maintaining proximity and being part of the care may reduce family anxiety and feelings of powerlessness. The study has emphasised that Muslim families have different needs from Western families in respect to cultural and spiritual needs. The Islamic cultural values and spiritual healing harness a belief that has a therapeutic calming and reassurance effect on families. The Saudi families' cultural and spiritual beliefs and practices including

faith in God as ultimate healer, reading the Qur'an, prayer, and charity were seen to lessen families stress and connect them to hope.

Healthcare providers showed positive attitudes towards family involvement during routine care, and negative attitudes towards family presence during resuscitation or other invasive procedures. It is evident from this study that family participation during the crisis of an ICU experience offers potential benefits to patients and families. These benefits include patients and families physically and psychologically being part of the care which may reduce the stress of medical staff. Currently clinical barriers may prevent the practice including resources, hospital policies and guidelines and staff and public education.

With respect to cultural and spiritual needs this study has demonstrated that Muslim families have unique needs some of which are similar and some are different to Western families, though acknowledging these have not been well reported in the literature. The study has also contributed in providing knowledge and awareness which is can be used to inform ICU healthcare providers in Saudi Arabia and those caring for Muslim patients and families elsewhere in the Middle East and other international settings. These findings are a new contribution to the comprehensive care of the critically ill patient in ICU.

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# Appendices

## Appendix A: Monash University Human Research Ethics Committee approval



**MONASH** University

**Monash** University Human Research Ethics Committee (MUHREC)  
Research Office

### Human Ethics Certificate of Approval

**Date:** 12 July 2011  
**Project Number:** CF11/1411 - 2011000794  
**Project Title:** Needs of families and their involvement in the care process for intensive care patients in Saudi Arabia  
**Chief Investigator:** Dr Virginia Plummer  
**Approved:** From: 12 July 2011 To: 12 July 2016

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#### Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.



Professor Ben Canny  
Chair, MUHREC

cc: Assoc Prof Anthony O'Brien, Mr Abbas Al Mutair

Postal – Monash University, Vic 3800, Australia  
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton  
Facsimile +61 3 9905 3831  
[www.monash.edu/research/ethics/human/index/html](http://www.monash.edu/research/ethics/human/index/html)  
ABN 12 377 614 012 CRICOS Provider #00008C

## Appendix B: General Administration for Medical Research Approval

### i. KSMC and KFMC letter

بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ



المملكة العربية السعودية  
وزارة الصحة  
الإدارة العامة للبحوث الطبية

الرقم: .....  
التاريخ: .....  
الشفوعات: .....

الموضوع: طلب تسهيل مهمة الطالب /  
عباس صالح المطير.

**سعادة مدير عام الشؤون الصحية بالرياض**

**المحترم**

السلام عليكم ورحمة الله وبركاته:  
إشارة إلى موضوع رسالة طالب الدكتوراه / عباس صالح المطير رقم السجل المدني (١٠٠٩٥٩٠٢٠٧) لدراسة مرحلة الدكتوراه في تخصص التمريض في جامعة أوتار موناش بأستراليا رقم الطالب الأكاديمي (٠١٠٧٨٢١٢) وعنوان الرسالة :-  
" احتياجات أهل المرضى السعوديين البالغين المنومين بالرعاية المركزة ومشاركتهم الفعالة في الرعاية الصحية "  
" The critically ill patients – needs of families and their involvement in the care process in Saudi Arabia. "

وحيث أن المذكور عاليه سينفذ جزء من دراسته في مستشفيات منطقة الرياض، نأمل تسهيل مهمته بزيارة المستشفيات التالية:  
١- مستشفى الملك سعود الطبي بالرياض.  
٢- مدينة الملك فهد الطبية بالرياض.  
لجمع البيانات اللازمة ، مع العلم بأن وزارة الصحة لا تتحمل أية أعباء مالية أو إدارية وأن لا يكون هناك أي تأثير على خدمة المراجعين والمرضى خلال قيامه بمهام بحثه.  
شاكرين لكم حسن تعاونكم.

ولكم أطيب تحياتي ،،،

**مدير عام**  
**الإدارة العامة للبحوث الطبية**  
**د. نبيل بن هزاع القحطاني**

ii. KFSH-D, DMC, QCH and KFH-H letter

بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

الرقم : ٥٦٧ / ٤٠٤٠ / ١٤٣٥  
التاريخ : ١٨ / ١٢ / ١٤٣٥  
الشفوعات :



المملكة العربية السعودية

وزارة الصحة

الإدارة العامة للبحوث الطبية

الموضوع: طلب تسهيل مهمة الطالب /  
عباس صالح المطير.

**المحترم سعادة مدير عام الشؤون الصحية بالمنطقة الشرقية**

السلام عليكم ورحمة الله وبركاته:  
إشارة إلى موضوع رسالة طالب الدكتوراه / عباس صالح المطير رقم السجل المدني (١٠٠٩٥٩٠٢٠٧) لدراسة مرحلة الدكتوراه في تخصص التمريض في جامعة أوتار موناش بأستراليا رقم الطالب الأكاديمي (٠١٠٧٨٢١٢) وعنوان الرسالة :-  
" احتياجات أهل المرضى السعوديين البالغين المنومين بالرعاية المركزة ومشاركتهم الفعالة في الرعاية الصحية "

" The critically ill patients – needs of families and their involvement in the care process in Saudi Arabia. "

وحيث أن المذكور عاليه سينفذ جزء من دراسته في مستشفيات المنطقة الشرقية، نأمل تسهيل مهمته بزيارة المستشفيات التالية:

١. مستشفى الملك فهد التخصصي بالدمام.
٢. مستشفى الدمام المركزي.
٣. مستشفى القطيف المركزي.
٤. مستشفى الملك فهد بالهفوف.

لجمع البيانات اللازمة ، مع العلم بأن وزارة الصحة لا تتحمل أية أعباء مالية أو إدارية وأن لا يكون هناك أي تأثير على خدمة المراجعين والمرضى خلال قيامه بمهام بحثه.  
شاكرين لكم حسن تعاونكم.

ولكم أطيب تحياتي ،،،

مدير عام

الإدارة العامة للبحوث الطبية

د. نبيل بن هزاع القحطاني

iii. KFCH-J letter

بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ



المملكة العربية السعودية  
وزارة الصحة  
الإدارة العامة للبحوث الطبية

الرقم : .....  
التاريخ : .....  
المشروعات : .....

الموضوع: طلب تسجيل مهمة الطالب /  
عباس صالح المطير

**سعادة مدير عام الشؤون الصحية بمنطقة جازان المحترم**

السلام عليكم ورحمة الله وبركاته:  
إشارة إلى موضوع رسالة طالب الدكتوراه / عباس صالح المطير رقم السجل المدني (١٠٠٩٥٩٠٢٠٧) لدراسة مرحلة الدكتوراه في تخصص التمريض في جامعة أوتار موناش بأستراليا رقم الطالب الأكاديمي (٠١٠٧٨٢١٢) وعنوان الرسالة :-  
" احتياجات أهل المرضى السعوديين البالغين المنومين بالرعاية المركزة ومشاركتهم الفعالة في الرعاية الصحية "

" The critically ill patients – needs of families and their involvement in the care process in Saudi Arabia. "

وحيث أن المذكور عاليه سينفذ جزء من دراسته في مستشفى الملك فهد بجازان ، نأمل تسجيل مهمته بزيارة المستشفى لجمع البيانات اللازمة ، مع العلم بأن وزارة الصحة لا تتحمل أية أعباء مالية أو إدارية وأن لا يكون هناك أي تأثير على خدمة المراجعين والمرضى خلال قيامه بمهام بحثه.

شاكرين لكم حسن تعاونكم.

ولكم أطيب تحياتي ،،،

مدير عام

الإدارة العامة للبحوث الطبية

د. نبيل بن هزاع القحطاني



## **Appendix C: Explanatory statements**

### **i. Explanatory statement for Family Members in Phase 1**

**Project title:** "The needs of families and their involvement in the care process of intensive care patients in Saudi Arabia"

My name is Abbas Al Mutair and I am conducting a research study under the supervision of Dr. Virginia Plummer and Associate Professor Anthony O'Brien researchers at Faculty of Medicine, Nursing and Health Sciences towards Doctor of Philosophy at Monash University.

The aim of the study is to identify the perceived needs of the Saudi families with a relative in intensive care and to investigate healthcare providers' behaviours towards family involvement patterns during routine and special care. The potential significance of the current study lies in the recognition of practices that explore the family involvement during routine and special care and to realise family as an important source to support patients in Saudi Arabia.

This study is designed to explore the needs of Saudi families in range of hospitals from healthcare providers and family members' perspectives. Participation in this study will involve completing a questionnaire that will take 5 to 10 minutes to complete. The questionnaire if you complete it, can be placed in the attached envelope and returned to the study box near the intensive care unit or can be handed to the researcher if available or alternatively sent to Abbas Al Mutair on P. O. Box: 12445, Al Mubarraz, KSA, 31892.

Participation in the research project is voluntary. If you do not wish to take part you are not obliged to submit the questionnaire. If you decide to take part and submit the questionnaire and change your mind, it will not be possible to withdraw, as the questionnaire has not identifying information. Your decision whether to take part or not to take part, will not affect your family member's treatment, your relationship with those treating your family member or your relationship with the hospital. I hope you feel comfortable about giving me your honest opinions. You will not be paid for your participation in this project.

The support system in the hospital is available should you experience any difficulties when completing the questionnaire, and you may contact the social worker (Phone number for each hospital will be inserted here) in the hospital to assist you in this process.

Any information obtained in connection with this study will remain confidential and only the researcher and study supervisors will have access to information provided by participants. The information collected during this study will be kept according to Monash University regulation in a locked cupboard/ filing cabinet for five years. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Please note that the student researcher is a nurse and has no link to any of the hospitals participated in the study.

If you have any queries or would like to be informed of the aggregate research finding, please contact:

Abbas Al Mutair

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

The findings are accessible from 01/11/2014.

If you have a complaint concerning the manner in which this research is being conducted, you can contact Mr Ali Al Shakhs at the following address to pass your complaints to the Monash University Human Research Ethics Committee:

4288 ALGARAH

ALGARAH GENERAL STREET

P.O.BOX :31982

**Thank you for participation**

**Abbas Saleh Al Mutair**

**Ph.D candidate**

ii. **Explanatory statement for Family Members in Phase 1 in Arabic Language**

بسم الله الرحمن الرحيم

أعزائي أفراد أسرة المريض تحية طيبة وبعد،،،

إسمي **عباس صالح المطير**، طالب دكتوراة بكلية التمريض في جامعة موناش بأستراليا. أقوم بإجراء دراسة لأسر المرضى تدور حول احتياجات أهل المرضى السعوديين البالغين الذين لديهم أحد أفراد العائلة يرقد كمريض في العناية المركزة.

أدعوك للمشاركة في هذا البحث لأنك أحد أفراد عائلة المريض الذي يرقد في العناية المركزة وذلك من خلال تعبئة الاستبانة المعدة للدراسة، علماً بأن الإجابة على الأسئلة تستغرق فقط خمس الى عشر دقائق من وقتك. يمكن وضع الاستبانة بعد الفراغ من تعبئتها في صندوق الدراسة القريب من العناية المركزة او تسليمها الى الباحث مباشرة او إرسالها عبر البريد على العنوان التالي: عباس صالح المطير صندوق بريد رقم: 12445 المملكة العربية السعودية الرمز البريدي 31892.

مشاركتك في هذا البحث ليست لها منافع مالية لكنها تعطيك فرصة للتعرف على احتياجاتك بالإضافة الى أن نتائج هذا البحث قد تساعد مقدمي الرعاية الصحية في إعطاء عناية أفضل للمريض ودعم أسرته. لن تلحق بك أية أضرار نتيجة مشاركتك في هذا البحث ولكنك ربما تشعر بالاستياء أثناء تعبئتك الاستبانة لذلك تستطيع التوقف عن المشاركة كما يمكنك الاتصال على الأخصائي الاجتماعي لمساعدتك و الترويج عنك على الرقم

يضمن لك الباحث السرية التامة خصوصا وأنك لن تذكر اسمك في أي من أسئلة هذا البحث، وسوف يتم فقط تحليل كل الأجوبة بشكل عام. بالإضافة الى أن الباحث والمشرفين على الدراسة

هم فقط هم من سيطلع على الإجابات و بعد ذلك سيتم حفظ الاستبانات في خزانة مؤمنة لخمس سنوات ثم يتم إتلافها بعد ذلك بحسب ما تنص عليه أنظمة الجامعة.

مشاركتك في الدراسة طوعية تمامًا، وتستطيع الرفض أو الإنسحاب من المشاركة في أي وقت تشاء، كما أن مشاركتك في هذه الدراسة أو عدمها لن يؤثر على العلاج والعناية التي يتلقاها قريبك الذي يرقد في العناية المركزة.

كما يقر الباحث بأنه ممرض سعودي لا تربطه اي علاقة مع اي من المستشفيات المشاركة بالدراسة

إذا كان لديك أي سؤال أو استفسار بخصوص البحث تستطيع التواصل معي على الرقم التالي:

جوال: +966555877487، أو بريد إلكتروني: [REDACTED]

إذا كان لديك اي شكوة بخصوص البحث يمكنك التواصل مع الأستاذ علي الشخص لأيصال شكواك الى لجنة الأخلاقيات بجامعة موناش بأستراليا عبر وسائل الأتصال التالية:

صندوق بريد: 4288 شارع القارة العام، القارة.

الرمز البريدي: 31982

هاتف: 00966533352852

أيميل: [REDACTED]

تقبلوا خالص شكري وتقديري

عباس صالح المطير

### iii. Explanatory statement for Healthcare Providers in Phase 1

**Project title:** "The needs of families and their involvement in the care process of intensive care patients in Saudi Arabia"

My name is Abbas Al Mutair and I am conducting a research study under the supervision of Dr. Virginia Plummer and Associate Professor Anthony O'Brien researchers at Faculty of Medicine, Nursing and Health Sciences towards Doctor of Philosophy at Monash University.

The aim of the study is to identify the perceived needs of the Saudi families with a relative in intensive care and to investigate healthcare providers' behaviours towards family involvement patterns during routine and special care. The potential significance of the current study lies in the recognition of those practices that explore the family involvement pattern during routine and special care and using family as an important source to support patients in Saudi Arabia.

This study is designed to explore the needs of Saudi families in range of hospitals from healthcare providers and family members' perspectives. Participation in this study will involve completing a questionnaire that will take 15 minutes to complete. The questionnaire if you complete it, can be placed in the attached envelope and returned to the study box inside the critical care unit or can be handed to the head nurse.

Participation in the project is voluntary. An anonymous questionnaire will be distributed to all healthcare providers in the intensive care unit. Please do not provide your name to ensure anonymity, once the questionnaire is submitted you will not be able to withdraw as it is anonymous. You will not be paid for your participation in this project.



iv. **Explanatory statement Healthcare Providers in Phase 1 in Arabic Language**

بسم الله الرحمن الرحيم

أعزائي مقدمي الرعاية الصحية في أقسام العناية المركزة  
وتحيه طيبه  
وبعد،،،

أسمي **عباس صالح المطير** طالب دكتوراة بكلية التمريض في جامعة موناش بأستراليا. أقوم بإجراء دراسته لأسر المرضى والتي تدور حول إحتياجات أهل المرضى السعوديين البالغين الذين لديهم احد أفراد العائله يرقد كمرريض في العناية المركزة.

أدعوك للمشاركة في هذا البحث لأنك أحد مقدمي الرعاية الصحية بالأقسام الحرجه وذلك من خلال تعبئة الاستبانة المعدة للدراسة وأود إعلامك بأن الإجابة على الأسئلة ستستغرق خمسة عشر دقيقة من وقتك فقط. عند الفراغ من تعبئة الاستبانة يرجى وضعها في الظرف المرفق ومن ثم وضعها في صندوق الدراسة في القسم او تسليمه الى رئيس/رئيسة القسم.

مشاركتك في هذا البحث ليست لها منافع مالمه لكنها تعطيك فرصة لتحديد إحتياجات الأسرة من منظورك بالإضافة الى أن نتائج هذا البحث قد تساعد مقدمي الرعاية الصحية في المملكة على إعطاء عناية أفضل للمريض ودعم أهله.

لا توجد أضرار عليك نتيجة مشاركتك في هذا البحث كما يضمن لك الباحث السرية التامه خصوصا انك لن تذكر أسمك على أي من أسئلة هذا البحث و كل الأجوبة سيتم تحليلها فقط بشكل عام. بالإضافة الى أنه فقط الباحث والمشرفين على الدراسة هم من سيطلع على الإجابات بعد ذلك سيتم حفظ الاستبانات في خزانة مغلقة لخمس سنوات وستتألف بعدها بحسب أنظمة الجامعة.

مشاركتك في الدراسة إختيارية وتستطيع الرفض أو الإنسحاب من المشاركة في اي وقت تريد.

كما يقر الباحث بأنه ممرض سعودي لا تربطه اي علاقة مع اي من المستشفيات المشاركة بالدراسة

إذا كان لديك أي سؤال أو استفسار بخصوص البحث تستطيع التواصل معي على الرقم التالي:

جوال: [REDACTED] أو بريد إلكتروني: [u](mailto:u) [REDACTED]

إذا كان لديك اي شكوة بخصوص البحث يمكنك التواصل مع الأستاذ علي الشخص لأيصال شكواك الى لجنة الأخلاقيات بجامعة موناش بأستراليا عبر وسائل الأتصال التالية:

صندوق بريد: 4288 شارع القارة العام، القارة.

الرمز البريدي: 31982

هاتف: 00966533352852

أيميل: [REDACTED]

تقبلوا خالص شكري وتقديري

عباس صالح المطير

**v. Explanatory statement for family members in Phase 2 (Interview)**

**Project title:** "The needs of families and their involvement in the care process of intensive care patients in Saudi Arabia"

My name is Abbas Al Mutair and I am conducting a research study under the supervision of Dr. Virginia Plummer and Associate Professor Anthony O'Brien researchers at Faculty of Medicine, Nursing and Health Sciences towards Doctor of Philosophy at Monash University.

The aim of the study is to identify the perceived needs of the Saudi families with a relative in intensive care and to investigate healthcare providers' behaviours towards family involvement patterns during routine and special care. The potential significance of the current study lies in the recognition of practices that explore the family involvement pattern during routine and special care that realises family as an important source to support patients in Saudi Arabia.

This study is designed to explore the needs of Saudi families in range of hospitals from healthcare providers and family members' perspectives. The study will employ a face-to-face semi-structured interview with the family members. You will only be interviewed if your age 18 years or above, available in the hospital during visiting time, able to read and write Arabic, and had a family member admitted in the ICU for 24 hours or more. The interview will last between 30 to 45 minutes of your time and can be conducted at a place and time that is suitable for you. The interview will be tape-recorded and then transcribed with your permission. You will have the opportunity to review the draft of the transcript

Participation in the research project is voluntary. If you do not wish to take part you are not obliged to do interview. If you decide to take part and do the interview and change your mind, it will be possible to withdraw. Your decision whether to take part or not to take part, will not affect your family member's treatment, your relationship with those treating your family

member or your relationship with the hospital. I therefore hope you feel comfortable about giving me your honest opinions. You will not be paid for your participation in this project.

If you experienced any challenges during the interview, the interview will cease. The hospital support system will be available to assist you; you may contact the social worker of the hospital (Insert phone numbers of the social worker of each hospital).

Any information obtained in connection with this study will remain confidential and only the researcher and the study supervisors will have access to information provided by participants. The information collected during this study will be kept according to Monash University regulation in a locked cupboard/ filing cabinet for five years. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Please note that the student researcher is a nurse and has no link to any of the hospitals participated in the study.

If you have any queries or would like to be informed of the aggregate research finding, please contact

Abbas Al Mutair on [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

The findings are accessible from approximately 01/11/2014.

If you have a complaint concerning the manner in which this research is being conducted, you can contact Mr Ali Al Shakhs at the following address to pass your complaints to the Monash University Human Research Ethics Committee

4288 ALGARAH

ALGARAH GENERAL STREET

P.O.BOX :31982

**Abbas Saleh Al Mutair**

**Ph.D candidate**

vi. **Explanatory statement for Family Members in Phase 2 (Interview) in Arabic Language**

بسم الله الرحمن الرحيم

أعزائي أفراد أسرة المريض تحية طيبة وبعد،،،

اسمي **عباس صالح المطير** طالب دكتوراه بكلية التمريض في جامعة موناش بأستراليا. أقوم بإجراء دراسة لأسر المرضى والتي تدور حول إحتياجات أهالي المرضى السعوديين البالغين الذين لديهم أحد أفراد العائلة يرقد كمرريض في العناية المركزة.

أدعوك للمشاركة في هذا البحث لأنك أحد أفراد عائلة المريض الذي يرقد في العناية المركزة وذلك من خلال إجراء مقابلة مع الباحث وأود إعلامك بأنّ المقابلة ستستغرق 30-45 دقيقة. المقابلات ستجرى فقط مع افراد الأسرة البالغين (18 سنة فما فوق) والمتواجدين أثناء وقت الزيارة بالعناية المركزة و لديهم قريب يرقد بالعناية المركزة وايضا يستطيعون القراءة والكتابة.

مشاركتك في هذا البحث ليست لها منافع مالية لكن مشاركتك تعطيك فرصة التعرف على إحتياجاتك، بالإضافة الى أن نتائج هذا البحث قد تساعد مقدمي الرعاية الصحية على تقديم عناية أفضل للمريض ودعم أسرته. لن تلحق بك أية أضرار نتيجة مشاركتك في هذا البحث، ولكن قد تشعر بالإستياء أثناء إجراء المقابلة لذلك تستطيع التوقف عن المشاركة كما يمكنك الاتصال على الأخصائي الاجتماعي لمساعدتك والترويج عنك على الرقم.

يضمن لك الباحث السرية التامة فكل الأجوبة سيتم تحليلها بشكل عام. بالإضافة الى أن الباحث والمشرفين على الدراسة هم فقط من سيطلع على الإجابات، بعد ذلك سيتم حفظ المستندات في خزانة مؤمنة لخمس سنوات، ثم يتم إتلافها بعد ذلك بحسب ما تنص عليه أنظمة الجامعة.

مشاركتك في الدراسة طوعية وتستطيع الرفض أو الانسحاب من المشاركة في أي وقت تشاء، كما أن مشاركتك في هذه الدراسة أو عدم مشاركتك لن يكون لها أي تأثير على العلاج والعناية التي يتلقاها قريبك الذي يرقد في العناية المركزة.

كما يقر الباحث بأنه ممرض سعودي لا تربطه أي علاقة مع أي من المستشفيات المشاركة بالدراسة.

إذا كان لديك أي سؤال أو استفسار بخصوص البحث تستطيع التواصل معي على الرقم التالي:

جوال: [REDACTED]، أو بريد إلكتروني: [REDACTED]

إذا كان لديك أي شكوة بخصوص البحث يمكنك التواصل مع الأستاذ علي الشخص لأيضال شكواك الى لجنة الأخلاقيات بجامعة موناش بأستراليا عبر وسائل الأتصال التالية:

صندوق بريد: 4288 شارع القارة العام، القارة.

الرمز البريدي: 31982

هاتف: 00966533352852

أيميل: [REDACTED]

تقبلوا خالص شكري وتقديري

عباس صالح المطير

## **Appendix D: Study Invitation Poster**

### **i. Research Participants Invitation Letter “English Version”**

The family members are invited to participate in the intensive care family needs study, a PhD research project at Monash University in Australia. The study will investigate the families' needs and their involvement in the healthcare process.

Participation is voluntary. If you are female you will be interviewed by a female research assistant.

Please feel free to contact me by telephone or email for further information. All information you give will remain confidential.

Explanatory statements are available from the Head Nurse of the intensive care unit.

**Abbas Al Mutair,**

**PhD Candidate, Monash University, Australia.**

██

██

## ii. Research Participants Invitation Letter “Arabic Version”

دعوة للمشاركة في دراسة تعني بإحتياجات أسر المرضى الراقدين بالعناية المركزة

إذا كان لديك قريب يرقد في العناية المركزة، أدعوك للمشاركة في هذا البحث والذي هو عبارة عن رسالة دكتوراة بكلية التمريض في جامعة موناش بأستراليا. تدور الدراسة حول احتياجات أهل المرضى البالغين الذين لديهم احد أفراد العائلة يرقد كمريض في العناية المركزة.

مشاركتك في الدراسة طوعية، ونضمن لك السرية التامة للمعلومات، وكما توجد امرأة لإجراء المقابلات مع النساء.

إذا كان لديك أي سؤال أو استفسار بخصوص البحث تستطيع التواصل معي على الرقم التالي:

جوال: [REDACTED]، أو بريد إلكتروني: [REDACTED]

## Appendix E: Informed consent

### i. Consent Form for Family Members “English version”

**Title:** "The needs of families and their involvement in the care process of intensive care patients in Saudi Arabia"

**NOTE:** A copy of this consent form will be given to the participant, and another copy will remain with Monash University for their records.

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have read the explanatory statements, which I will keep for my records. I understand that willing to take part means that I am willing to:

1. I agree to be interviewed by the researcher  
Yes ( )      No ( )

2. I agree to allow the interview to be audiotape and transcribed  
Yes ( )      No ( )

I understand that any data that the researcher extracts from the interview for reports or published findings will not, under any circumstances, contain names or identifying characteristics.

**Participants name:**

**Signature:**

**Date:**

## ii. Consent Form for Family Members “Arabic version”

وثيقة موافقة أهالي المرضى الراقدين في العناية المركزة للمشاركة في البحث

عنوان الدراسة: "إحتياجات أهل المرضى السعوديين البالغين الراقدين بالعناية المركزة ومشاركتهم الفعالة في الرعاية الصحية"

ملاحظة: هذه الوثيقة ستحفظ في سجلات جامعة موناش بأستراليا وسيتم تزويدك بنسخة منها.

أعطي موافقتي الطوعية للمشاركة في البحث المذكور أعلاه، مشاركتي تعني فهمي لكافة مجريات البحث من خلال قراءتي لشرح الدراسة المفصل وأيضا من خلال شرح الباحث. مشاركتي بالبحث تعني التالي:

1. موافقتي على إجراء المقابلة مع الباحث. ( ) نعم ( ) لا
2. موافقتي لتسجيل صوتي أثناء المقابلة. ( ) نعم ( ) لا

أعي بأن النتائج التي سيحلها الباحث من المقابلة لإعداد أي تقرير أو بحث ينشر في المستقبل لن تتضمن، وتحت أي ظرف، أية أسماء أو أية معلومات أخرى يمكن التعرف من خلالها على المشاركين.

الاسم:

التوقيع:

التاريخ:

## Appendix F: Family Members Questionnaire

### PART ONE: SOCIO-DEMOGRAPHIC INFORMATION.

Questions 1-11: Please answer all the following questions by ticking (√) in the answer that matches you or write your answer in space provided.

#### A. Would you tell me about yourself:

1. What is your age? \_\_\_\_\_
2. What is your gender?       Male.                       Female.
3. What is your nationality?       Saudi                       Non-Saudi
4. What is your educational background?  
 Less than high school.                       High School.  
 Diploma.                       Bachelor.  
 Other please specify \_\_\_\_\_
5. Have you been involved in the care of patients while they have been in the intensive care unit?                       Yes                       No

#### B. Would you tell me about your ill relative:

6. What is your relationship to the patient?  
 Spouse/Partner                       Sibling                       Parent  
 Son/Daughter                       Other relative                       Friend
7. How long has this patient been in the unit? \_\_\_\_\_
8. What is the age of the patient? \_\_\_\_\_
9. What is the gender of the patient?       Male.                       Female.
10. How often does the family wish to visit?  
 Once a day.                       Twice a day.                       Three times a day.   
Every other day.                       Every two days                       Others  
specify \_\_\_\_\_

## PART TWO: CRITICAL CARE FAMILY NEEDS INVENTORY

Questions 1-35: **Please tick (√) how important each of the following needs is to you.** 1: Not Important (NI), 2: Slightly Important (SI), 3: Important (I), 4: Very Important (VI), then tick (√) to whether the need is being **MET or UNMET** to you **and** specify **THE PERSON** who met or should meet each need even if the need is not important to you.

No	Statement	How important				Tick (√) is the need being met or not		Tick (√) the person who met, or should meet each need most of the time		
		NI	SI	I	VI	Met	Unmet	Doctor	Nurse	Admini- stration
1	To know specific facts concerning the patient's progress.									
2	To educate the family about the condition of the patient									
3	To feel accepted by the hospital staff.									
4	To relieve our families' anxiety by exploring the medical facts with them in a nonjudgmental manner.									
5	To feel that healthcare providers care about my relative.									
6	To communicate effectively with healthcare providers to improve families ability to make care decisions									
7	To be allowed to visit whenever we wish.									
8	To have waiting room with comfortable furniture available for us in the intensive care unit.									
9	To have explanations given in terms that are understandable.									
10	To request to stay during the care of my family member.									
11	To face the patient's bed towards the Holy Mosque in Mecca.									
12	To have questions answered honestly.									
13	To know exactly what is being done for the patient.									

No	Statement	How important				Tick (√) is the need being met or Unmet		Tick (√) the person who met, or should meet each need most of the time		
		NI	SI	I	VI	Met	Unmet	Doctor	Nurse	Admini- stration
14	To ensure the healthcare providers who are the opposite sex from the deceased Muslim have no physical contact with the body.									
15	To be assured that the best care is being given to the patient.									
16	To have an explanation in detail about the condition of the patient when it becomes worse.									
17	To understand everything that occurs with the condition of the patient.									
18	To have staff accompany me while visiting the intensive care unit.									
19	To ensure that the Saudi culture is fully understood by the healthcare providers caring for Saudis.									
20	To talk to the doctor every day									
21	To know the expected outcomes									
22	To have staff providing psychosocial support to families during daily patient care.									
23	To ensure that healthcare providers respect the spiritual healing practices of the Saudi patients and families.									
24	To let the Saudi family know first about the bad news, not the patient.									

No	Statement	How Important				Tick (✓) is the need being met or Unmet		Tick (✓) the person who met, or should meet each need most of the time		
		NI	SI	I	VI	Met	Unmet	Doctor	Nurse	Admini- stration
25	To help with the patient's physical care.									
26	To have explanations of the critical care environment before going to the critical care area for the first time.									
27	To have healthcare providers discuss with the family members what helps the patient deal with events during hospitalization.									
28	To have healthcare providers respect relatives' opinions.									
29	To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect									
30	To be told of the reason for the chosen treatment of my relative.									
31	To ensure that healthcare providers never attempt to interview or examine a female patient alone.									
32	To be told about other healthcare professionals that could help.									
33	To communicate information to help families understand each aspect of care.									
34	To develop trust with healthcare providers									
35	To know how the patient is being treated medically									



## Appendix G: CCFNI Permission Letter

Dear Researcher,

Please find enclosed a copy of the *Critical Care Family Needs Inventory*. You have my permission to use and/or translate the tool to meet your research needs as long as credit is referenced in your work. The psychometric properties of the instrument are published in Leske, J.S. (1991). Internal psychometric properties of the Critical Care Family Needs Inventory, Heart & Lung, 20, 236-244. Please do not hesitate to contact me if you have any questions. Best wishes for a successful research project.

Sincerely,

Jane S. Leske PhD, RN

## Appendix H: Health Care Providers Questionnaire

### PART ONE: SOCIO-DEMOGRAPHIC INFORMATION

Question 1-7: Please answer all the following questions by ticking (✓) in the answer that matches you or write your answer in space provided.

1. What is your age?\_\_\_\_\_
2. What is your gender?  
 Male.                       Female.
3. What is your nationality?\_\_\_\_\_
4. Level of education?  
 Diploma.                       Hospital training.  
 Bachelor.                       Master.  
 Ph.D.                               Others please specify\_\_\_\_\_
5. What is your current job title?\_\_\_\_\_
6. Years of employment?  
 Less than one year.               1 to 5 years.  
 6 to 10 years.                       More than 10.
7. Years of working experience in Saudi Arabia?  
 Less than one year.               1 to 5 years.  
 6 to 10 years.                       More than 10.

**PART TWO: CRITICAL CARE FAMILY NEEDS INVENTORY**

Questions 1-35: **Please tick (√) how important you think each of the following needs is to the family member.** 1: Not Important, 2: Slightly Important, 3: Important, 4: Very Important, then tick (√) to whether the need is being **MET or UNMET** to the family in your hospital **and** specify **THE PERSON** who met or should meet each need even if the need is not important.

No	Statement	How important				Tick (√) is the need being met or unmet		Tick (√) the person who met, or should meet each need most of the time		
		NI	SI	I	VI	Met	Unmet	Doctor	Nurse	Admini- stration
1	To know specific facts concerning the patient's progress.									
2	To educate the family about the condition of the patient									
3	To feel accepted by the hospital staff.									
4	To relieve the families' anxiety by exploring the medical facts with them in a nonjudgmental manner.									
5	To feel personal care about the patient.									
6	To communicate effectively with healthcare providers to improve families ability to make care decisions									
7	To be allowed to visit whenever they wish.									
8	To have waiting room with comfortable furniture available for visitors in the intensive care unit.									
9	To have explanations given in terms that are understandable.									
10	To request to stay during the care of the patient.									
11	To face the patient's bed towards the Holy Mosque in Mecca.									
12	To have questions answered honestly.									
13	To know exactly what is being done for the patient.									

No	Statement	How important				Tick (√) is the need being met or Unmet		Tick (√) the person who met, or should meet each need most of the time		
		NI	SI	I	VI	Met	Unmet	Doctor	Nurse	Admini- stration
14	To ensure that healthcare providers who are the opposite sex from the deceased have no physical contact with the body.									
15	To be assured that the best care is being given to the patient.									
16	To have an explanation in detail about the condition of the patient when it becomes worse.									
17	To understand everything that occurs with the condition of the patient.									
18	To have another person accompany the family while visiting intensive care.									
19	To ensure that the Saudi culture is fully understood by the healthcare providers caring for Saudis.									
20	To talk to the doctor every day									
21	To know the expected outcomes									
22	To have someone providing psychosocial support to families during daily patient care.									
23	To ensure that healthcare providers respect the spiritual healing practices of the Saudi patients and families.									
24	To let the Saudi family know first about the bad news, not the patient.									

No	Statement	How Important				Tick (√) is the need being met or Unmet		Tick (√) the person who met, or should meet each need most of the time		
		NI	SI	I	VI	Met	Unmet	Doctor	Nurse	Admini- stration
25	To help with the patient's physical care.									
26	To have explanations of the critical care environment before going to the critical care area for the first time.									
27	To have healthcare providers discuss with the family members what helps the patient deal with events during hospitalization.									
28	To have healthcare providers respect relatives' opinions.									
29	To have the healthcare providers handle the body of the dead Muslim with extreme caution and respect									
30	To be told of the reason for the chosen treatment of their relative.									
31	To ensure that healthcare providers never attempt to interview or examine a female patient alone.									
32	To be told about other healthcare professionals that could help.									
33	To communicate information to help families understand each aspect of care.									
34	To develop trust with healthcare providers									
35	To know how the patient is being treated medically									

**PART THREE: BEHAVIOUR OF HEALTHCARE PROVIDERS OF FAMILY INVOLVEMENT DURING ROUTINE AND SPECIAL CARE.**

Questions 1-19: Please tick (✓) the extent to which you agree or disagree with each statement

No	Statement	Strongly Disagree	Disagree	Agree	Strongly Agree
1	If requested by the family they should be allowed to provide activities of daily living.				
2	I support patient wishes for family members to be present during daily patient care.				
3	Family presence during patient care would help family to gain spiritual comfort.				
4	Allowing family presence during patient care will reduce the family anxiety and fear				
5	The presence of family members impacts positively on the patient's treatment progress				
6	If present, family members will be able to recognize that everything possible was done to save the patient				
7	It is easier to manage critical family members' issues when they are present in the room with the patient				
8	My clinical performance will be affected by relatives' presence				
9	The presence of family members makes me feel stressed.				
10	I believe I have had sufficient training to involve the family.				
11	I am too busy to be able to involve the family in their care process.				
12	The presence of family during invasive procedure or CPR would assist the staff to get the history quickly				
13	Relatives have the right to request to stay during resuscitation or any other invasive procedure				
14	I believe I have had sufficient training to meet the family needs.				
15	If relatives would like to be present during resuscitation and other invasive procedures they should be well informed and sign consent				
16	Family presence during invasive procedure or resuscitation is a traumatic experience for the family members				
17	The hospital should develop guidelines to support family involvement and give family the option to attend invasive procedures and resuscitation.				
18	The hospital should develop training program for nurses to support family when they attend invasive procedure or resuscitation.				
19	I support the practice of allowing family members to be present during invasive procedures and resuscitation				



## Appendix I: Letter of Translation Certification

**MUEEN ALBREIHI**  
NAATI ACCREDITED TRANSLATOR [ENGLISH<==> ARABIC] AT LEVEL 3. NAATI No: 53806  
Tel: 9402 5229 Mobile: 0412 209 977 Email: [amueen@gmail.com](mailto:amueen@gmail.com)  
Address: 1 Clover Ct Thomastown Vic 3074

### Letter of Translation Certification

9<sup>th</sup> May 2011

To whom it may concern

This is to certify that I have read, checked and confirmed, with my stamp and signature, the Arabic translation of the following English documents:

1. Family members' questionnaire. (full translation)
2. Healthcare providers' questionnaire. (full translation)
3. Consent form. (full translation)
4. Explanatory statement for healthcare providers' survey. (extract translation)
5. Explanatory statement for family members' survey. (extract translation)
6. Explanatory statement for family members' interview. (extract translation)
7. Research participants' invitation for the study. (full translation)

Please do not hesitate to contact me should you have any enquiries,

Yours sincerely,  
Mueen Albreihi  
*NAATI Level Three Arabic-English translator - both directions*  
*Masters Degree of Translation – RMIT University 2008*

## Appendix J: Interview Schedule

<b>Name of Participant</b>			
<b>Name of Hospital</b>			
<b>Interviewer</b>			
<b>Date</b>			
<b>Start Time</b>		<b>End Time</b>	
<b>Consent</b>			

### Introduction

<b>Would tell me about yourself?</b>			
<b>Age</b>		<b>Gender</b>	
<b>Nationality</b>		<b>Educational background</b>	

<b>Would tell me about your ill relative?</b>			
<b>Relationship</b>		<b>Age</b>	
<b>Gender</b>		<b>Diagnosis</b>	
<b>Admission period</b>		<b>Perceived condition</b>	

### Body

<b>Question</b>	<b>Interviewer comments</b>
1. What do you consider to be your needs and concerns during the first 2 or 3 days following the critical illness of your loved one?	
2. What do you think is the staff attitudes to family presence in the ICU?	
3. What kind of support do you need while your relative is in the ICU?	
3. How have the critical care professionals supported you while your relative has been in the ICU?	
4. How have you found the communication between you and the critical care professionals? <b>If family members identified any problems in</b>	

<p><b>communicating with the healthcare providers, a further question will be asked:</b></p> <p>5. What do you think would help improve communication between you and healthcare providers?</p>	
<p>6. Would like to add anything?</p>	

**Closing**

<p><b>Interviewer comments if any:</b></p>
--

## Appendix K: Article I: Providing culturally congruent care for Saudi patients and their families

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### Providing culturally congruent care for Saudi patients and their families

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**ABSTRACT:** *This article aims to increase an awareness of caring for Saudi families by non-Saudi nurses to improve their understanding of culturally competent care from a Saudi perspective. Healthcare providers have a duty of care to deliver holistic and culturally specific health care to their patients. As a consequence of 'duty of care' obligations, healthcare providers must facilitate culturally congruent care for patients of diverse cultural backgrounds. For the Saudi family considerable cultural clashes may arise when Saudi patients are hospitalized and receive care from healthcare professionals who do not understand Islamic principles and Saudi cultural beliefs and values. The healthcare workforce in Saudi Arabia is a unique multicultural workforce that is mix of Saudi and significant other nationalities. Saudi nurses for example represent only 36.3% of the workforce in the different health sectors. Whilst the different ethnic and cultural background expatriate nurses represent 63.7% (Ministry of Health, 2010). This article also could increase the awareness of healthcare professionals caring for Arab and Muslims patients in another context in the world.*

**KEYWORDS:** religion, culture, family care, Saudi, culturally congruent care, religious influences

Culture can be defined as a combination of knowledge, belief, art, law, morals, custom, and any other capabilities and habits acquired by a person as a member of society (Tylor, 1920). In healthcare culture must be learned and adopted by newcomer (Tomey, 2000). This article aims to increase an awareness of caring for Saudi families by non-Saudi nurses to improve their understanding of culturally congruent care from a Saudi perspective. Saudi Arabia occupies 80% of the Arabia peninsula and has a total area of 2.24 million km<sup>2</sup>. It is the largest Arab state in Western Asia by land area and the second-largest in the Arab world. Saudi Arabia is the homeland of Islam, the second-largest religion in the world and the homeland of the Arab peoples (Central Intelligence Agency, 2010). It is estimated that 100% of Saudi citizens are Muslim; just like any cultural group, Muslims around the world can be conservatives, traditionalists or liberals. They may share commonalities and differences in beliefs, practices, values and norms.

The Islamic teachings and culture guide the ways of living for the majority of Saudis. Islam is a driving cultural force it means a submission to the will of God. A Muslim is a follower or one who obeys the will of God (Peachy, 1999). The

Islamic teachings in this context may include faith in God, performing the ritual worships per the Islam and performing good deeds to the benefit of oneself, family and community. The religious laws of Islam are derived from two sources the *Noble Qur'an* and *Sunnah*. The Holy Book (Noble Qur'an) revealed to the Prophet Mohammed through the angel Gabriel. The Qur'an is the highest authority for information on Islam followed by Sunnah. Sunnah refers to sayings, deeds and sanctions of the Prophet Mohammed Peace Be Upon Him and His Progeny (PBUHHP).

#### SAUDI FAMILY STRUCTURE

One of the key facts that is not in dispute is that the family in Islam is considered the main foundation of Muslim society and culture. Nevertheless, undoubtedly Islamic religion in Saudi Arabia influences the structure of the family and the nature of the relationship between family members. The Saudi family operates as a unit with family members socially and emotionally who are involved in all aspects of family life. In Islamic tradition and Arabic culture the family reflects a joint commitment within the family relationships and marriage which is the only legitimate reason for family formation uniting not just two people

but two families (Khalaf & Callister, 1997). In Muslim society, marriage is a contract that occurs with the consent of parents or guardians (Lemu & Heeren, 1992). Furthermore, marriage is considered the only legitimate outlet for sexual desires and sex outside marriage is considered a crime that is punished under Islamic law.

According to Eickelman (1998) the structure of the Muslim family takes three forms. The first consists of the husband, wife, their children and their parents who live with them. The second consists of a number of close relatives and the third is those relations which are based on affinity and their families. The Saudi family usually extend beyond the first generation to include other generations. For Saudi and other Muslims, the extended family provides the individual with a sense of identity (Luna, 1989). The roles of man and woman within the family in Islam are well ordered and organized. In this context the father is often the leader, breadwinner, provider, protector and spokesperson of the family (Luna, 1989). On the other hand, the mother is the maker of the home and the main nurturer of the children. Men and women are complementary to each other. The Prophet Mohammed (PBUHHP) has said 'I command you to be kind to women ... The best of you is the best to his family/wife' (Badawi, 1999).

#### ATTITUDES TOWARD PARENTS

In Islamic religion, parents are regarded with high respect and children are highly encouraged to respect and obey their parents (Ghazwi & Nock, 1989). This value has been mentioned many times in the Noble Qur'an and Sunnah. God says in the Noble Qur'an 'Your lord has decreed that you should worship nothing except Him, and show kindness to your parents, whether one or both of them get to old age while they are still with you, never say to them "shame" nor scold either show mercy, just as they cared for me as a little child' (The Noble Qur'an, Surat Al-Isra, p. 23). The two sources of wisdom emphasize the importance of respecting parents and linked the thankfulness to parents with the thankfulness to God (Omari, 2005). On the value of the mother, God says 'we have enjoined on man to respect his parents; his mother bears him with fainting after fainting, while his wearing

takes 2 years. Thank me as well as your parents; toward Me lies the goal' (Al-Hilali & Khan, 1998; The Noble Qur'an, Surat Lukman, p. 14). Prophet Mohammed (PBUHHP) has also said, 'Paradise is under the feet of mothers' (Khan, 1994). Often families will look after and provide care for elderly parents as they grow up. Traditionally also, elderly parents tend to live with the oldest son. Commonly the son will accompany his father and the daughter will accompany her mother during their stay in the hospital, this particularly the case when they get old as the custom in Saudi hospitals is to have separate wards for opposite sex. The son or daughter will look after their parents and will mediate the communication between their parent and the healthcare professional.

#### ATTITUDES TOWARD OLD PEOPLE

In Saudi culture which is derived from Islamic teaching, the young family members are highly encouraged to respect the older members within or out of the family unit (Ahmad, 1988). In the home environment, the older member (male or female) usually dictates to the younger family member. During their stay in the healthcare facility elderly patients might expect no dramatic changes in the way they are accustomed to being regarded and respected in the home (Al-Shahri, 2002). Therefore, healthcare professionals when dealing with elderly patients are encouraged to be more soft-spoken, humble, gentle and patient.

The Saudi system of personal address is different from that of most of the west. For instance, in the Saudi culture it is considered disrespectful calling old persons by their own names, for such attitude might be viewed as insulting. Health care professionals, therefore, are required to call old patient as 'father' 'Baba' and 'mother' 'Mama' or calling them by a name they like and feel comfortable with such as by their eldest son's name.

Until recently, the concept of a 'nursing home' is not widely known in Saudi Arabia. Because the idea of sending one's parents to a nursing home is still culturally unacceptable to Saudis or even to other Arab Muslims (Elkholy, 1981 cited in Luna, 1989). Few such old age institutions exist in the country. For the Muslim family in Saudi, caregiving is classified as a responsibility shared by

all members of family, and community members generally, regardless of diversities in age or gender (Wehbe-Alamah, 2008). Friends, neighbors and social acquaintances as well as family members including children, spouses, siblings, aunts, uncles and grandparents are all expected to participate in the care giving process (Wehbe-Alamah, 2005).

#### VISITING A SICK PERSON IN SAUDI CULTURE

The Saudi family reflects a mutual commitment of family members to the others and has strong ties with the extended family. This includes visiting family members as well as neighbors and friends especially at hard times such as sickness or death of a family member. Visiting a family member during sickness is highly encouraged in Islam and a valued act in Saudi culture and hence considerably practiced by Saudis (Khan, 1994). A common saying for Prophet Mohammed (PBUHHP) 'When a Muslim visits a sick person; Almighty God is blessed, and position him in Paradise' (Khan, 1994). Additionally, strong bonds among the family members are appreciated and required, and providing support from the family to the ill members is highly recommended.

The hospitalization of a family member might result in psychological difficulties not only for the patient but also for the family members. Accordingly, healthcare providers should anticipate a large number of visitors and their number can be large enough to interfere with health care delivery. Relatives, neighbors and friends in Saudi Arabia often travel periodically for long distances to visit patient admitted in hospital. The visitors can stay throughout the visiting time and beyond it if possible and the patient can not dismiss his visitors as such behavior is culturally unacceptable in Saudi Arabia (Al-Shahri, 2002). However, dismissal of the visitors by the health care provider is unacceptable and can also be embarrassing to the patient. Therefore, health care professionals are not encouraged to modify these mores but adapt them gradually. For instance, the nurse may provide a comfortable location in the room and the hospital setting to accommodate the extended family members, friends and neighbors.

On the other hand, visiting the sick person is considered to be providing emotionally, psychologically and financially support not to the patient only but also to the whole family of the

ill member. The Islamic teaching concerns the tangible support to the patient which include the patient hearing kind words by relatives; praying for the sick recovery and urging the sick person to patience. As feeling of love and a sense of interest by family members, friends and community is often associated with healing and improvement. Additionally, providing financial care may be carried out in a confidential or anonymous manner to protect people's honor and pride.

#### OTHER PRACTICES TO PROVIDE CULTURALLY CONGRUENT CARE FOR SAUDI FAMILY

Other culturally sensitive attitudes and practices for Saudi family should be fully understood by the healthcare providers to achieve the ultimate goal of providing quality care to the Saudi patients and their families. It is preferred that nurses offer medication and food with the right hand. Nurses and other healthcare providers are also required to avoid the initiation of hand shaking or hugging of patients or their family members of the opposite sex as this is unaccepted practice by Muslims like Saudis. Furthermore, adult Muslim are required to perform five prayers a day that take about 5 minutes each. During sickness, patients are permitted not to pray but they have to make it up later on. Some patient especially the elderly place great importance on performing the prayers during the sickness in the hospital following *Azhan* (the ritual public announcement for prayers). Such patients and their families would appreciate it if the medical and nursing intervention during these prayer times could be avoided (Al-Shahri, 2002). The nurse may provide a basin of water to the patient for ablutions which is required before performing the prayer according to the Islamic teachings. The Muslims during prayers need to face the Holy Mosque in Mecca in Saudi Arabia; therefore healthcare providers might be asked to reposition the hospital bed to face Mecca for patients who are not fully independent.

In Saudi culture, the views of the family members can alter the decision taken by the patient. For the reason that the Saudi's individual autonomy is often overruled by the family authority. The custom in Saudi culture is for the family to know first about the bad news and then they will decide on how and how much to tell the patient. Saudi families commonly show understanding

when healthcare professionals are honest and emphasize their ethical obligations not to tell lies to the family members (Al-Shahri, 2002). Nurses and other healthcare professionals may communicate bad news to the Saudi family by breaking them without dramatic modifications.

Death in Islam is regarded as a reflection of God's will and as a test from God to the dying person, the family and the community. Saudi patients and families during the discussions about life expectancy will be satisfied if reference to this doctrine is made (Al-Shahri, 2002). Muslims usually receive death with patience, prayers, reciting Qur'an and meditation (Cheraghi, Payne, & Salsali, 2005; Lawrence & Rozmus, 2001). When patients are dying, their families might request to face them to the direction of prayer which is Mecca. Additionally, the Muslim family may prefer to be with their loved one during the last moments to deliver the *Shahada* or testimony. It is believed by Muslims that the death that coincides with the uttering of *Shahada* can facilitate one's admittance to heaven (Wehbe-Alamah, 2008). The *Shahada* consists of saying: There is no God but Allah (God) and Mohammed is the Messenger of Allah (God).

Following death, healthcare providers should handle the body of the dead Muslim with extreme caution and respect as it is believed to feel pain and pressure. Nurses also should minimize touching the body as much as possible and for nurses and other healthcare providers not sharing the same gender of the deceased are discouraged from touching the body (Wehbe-Alamah, 2008). In Islam, it is highly preferred to bury the dead within 24 hours of death. Therefore, the most appreciable support to the Saudi family at this stage according to Al-Shahri (2002) is that nurses facilitate the process of documentation and discharge quickly to allow family members to start the special rituals including: Rites of washing, shrouding and burying the body.

#### MOVING TOWARD FAMILY-CENTERED

##### MODEL OF CARE

The Saudi cultural concerns necessitate a change in the conventional medical approach to one that respects all needs of the patient and their families. The delivered care must involve individuals from a variety of disciplines working together to achieve better physical, psychological and spiritual health.

Thus, healthcare system in Saudi Arabia should move toward more family centered care and supporting the inclusion of family or friends. In the Family-Centered Care theory Kerr and Bowen (1988) suggest that individual behavior may be influenced and changed based on the presence of family unit. The family presence and support then may affect the response of patients undergoing hospitalization or medical procedure. The family is considered to be the greatest single social institution that can influence on a patient's health (Friedman, Bowden, & Jones, 2003). In addition, patients' families during illness fulfill an additional essential role for patients who may be unconscious or unable to communicate or make decisions (Bennet, & Alison, 1997; Mitchell, Chaboyer, Burmeister, & Foster, 2009). As a result the families may not only provide vital support to patients but also become the voice of the patients (Granberg, Engberg, & Lundberg, 1999). Therefore, caring for family is a component of caring for the patient. The family-centered care model requires nurses and other healthcare providers to shift from a professionally-centered view of health care to a collaborative model that recognizes families as a central in the plan of care (Ahmann, 1994). This includes recognizing and accepting diverse styles of family coping, helping families recognize their strengths and methods of coping and facilitating family involvement and caregiving.

In addition, the non-Muslim healthcare provider caring for Saudi patients, from all levels, must fully understand the Saudi culture. In other words, when workers integrate effectively and harmoniously by their behaviors and values with the Saudi culture, they can improve the organisation's performance completely and adapt to the changes easily. This as a result, would ensure that families receive more holistic and family centered care in healthcare facilities.

#### CONCLUSION

This article has raised awareness of traditional cultural concerns, expressions, beliefs and practices of the Saudi family to assist nurses and other healthcare professionals in providing culturally congruent care. The article has also addressed the need to move toward family-centered care model to enable a greater integration of family care into the Saudi health care system. It cannot be assumed that all Saudi families share the same cultural

customs, beliefs and practices due to the large land area and different ways of living, however, it is preferred that nurses and other healthcare professionals when caring for Saudi patients perform individual cultural assessments to identify cultural needs and provide culturally competent care. There is a paucity of literature concerning the effectiveness of current or past models of nursing care in Saudi Arabia or other Muslim countries which is designed to preserve the special customs of Islamic law. Clearly more research is needed to produce the evidence for practice in the culturally congruent care of patients and their families in Saudi and Muslim communities.

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# Appendix L: Article II: Family needs and involvement in the intensive care unit: a literature review

REVIEW ARTICLE

## Family needs and involvement in the intensive care unit: a literature review

Abbas Saleh Al-Mutair, Virginia Plummer, Anthony O'Brien and Rosemary Clerehan

**Aims and objectives.** To understand the needs of critically ill patient families', seeking to meet those needs and explore the process and patterns of involving family members during routine care and resuscitation and other invasive procedures.

**Methods.** A structured literature review using Cumulative Index to Nursing and Allied Health Literature, Pubmed, Proquest, Google scholar, Meditext database and a hand search of critical care journals via identified search terms for relevant articles published between 2000 and 2010.

**Results.** Thirty studies were included in the review either undertaken in the Intensive Care Unit or conducted with critical care staff using different methods of inquiry. The studies were related to family needs; family involvement in routine care; and family involvement during resuscitation and other invasive procedures. The studies revealed that family members ranked both the need for assurance and the need for information as the most important. They also perceived their important needs as being unmet, and identified the nurses as the best staff to meet these needs, followed by the doctors. The studies demonstrate that both family members and healthcare providers have positive attitudes towards family involvement in routine care. However, family members and healthcare providers had significantly different views of family involvement during resuscitation and other invasive procedures.

**Conclusion.** Meeting Intensive Care Unit family needs can be achieved by supporting and involving families in the care of the critically ill family member. More emphasis should be placed on identifying the family needs in relation to the influence of cultural values and religion held by the family members and the organisational climate and culture of the working area in the Intensive Care Unit.

**Key words:** acute care, critical care, family, family care, needs

Accepted for publication: 28 August 2012

### Introduction

The admission of a family member to the intensive care unit (ICU) places heavy stress on a family. The critical illness of a family member often occurs without any warning, and the stress for families is generally unanticipated. Stress is manifested through psychological pre-occupations, anxiety,

uncertainty and the fear of losing a family member (Leske 1986, Horn & Tesh 2000). Many healthcare providers tend to view family members as merely an extension of the critical care patient, without placing any emphasis on the needs of the families (McLaughlin 1993). However, this perception is becoming unsustainable because the profession is moving towards more holistic care, and the family influence

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and presence have a strong impact on the patient's response to treatment (McLaughlin 1993). The family acts as a buffer for patient anxiety because when family anxiety is high, they will be unable to support the patient and inadvertently transfer their anxiety to the patient (Leske 2002). Accordingly, caring for the family is an important component of caring for the patient. This can be achieved when the family members are supported and involved in the care of the patient (Beeby 2000). Involvement of family members in routine daily living activities such as feeding the patient, helping with bathing, linen change, providing pressure and back care and turning the patient as well as family presence during resuscitation and other invasive procedures enable the family to be involved in the care of their loved one.

### Aim

The aim of this review of the literature was to describe the experiences of ICU healthcare providers and family members of adult critically ill patients in ICU, regarding family needs and involvement in the care.

The following specific research questions will be used:

- 1 What are the family needs of critically ill patients?
- 2 How well are those needs being met and by whom?
- 3 What are the family members and healthcare providers attitudes towards family involvement during routine care and resuscitation and other invasive procedures.

### Methods

To collect the literature, a comprehensive search was carried out on the following databases: CINAHL, Pubmed, Proquest, Google Scholar and Meditext and retrieved articles published between January 2000 and July 2012. Records were retrieved using a combination of the following search terms 'family', 'families in intensive care', 'family involvement in patient care', 'family involvement in nursing care', 'family needs', 'critical care nurse perceptions of family needs', 'nurses perceptions of family needs', 'attitude of healthcare providers', 'family presence in cardio-pulmonary resuscitation (CPR)', 'health professionals', 'nurses' with 'family witnesses resuscitation' and 'relatives'.

The inclusion criteria established for this literature review were that the research:

- 1 Published in English;
- 2 Addressed aspects of family needs and family involvement during routine care and resuscitation and other invasive procedures;

- 3 Involved subjects/informants who were healthcare providers such as nurses, doctors and relatives or significant others of patients; and

- 4 Conducted in adult intensive care units.

Publications were excluded if they cover the topics of:

- 1 Paediatric care.
- 2 End-of-life care.

A hand search of critical care journals was also carried out for any recently published studies that were not included in the electronic databases. After collecting the research articles, they were reviewed for a general understanding of the contents. The quality of the studies included in the review was appraised using Polit and Beck (2012) guide to critique research. As a result of the search performed, over 45 articles were retrieved, and only 30 articles met the initial selection criteria. Of the 15 excluded, nine studies did not meet the inclusion criteria, and six were excluded from the review because of poor quality. Accordingly, a total of 30 articles were included in the literature review, published between 2000 and 2012. Of the studies, 19 (63.3%) adopted a quantitative research design, using a survey; ten (33.3%) adopted a qualitative research design using an interview method or open-ended questionnaire and one study adopted a mixed method design using a survey and a semi-structured interview. Twelve studies were related to family needs and meeting those identified needs, eight dealt with family involvement in routine care and the remaining ten studies focused on family presence during resuscitation and other invasive procedures (see Table 1–3). The studies examined the perspectives of family members or healthcare providers or compared the two perspectives. Those studies chosen were conducted in different locations, languages and cultures including USA, Canada, Britain, Sweden, Norway, Australia, Turkey, Jordan, Germany, Greece, Hong Kong, Iran and Saudi Arabia.

### Results

The research articles were then critically analysed and divided into distinct but inter-related areas: family needs, family involvement in routine care and family presence during resuscitation and other invasive procedures, these are the focus of this paper.

#### Family needs

The main focus of the family needs studies was the identification of the importance of those needs. The review revealed that all of the family needs studies, which adopted

Table 1 Studies on family needs

Authors	Aim	Setting	Method – design	Population
Al-Hassan and Hweidi (2004)	To identify the needs of Jordanian families of hospitalised critically ill patients	CCUs of four large hospitals	Quantitative descriptive study using CCFNI	158 family members
Yang (2008)	To achieve an understanding of the needs and experiences of Korean families in ICU	Nine medical ICUs of nine general hospitals	A triangulation mixed methods design using CCFNI and semi-structured interview	85 families for the quantitative inventory and 25 family members for the interview
Ouari (2009)	To identify the self perceived needs of adult Jordanian family members who have a family members admitted in the ICU and to explore whether these needs were being met and by whom	Six ICUs of three hospitals	Quantitative –descriptive study using CCFNI	139 family members
Bailey <i>et al.</i> (2009)	To describe family members perceptions of informational support, anxiety, satisfaction with care and the inter-relationships with these variables	Medical-surgical ICU of a teaching hospital	A cross-sectional descriptive correlational pilot study using a modified version of the CCFNI and a satisfaction with care questionnaire	29 family members
Bond <i>et al.</i> (2003)	To discover the needs of families of patients with sever traumatic brain injury during the families experience in neurosurgical ICU	Neurological ICU of a level I trauma center	Exploratory qualitative descriptive design using interview	Seven family members
Fry and Warren (2007)	To examine the perceived needs of the critical care family members in the waiting room viewed through their own words and to stimulate discussion about the meaning of the language expressed by the participants	ICU of large hospital	Qualitative-Heideggerian hermeneutic contextual analysis using interview	15 family members
Keenan and Joseph (2010)	To identify family needs of a critically ill member who sustained a severe Traumatic Brain Injury and to determine whether these needs change over time	ICU of large hospital	Qualitative approach with semi-structured interview	25 family members
Takman and Severinsson (2006)	To investigate the healthcare providers (registered nurses, physicians and enrolled nurses) perceptions of the needs of critically ill adult patients' significant others based on CCFNI	21 medical and surgical adult ICUs of eight emergency hospitals	Qualitative approach using open-ended questions	Two hundred and thirty-two enrolled nurses, 292 registered nurses and 79 physician from Sweden and 275 registered nurses and 36 physicians from Norway
Kosco and Warren (2000)	To determine whether nurses' perceptions of meeting families' needs were correlated to the families' perception of these needs being met	Adult ICU of large hospital	Comparative, descriptive, exploratory study –using structured interview (CCFNI)	45 family members and 45 nurses

Table 1 (Continued)

Authors	Aim	Setting	Method – design	Population
Hinkle <i>et al.</i> (2009)	To describe the family members' needs of patients with critical illness identified by family members and nurses and to compare and identify the differences in the needs identified by family members visiting patients with critical illness and nurses working in ICUs	Six ICUs of large medical center	Qualitative approach	101 family members and nurses
Kinrade <i>et al.</i> (2010)	To study the needs of Australian relatives whose family member is unexpectedly admitted to the ICU and compare them with perspectives of family needs	ICU of regional hospital	Descriptive quantitative design using questionnaire	25 family members and 33 nurses
Chatzaki <i>et al.</i> (2012)	To define the needs of families with ICU patients in the suburban/rural population of Crete Island	Closed-model, mixed medical-surgical 11-bed ICU	Prospect cohort study	230 family members

a quantitative research design used the Critical Care Family Needs Inventory (CCFNI), as the data collection instrument to investigate the importance of family needs. The CCFNI is a self-report questionnaire developed by Molter (1979) and has been used in over 50 studies listing the needs statements on a four-point Likert-type scale from '1' not important to '4' very important. The instrument consists of 45 needs statements and is divided into five dimensions: assurance, information, proximity, comfort and support (Leske 1986).

The assurance dimension consists of seven items, which concerned the family's need for being re-assured by healthcare providers about the health status of their family member. The information dimension can be explained as families seeking knowledge of the patient's problem in many different ways, and this particular dimension in the reviewed studies consisted of eight needs statements. The need for proximity is understood as the state of being physically near to the patient, as family members are physically and emotionally distressed and they need to be close to their relative. Nine needs statements are defined in the proximity needs dimension. Under the comfort dimension in the CCFNI, there are six statements. Support is a multi-dimensional need that includes physical, environmental, psycho-spiritual and socio-cultural such as food and a bathroom. The support needs dimension comprises one-third of the 45 statements in the CCFNI and has the largest number of needs statements (15 items), concerning the support

needs to be met by healthcare providers, family members, friends and religious groups.

Some studies have used the CCFNI to gather data from family members as well as healthcare providers (Kosco & Warren 2000, Kinrade *et al.* 2010). The CCFNI has also been used to investigate the perceived needs of family members of critically ill patients in ICU from the healthcare providers' perspective, comparing them with the family needs as perceived by the family members. Only a few wording modifications were made on the healthcare providers' questionnaire to make it relevant for them. Generally speaking, findings from studies such as those of Kosco and Warren (2000), Al-Hassan and Hweidi (2004), Yang (2008) and Omari (2009) have demonstrated that family members ranked the needs for assurance and the needs for information as the most important, followed by proximity, comfort and support.

Qualitative methods to explore family needs from the perspectives of family members were used in five studies: Bond *et al.* (2003), Takman and Severinsson (2006), Fry and Warren (2007), Keenan and Joseph (2010) and Hinkle *et al.* (2009). Qualitative approaches of family needs studies enabled family members to present their perspectives more explicitly (Hinkle *et al.* 2009). The qualitative methods also allowed exploring in-depth data, and rich themes were able to be produced (Hinkle *et al.* 2009). The need for information and the need for hope have emerged from the qualitative studies (Bond *et al.* 2003, Takman &

Severinsson 2006, Fry & Warren 2007, Keenan & Joseph 2010). That information should be accurate about the condition of the loved one and be delivered in comprehensible terms.

One of the challenges that healthcare providers encounter in critical care is their ability to identify, meet and to 'satisfy' the family needs of a critically ill patient. Daley (1986) and Molter (1979) suggest that this challenge may be related to the fact that healthcare providers in critical care areas focus solely on patient care and spend little time in meeting their families' needs. The family needs studies have focused on the phenomenon of gaining better understanding of how well families' needs are being met and who is the most appropriate healthcare provider to help the family members to fulfil each need. The family members perceived their important needs as being unmet. They also identified the nurses as the best to meet these needs followed by the doctors.

#### Family involvement during routine care

There is some evidence to suggest that the inclusion of family members in routine care can provide them with some satisfaction and emotional re-assurance. The review of studies identifying family involvement in providing routine care to their critically ill patient in the ICU highlighted the families desire to be involved in the care of their loved one (Schiller & Anderson 2003, Soderstrom *et al.* 2003, Eldredge 2004, Vandall-Walker *et al.* 2007, Benzein *et al.* 2008, Fisher *et al.* 2008, Mitchell *et al.* 2009, Wahlin *et al.* 2009). Families in the reviewed studies (see Table 2) endorsed the need to be involved in the routine care of the critically ill family member (Soderstrom *et al.* 2003, Benzein *et al.* 2008, Fisher *et al.* 2008). The studies also revealed that when families are involved in this care that their anxiety is reduced through

**Table 2** Studies on family presence during routine care

Authors	Aim	Setting	Method – design	Population
Eldredge (2004)	To describe the spouses' helping behaviours at ICU bedside and to explore how well preferences for closeness and helpfulness explain variation in spouses' emotional outcomes during their partners illness	Medical ICU/ Coronary care unit in tertiary teaching hospital	Quantitative repeated-measures design	88 spouses
Vandall-Walker <i>et al.</i> (2007)	To address a gap in the theoretical about how nurses help family members	Seven ICUs of two teaching hospitals	Grounded theory using interview	Twenty family members
Mitchell <i>et al.</i> (2009)	To determine the effect of family-centered nursing intervention on the perceptions of family members of critical care patients of centered care as measured by respect, collaboration and support	Two teaching hospitals	Pretest-post-test design	174 family members (75 control, 99 intervention)
Wahlin <i>et al.</i> (2009)	To describe next of kin empowerment in an intensive care situation	Two general ICUs	Phenomenological method using interview	Ten family members
Soderstrom <i>et al.</i> (2003)	To describe nurses' experiences of interactions with family members in the ICU	ICUs of two hospitals	Qualitative design using interview	10 nurses
Fisher <i>et al.</i> (2008)	To assess the attitudes and values of nursing staff towards family presence during routine nursing care	Rural community hospital	Cross-sectional descriptive study using a survey technique	89 nurses
Benzein <i>et al.</i> (2008)	To investigate the attitudes of registered nurses (RNs) about the importance of involving of families in nursing care	Swedish critical care nurses of diverse hospitals	Descriptive Quantitative study using questionnaire	634 Swedish registered nurses
Schiller and Anderson (2003)	To explore the family members and nurses' perceptions of family involvement in the daily work rounds with the Trauma Team	ICU of large hospital	Quantitative descriptive study using questionnaire	34 family members and ten nurses

the support provided to their loved one (Mitchell *et al.* 2009). Additionally, the studies demonstrate that healthcare providers have positive attitudes towards family involvement in routine care, and that staff consider family members as important in the care of their critically ill relative (Benzein *et al.* 2008, Fisher *et al.* 2008). The healthcare providers indicated that the inclusion and

interaction with families can improve communication and build relationships, which ultimately result in providing good care for both patient and family (Schiller & Anderson 2003). Such a positive outcome for patients and their families warrants further investigation, and it is feasible that such family involvement could provide a basis for improved recovery.

**Table 3** Studies on family presence during resuscitation and other invasive procedures

Authors	Aim	Setting	Method – design	Population
Wanger <i>et al.</i> (2004)	To describe the family members' the experiences, thoughts and perceptions of their critically ill patients during resuscitation in the ICU	Coronary care unit of a 700-bed urban community hospital	Qualitative- interview	Six family members
Holzhauser <i>et al.</i> (2006)	To study the attitudes of family members being present during resuscitation	A major tertiary referral teaching hospital	A randomised control trial design	108 family members control group ( $n = 40$ ) experimental group ( $n = 58$ )
Knott and Kee (2005)	To explore nurses' beliefs regarding family presence during resuscitation	ICUs of diverse hospitals	Descriptive qualitative using semi-structured interviews	Ten Registered Nurses
Fulbrook <i>et al.</i> (2005)	To explore the experiences and attitudes of the European critical care nurses to the family presence during resuscitation of adult patients	Critical care nurses attended the European Federation of Critical Care Nursing Associations	Quantitative descriptive study using questionnaire	124 European critical care nurses
Badir and Sepit (2007)	To explore experiences and opinions of critical care nurses regarding family presence during resuscitation in Turkey	ICUs of ten hospitals	Descriptive quantitative design using questionnaire	409 critical care nurses
Cunes and Zaybak (2009)	To determine the experiences and attitudes of Turkish critical care nurses concerning family presence during resuscitation	Acute care areas of two university hospitals	Descriptive quantitative design using questionnaire	135 critical care nurses
Koberich <i>et al.</i> (2010)	To explore the German intensive care nurses' experiences and attitudes towards family presence during resuscitation	26th Reutlinger Fortbildungstage	Descriptive quantitative design using questionnaire	164 intensive care nurses
Kianmeher <i>et al.</i> (2010)	To determine the opinions of healthcare providers of family presence during resuscitation and other invasive procedures	ICUs of four teaching hospitals	Descriptive quantitative design using questionnaire	200 healthcare providers
Al-Mutair <i>et al.</i> (2012)	To identify the nurses' attitudes towards family presence during resuscitation	Two major trauma centers	Descriptive study using survey design	132 nurses
Leung and Chow (2012)	To investigate the family members and healthcare providers attitudes towards family presence during resuscitation	ICU of regional hospital	Cross-sectional using survey design.	69 family members and 163 healthcare providers.

### Family presence during resuscitation and other invasive procedures

Most of the studies in family presence during resuscitation and other invasive procedures were descriptive using either quantitative or qualitative approaches (see Table 3). The studies reviewed here have examined the attitudes of both family members and healthcare providers towards family presence during resuscitation and other invasive procedures in the ICU. The family members indicated their desire and supported family presence during resuscitation and other invasive procedures (Wanger *et al.* 2004, Holzhauser *et al.* 2006). They also identified further benefits including helping the patient, knowing everything possible was done to save their loved one and provided care and support to grieving family members (Holzhauser *et al.* 2006).

Increasingly, the reviewed studies highlight that healthcare providers have significantly different opinions regarding family presence during resuscitation and other invasive procedures. Some oppose the family presence for many reasons including that the practice would be offensive and produce stress in staff and that family members may interfere with the treatment (Badir & Sepit 2007, Cunes & Zaybak 2009, Kianmehr *et al.* 2010, Koberich *et al.* 2010). Other healthcare providers were comfortable with the family presence and believed that it would positively influence patient care outcomes, agreeing that family presence would re-assure them that the best care was being given to the patient (Fulbrook *et al.* 2005, Knott & Kee 2005). Importantly, there is an endorsed need for written policies to guide staff during family presence in selected situations in routine or resuscitation and other invasive procedures. Others suggest that a 'nurse facilitator', dedicated to evaluate the readiness of the family members to attend the procedure and explain it to them when they attend, is warranted (Fulbrook *et al.* 2005, Knott & Kee 2005, Koberich *et al.* 2010).

### Discussion

The integration of family in the care of hospitalised patients is a growing trend in today's hospital care. With regard to family involvement, the attitudes of healthcare providers have changed towards a greater need impetus to understanding family needs and to practically involve them in the care process.

#### Family needs

Findings from the reviewed studies have highlighted that the family members in several quantitative studies, through

**Table 4** Comparison of family members rank order of the CCFNI for three studies

Dimension	Ranking: mean			
	Kosco and Warren (2000)	Yang (2008)	Omari (2009)	Chatzaki <i>et al.</i> (2012)
Assurance	1 (3-16)	1 (3-67)	1 (2-65)	1 (1-09)
Information	2 (2-99)	2 (3-49)	5 (2-15)	2 (1-48)
Proximity	3 (2-95)	3 (3-23)	2 (2-56)	3 (1-49)
Comfort	4 (2-94)	4 (2-93)	3 (2-22)	5 (1-9)
Support	5 (2-57)	5 (2-63)	4 (2-18)	4 (2-11)

In Chatzaki *et al.*'s (2012) study the mean was judged by the lowest, the mean score of  $\leq 1.25$  was defined as 'most important'.

the use of CCFNI and in qualitative studies, have identified the need for assurance and the need for information as the highest priority needs followed by proximity, comfort and support, respectively.

A comparison of four studies of family needs of critically ill patients was conducted for the purpose of this review, which used CCFNI with different populations. As shown in Table 4, the rank order by mean scores on CCFNI as perceived by family members were assurance, followed by information as the 'most important' needs. Proximity, comfort and support dimensions were the lowest subscales, demonstrating that family members perceived the needs under these dimensions as 'least important'. These quantitative studies using the CCFNI revealed many similarities in the importance of family needs identified by the families in different populations and locations and with different cultural backgrounds. The studies from the United States, Korea, Jordan and Greece (Kosco & Warren 2000, Yang 2008, Omari 2009, Chatzaki *et al.* 2012) show a number of similarities in the importance of family needs, as ranked by the family members.

The review clearly indicated that family members ranked the family needs significantly differently from the healthcare providers in the ICU. Family members identified information and assurance needs as the highest priority as in the previous reported studies, whereas healthcare providers mainly identified personal, cognitive and trust needs as the highest priority for families with a critically ill member (Takman & Severinsson 2006, Keenan & Joseph 2010, Kinrade *et al.* 2010).

The ability to meet or 'satisfy' the family needs of a critically ill patient is one of the challenges that healthcare providers encounter in the critical care area. Of the family needs studies identified, Kosco and Warren (2000) and Omari (2009) focused on gaining a better understanding of how well families' needs were being met and who met them. Kosco and Warren (2000) found that only three of

the ten most important needs identified were perceived by family members as being met. The findings were similar to a study, which sampled 139 family members from the Muslim community of Jordan by (Omari 2009). Results highlight that none of the 10 most important needs identified by the family members were considered as being met.

The findings of the qualitative studies (Bond *et al.* 2003, Takman & Severinsson 2006, Fry & Warren 2007, Hinkle *et al.* 2009, Keenan & Joseph 2010) demonstrate that the need to receive understandable information was identified as important and remained unmet. These qualitative findings added a more in-depth understanding of the family needs issue and confirmed the previously mentioned CCFNI findings. Therefore, healthcare providers should recognise that the family needs information about their critically ill relative to be delivered to them in understandable nonjargonistic language. The use of simple and clear terms in communicating information to family members can foster family members' understanding of their relative's health condition and re-assure them of the quality of care being delivered (Al-Hassan & Hweidi 2004).

In brief, family members with critically ill patient admitted to the ICU identified information and assurance needs as their highest priority (Yang 2008, Omari 2009), whereas healthcare providers mainly identified personal and cognitive needs as the highest priority (Takman & Severinsson 2006, Keenan & Joseph 2010, Kinrade *et al.* 2010). Age, gender, relationship to the patient, length of the patient stay in the ICU and the patient diagnosis were not found to be correlated to the family members' ranking of their needs in previous CCFNI studies (Kosco & Warren 2000, Omari 2009). Also, age, gender, qualifications and working experience did not predict the healthcare providers' ranking needs of the family of the critically ill patient (Takman & Severinsson 2006).

#### Family involvement during routine care

Eight studies were reviewed, which investigated either the perception of family members towards family involvement in routine care or the healthcare providers or comparing the two perceptions (see Table 3). The inclusion of family members in routine care was found to provide them with some satisfaction. A study by Eldredge (2004) explored the spouses' helping behaviours at the ICU bedside, suggesting that closeness and helpfulness feelings are integrated concepts and attachment helped the family members to understand their spouse's emotional responses to their critical illness. It also facilitated the spouse's feeling that they were helping the patient. This finding was similar to Mitchell

*et al.*'s (2009) where they argue that partnering with patients' family members to provide fundamental care to the patient significantly improved their feeling of respect, collaboration and support. There is evidence that family involvement in the care of the patient in ICU will empower family members to further support the ICU patient. Some of the informants (spouses, siblings, parents or children of ICU patient) were strengthened by support from other family members or healthcare providers and by being involved in caring for the patient. Wahlin *et al.* (2009) argue that it is critical to discuss attitudes and behaviours of family members as well as involving them in the care in the intensive care unit to improve the care of family members in the intensive care unit. However, challenging this may be for healthcare providers, the evidence is resoundingly in favour of enabling family presence and support during the intensive care episode of care.

Thus, behaviour of healthcare providers regarding family involvement during routine care is a key priority to facilitate family involvement patterns. Soderstrom *et al.* (2003) interviewed 10 nurses working in the ICU of two hospitals in Sweden, asking them to describe their experiences of interactions with family members in the ICU. The interviewed nurses considered family members as important in nursing care and important to create contact and engage them in the nursing care. Nurses believed that having a good relationship with families was a prerequisite for providing good care for both patient and family. In this regard, Fisher *et al.* (2008) revealed congruent results in a survey of 89 nursing staff, which indicated that nurses' attitudes and behaviours regarding family presence during routine nursing care, were favourable. Nursing staff also believed that family involvement was important, and moreover that they were likely to include families in daily care. This is again similar to a study by Benzein *et al.* (2008) from Sweden that investigated the attitudes of 634 registered nurses about the importance of involving of families in nursing care. This large survey reported that Swedish RNs held a supportive attitude to involving families in routine nursing care.

The involvement of relatives may provide the healthcare providers with the opportunity to develop and build a relationship with families and enhance the care given to the patient and family as a whole. A study by Schiller and Anderson (2003) compared the family members' and nurses' perceptions of family involvement in the daily work rounds with the Trauma Team. A 25-question survey was sent to select family participants in order to obtain their retrospective opinions about the inclusion of family members in the daily work rounds. The ICU nursing staff also

completed an abbreviated survey to document their perceptions as to how family rounds facilitated care. The study reported that the rounds with family members resulted in much improved relationships that the stress diminished, hostility reduced and system dysfunction in the work process was less frequent. Furthermore, family members reported that the daily rounds allowed them to understand the patient's condition and plans for care. No areas of dissatisfaction were documented by the family members. Additionally, nurses indicated satisfaction with the communication provided by the team and in the resultant facilitation of more positive relations with the families. As an outcome, the presence of family members on daily work rounds has been a success as judged by both the healthcare providers and family members. There have been no reported adverse events of the family inclusion in the daily trauma rounds.

#### Family presence during resuscitation and other invasive procedures

Significantly, different perceptions can be perceived regarding the presence of family members during resuscitation and other invasive procedures. Six family members, who were barred from the patients' room and asked to wait in another room during resuscitation, were interviewed by Wanger *et al.* (2004). All family members expressed their desire to be with their loved one. They believed that when families were not provided information during resuscitation that they could not determine what was going on. Participants maintained that during the resuscitation of the loved one, the family was in crisis needing re-assurance and informational support to cope effectively.

Two years after the release of the Wanger *et al.* (2004) study, another study by Holzhauser *et al.* (2006) explored the attitudes of family members who were present during resuscitation. While Wanger *et al.* (2004) was a qualitative study, Holzhauser *et al.* (2006) used a randomised control trial design to study the attitudes of family members regarding family presence during resuscitation. Family members who met the inclusion criteria were randomised to either the control group or experimental group. The control group ( $n = 40$ ) did not attend the procedure and remained out of the resuscitation room. The experimental group ( $n = 58$ ) were invited to the resuscitation room during resuscitation. The participants were asked to complete a questionnaire that was developed for the study, based on clinical staff experience and review of literature. Consistent with Wanger *et al.* (2004), the findings of Holzhauser *et al.* (2006) demonstrated that the majority of family members in both the

control and experimental groups were content to be present during the resuscitation of their loved one. None of the family members participating in the experimental group felt pressured or traumatised to be present. Also, 67% of the control group participants would prefer to be present.

The findings of this research strongly support the presence of family members during resuscitation and have several clinical implications. The results demonstrated that 100% of the family members who were present during resuscitation (experimental group) were glad, they were present to support their relatives, knowing that everything possible has been done, beneficial to their patient's recovery, and reducing family anxiety and fear. They also agreed that their presence helped them to come to terms with the patient's outcomes. Additionally, of those who did not attend the procedure the majority (71.2%), strongly believed that their presence would have helped them to cope better with their loved one's final treatment outcome.

Findings from the reviewed studies identify mixed opinions among healthcare providers about family presence during resuscitation and other invasive procedures. Two studies, using different methods and sampling from different locations, were released in the same year: the first was by Knott and Kee (2005), which explored the nurses' beliefs regarding family presence during resuscitation. The data were gathered from ten registered nurses (RNs), one man and nine women, with a minimum of four years clinical experience working in diverse acute care units through a semi-structured interview. The second study by Fulbrook *et al.* (2005), explored the experiences and attitudes of 124 European critical care nurses to family presence during resuscitation of adult patients, through the use of a self-administered questionnaire. Generally, nurses in both studies displayed positive attitudes to the presence of family members and thought that allowing family members to be present would re-assure them to see that everything possible was done to save the patient. Additionally, the two studies endorsed the need for policies to guide the practice, and the nurses participating in those studies also expressed their feeling that there should be a member of the resuscitation team facilitating family members comprehension of what transpires throughout the experience, including providing emotional support, explanations and interpretations of the procedure to the attending families.

Contrary to the previous studies that reported strong agreement with family presence among critical care nurses were two studies, including critical care nurses from Turkey and one from Germany (Badir & Sepit 2007, Cunes & Zaybak 2009, Koberich *et al.* 2010). A further sample incorporated both nurses and physicians from Iran

(Kianmeher *et al.* 2010) and nurses from two hospitals in Saudi Arabia (Al-Mutair *et al.* 2012). These four studies concluded that there was a high percentage of opposition among healthcare providers to the family presence. The most common reasons for the participants' opposition were that family members if present, would interfere with the resuscitation team's performance, with the participants suggesting that family members witnessing resuscitation was a traumatic and stressful experience for family. Researchers interpreted the participants' decision regarding the practice of being present during invasive procedures, such as those, which can occur during resuscitation, as being influenced by cultural values and societal traditions. This might well be the case in Germany, where German culture and traditions were thought to be the reason behind the negative attitudes held by the participants (Koberich *et al.* 2010). The other three studies reporting negative attitudes were undertaken in Muslim communities: these were Badir and Sepit (2007), Cunes and Zaybak (2009) and Kianmeher *et al.* (2010). The cultural background of a Muslim society is unlike the Western background. Muslim family members are invariably close to each other and more prone to display strong emotions (Kianmeher *et al.* 2010). This can be understood as the reason to the general opposition and resistance to allow family presence during resuscitation and other invasive procedures.

Studies on family presence during resuscitation and other invasive procedures were restricted to western countries such as US and Europe until 2004 (Leung & Chow 2012). Recently, healthcare providers of nonwestern countries became aware of the practice and conducted studies to examine the staff and families attitudes towards the practice. The practice is relatively new to those countries and the majority of the healthcare providers did not support the practice (Badir & Sepit 2007, Al-Mutair *et al.* 2012). The same was revealed by Leung and Chow (2012), which investigated the attitudes of both healthcare staff and family members towards the practice in one single study. It was found in that study that the majority of healthcare providers did not accept the practice; in contrast, nearly 80% of the family members welcomed the practice. Healthcare providers with previous experience of family presence were found to be more supportive compared with the healthcare providers with no previous experience. By contrast, in Saudi Arabian study by Al-Mutair *et al.* (2012) nurses with previous experience of family presence opposed the practice more than nurses with no previous experience ( $p = 0.001$ ). This was interpreted as healthcare providers concerns about the negative effects on practice of family presence during resuscitation.

## Conclusion

The literature has demonstrated that the perceptions of family members and the perceptions of healthcare providers were found to be incongruent in relation to: family needs; and family involvement during resuscitation and other invasive procedures and congruent in family involvement in routine care. Several studies focused on the needs of family members within the critical care environment, adopting a quantitative approach utilising Molter's (1979) CCFNI and obtained very similar results. Most of the studies indicated that family members ranked the information and assurance need statements as highest in importance, while healthcare providers were found to prioritise the family needs differently than did the family members. The review clarifies the family members' perception of how their important needs are not met and identifies the nurses as the best healthcare staff to meet these needs, followed by the doctors.

This review of the evidence surrounding family member involvement during the crisis of an ICU experience demonstrates that family involvement offers potential benefits to patients and families. Both family members and healthcare providers held positive attitudes towards family involvement during routine care and believed that the involvement of family members in aspects of patient physical care would be empowering and supportive to both the patient and their family members. In contrast, studies on family presence during resuscitation and other invasive procedures showed that family members mostly had positive perceptions, while the healthcare providers held mixed sometimes oppositional opinions.

## Limitations

Many of the family needs studies have adopted a quantitative approach utilising Molter's (1979) CCFNI and most were repetitions of the work of Moler and Leske (1983). The CCFNI includes very loose criteria for inclusion of subjects, using convenience and small sample sizes, which limits generalisation of the findings. All of the family needs studies obtained data from the family members within 24–72 hours of their family members' admission to the ICU, which could affect the validity of the data because family members experience intense emotions during such times. Only a few studies have sought to uncover family members' and healthcare providers' experience of involvement in care and family needs using qualitative approaches. Additionally, the interview methods conducted in the reviewed qualitative studies were

with a small number of respondents, making it hard to determine whether the interviews were adequate to ensure theoretical saturation. Studies on family presence during resuscitation and other invasive procedures were mainly descriptive quantitative studies using a questionnaire design with healthcare providers, and only a few studies sought to discover the attitudes of family members in depth. It would, therefore, be worthwhile to use qualitative methods in a mixed method study with both family members and healthcare providers to further explore their attitudes of family needs, family involvement and, indeed, any effects of cultural differences in greater depth.

#### What is already known about the topic?

- The needs for information and assurance have been perceived by the family members as the most important needs followed by the need for proximity, comfort and support.
- Nurses followed by doctors were found to be the best to meet family needs although family needs not always met.
- The perceptions of family members and healthcare providers' of family involvement and needs have been found to be incongruent.
- Family members and healthcare providers' professionals hold mixed opinions towards family presence during resuscitation and other invasive procedures.

#### What this review adds?

- The literature neglected to recognise the family needs in relation to the influence of cultural rituals, beliefs and values and patient and family members religious views.
- The literature has neglected to take into account the influence of the organisational climate and culture of the

working area on the healthcare providers' perception of family involvement in care.

#### Relevance to clinical practice

Three principle reasons were acknowledged for identifying and meeting the family needs. First, holistic care that if it is to be practised effectively should include consideration of the family in the care planning (Woolley 1990). Second, meeting the family needs reduces the stress of family members, which ultimately benefit improving patient care (Dyre 1991). Third, family members might be a source of stress for nurses and other healthcare providers and if family stress can be reduced this may serve to reduce stress on healthcare providers (Wilkinson 1995). In addition, the involvement of family in the care of hospitalised patients has implications for the working situation of nurses and other healthcare providers and ultimately for the quality of care delivered to the patient. Angood *et al.* (2010) stated that family requirements must always be respected and everything possible must be done by healthcare providers to honour the wishes of the patient and family. Family involvement in some of the patient's personal care may serve to decrease the powerlessness and the anxiety the family might experience during the patients admission (Hammond, 1995).

#### Contributions

Study design: ASA-M; data collection and analysis: ASA-M and manuscript preparation: ASA-M, VP, AO, RC.

#### Conflict of interest

None.

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# Appendix M: Article III: Needs and Experiences of Intensive Care Patients' Families: A Saudi Qualitative Study

RESEARCH

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## Needs and experiences of intensive care patients' families: a Saudi qualitative study

Abbas S Al-Mutair, Virginia Plummer, Rosemary Clerehan and Anthony O'Brien

### ABSTRACT

**Aim:** To identify the perceived needs of Saudi families of patients in Intensive Care in relation to their culture and religion.

**Background:** Admission of a family member to an intensive care unit (ICU) is a deeply distressing and often unexpected life event to the family. Families of critically ill patients have needs that should be acknowledged and met by the ICU team. Literature is virtually silent on the issue of recognizing the ICU family needs in relation to the influence of their cultural values and religious beliefs.

**Design:** A descriptive exploratory qualitative study.

**Method:** Individual, semi-structured interviews of a purposive sample of 12 family members were carried out between November 2011 and February 2012. The closest family members were recruited to participate in the interviews with a mean age of 44-25 years in eight mixed medical-surgical ICUs of eight major trauma hospitals in Saudi Arabia.

**Results:** The family needs and experiences are described via six major themes: looking for information, maintaining reassurance, spiritual healing, maintaining close proximity, involvement in care and support not being facilitated. The results indicated that family members sought to access information readily to diminish their anxiety. They also needed to be reassured that the best care was being delivered to their loved one and to feel supported during this critical time. Saudi families have cultural and spiritual healing beliefs and practices including faith in God and that God is the ultimate healer, reading of the Qur'an, prayer and charity. These lessen their stress and connect them to hold on to hope. In addition, maintaining proximity to their ill family member was considered of the greatest importance to the families.

**Conclusion:** The study provided an in-depth understanding of the family members' experience of having a relative in Intensive Care and focussed on a range of unmet needs, particularly those related to culture and religion. The ICU team need to work collaboratively with family members to improve their experience.

**Relevance to practice:** The recognition of family needs, experiences and situations can enhance the care provided by the critical care team to patients and families.

**Key words:** Cultural and spiritual comfort • Family members • Intensive care patient • Saudi family needs • Shahadatain

### INTRODUCTION

Admission to an intensive care unit (ICU) is often associated with an acute life-threatening illness that often occurs without any warning and is recognized as a stressful situation not only for patients but also for the family members. Being a family member of a critically ill patient in the ICU is a distressing life event (Davidson *et al.*, 2007; Linnarsson *et al.*, 2010; Al Mutair

*et al.*, 2013). Family response to a critical care situation may include denial of the seriousness of the event, overreaction or panic (Fry and Warren, 2007).

Saudi Arabia is the homeland of Islam, where the Prophet Mohammed founded Islam and is the location of the two holy pilgrimage cities of Mecca and Medina. Culturally, Muslim families are characterized by strong ties and operate as a family unit where members are involved socially and emotionally in all aspects of life. Therefore, during a critical illness all family members are expected to participate in the caregiving process (Wehbe-Alamah, 2008). Families will often travel long distances to visit the patient admitted in hospital. However, the majority of ICUs in Saudi Arabia have restricted visitation policies and in most public hospitals visiting ICU patients is limited to only 1 h each day. Saudi families can often be found waiting in the ICU corridor because many of the

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ICUs have no waiting room. Therefore, the impetus of this study was to provide a voice for Saudi families to explore the uniqueness of Muslim culture around the issues of the family being part of the care of the loved one in ICU.

## LITERATURE REVIEW

Families of ICU patients have a variety of needs which if unmet stress levels rise (Davidson *et al.*, 2007). Those needs may include maintaining hope, having their questions answered honestly and to be allowed to visit anytime. The critical care family members' needs have been investigated extensively over the last three decades using the Critical Care Family Needs Inventory (CCFNI) (Kleinpell and Powers, 1992; Engli and Kirsivali-Farmer, 1993; Mi-kuen *et al.*, 1995; Burr, 1998; Lee *et al.*, 1999; Kosco and Warren, 2000; Al-hassan and Hweidi, 2004; Omari, 2009; Al Mutair *et al.*, 2013). The CCFNI is a self-report scale to identify family needs and was first developed by Molter (1979). The family needs for information and to be reassured that their relative is receiving the best care possible were identified as the most important needs (Quinn *et al.*, 1996a, 1996b; Gelling and Prevost, 1999; Al-hassan and Hweidi, 2004; Yang, 2008; Bailey *et al.*, 2009; Kinrade *et al.*, 2009; Chatzaki *et al.*, 2012). However, the needs to remain near the patient, and the family needs for support were perceived as least important (Verhaeghe *et al.*, 2005; Paul and Rattray, 2008). Most of the studies which examined family members' needs adopted a quantitative approach utilizing the CCFNI and obtained very similar results. A review of these studies which adopted the CCFNI revealed a broad range of inclusion criteria of participants, and the use of convenience samples and small sample sizes may limit the generalization of the findings (Al Mutair *et al.*, 2013).

Qualitative research, however, enables the perspectives of experiences and needs of family members to emerge in real time (Holden *et al.*, 2002). In qualitative studies, the life-world of participants is explored, enabling them to present their perspectives clearly and rich themes developed (Holden *et al.*, 2002). Wilkinson (1995) for example used grounded theory to identify the self-perceived family needs of six family members in the ICU in Essex, England. Bond *et al.* (2003) interviewed a convenience sample of seven family members of patients with traumatic brain injury in an 11-bed neurosurgical ICU of a level I trauma centre Wilkinson (1995) and Bond *et al.* (2003) revealed that the family need for knowledge about the patient's condition, their hoping for a positive outcome and to be part of the care of the family member is crucial to the patients'

and families' well-being. In a larger qualitative study using semi-structured interviews, Keenan and Joseph (2010) interviewed 25 family members of patients with severe traumatic brain injury. Themes from this study described the trajectory of families' experiences during the critical illness of their loved family member, including involvement in the care; holding on to hope; professional and community support and need for information. As described studies of family needs have been conducted mainly in the West, only two studies have been conducted in Muslim societies but they did not identify the family needs in relation to religious beliefs and cultural values (Al Mutair *et al.*, in press). Furthermore, either of the studies were conducted in Saudi Arabia therefore, in this study, the needs of Saudi families have been investigated for the first time.

## METHODS

### Aim

To identify the perceived needs of Saudi families of patients in Intensive Care in relation to their culture and religion.

### Study design and setting

A descriptive exploratory, qualitative design was employed using semi-structured interviews to gather in-depth information from family members. This study is Phase 2 of larger study which consisted of two phases. Phase 1 was a quantitative phase and is reported elsewhere (Al Mutair *et al.*, in press). This report relates to Phase 2 which was the qualitative phase taking place in eight major trauma hospitals operated by the Ministry of Health (MOH) from different areas in Saudi Arabia. The hospitals selected for this study were located in six major cities to capture different views and opinions from family members situated in different areas of the country. A purposive sampling strategy was used comprising the closest family member available during the visiting time who met the inclusion criteria as illustrated in Table 1. The exclusion criteria were their potential vulnerability as study participants. Potentially vulnerable participants were relatives of patients whose condition was considered to be unstable such as those with unstable vital signs, major complications or whose death was considered to be imminent.

The saturation of ideas and themes was the general rule used for the data collection of the purposive sampling of family members; the data collection was continued until saturation was achieved. A total of 12 participants participated in the study. After a written and verbal explanation of the project by the

**Table 1** Inclusion and exclusion criteria for family members

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>● Age 18 years or above</li> <li>● Available in the hospital during visiting time</li> <li>● Able to read and write Arabic</li> <li>● Had a family member in the ICU for 24 h or more</li> </ul>	A family member deemed by the assigned ICU nurse as too vulnerable to participate in the study

ICU, intensive care unit.

researcher the written consent was obtained from the participating family member. The interviews were held in a private room made available for the researcher in the ICU. All interviews were conducted after 24 h of patient admission to the ICU, this was considered to ensure that family members had had sufficient time to experience the ICU environment and also to ensure that they could express their real experience without being overheard by staff or other visitors.

#### Data collection

Data was collected by A. S. A.-M., who is a critical care nurse and was not an employee in any of the hospitals or related to any of the participants. A. S. A.-M. is an indigenous Muslim Saudi and aware of the sensitive cultural issues that potentially could have arisen during the conduct of the research. The semi-structured interviews were conducted in Arabic language lasting 30–45 min, to give participants the freedom to voice their experience, illustrations and explanations of being a family member of a critical care patient in the ICU (Streubert and Carpenter, 2011). Data was collected between November 2011 and February 2012.

Preparation of the interview questions was directed by the findings of the quantitative phase of the overall study and the literature review (Al Mutair *et al.*, in press). In preparing the semi-structured interview guide, questions were ordered from the general to the specific. A definition of family needs was provided to the participants at the beginning of the interview to allow them to fully understand the meaning. After that, the interviewer posed general questions before moving towards the core questions related to the topic. This was considered to allow the participant to freely express themselves in the description of his/her lived experience of having a critically ill relative admitted in the ICU.

#### Data analysis

The interviews analysis was carried out by A. S. A.-M., the interviews were transcribed verbatim, translated

into English language using back-translation process and analysed in accordance with Holloway and Wheeler's (2010) process of content analysis. The transcripts were read and re-read several times, cross-checked and labelled to gain a broad understanding of the family members' experience. Line-by-line coding was performed to identify information that participants considered important. The result was six major mutually exclusive themes around central study phenomena. The final themes generated provided answers that explained the perceived needs of family members of a critically ill patient admitted in the ICU. Trustworthiness was promoted by letting the participants speak and then listen to their responses in case they wanted to change anything. The researcher noted any important responses by the participants and took notes for each answer. Finally, a peer review was performed with colleagues to confirm that the themes emerging from content analysis accurately reflected the subjective data.

#### Ethical consideration

The study was approved by the General Administration of Medical Research (GAMR) in the Saudi Arabian MOH. Before consent was obtained, participants received an explanation of the aim of the study and the voluntarily nature of participation, the confidentiality of the data; their right to discontinue the interview at any time; and the potential benefits and risks of participation in the study. The family members were fully informed both in writing and verbally of the support system within the hospital which was available at the time of conducting the study.

#### RESULTS

Twelve family members took part in the study, with a mean age of 44.25 years (Table 2). The majority of the participants were males 10 (83.3%), two (16.7%) were females, with 50% being the son/daughter of the patients. The participants' academic qualifications varied from less than high school to university degree. Family members were associated with 12 patients who were admitted in the ICU for periods of 3 days to 4 months. Half the patients were male and half female and had mean age of 57.5 years.

Six major themes relating to the Saudi families' needs and experiences of critically ill patients in this study have been derived from the analysis of the interviews (Table 3). The six themes are:

#### Looking for information

Almost all family participants indicated that not knowing the prognosis of their ill relative contributes to

**Table 2** Participants profile

Participant's No	MF	Age	Education	Relationship to patient	Pt. MF	Pt. Age	Admission period	Patient diagnosis
1	M	41	Less than high school	Father	M	18	11 days	Trauma
2	M	29	High school	Nephew	M	21	3 days	Trauma
3	F	45	University	Daughter	F	72	42 days	Pneumonia
4	M	53	Less than high school	Son	M	83	4 months	COPD
5	M	55	Less than high school	Son	F	70	5 days	Trauma/Dyspnoea
6	F	50	University	Daughter	M	90	5 days	Aspiration pneumonia
7	M	43	Master degree	Son	M	78	43 days	Pneumonia
8	M	32	University	Husband	F	32	6 weeks	Hypoxia
9	M	61	Less than high school	Son	F	88	33 days	Pneumonia
10	M	53	University	Cousin	M	18	1 month	Trauma
11	M	23	High school	Brother	F	26	2 weeks	DVT
12	M	46	University	Grandson	F	95	3 weeks	CVA

M, male; F, female; COPD, chronic obstructive pulmonary disease; DVT, deep vein thrombosis; CVA, cerebrovascular accident.

**Table 3** Needs and experiences of family members of ICU patients in Saudi Arabia

No	Themes	Sub-themes	Example
A	Looking for information	Honest information Comprehensive understandable information Open communication Family spokesperson	<i>They don't give honest information; they (doctors) told me something and wrote something else in the report . . . they said that my son was in a stable condition whereas they wrote in the report that my son's status was critical</i>
B	Maintaining reassurance	Hold on hope Maintain optimism	<i>Three times when I approached the physicians to reassure me about my mother's condition, they replied that they were busy . . . they are very tough in their words</i>
C	Spiritual healing	Illness is a test of faith on God Reading Qura'n Paying charity Shahadain	<i>I don't feel calmed unless I read the Qur'an every day I visit her [grandmother]; you know the Qur'an heals and reassures hearts "By remembering God, the hearts rejoice</i>
D	Maintaining close proximity	Flexible visiting practices ICU resources	<i>Every time we [family] visit, my father says do not go, stay longer, I need you to be with me, he feels good when we visit and we feel the same too, but unfortunately this is not allowed here with such restricted visiting policy</i>
E	Involvement in care	Culturally appreciated Do no harm Health care providers behaviours	<i>I always want to participate in the care of my mother, you know this makes me feel good, but nurses never let me do this</i>
F	Support is not facilitated	Coping strategy Social services Meeting support needs	<i>The patient's mother is very anxious, she needs to be supported</i>

ICU, intensive care unit.

intense feelings and deep anxiety. Information was the first and the most frequent need recognized by the participating family members in the interviews. Families sought to receive consistent and understandable information in their own vernacular using simple and clear terms. They sought honest information, regardless of whether it was good news, or bad news. One family member vowed:

*'Every time I ask about the prognosis of my father they are just brushing you off, they give very brief and not detailed explanation, just a word or two . . . for four days I haven't talked to the doctor, today he gave me a*

*very short explanation that I couldn't understand very well. Nurses also, when asked, would reply that they were unauthorized to communicate any information with relatives'*

Family members needed information about the medications, vital signs, surgical procedures or any tests and procedures that were performed on their ill loved one. Families desired information about the technical equipment, wires and tubes attached to their critically ill loved one and wanted to know about the meaning of the numbers and waves on the digital display of the monitor screens. Questions were

asked and some families would not leave until their questions were answered. It appeared that health care providers regarded families as uninterested, unpleasant and neglectful. Family members were not always welcome; in some situations they were treated in an unprofessional or even an impolite manner. Some health care providers may regard family members as 'ignorant' knowing nothing about the patient condition as stated by a family member. One family member stated:

*'Some healthcare providers treat us as heavy-going ... I will ask many questions and this is anticipated ... because I have a family member between life and death'*

Participants in the interviews indicated that the family need for information was not always fulfilled and many times was hindered by the ICU's inflexible working style due to the 'inability to meet the treating doctor', 'restricted visiting time' or 'unanswered phone calls'. As a result, families referred to their relationship or a contact (in Arabic 'Wasta') in the hospital to access enough information or to ease their communication with the ICU health care providers. A participant stated:

*'Honestly, I know somebody who works in the hospital that eased my communication with the ICU staff ... I'm sure without this person [backer] my communication and accessing ICU wouldn't be as easy'*

While honest and understandable information about the patient's progress was not always delivered to the families, some families were able to obtain consistent and sufficient information. These family members appeared satisfied with the care and were coping with the situation as a result of the information received which allowed them to anticipate and accept whatever might happen in future. A participant said:

*'Excellent, yes our questions were always answered in an honest and consistent manner ... Dr X called me to deliver some information regarding my father's condition; a day later my older brother met Doctor X and he gave him the same information that was given to me earlier'*

The participants believed that family access to quality information was highly important and could ease their stress. However, they suggested that information should not be released to every family

member; instead a very close, adult family member should be nominated by the family to receive information and liaise with the rest of the family:

*'The hospital administration must ensure that the ICU staff do not release information to every and each family member and I suggest nominating one member to obtain information, and he/she in turn delivers to the rest of the family.'*

### Maintaining reassurance

During the immediate phase of critical illness sufficient and honest information, as well as open communication between health care providers and family members, led in many circumstances to families being reassured of the care provided. Family members in Saudi Arabia relied on the health care providers to be optimistic, use encouraging words and maintain a smiling face. They valued non-verbal actions such as maintaining eye contact and varied facial expression by ICU health care providers to reassure them. A participant shared his opinion of the importance of health care providers being positive, hopeful and optimistic:

*'As a second patient (he called the family member second patient) we need care, hope, optimism, use of encouraging words and we need the care givers to take into account the humanitarian aspect ... sometimes the information made us tense and prevents us from sleep ... you can give honest information with a bit of optimism. Don't lie or deceive, we all know that all ICU patients are critical but how to offer suitable words? I think they [healthcare providers] need courses to do this'*

Families realize the severity of their loved one's condition, although they maintain a hold on hope and reassurance:

*'Oh, we are dying to hear happy news, but the physicians' discouraging words increase our stress and suffering; you know, they should be more positive'*

### Spiritual healing

All 12 family members held a strong belief that the illness of their relative was a test of their faith in God and that God is the ultimate healer. The illness of their loved one enhanced their spiritual connections and meditation. Family members were behaving with stoicism and were found to be more engaged in reading the Qur'an, prayer, and charity. Families' faith in God and being supported by spiritual aspects connected

them to hold on to hope and to be convinced that things were going to change.

*'The illness is a test of patient's faith in Allah (God) almighty; the patient and relatives should be always reminded of this thing to be more positive and hold on to hope'*

Also, by remembering God's word, families were behaving with quiet strength.

*'We believe in Allah's (God) predestined will; therefore, if anything happens to the patient that's a reflection of Allah's will and we'll accept it'*

Participants believe that illness and cure are God's will and that treatments come only after God's will and believed that God is the best healer of any physical and spiritual illnesses.

*'We [as Muslims] say that all available treatments are only after Allah's will; Allah is the ultimate healer'*

Reading the Qur'an was an every-day practice; all families stated that they read the Qur'an in the patient's bedside during visiting time. Families also believed that this action facilitated some meditation and comfort, maintaining hope, patience, and remembrance of God and calmness of heart.

*'Thank God I read Qur'an to my wife every day, I believe she has improving because of the Qur'an not because of me or the doctor'*

In some instances family members may gather to pray for the cure of their patient. Saudi families' cultural and spiritual practices include also paying charity on behalf of their relative. This action includes giving money to the poor, the charity organizations or can be spent in the cause of God for the sake of their loved one. It is believed by Muslims that this action may cure their patient.

*'We pay charity on behalf of my father every day, it holds off disaster'*

Some families were realistic and knew that all efforts and outcomes may not end in their relatives recovering. Therefore, they desired to ensure that their ill family member be reminded to deliver Shahadatain or the testimony of faith before the commencement of intubation. It is additional practice surrounding

death for Muslims, the Shahadatain consists of saying: there is no God but Allah and Mohammad is the Messenger of Allah. To some Muslims, the recitation of Shahadatain in front of a dying Muslim is believed to facilitate one's admittance to heaven. Overall, the Saudi family's spiritual healing needs emerged as a unique and very important finding which contributes to the care of Saudi and Muslim ICU patients in any part in the world.

### Maintaining close proximity

Remaining close to the critically ill patient in the ICU was perceived to be of greatest importance. Some family members wanted to remain in the ICU close to their loved one, to see the patient frequently and be able to visit the patient whenever they desired. The family members interviewed said that the restricted visiting time decreased the flow of information, they were not able to spend more time with their family member and to feel more informed about their condition and progress:

*'The visiting time was neither sufficient nor appropriate; we come from a very far place. Due to the traffic sometimes we arrive towards the end of the visit, we stay for only five to ten minutes then the security asks us to leave ... when visiting time is flexible we can at least meet the treating doctor and have more information about the patient's condition'*

Participants reported that a family visit 'encourages the patients, raises their spirits and gives a sense of love and belongingness'. In contrast, restricted visiting time decreases interaction between family and patient which may result in adverse consequences for the patient's condition:

*'Absolutely, an hour visiting time isn't enough; the patient needs his/her family close during such crisis situation which is not facilitated with such inflexible visiting practices. My wife was distressed that nobody visited her in spite of the fact that I visit her every day however; due to the sedation sometimes she does not realize this'*

To offer proximity for the family members to be with their loved one there are additional physical prerequisites such as having a waiting room with comfortable furniture, which was not available in most of the participants hospitals. This issue was raised by a participant who said:

*'I prefer flexible, the least rigid visiting protocols as this will have its positive impact on the family and the*

*patient. Also, more flexible visiting practices require a visitor's waiting room with good amenities'*

### **Involvement in care**

As a consequence of not being informed about the further developments concerning the patient's condition, lack of communication, restricted visiting practices and families never being asked their opinion regarding the treatment, family members did not feel involved in the care process. Most of the family members were willing to assist with the care and thought that while they were present they would be able to support and calm their critically ill loved one. All family members indicated they were not allowed to be involved in the caring of their family member.

*'If I'm given the choice, I would sit in front of him [father] all the time, feed him, take care of him, talk to him, read Qur'an for him, I would stay beside him even if he is sleeping; at least this will reassure me and reduces my anxiety but unfortunately this is not allowed'*

All members of the family expected to participate in the care process of their ill member to varying degrees as this is culturally highly appreciated. Close relatives are expected to look after their ill relative especially if the patient is a parent as this is considered as honouring in Islamic culture:

*'If I'm offered the opportunity to look after her, I will certainly do it, you know this is my mother the reason for my being in this world; whatever I do will never pay her back'*

Some Saudi family members desired to be more involved in the care, but were uncomfortable caring for patients in such a critical situation, and were concerned that they did not 'harm' the patient. Relatives were concerned that they do the right thing.

*'Well, if I'm offered the opportunity I'll be very happy to assist in the care, but I'm concerned to do the right thing, I don't want to harm her [wife] instead of helping'*

Involving family members in direct patient care activities decreased their feeling of powerlessness and was most meaningful to them. Despite the fact that they wanted to be part of the care of their critically ill loved one, they were concerned about the ICU environment and health care providers' behaviours.

Families wanted, first for the ICU to be well-prepared and equipped and the health care providers to accept them being involved in the care:

*'to involve us, the ICU should be well-prepared and the healthcare providers should accept the practice and allow us to participate in the care'*

### **Support is not facilitated**

This theme embraced the need for support, family members regarded support to be a crucial factor that could assist them in coping during such a time of high stress. However, interviews results have shown that family needs for support were not always being met, placing them in a stressful critical care situation. ICU Health care providers did not initiate meaningful interactions or engagement with the family members interviewed. There was also 'a lack of communication' between the two groups; this in turn, may obstruct the health care providers from knowing the families' support needs which ended in support is not being facilitated. In addition, family members were not informed of the 'social services' available in the hospital so the family coping patterns could be supported.

*'The patient's mother is very anxious, she needs to be supported and reassured that her son is receiving the best care to cope during this critical time'*

In spite of the fact that it was absent, support provided by the social services in the hospital was described as a necessary part of this challenging period.

*'I think this is the social services duty it should take action in helping families to cope and supporting them either psychologically or financially, and in some cases, if needed, maybe seeking for help outside of the hospital'*

Health care professionals were identified as giving 'very bad' support during this phase of acute care of ICU hospitalization. A family member 'wondered about the reason for this lack of emotional support to the families by the ICU health care providers'. Accordingly, in order for the health care providers to be able to meet the family support needs, participants suggested:

*'Training for the healthcare providers to improve family knowledge of patient condition and meeting the support needs of family members'*

## DISCUSSION

This is the first descriptive qualitative study on the needs of ICU patients' families in Saudi Arabia. The findings shed light on the lived experience of being a family member of a critically ill patient in ICU and provide a foundation for future nursing research into the topic.

The clearly identified need for information corresponds with earlier literature (Kleinpell and Powers, 1992; Bond *et al.*, 2003; Fry and Warren, 2007; Yang, 2008; Keenan and Joseph, 2010). Providing adequate and honest information is of great importance especially in the patient's early stay in the ICU. The use of communication boards, family meetings and rounds, having a family spokesperson, and flexible visiting practices can also facilitate information dissemination to families. Instructional materials including education books with pictures which describe the nature of the ICU, the equipment families are likely to encounter and suggestions for interacting with their critically ill member can help families meeting their information needs (Titler *et al.*, 1995). Fry and Warren (2007) also noted that encouraging relatives to ask questions and acknowledging their statements can make them feel part of the caring team. Interpreter choice is important as family members should not be placed in difficult or embarrassing situation. (Davidson *et al.*, 2007). The complex medical issues that may arise in ICU require an interpreter to communicate the information effectively.

During the immediate phase of critical illness, the shock of admission to ICU requires the family to be supported and assured that the patient is receiving the best care and that the health care providers care about the patient. Recruiting a social worker to the ICU, as suggested by the family members, can assist the family's ability to cope with the critical care situation. The family members perceived the social worker as a complement to the ICU health care providers in terms of supporting and reassuring families. Social workers are also qualified to present information in terms the family can understand in an honest and empathetic manner. Davidson *et al.* (2007) indicated that social workers were the most comfortable approaching patients and families about religion, spirituality and critical care issues and had the skills to do so. Nevertheless, family support and interaction is a duty of care crossing over professional domains and also the responsibility of nurses and doctors caring for patients in intensive care. Therefore, ICU health care providers should also have a caring attitude and show friendliness to give support to families. The use of group support in which families can share their feelings and concerns is another

intervention that provides support and assurance to the families (Holden *et al.*, 2002). Culturally in Saudi Arabia, the critical illness events strengthen the family ties. The Saudi family is characterized by strong bonds and reflects a mutual commitment between the family members. This commitment includes visiting and supporting family members, especially during illness or injury to a family member. This also considers providing emotional and psychological support to the patient and to the closest family members as this is highly encouraged in the Islamic teachings and Saudi culture. The health care providers should encourage and facilitate having family and friends around to provide these different types of support.

Restricted visitation policies prevent families from seeing the patient frequently as they would wish and spending time with their loved one. These practices also hinder families from obtaining information regarding the patient's condition and decrease their satisfaction (Davidson *et al.*, 2007). It can be argued that restricted visitation practices in the ICU in Saudi Arabia are based on tradition rather than evidence and the qualitative findings clearly revealed that family members prefer flexible visiting practices. Research also shows that both patients and families benefit emotionally from being in close proximity to each other (Al Mutair *et al.*, in press). Wilkinson (1995) stated that it is paradoxical, at a time when the patient and family need each other, that they may find themselves isolated by the restricted visiting practices. Helping families meet these needs will enhance their well-being and coping abilities.

This study highlights that family involvement in patient care activities decrease family anxiety and feelings of powerlessness and, more importantly, it is culturally appreciated. These participants' wishes are consistent with participants who expressed frustration at being restricted from helping with the care the patient required as reported by Bond *et al.* (2003), Fry and Warren (2007) and Keenan and Joseph (2010). Being involved in assisting with the daily tasks for the patient enhances the family's coping mechanism (Fry and Warren, 2007). Involvement may elicit the benefit of deepening the ICU health care professionals' understanding of the patient and strengthen the relationship with the families because patients often give important information to relatives that they do not share with ICU team (Titler *et al.*, 1995). Therefore, the family is an important resource in the care of the patient to alleviate patient's stress and improve patient's outcomes. Bond *et al.* (2003) indicated that including family members can increase their understanding of the gravity of the patient's situation and prepare them

for the upcoming care-giving role, if needed, when the patient is discharged from the hospital. As identified in the current study it is important to note that not all family members desire to participate in the care; therefore they are not supposed to be forced into participation if they do not want it. In this study, some family members were uncomfortable to participate in the care of critically ill patients in ICU, and were concerned that they did not cause any harm to the patient.

### LIMITATIONS

A limitation of this study was that only family members who were present at the ICU at the time of conducting interviews were asked to participate in the study. Perhaps those other family members who did not visit their critically ill relative during the data collection period had other experiences to be shared. Another limitation is related to the inclusion of family members within 24 h of their relative's admission to the ICU, as family members are usually highly stressed during such times and their needs are complex and variable. Also, family members with a relative who was considered unstable patient or family members whose relative had died in the ICU were not included in the study. It is also hard to draw detailed recommendations for practice from this study due to the fact that the transferability is limited by the small sample size ( $n = 12$ ). Therefore, the results need to be interpreted with caution.

### CONCLUSIONS AND IMPLICATIONS

This study is unique as was the first empirical study focused on identifying the needs of families of ICU patients in Saudi Arabia. The findings of this study provide a deeper understanding of the family needs, particularly in relation to cultural beliefs and religion values. The findings of this study are likely to inform intensive care nursing services and other health professionals such as medical intensivists about what Saudi families need so that family centred care may be enhanced in the ICU in Saudi Arabia. The findings are also likely to inform the care of Muslim families elsewhere in the Middle East and other international settings. In a clinical setting that is known to be fast paced and clinically focused, these findings are a welcome contribution to the comprehensive care of the critically ill.

### ACKNOWLEDGEMENT

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### CONFLICT OF INTEREST

A. Al-Mutair was responsible for the study conception/design as well as for the data collection/analysis and drafting of the manuscript. V. Plummer, R. Clerehan and A. O'Brien were responsible for the critical revisions for important intellectual content and supervision.

#### WHAT IS ALREADY KNOWN ABOUT THE TOPIC?

- Families want a flow of sufficient information and to be reassured that the patient is receiving the ultimate care.
- Some family members perceive that important needs are not always met.
- Researchers have neglected to recognize the family needs in relation to the influence of cultural values and religious beliefs held by the family members.

#### WHAT THIS PAPER ADDS?

- The Saudi families' cultural and spiritual beliefs and practices including faith in God as ultimate healer, reading the Qur'an, prayer, and charity which were seen to lessen families stress and connect them to hope.
- Access to understandable, consistent information; assurance that the best care is being delivered to the patient; support; maintaining proximity and being part of the care may reduce family anxiety and feelings of powerlessness.

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# Appendix N: Article IV: Families' needs of critical care patients in Saudi Arabia: a quantitative Study

RESEARCH

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## Families' needs of critical care Muslim patients in Saudi Arabia: a quantitative study

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### ABSTRACT

**Aim:** To identify the needs of families of adult intensive care unit (ICU) patients in Saudi Arabia as perceived by family members and health care providers.

**Background:** Family members of critically ill patients are likely to have specific needs that should be addressed by the critical care team and which, if unmet, may produce stress for patients' families and health care providers. The literature has yet to identify the needs of Muslim families in relation to religious beliefs and cultural values in critical care settings in Saudi Arabia.

**Design:** A cross-sectional survey design.

**Method:** A total of 176 family members and 497 intensive health care providers were recruited from eight adult mixed medical-surgical ICUs between November 2011 and February 2012 utilizing a four-point Likert type scale self-administered questionnaire.

**Results:** The findings revealed that family members and health care providers ranked assurance, information and cultural and spiritual needs as the most important, and support and proximity as least important. There were significant differences in the mean values found between family members and health care providers. A significant finding not identified in other studies was 'The need to have the health care providers handle the body of the dead Muslim with extreme caution and respect' which, under the dimension of cultural and spiritual needs, was perceived by family members to be the most important and by the health care providers as the fifth most important need.

**Conclusion:** The recognition of family needs in the critical care unit informed the development of interventions to meet family needs and improve the care quality.

**Key words:** Critical care family needs inventory • Critical care units • Cultural and spiritual needs • Family needs • Intensive care units • Muslims • Qur'an reader • Saudi Arabia

### INTRODUCTION

Officially it is estimated that 100% of the Saudi population belong to the Islamic religion. The statistic of 100% only applies to citizens of Saudi Arabia, while expatriates have many different independent religions (Central Intelligence Agency, 2010; Ministry of Economic and Planning, 2010). The Muslim family has an extended-family model and is characterized

by strong ties, with family members sharing cultural, social and religious obligations towards each other (Wehbe-Alamah, 2008). The health care workforce in Saudi Arabia, however, is a heterogeneous mix of Saudi and a significant expatriate international workforce (Al-Mutair *et al.*, 2012).

Family needs are defined as the requirements of family members which, if fulfilled, relieve or diminish family distress and, if unmet, may produce distress in family members and the Intensive Care Unit (ICU) team (Kosco and Warren, 2000). Researchers have demonstrated that families have information, assurance, support' and proximity needs that must be met in order for the family to cope with the critical illness of their relative (Titler *et al.*, 1995; Verhaeghe *et al.*, 2005).

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### BACKGROUND

Since the seminal study by Molter (1979), the issue of 'family needs' has received significant research attention in the nursing field (Kinrade *et al.*, 2010). The

family needs have been well-researched using quantitative approach and the Critical Care Family Need Inventory (CCFNI), which was originally developed by Molter (1979) evolved: a highly validated research tool consisting of five subscales such as information, assurance, proximity, support and comfort (Leske, 1992; Chazaki *et al.*, 2012). Many studies using the CCFNI have demonstrated that family members have basic needs which have to be met (Kleinpell and Powers, 1992; Mi-kuen *et al.*, 1999; Gelling and Prevost, 1999; Lee *et al.*, 1999, Kosco and Warren, 2000; Holden *et al.*, 2002; Al-Hassan and Hweidi, 2004; Takman and Severinsson, 2006; Omari, 2009).

Furthermore, research on family needs has shown that the need to be reassured of the health status of their family member and that they are receiving the best care has been identified as the most important family need in a number of studies conducted in different contexts (Quinn *et al.*, 1996a, 1996b; Burr, 1998; Gelling and Prevost, 1999; Lee *et al.*, 1999; Al-Hassan and Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki *et al.*, 2012). The family need to access sufficient information and knowledge has also been perceived as one of the highest priority needs (Leske, 1992; Engli and Kirsivali-Farmer, 1993; Warren, 1993; Mi-Kuen *et al.*, 1999; Quinn *et al.*, 1996a, 1996b; Gelling and Prevost, 1999; Al-hassan and Hweidi, 2004; Bailey *et al.*, 2009; Omari, 2009; Kinrade *et al.*, 2010). Previous research has proposed that health care professionals must ensure that family members are provided with appropriate and sufficient information at the right time and that such information should be given in an understandable format that can be absorbed by family members. Information and knowledge can be given in many different ways either verbally or written. Family members may use the internet to access information, stay with the patient to be involved in the care and gain information, ask the ICU health care providers, and attend programmes. The programmes are to help families gather information about the intensive care environment and their role in the care of their relative if they wish to participate.

Proximity and support needs were perceived as the least important needs for families of ICU patients (Leske, 1992; Lee *et al.*, 1999; Al-Hassan and Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki *et al.*, 2012). Although, the CCFNI has been used extensively in several international studies, cultural and spiritual family needs during critical illness have been neglected. In addition, studies on family needs have been exclusively conducted in urban setting in developed countries. Only a few have taken place in developing countries (Chazaki *et al.*, 2012). No such study has been carried out in Saudi Arabia and no

studies have focused on recognizing the family needs related to the cultural and religious values held by the family members and the health care providers.

## THE STUDY

### Aim

The aim of this study was to identify the needs of ICU patients' families in Saudi Arabia as perceived by family members and ICU health care providers utilizing the CCFNI.

### Study design and setting

A cross-sectional design using a questionnaire was adopted. The study was conducted in eight mixed medical-surgical adult ICUs with restricted visiting practices of eight major hospitals located in six different cities in Saudi Arabia. The hospitals are affiliated with the Ministry of Health (MOH) and the General Administration of Medical Research ethics committee (GAMR) in the MOH reviewed and approved the study protocol. The GAMR is the principal governing body of approving medical research in all hospitals affiliated with the MOH in Saudi Arabia. The ICUs had between 8 and 70 beds and generally care for approximately 600 to 1778 patients every year. Most of the ICUs involved in the survey had rigid visiting practices where families could visit only 1 h a day, and only one to two family members could visit at once for a maximum of 5 min. Also most of the units had no waiting room to accommodate family members during the visiting period, so visitors waited in the ICU corridor before being allowed to visit their loved one.

### Sample

A convenience sampling was employed for the subjects who met the inclusion criteria. Family members were included in the study if they were aged 18 years or above, were able to read and write Arabic and had a family member in the ICU for 24 h or more. Family members were excluded if the patient had unstable vital signs, major complications, or whose death was considered to be imminent. The inclusion criteria of health care providers were those working permanently in adult ICUs. All professional groups of health care providers were asked to participate in the study by completing a questionnaire. There are three professional groups who were in the ICUs: physicians, nurses and respiratory therapists.

A power analysis was used to estimate the required sample size of family members and health care providers using the G Power computer programme based on the following parameters: a power of 0.80,

a level of significance of 0.05 and a medium effect size of 0.4 (Munro, 2005; Burns and Grove, 2009). The minimum required sample size was a total of 250 subjects: a minimum of 125 family members and 125 health care providers.

### The instrument

The CCFNI was identified as a validated tool that would be suitable for this study if it was modified for the Saudi family and health care providers with permission from the original author and also to translate it into Arabic. Modifications were undertaken and validated with Saudi and non-Saudi experts. The Saudi modified version of CCFNI tool was used as the foundation for the two questionnaires administered in the study – one for family members and one for health care providers. The questionnaire consisted of two parts: part one collected information on demographic characteristics and part two was the Saudi modified version of the CCFNI consisting of 35 need statements. A total of 22 need statements were adapted from the original CCFNI to develop the Saudi version.

The rest of the statements were adapted from a wide range of literature and professional nursing experience. Particular statements relevant to Saudi families' religious, cultural and spiritual needs were added. This was to identify the various aspects of the cultural and spiritual needs of Saudi family. The Saudi version of CCFNI measures five dimensions such as assurance (7 items), information (10 items), proximity (5 items), support (5 items) and spiritual and cultural needs (8 items). The items were mixed and listed randomly and a four-point Likert-type scale was used to rate the items in order of importance, 1 not important, 2 slightly important, 3 important and 4 very important.

### Validity and reliability

The questionnaire was reviewed by a panel of experts which consisted of 12 members. The experts were nurse academics, critical care nurses, nurse managers and a statistics consultant. Based on the feedback, changes were made as necessary. After this review a pre-test of the instruments was carried out in one of the participating hospitals in the study over a period of 3 weeks. The pre-test yielded seven family members of adult patients who were admitted in the ICU and met the initial inclusion criteria for the seven ICU health care providers. The pre-testing revealed that family members and health care providers' feedback was positive and indicated that the questionnaires were clear and accessible to understand. The internal consistency of the Saudi modified version of the CCFNI was evaluated by using Cronbach's Alpha Coefficient. The total alpha

**Table 1** Cronbach's alpha for internal consistency for each subscale and total for Saudi modified version of the CCFNI

Subscales	Alpha coefficient
Assurance	0.85
information	0.85
Proximity	0.87
Support	0.86
Cultural and spiritual	0.85
Total	0.88

CCFNI, Critical Care Family Need Inventory.

coefficient of the CCFNI was 0.88 for the overall scale and from 0.85 to 0.87 for the five subscales (Table 1).

### Data collection

Data collection was commenced in November 2011 and concluded in February 2012. The first author handed out the study information sheet to the eligible family members during the visiting time. Anonymous questionnaires were distributed to the families of 294 patients who were admitted in the ICUs during the study period, of which a total of 176 questionnaires were returned. Health care providers' questionnaires were distributed to all categories of ICU patient care givers which included physicians, nurses and respiratory therapists. A total of 1100 health care providers were approached to participate in the study, of which 497 returned the questionnaires. The overall response rate was 59.8% ( $n = 176$ ) for family members and 45.1% ( $n = 497$ ) for ICU health care providers. A total of 9 and 20 questionnaires from family members and health care providers' samples, respectively were excluded because of missing responses to too many items. This may have occurred because those excluded participants were less interested in the topic. Another reason could have been inaccuracy and ambiguity in the questionnaire.

### Data analysis

Before analysis was commenced, the data set was screened and checked for errors (Pallant, 2011). Data analysis was performed using SPSS 20, the mean and standard deviation for each need statement were computed to determine which needs were perceived as most important based on mean scores. Mean scores were calculated for each of the five subscales – assurance, information, proximity, support and spiritual, and cultural needs, to determine which of these subscales was most important based on mean scores. Independent sample *t*-test and analysis of variance (ANOVA) with post-hoc test were used to determine any statistically significant differences

between participants' demographic characteristics and family needs. All statistical analyses were considered significant at the 0.05 level (Munro, 2005).

## RESULTS

### Sample characteristics

The mean age of the family members was 33.16 years, and there was an uneven sex spread: 110 (65.9%) were males and 57 (34.1%) were females (Table 2). The families were predominantly Saudi 151 (91%) with only 15 (9%) non-Saudi. Academic qualification of family members varied from less than high school level to a postgraduate university degree. The largest proportion of the participants identified themselves as parents of the patients (45% or 28%) or other relatives of the patient (44% or 27.3%). With regard to the length of patient stay in the ICU, the period ranged between 1 day and 3 years with mean 40.1 days. The majority of the patients were males (62.1%) and with 37.9% female. The patient age ranged from 17 to 102 years old, with a mean age of 44.6 years. The families mostly preferred to visit their loved one in the ICU twice a day (39.6%) or even thrice a day (25.6%). Figure 1 presents the family members response concerning their previous experience in the care of patients while they have been in the intensive care unit. The results indicated that more than half of the sample (62%) had previous experience in the ICU, whereas 38% had no experience.

The health care providers' demographics are summarized in Table 3. The mean age was 30.7 years, with more than 84% of the sample female and only 15.2% male. Health care providers of 13 nationalities participated in the study, in which Saudis health care providers represented only 12.6% of the total sample. The largest proportion of the participating health care providers were nurses, who represented 83.9%, while respiratory therapists and physicians were 8.8% and 7.3% of the total, respectively. Figure 2 reports the level of education by profession. A total of 49.7% reported that they held a bachelor degree and 45.9% reported having a diploma in either nursing or respiratory therapy. Only 4% reported having a postgraduate qualification. Most of the respondents had between 1 and 10 years of working experience and experience working in Saudi Arabia.

### Ranking of needs

Families perceived 31 needs items (88.6%) of the total needs statement as either important or very important and 4 (11.4%) were ranked as slightly important (Table 4). Of the five most important needs identified by family members in this study, three were related to assurance, two to information and one to the cultural

**Table 2** Family members socio-demographic details ( $N = 167$ ).

Scio-demographic item	Subgroups	Frequency	Percentage
Age	18–24	33	24.1
	25–27	25	18.2
	28–33	25	18.2
	34–42	29	21.2
	43+	25	18.2
Sex	Missing	30	
	Male	110	65.9
Nationality	Female	57	34.1
	Saudi	151	91
Level of education	Non-Saudi	15	9
	Missing	1	
	Less than high school	31	18.6
Relationship to patient	High school	47	28.1
	Diploma	26	15.6
	Bachelor	59	35.3
	Master	4	2.4
Length of patient stay in the ICU in days	Spouse/partner	5	3.1
	Sibling	32	19.9
	Parent	45	28
	Son/daughter	24	14.9
	Other relative	44	27.3
Patient's age	Friend	11	6.8
	Missing	6	
	1–2	25	16.8
	3–7	46	30.9
	8–9	6	4
	10–17	23	15.4
	18–45	30	20.1
Patients sex	46+	19	12.8
	Missing	18	
	17–21	36	23.4
	22–30	26	16.9
	31–53	31	20.1
	54–68	31	20.1
Visit preference	69+	30	19.5
	Missing	13	
	Male	100	62.1
Visit preference	Female	61	37.9
	Missing	6	
	Once a day	39	23.8
	Twice a day	65	39.6
	Three times a day	42	25.6
	Every other day	11	6.7
	Every 2 days	1	0.6
Open	6	3.7	
Missing	3		

ICU, intensive care unit.

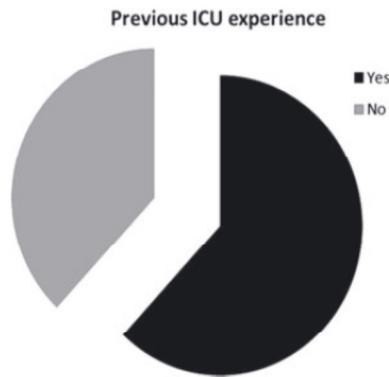


Figure 1 Family members' previous ICU experience.

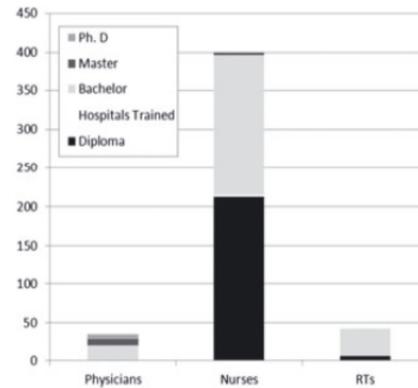


Figure 2 Health care providers' education level.

Table 3 Health care providers' socio-demographic details (N = 477)

Socio-demographic item	Subgroups	Frequency	Percentage
Age	22–25	82	17.9
	26–27	115	25.2
	28–28	44	9.6
	29–31	66	14.4
	32–36	74	16.2
	37+	76	16.6
	Missing	20	
Sex	Male	72	15.2
	Female	403	84.8
	Missing	2	
Nationality	Saudi	59	12.6
	Non-Saudi	408	87.3
	Missing	10	
Level of education	Diploma	219	45.9
	Hospital training	2	0.4
	Bachelor	237	49.7
	Masters	13	2.7
	PhD	6	1.3
Health care profession	Nurse	400	83.9
	Physician	35	7.3
	Respiratory therapist	42	8.8
	Missing	2	
Years of employment	Less than 1 year	16	3.4
	1–5 years	219	46.2
	6–10 years	130	27.4
	More than 10 years	109	23
	Missing	3	
Years of experience in Saudi Arabia	Less than 1 year	56	11.8
	1–5 years	301	63.6
	6–10 years	65	13.7
	More than 10 years	51	10.8
	Missing	4	

and spiritual needs (Table 7). As reported in Table 5, assurance and information dimensions had the highest mean score with 3.66 and 3.52 indicating that family members perceived these needs as most important. Proximity and support dimensions had the lowest mean scores with 3.23 and 3.19 revealing that family members perceived these needs as least important.

There were statistically significant differences in scores of family's views of support for male patients ( $M = 15.69$ ,  $SD = 3.24$ ) and female patients [ $M = 17.03$ ,  $SD = 3.04$ ;  $t(133) = -2.11$ ,  $p = 0.03$ ]; family members of female patients ranked support as more important than family members of male patients. Also, families of patients admitted in the ICU for 10–30 days rated assurance needs as less important than families of longer or shorter patients stays ( $M = 24.62$ ,  $SD = 3.34$ ,  $p = 0.02$ ).

The health care providers perceived ( $n = 28/80\%$ ) of the total family needs as very important or important; five (14.2%) were identified as slightly important (2.00) and two needs (5.7%) were perceived as not important (refer to Tables 4 and 6). Of the five most important needs, three were related to information, two to assurance and one is related to cultural and spiritual needs (Table 7). The analysis of the results revealed that the assurance subscale received the highest ranking by health care providers with a mean score of 3.49, followed by information at 3.41. Cultural and spiritual needs were perceived as the third most important needs with a mean score of 3.15. In addition, support and proximity chronologically were perceived as least important, as identified by the health care providers (Table 5).

The expatriate health care providers ranked the assurance needs significantly higher than Saudi health care providers ( $p = 0.03$ ,  $M = 24.74$ ,  $SD = 2.84$ ). The expatriate health care providers also rated the

Table 4 Saudi modified version of CCFNI items, Means and standard deviations for FM and HCP

Need	FM (167) Mean (SD)	HCP (477) Mean (SD)	Difference in mean (95% CI)	p Value*
To know specific facts concerning the patient's progress	3.70 (0.55)	3.58 (0.61)	0.12 (0.016, 0.218)	0.04
To educate the family about the condition of the patient	3.60 (0.59)	3.65 (0.59)	0.05 (-0.152, 0.048)	0.3
To feel accepted by the hospital staff	3.36 (0.73)	3.34 (0.69)	0.02 (-0.101, 0.153)	0.6
To relieve our families' anxiety by exploring the medical facts with them in a non-judgemental manner	3.53 (0.67)	3.36 (0.78)	0.17 (0.043, 0.297)	0.009
To feel that health care providers care about my relative	3.64 (0.60)	3.40 (0.75)	0.24 (0.127, 0.359)	<0.0005
To communicate effectively with health care providers to improve families' ability to make care decisions	3.48 (0.67)	3.48 (0.66)	0.005 (-0.115, 0.125)	0.9
To be allowed to visit whenever we wish	2.81 (1.13)	1.85 (0.83)	0.96 (0.781, 1.137)	<0.0005
To have waiting room with comfortable furniture available for us in the intensive care unit	3.08 (1.02)	2.52 (1.12)	0.56 (0.375, 0.751)	<0.0005
To have explanations given in terms that are understandable	3.66 (0.62)	3.30 (0.79)	0.35 (0.237, 0.477)	<0.0005
To request to stay during the care of my family member	3.06 (1.00)	1.71 (0.96)	1.34 (1.169, 1.520)	<0.0005
To face the patient's bed towards the Holy Mosque in Mecca	3.29 (0.983)	2.69 (1.07)	0.60 (0.417, 0.785)	<0.0005
To have questions answered honestly	3.72 (0.548)	3.46 (0.66)	0.26 (0.160, 0.368)	<0.0005
To know exactly what is being done for the patient	3.65 (0.627)	3.58 (0.63)	0.06 (-0.048, 0.180)	0.25
To ensure the health care providers who are the opposite sex from the deceased Muslim have no physical contact with the body	2.99 (1.16)	2.77 (1.07)	0.22 (0.026, 0.430)	0.02
To be assured that the best care is being given to the patient	3.65 (0.614)	3.71 (0.52)	0.06 (-0.167, 0.045)	0.25
To have an explanation in detail about the condition of the patient when it becomes worse	3.75 (0.54)	3.69 (0.54)	0.06 (-0.037, 0.157)	0.22
To understand everything that occurs with the condition of the patient	3.68 (0.61)	3.50 (0.67)	0.18 (0.083, 0.295)	0.002
To have another person accompany me while visiting the intensive care unit	2.82 (1.14)	2.00 (0.99)	0.82 (0.618, 1.014)	<0.0005
To ensure that the Saudi culture is fully understood by the health care providers caring for Saudis	3.31 (0.94)	3.42 (0.75)	0.11 (-0.266, 0.053)	0.18
To talk to the doctor every day	3.52 (0.75)	3.20 (0.88)	0.32 (0.180, 0.463)	<0.0005
To know the expected outcomes	3.63 (0.60)	3.41 (0.72)	0.22 (0.108, 0.336)	<0.0005
To have someone providing psychosocial support to families during daily patient care	3.40 (0.83)	3.18 (0.86)	0.22 (0.071, 0.378)	0.004
To ensure that health care providers respect the spiritual healing practices of the Saudi patients and families	3.42 (0.81)	3.34 (0.75)	0.07 (-0.062, 0.216)	0.27
To let the Saudi family know just about the bad news, not the patient	3.45 (0.79)	2.65 (1.05)	0.795 (0.639, 0.950)	<0.0005
To help with the patient's physical care	3.12 (0.98)	3.30 (0.86)	0.18 (-0.346, -0.020)	0.02
To have explanations of the critical care environment before going to the critical care area for the first time	3.37 (0.85)	3.37 (0.75)	0.007 (-0.148, 0.133)	0.9
To have health care providers discuss with the family members what helps the patient deal with events during hospitalization	3.52 (0.70)	3.33 (0.71)	0.19 (0.072, 0.325)	0.002
To have health care providers respect relatives' opinions	3.30 (0.84)	3.13 (0.77)	0.17 (0.017, 0.316)	0.02
To have the health care providers handle the body of the dead Muslim with extreme caution and respect	3.80 (0.51)	3.56 (0.65)	0.24 (0.137, 0.336)	<0.0005
To be told of the reason for the chosen treatment of their relative	3.70 (0.545)	3.23 (0.78)	0.47 (0.366, 0.586)	<0.0005
To ensure that health care providers never attempt to interview or examine a female patient alone	2.88 (1.16)	3.40 (0.82)	0.52 (-0.723, -0.332)	<0.0005
To be told about other health care professionals that could help	3.31 (0.77)	3.12 (0.75)	0.19 (0.063, 0.328)	0.007
To communicate information to help families understand each aspect of care	3.41 (0.71)	3.26 (0.75)	0.14 (0.007, 0.274)	0.04
To develop trust with health care providers	3.65 (0.59)	3.54 (0.61)	0.11 (0.003, 0.219)	0.04
To know how the patient is being treated medically	3.51 (0.70)	3.43 (0.68)	0.083 (-0.040, 0.207)	0.1

CCFNI, Critical Care Family Need Inventory; FM, family members; HCP, health care providers.

\*Significant at 0.05 level.

**Table 5** CCFNI subscales, means and standard deviations for FM and HCP

Subscale	FM (N = 167) Mean (SD)	HCP (N = 477) Mean (SD)	Difference in mean (95% CI)	p Value*
Assurance	3.66 (0.43)	3.49 (0.67)	0.16 (0.582, 1.681)	<0.0005
Information	3.52 (0.68)	3.41(0.70)	0.12 (0.283, 2.041)	0.01
Proximity	3.23 (0.86)	2.71(0.796)	0.30 (2.038, 3.027)	<0.0005
Support	3.19 (0.92)	2.83 (0.900)	0.38 (1.360, 2.460)	<0.0005
Cultural and spiritual	3.33 (0.88)	3.15 (0.871)	0.19 (.788, 2.299)	<0.0005

CCFNI, Critical Care Family Need Inventory; FM, family members; HCP, health care providers.

\*Significant at 0.05 level.

**Table 6** Five least important family needs as identified by FM and HCP

Need	FM	HCP
To be allowed to visit whenever we wish	2.81 (1.13)	1.85 (0.93)
To have another person accompany me while visiting the intensive care unit	2.82 (1.14)	2.00 (0.99)
To ensure that health care providers never attempt to interview or examine a female patient alone	2.88 (1.16)	-
To ensure the health care providers who are the opposite sex from the deceased Muslim have no physical contact with the body	2.99 (1.16)	-
To request to stay during the care of my family member	3.06 (1.00)	1.71 (0.96)
To have waiting room with comfortable furniture available for us in the intensive care unit	-	2.52 (1.12)
To let the Saudi family know first about the bad news, not the patient	-	2.65 (1.05)

FM, family members; HCP, health care providers.

information needs higher than Saudi health care providers ( $p < 0.0005$ ,  $M = 34.61$  SD 4.33). There was a statistically significant difference between health care providers profession and the rating of importance of information and support needs ( $p = 0.01$ ). Nurses rated the family need for information as more important than physicians and respiratory therapists ( $M = 3.44$ , SD + 0.44). In addition, respiratory therapists rated support as less important than physicians and nurses ( $M = 2.59$ , SD + 0.54). There was also a statistically significant difference between health care providers' years of employment and support needs ( $p = 0.03$ ). Health care providers with less than 1 year's employment ranked support slightly higher than the other groups ( $M = 3.06$ , SD + 0.39).

## DISCUSSION

This was the first prospective study to identify the family needs of ICU patients in Saudi Arabia and the first to recognize family needs in relation to the influence of religious and cultural values held by families through the use of the CCFNI.

Family members' demographic characteristics indicate that they comprise a reasonably homogeneous sample of Saudi nationals (91%). Although, religion was not assessed in the demographic section of the questionnaire, the fact that 100% of the general Saudi population is estimated to belong to Islam (Central Intelligence Agency, 2010). This suggests that it is safe to assume the majority of the participants practise Islamic religion. Over half (62%) of the family members in this sample had some previous ICU experience. Some researchers have suggested that the family members' previous ICU experience influences the family members' rating of needs. In this sample, however, it did not appear to influence the ranking of importance of family needs. This was similarly reported by Al-Hassan and Hweidi (2004) and Omari (2009). This may suggest that all family needs were important to families in Saudi Arabia whether they had previous ICU experience.

## Important family needs

The results of this study suggest that family members and ICU health care providers had many areas of similarities in the ranking important needs. Those findings are generally inconsistent with those of Quinn *et al.* (1996a, 1996b), Mi-kuen *et al.* (1999) and Kosco and Warren (2000) who found that relatives and critical care nurses differed in their perceptions of the family needs. An interpretation of this is that the similarity in answers between both groups in this study occurred because ICU health care providers in Saudi Arabia had an understating of the family needs. It also seems that expatriates health care providers learned and adopted the Saudi culture.

## Assurance and information needs

The assurance and information subscales were ranked as the first and second most important dimensions on the CCFNI as perceived by both family members and health care providers. Previous studies conducted in both Western and Asian countries also indicate

**Table 7** Five most important family needs as identified by FM and HCP.

Need	FM	HCP
To have the health care providers handle the body of the dead Muslim with extreme caution and respect	3.80 (.51)	3.56 (0.65)
To have an explanation in detail about the condition of the patient when it becomes worse	3.75 (.54)	3.69 (0.54)
To have questions answered honestly	3.72 (.54)	–
To be told of the reason for the chosen treatment of my relative	3.70 (.54)	–
To understand everything that occurs with the condition of the patient	3.68 (.61)	–
To be assured that the best care is being given to the patient	–	3.71 (0.52)
To educate the family about the condition of the patient	–	3.65 (0.55)
To know specific facts concerning the patient's progress	–	3.58 (0.61)

FM, family members; HCP, health care providers.

that assurance and information needs were the most important needs for ICU families (Kleinpell and Powers, 1992; Kosco and Warren, 2000; Al-Hassan and Hweidi, 2004; Omari, 2009; Chatzaki *et al.*, 2012). This finding reveals that during the immediate phase of the patient's stay in the ICU when the family's anxiety is high the major concern of Saudi families is to be reassured that their patient is receiving the best care and to receive straightforward, realistic and consistent information.

The need for assurance is important as it can alleviate stress and reduce uncertainty and increase families' hopes of better outcome expectations (Leske, 1992). Saudi families expressed a need to be reassured by the ICU team. Such an outcome indicates that the admission of a family member to ICU increases family stress, sense of hopelessness and anxiety which leads towards a greater need for reassurance. However, reassurance by the ICU team does not occur with such restricted visiting practices in ICUs of most hospitals in Saudi Arabia where family members can infrequently meet the treating doctors and where nurses are not authorized to release any information to families.

Assurance needs were rated significantly ( $p=0.02$ ) less important by families of patients admitted in the ICU for 10–30 days. During the immediate phase of critical illness (within the first 72 h) relatives need to be more assured of the best care provided and about the condition of their loved one and thus, this statistically significant relationship is not surprising (Titler *et al.*, 1995). After that, relatives' need for information, support and remaining close to their patient are considered more important and of higher priority than assurance needs.

The families of ICU patients perceived receiving information and knowledge as the next most important subscales. They needed detailed information of the patient's condition and about what is being done for the patient. It is entirely reasonable that family of a critically ill member seeks information and knowledge of their family member's condition. Saudi Arabia has a young population in general, with a median age of 21.5 years (MOH, 2011), resulting in families being more educated and more aware of their needs regarding information. In addition, information, if communicated effectively, should help families to make the right decision and assist to alleviate their anxiety and stress. A variety of instructional materials should be made available to help families gather information about their ICU patient and critical care environment; for instance, providing information in the form of pamphlets or planned telephone calls and information websites (Paul & Rattray, 2007).

Expatriate health care providers demonstrated better understanding of assurance and information needs than did Saudi health care providers. The expatriates ranked the needs under categories of assurance ( $p=0.03$ ) and information ( $p<0.0005$ ) higher than Saudi health care providers. This raises questions about the medical and nursing curriculum in Saudi Arabia, whether they place emphasis on the needs of families. These data strongly suggest placing greater emphasis in the nursing and medical curriculum in Saudi Arabia to include family needs and building an empathetic collaborative partnership with the families of ICU patients.

A recent study conducted by Chatzaki *et al.* (2012) reported a statistically significant relationship between older respondents and ranking of family needs. Contrary to Chatzaki *et al.* (2012) in this study, age of family members as well as health care providers was found to have no influence on family needs. Nationality of family members, level of education and the relationship to the critically ill patient in this study also did not give rise to differences in the importance of family needs. This is again in contrast to research where these variables have been associated with the family needs. Leske (1992) for example, reported that adult children rated the family needs for comfort as less important than did the spouses of the patients. Furthermore, Chatzaki *et al.* (2012) reported that family members' education level greatly influenced the families ranking of importance of needs for support.

### Cultural and spiritual needs

The cultural and spiritual dimension in the Saudi modified version of CCFNI was perceived by both family members and ICU health care providers as the third

most important need, this has not been identified in previous studies. A significant finding of this study concerned the item 'To have the health care providers handle the body of the dead Muslim with extreme caution and respect'. This need was perceived as the most important need by family members and the fifth most important need by the health care providers. Muslims believe that the dead feel pain and pressure and therefore, should be handled minimally and with great gentleness (Wehbe-Alamah, 2008). In addition, the Saudi families might be concerned to minimize touching the body of the dead Muslim as much as possible by the health care providers and to discourage them from touching the body, if they are not of the same sex.

These findings in relation to the handling the body of the deceased Muslim provide further validation that the Islamic religion and the Saudi culture guide the ways of living for many of Saudis. The health care providers in this regard shared the same perception with family members, despite the fact that health care providers in this study were of 13 different nationalities. These findings suggest that beliefs of the Saudi culture were adopted and learned by the expatriate health care providers and that they are sensitive to the importance of respecting the Muslim body after death. Such results indicate that cultural and spiritual needs are important and should be of major concern to the hospital administration and ICU staff. It is crucial that health care providers understand the family needs from the perspective of families. Non-Muslim health care providers when caring for Saudi patients and families should be fully aware of the Islamic religion and Saudi culture. This should assist Saudi families to receive more holistic and family-centred care and can facilitate some meditation and comfort, hope to hold onto, quiet strength and calmness of heart.

In fact, providing culturally congruent care to the patients and their families is the duty of each health care provider. Also, the administration should ensure that Saudi patients and families receive culturally congruent care and that the Saudi cultural values and beliefs are learned and adopted by the non-Saudi health care workers. The family anxiety can be decreased through exploring and explaining the medical facts in a merciful manner. The hospital administration should take action to face the patient's bed towards the Holy Mosque in Mecca if possible, as the beds in the participating ICUs were not entirely directed towards the Holy Mosque in Mecca.

#### Proximity and support needs

In this study, proximity was ranked fourth and support fifth as the most important family needs dimension by family members, whereas health care providers ranked

support fourth and proximity fifth as the most important family needs. Of the five least important item needs that were identified by family members two were listed in the proximity, and one was listed in the support subscale. This is applied to findings of other studies which were conducted in Western and Muslim cultures (Lee *et al.*, 1999; Kosco and Warren, 2000; Al-Hassan and Hweidi, 2004; Yang, 2008; Omari, 2009; Chatzaki *et al.*, 2012). An important comment to be made here is that families and health care providers do not consider the needs of support and proximity unimportant but they score them lower than the assurance, information and cultural and spiritual needs (Verhaeghe *et al.*, 2005).

The Saudi family has strong ties and reflects a mutual commitment between the family members. The implication of this mutual commitment between family members includes visiting ill relatives, as this is highly encouraged in the Islamic teachings and Saudi culture. Visiting the sick person also considers providing emotional, psychological and financial support to the patient and to the whole family. Participants in this study possibly regarded proximity and support as least important because they wanted ICU staff to focus on the health condition and preserve the patient's life, and families sacrificed their needs for proximity and support. This finding also can be explained from the perspective of Saudi culture as this type of support can be provided by the extended family to the patient and to the close relatives.

An interesting association was that family members of female patients ranked support significantly ( $p=0.03$ ) more important than family members of male patients. This contradicts Omari's (2009) findings which detected no influence of family members of male and female patients on rating of importance of family needs. Almost 38% of the patients were females of siblings, parents or daughters of the participant family members. Women in Islam are regarded as more vulnerable than men and accorded special support and protection, especially during such crisis situations. This vulnerability of women necessitates the protection and support from men which is highly reflected in the Islamic teachings. The Prophet Mohammed has said 'I command you to be kind to women ... The best of you is the best to his family/wife'.

Nurses in this study rated the family need for information ( $p=0.01$ ) as more important than physicians and respiratory therapists. Respiratory therapists rated support ( $p=0.01$ ) as less important than physicians and nurses. These findings are similar to the results of earlier study by Gelling and Prevost (1999), which demonstrated that nurses and doctors do not share the same perception of family needs. These discrepancies might be due to that the perception of the critical care

team was influenced by their profession and the role of each profession. Gelling and Prevost (1999) suggested that relatives were answering the questionnaire for their single loved one. Health care providers, however, were answering the same questionnaire based on many past experiences with patients and their families this also serves to explain the finding in this current study. It is significant that ICU staff assess each family individually and plan to help that family.

One study found that years of ICU health care providers experience had an influence on perception of family needs (Kosco and Warren, 2000). The authors noted that the less experienced ICU staff may not be as prepared to deal with the family needs, as the more experienced staff. In this study, however, it was found that ICU health care providers with less than 1 year working experience ranked support needs ( $p=0.03$ ) more important. This result reveals that the novice ICU health care providers demonstrated more conscious awareness and understanding of the support needs than did the more experienced staff.

#### Limitations

This study has several limitations; a limitation in the data collection process related to the inclusion of family members within 24 h of their family members' admission to the ICU, because family members are highly stressed during such times. The use of a non-probability convenience sample with family members and ICU health care providers limits the generalizability of the findings. The low response rate of doctors and respiratory therapists could result in biased doctor-nurse and respiratory therapist-nurse comparisons. Only those who were interested in the topic completed the questionnaire which may cause non-respondent bias.

#### CONCLUSION AND CLINICAL IMPLICATION

Most family members and health care providers identified assurance, information, cultural and spiritual needs as most important, and support and proximity as least important needs. This family needs study has produced the first results in relation to clarifying family and relatives and health care provider needs in Saudi Arabian intensive care environments. Of critical importance is the acceptance that Muslim families have different needs to Western families in respect to cultural and spiritual needs. Families are also in need of support by the health care team in a much more patient and family-centred fashion. In previous studies and in this study, it has been demonstrated that families have needs and developing interventions to meet these needs must become a priority which can enhance the care provided by the ICU health care providers. The study can help in providing knowledge and awareness which can help ICU health care providers caring for Muslim patients and families in any place in the world. The findings can also help to change the care model from conventional medical approach to a family-focused care model that respects all needs of the patient and their families. It could also contribute to the development of nursing curricula and staff support training programs in Saudi Arabia to identify and meet family needs through a more empathetic model of patient-centred care.

#### ACKNOWLEDGEMENT

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#### WHAT IS ALREADY KNOWN ABOUT THE TOPIC?

- Family needs for information and to be assured that their relative is receiving the best care were perceived as the most important family needs.
- Family members have needs which if unmet may produce stress on patients, families and critical care medical team.

#### WHAT THIS PAPER ADDS?

- Both family members and health care providers perceived assurance, information, cultural and spiritual needs as most important, and support and proximity as least important needs.
- Muslim families have different needs to Western families in respect to cultural and spiritual needs.
- The Islamic cultural values and spiritual healing beliefs have therapeutic calming and assurance effects on families.

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# Appendix O: Article V: Attitudes of healthcare providers towards family involvement and presence in adult critical care units in Saudi Arabia: a quantitative study

ORIGINAL ARTICLE

## Attitudes of healthcare providers towards family involvement and presence in adult critical care units in Saudi Arabia: a quantitative study

Abbas Al Mutair, Virginia Plummer, Anthony Paul O'Brien and Rosemary Cleehan

**Aims and objectives** To describe healthcare providers' attitudes to family involvement during routine care and family presence during resuscitation or other invasive procedures in adult intensive care units in Saudi Arabia.

**Background** Previous research has shown that healthcare professionals have revealed a diversity of opinions on family involvement during routine care and family presence during resuscitation or other invasive procedures. Attitude assessment can provide an indication of staff acceptance or rejection of the practice and also help identify key potential barriers that will need to be addressed. It has also been evident that participation in the care has potential benefits for patients and families as well as healthcare providers.

**Design** A quantitative descriptive design.

**Methods** A questionnaire was used with a convenience sample of 468 healthcare providers who were recruited from eight intensive care units.

**Results** The analysis found that healthcare providers had positive attitudes towards family involvement during routine care, but negative attitudes towards family presence during resuscitation or other invasive procedures. Physicians expressed more opposition to the practice than did nurses and respiratory therapists. Staff indicated a need to develop written guidelines and policies, as well as educational programmes, to address this sensitive issue in clinical practice.

**Conclusion** Family is an important resource in patient care in the context of the critical care environment. Clinical barriers including resources, hospital policies and guidelines, staff and public education should be taken into account to facilitate family integration to the care model.

**Relevance to clinical practice** The findings can help to develop policies and guidelines for safe implementation of the practice. They can also encourage those who design nursing and other medical curricula to place more emphasis on the role of the family especially in critical care settings.

What does this paper contribute to the wider global clinical community?

- Family is an important resource in patient care that should receive support and be involved for better patient outcomes.
- Physicians may oppose family involvement more than nurses as they generally spend less time at the bedside, less time engaging with families and have less time to observe the benefits of family involvement to patient and family.
- The most common reason for opposing family presence during resuscitation and other invasive procedures in this study was that healthcare providers were concerned that the family members might suffer from traumatic effects.

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**Key words:** attitudes, family involvement during routine care, family presence during resuscitation or other invasive procedures, healthcare providers, intensive care unit, quantitative, Saudi Arabia

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## Introduction

The urgent admission of a patient to the intensive care unit (ICU) increases family stress exponentially. The family is left with considerable psychological tension, including anxiety, uncertainty and the fear of losing a loved one (Hom & Teoh 2000). Healthcare providers are generally very patient-focused and can be seen to neglect the family because of their concern for the patient. Nevertheless, to focus on the person should be inclusive of the family especially when the care is holistic and collaborative and when it has been demonstrated that family has a strong impact on the patient's response to treatment (McLaughlin 1993).

The Ministry of Health (MOH) is responsible for overseeing a network of health services in Saudi Arabia, and it is the largest provider of public health services across the country. Health care is delivered through an integrated system organised at national, regional and district levels and supported by a viable private sector. Clinical and medical research centres are growing rapidly in number, size and complexity to keep pace with population growth and demand – an outcome of the Kingdom's improved socio-economic position as a major oil-producing country since 1950. Hospitals serve as treatment and referral centres supported by primary healthcare centres at the community level. The workforce in MOH is a mix of Saudi and a significant expatriate workforce, which is recruited primarily from other Arab and Muslim countries, but also from countries such as India, China and the Philippines and several Western countries.

## Literature review/Background

Caring for the family is an important component of caring for the patient which can be achieved when the families are involved in the care, taking into account their contributions and input (Booby 2000). This development has implications for the working situation of nurses and other healthcare professionals and ultimately for the quality of care delivered (Takman & Severinsson 2006). The inclusion of families in the care of the ICU patient can provide them with

some satisfaction and emotional re-assurance and would be empowering and supportive to the ICU patients and their family members (Al Mutair *et al.* 2013). Studies related to family involvement in routine care and family presence during resuscitation and other invasive procedures examined the perspectives of family members or healthcare providers or compared the two perspectives. Those studies chosen were conducted in different locations, languages and cultures including USA, UK, Sweden, Canada, Australia, Turkey, Greece, Hong Kong, Iran and Saudi Arabia. Most of the studies used quantitative descriptive approaches using a convenience sample, and only a few studies used qualitative approaches to explore the family involvement in the care. Prior to this study, there had been only one quantitative study which addressed the issue of family presence during resuscitation in Saudi Arabia, which revealed a general opposition to the practice by the participating nurses (Al-Mutair *et al.* 2012).

## Family involvement during routine care

Family members have suggested that their participation in the care of their family member provides them with some satisfaction due to the belief that they can be of help to support the patient physically and psychologically (Astedt-Kurki *et al.* 1997, Eldredge 2004, Vandall-Walker *et al.* 2007). Healthcare providers, however, have a diversity of opinions about the role of family members in the patient care process. Hammond (1995) investigated family members' and nurses' perceptions regarding family involvement during routine care. The major concerns emerging from the nurses' sample were the problems of role adaptation for nurses and building their relationship with families.

Schiller and Anderson (2003) also explored the ICU nurses' perceptions of family involvement; unlike Hammond (1995), nurses here indicated satisfaction with family participation which eased the communication and facilitated better more positive relations with the families. Soderstrom *et al.* (2003) interviewed 10 nurses working in the ICU of two hospitals in Sweden who described their experiences of interactions with family members. The study

revealed that nurses considered family members important in the care provided to the patient, and attempts to engage them in care provision were fruitful. Nurses, however, also believed that medical and technical tasks were considered to be the most important nursing duties. They described themselves as experts, having little time for family members and having difficulties in the development of relationships with families. They also did not want interference in their work by the family members and felt disturbed by the family's presence in the ICU. In the Benzein *et al.* (2008), Fisher *et al.* (2008) and other recent studies, results indicated that nurses' attitudes and behaviours towards family presence were favourable. Importantly, when nurses held a supportive attitude, families would be invited to cooperate as partners in nursing care (Soderstrom *et al.* 2003, Benzein *et al.* 2008, Fisher *et al.* 2008).

#### Family presence during resuscitation and other invasive procedures

Family presence during resuscitation or other invasive procedures is a perennial topic of debate among healthcare providers. The literature has shown that attitudes of nurses, physicians and families towards family presence have been found to be significantly different (Meyers *et al.* 2004, Moreland & Manor 2005). Some healthcare providers fear that family members may end up having traumatic memories of the experience of being in the ICU and are concerned that family presence would adversely affect the performance of the resuscitation team (Koberich *et al.* 2010), whereas many family members indicated they would prefer to remain with the patient during resuscitation and other invasive procedures (Meyers *et al.* 2004, Holzhauser *et al.* 2006). Physicians were found to be more against family presence during resuscitation and other invasive procedures than nurses (Meyers, Ebbom, Guzzetta, Clark, Klein & Taliaferro 2000; McClenathan *et al.* 2002, Maclean *et al.* 2003, Knott & Kee 2005, Mian *et al.* 2007). In other research, healthcare providers suggested that family members who are present during resuscitation or other invasive procedures might draw comfort from sharing the last moment with the patient (Fullbrook *et al.* 2005). According to this view, allowing family members to be present would reassure them to see that everything possible was done to save the patient.

Studies on family presence have mostly been undertaken in Western countries, but recently, a number of studies have been conducted in nonWestern and Muslim communities to assess the healthcare providers' attitudes

towards the practice (Badir & Sepit 2007, Cunes & Zaybak 2009, Kianmehr *et al.* 2010, Al-Mutair *et al.* 2012, Leung & Chow 2012). These healthcare providers seemed to oppose allowing families to be present during resuscitation or other invasive procedures. However, they also endorsed a need to develop written guidelines, policies and education standards for safe implementation of the practice and to increase public awareness. Al-Mutair *et al.* (2012) and Leung and Chow (2012) suggest that if the staff have a positive attitude towards the family and they are well informed and accompanied by a medical staff member to assess the family, such an event provides greater emotional and psychological support. To test this further, the aim of the current study is to describe the attitudes of healthcare providers towards family involvement during routine care and family presence during resuscitation or other invasive procedures in adult ICUs in Saudi Arabia.

## Methods

### Study design and setting

A quantitative descriptive design was adopted to capture the attitudes of the healthcare staff. This study is part of a larger one and was conducted in eight mixed medical-surgical adult ICUs at eight different hospitals. The hospitals were located in different geographical areas of Saudi Arabia. The care model in the units was a patient-focused care model, and the units had restricted visiting practices where relatives commonly could visit only one hour per day. There are no waiting rooms in most of the ICUs in Saudi Arabia to accommodate family members during visiting time. Therefore, the ICU visitors wait in the ICU corridor to be allowed to visit their loved one. This can be seen as a way of actively discouraging visitors who can be numerous and perceived as emotional and demanding of the health professionals.

The inclusion criteria were permanent healthcare providers who worked in the adult ICU to ensure that they expressed their experience and comment on the environment in which they regularly worked. There are three professional groups who work in the ICUs – physicians, nurses and respiratory therapists. All professional groups were asked to participate in the study by completing a questionnaire developed for the study. A power calculation indicated that a total of 125 respondents were needed to detect a 5% difference in index means between hospitals and professional groups. The power was calculated at 80% ( $p < 0.05$ , two-tailed).

### Questionnaire

The questionnaire developed by the first author consisted of two parts – part one related to demographic characteristics and part two was designed to identify healthcare providers' attitudes to family involvement during routine care and family presence during resuscitation and other invasive procedures. This second part consisted of 19 statements and was divided as follows: there were 12 items on healthcare providers' attitudes towards family involvement during routine care and seven items on family presence during resuscitation or other invasive procedures scale. The statements were derived through a process of analysis of the related literature and personal clinical experience. Responses to these items were recorded on a four-point Likert-type scale where respondents indicated to what extent they agreed or disagreed with each statement. Polit and Beck (2004) state that a Likert-type scale response format is used to place respondents on a continuum with respect to an attribute or content domain. This method of rating is also, fairly simple to construct, very reliable and amenable to measuring many types of abstract qualities (Polit & Beck 2004). Free comments were sought at the end of the questionnaire to add further opinions which may not be covered by the questions.

### Pilot test

Ethical approval to undertake this study was granted by a local ethics committee, the General Administration of Medical Research (GAMR), in the Saudi Arabian Ministry of Health. The research questionnaire was tested for validity and reliability. Content validity was determined by a panel of 12 experts: nine academics, critical care nurses, nurse managers and a statistics consultant, and their comments were considered in revising the questions. The questionnaire was then trialled in one of the participating units. A total of seven ICU staff including physicians, nurses and respiratory therapists completed the questionnaire. Results from the pilot study showed that the questionnaire items were relevant and easy to understand. The reliability of the instrument was determined by the application of Cronbach's  $\alpha$  coefficient, and the  $r$ -value was accepted as 0.79.

### Data collection

Data were collected over four months between November 2011–February 2012. Participation was anonymous, and an information sheet accompanied all questionnaires. The

information sheet explained the study purpose, a statement of assurance of anonymity, confidentiality and voluntary participation. Participants were allowed to keep the information sheet.

Due consideration was given to recruitment of the largest possible sample size, as in quantitative research, the sample size needs to generate a sample representative of the population (Teddle & Tashakkori 2009). Polit and Beck (2012) also made a similar recommendation noting that the larger the sample, the more representative it is likely to be. Quantitative studies with inadequate sample sizes run the risk of gathering data that will not support the research hypotheses (Burns & Grove 2009, Polit & Beck 2012). Consequently, the larger the sample, the smaller the sampling error (Polit & Beck 2012). Therefore, a total of 1100 questionnaires were distributed to a nonprobability convenience sample of healthcare providers, and 468 (42.5%) of eligible healthcare providers completed the questionnaire.

### Data analysis

Analysis was conducted using *SPSS*, version 20.0 (IBM, Melbourne, Vic., Australia), and the data set was screened and checked for errors. Descriptive statistics were employed to describe the data by summarising them into more understandable terms (Munro 2005), and descriptive statistics including mean, standard deviation and percentages were used to describe the healthcare providers' demographic characteristics and attitudes. Inferential statistics were also used which involved testing the differences or relationships between groups or variables (Teddle & Tashakkori 2009). An independent sample *t*-test and analysis of variance (ANOVA) were used to test for the differences in means across categories. An independent sample *t*-test was also used to determine the relationship between demographic characteristics and attitudes towards the practice to predict the factors for and against the practice. All statistical analyses were considered significant at the 0.05 level (Munro 2005). The comments were read several times and then were aggregated and analysed for common themes and meanings. It was noted whether the comment originated from a physician, nurse or respiratory therapist.

## Results

### Sample characteristics

The age range of participants was from 22–62 years, and there was an uneven gender spread (72 male, 394

Table 1 Socio-demographic details (n = 468)

Socio-demographic item	Subgroups	Frequency	Percentage
Age	22	2	0.4
	23–42	414	92.4
	43–62	32	7.1
	Missing	20	
Sex	Male	72	15.5
	Female	394	84.5
	Missing	2	
Nationality	Saudi	59	12.6
	Non-Saudi	408	87.3
	Missing	1	
Level of education	Diploma	215	45.9
	Hospital training	2	0.4
	Bachelor	232	49.6
	Master	13	2.8
	PhD	6	1.3
Healthcare profession	Nurse	391	83.5
	Physician	35	7.5
	Respiratory therapist	42	9
Years of employment	Less than one year	15	3.2
	One to five years	216	46.5
	6–10 years	126	27.1
	More than 10 years	108	23.1
	Missing	3	
Years of experience in Saudi Arabia	Less than one year	54	11.6
	One to five years	297	64
	6–10 years	62	13.4
	More than 10 years	51	11
	Missing	4	

female). Healthcare providers were predominantly non-Saudi (87.3%), nurses (83.5%), and their academic qualifications varied from diploma level to a postgraduate university degree. The healthcare providers' years of working experience and experience in Saudi Arabia mainly ranged from <1–10 years (Table 1).

#### Involvement during routine care

As illustrated in Table 2, the analysis showed that the healthcare providers were in general agreement with most of the 12 items and revealed positive attitudes towards family involvement during routine care in the ICU. Participants agreed that family members should be given the option to provide activities of daily living. Healthcare providers expressed the view that allowing family involvement would reduce the family anxiety and fear and would impact positively on the progress of the patient's treatment. Also, 57.9% believed that 'the presence of family members impacts positively on the patient's treatment progress'. Sixty-per cent of the healthcare providers 'agreed' and 'strongly agreed' that 'if present, family members will be able to recognise that everything possible was done to save the patient', and 63.3% believed they were 'not too busy to be able to involve the family in the care process'. In addition, the majority (64.5%) claimed that they 'had sufficient training to meet the family needs'. However, they disagreed with the statement that 'it is easier to manage critical

Table 2 Attitudes of healthcare providers towards family involvement during routine care (n = 468)

Statement	Strongly disagree%	Disagree%	Agree%	Strongly agree%
If requested by the family, they should be allowed to provide activities of daily living	14.4	41	41	3.9
I support patient wishes for family members to be present during daily patient care	21.6	46.3	27	5.1
Family presence during patient care would help family to gain spiritual comfort	16.3	39.9	38	5.9
Allowing family presence during patient care will reduce the family anxiety and fear	15.6	40.7	38.5	5.2
The presence of family members impacts positively on the patient's treatment progress	7.7	34.9	48.7	9.2
If present, family members will be able to recognise that everything possible was done to save the patient	9.4	30.7	50.8	9.2
It is easier to manage critical family members' issues when they are present in the room with the patient	27.4	48.4	21.4	2.8
My clinical performance will be affected by relatives' presence	8.8	28	43	20.2
The presence of family members makes me feel stressed	7.5	36.6	43.9	12
I believe I have had sufficient training to involve the family	6.9	29.9	54	9.1
I am too busy to be able to involve the family in the care process	11.6	51.7	31	5.6
I believe I have had sufficient training to meet the family needs	6.5	29	54.1	10.4

family members' issues when they are present in the room with the patient'.

There was a statistically significant difference between Saudi and nonSaudi healthcare providers and their attitudes towards family involvement. Saudi healthcare providers agreed with family involvement during routine care more than did the nonSaudis. With a mean difference of 2.50,  $t_{453} = 3.81$ ,  $p = 0.006$ , Saudi scored higher (mean 30.76, SD 3.885) than did nonSaudi healthcare providers (Table 4). There were also statistically significant differences in attitudes among physicians, nurses and respiratory therapists. Physicians expressed more opposition to family involvement than did nurses and respiratory therapists  $F_{2,465} = 3.20$ ,  $p = 0.04$ , physicians scored less mean (31.00, SD 4.16) than did nurses and respiratory therapists (Table 4).

#### Family presence during resuscitation or other invasive procedures

The healthcare providers showed opposition to family presence and a resistance to the suggestion of allowing family members to be present during resuscitation and other invasive procedures of their critically ill patients in the ICU (Table 3). Healthcare providers who opposed the practice expressed a variety of reasons. Of the participants, 79.2% 'agreed' and 'strongly agreed' that 'family presence during invasive procedures or resuscitation is a traumatic experience for the family members'. However, despite their opposition, healthcare providers (64.2%) suggested that 'if relatives would like to be present during resuscitation or other invasive procedures, they should be well informed and sign consent'. Moreover, almost half (49.4%) stated that 'the hospital should develop guidelines to support family involvement and give family the option to attend invasive procedures and resuscitation', and 64.2% expressed

**Table 4** Comparisons of statistically significant relationships among groups according to mean and standard deviation

Practice	Comparison group	Mean (SD)
Family involvement during routine care	Saudi	30.76 (3.88)
	NonSaudi	28.26 (4.74)
	Nurses	32.83 (4.76)
	Physicians	31.00 (4.16)
Family presence during resuscitation and other invasive procedures	Respiratory therapists	32.30 (4.22)
	Male	18.00 (3.97)
	Female	19.69 (3.48)
	Saudi	17.91 (3.93)
	NonSaudi	16.02 (3.51)
	Nurses	18.80 (3.53)
	Physicians	17.18 (3.80)
	Respiratory therapists	18.62 (3.92)

the view that 'the hospital should develop training programme for nurses to support families when they attend invasive procedure or resuscitation'.

There was a statistically significant relationship between sex and healthcare providers' attitudes to family presence during resuscitation or other invasive procedures. Male healthcare providers opposed family presence during resuscitation and other invasive procedures significantly more than females with a mean difference of 1.69,  $t_{464} = 3.78$ ,  $p = 0.0005$  (Table 4). As illustrated in Table 4, male healthcare providers scored less mean (18.00 SD, 3.97) than female healthcare providers (19.69 SD, 3.48). The results also indicated a statistically significant relationship between Saudi and nonSaudi healthcare providers and attitudes towards the practice. The Saudi healthcare providers indicated more agreement with the family presence during resuscitation or other invasive procedures than did non-Saudis mean (17.91 SD, 3.93) with a mean difference of

**Table 3** Attitudes of healthcare providers towards family presence: resuscitation or other invasive procedures ( $n = 468$ )

Statement	Strongly disagree%	Disagree%	Agree%	Strongly agree%
The presence of family during invasive procedure or CPR would assist the staff to get the history quickly	43.5	36.4	17.3	2.8
Relatives have the right to request to stay during resuscitation or any other invasive procedure	4.5	33.8	18.8	2.4
If relatives would like to be present during resuscitation and other invasive procedures, they should be well informed and sign consent	16.7	1.9	45.2	1.9
Family presence during invasive procedure or resuscitation is a traumatic experience for the family members	7.6	13.3	45.9	33.3
The hospital should develop guidelines to support family involvement and give family the option to attend invasive procedures and resuscitation	21.7	2.9	35.2	14.2
The hospital should develop training programme for nurses to support family when they attend invasive procedure or resuscitation	11.9	23.9	45.7	18.5
I support the practice of allowing family members to be present during invasive procedures and resuscitation	35.3	43.6	17.1	4.1

1.89,  $t_{72.75} = 3.62$ ,  $p = 0.001$  (Table 4). Additionally, statistically significant differences were detected in attitudes among physicians, nurses and respiratory therapists. Physicians expressed more opposition to family presence during resuscitation and other invasive procedures than did nurses and respiratory therapists  $F_{2,465} = 5.63$ ,  $p = 0.0005$  (Table 4).

While the open-ended item did not provide any new data, it served to confirm the survey results. One healthcare provider confirmed the findings that families benefit from being involved in the care as follows *Family involvement during routine care can be integrated in spiritual and mental development and this decreases family stress*. Participants supported family involvement during routine care, but were concerned that they were breaking new ground without proper guidance, one participant suggested *there should be a guideline to implement the practice*. On the other hand, some expressed caution, possibly reflecting on their experience of past traumatic resuscitations, and one participant expressed the view that *family presence during resuscitation and invasive procedures may worsen the patient's condition and upset the family*.

## Discussion

The purpose of the study was to describe the attitudes of ICU healthcare providers towards the involvement of families during care and family presence during resuscitation or other invasive procedures concerning their loved ones in ICU. This study is the first of its kind on the attitudes of ICU healthcare providers towards family involvement during routine care in Saudi Arabia.

### Healthcare providers' attitude towards family involvement during routine care

Healthcare providers had a positive attitude towards family involvement during routine patient care. The healthcare providers reported agreement with most of the 12 items of family involvement during routine care. The healthcare providers indicated that 'the presence of family members impacts positively on the patient's treatment progress', and family members 'if present, will be able to recognise that everything possible was done to save the patient'. This finding is consistent with current literature (Benzein *et al.* 2008, Fisher *et al.* 2008). The ICU staff also agreed that their clinical performance would not be affected by relatives' presence. Healthcare providers who had positive attitudes towards family involvement acknowledged families as a resource, believed that family members were

important and a prerequisite for good care and were regarded as a natural part of the caring process. They did not complain about the lack of time to look after families. Furthermore, ICU healthcare providers believed that they had sufficient training to involve the family and to meet the family needs. This perception, however, should ease the integration of family into the critical care environment, highlighting the implementation of family-centred care by including the Patients' significant others.

Participants who did not support patients' requests for family participation during daily care agreed that the presence of family members made them feel stressed. They stated that they could barely manage critical care issues when family members were present in the ICU. It seems that those healthcare providers felt threatened by family involvement and therefore opposed the practice because of they are stressed by the change caused by family presence or lack of time or even impacts on clinical performance. Soderstrom *et al.* (2003) have suggested that some nurses believed that patient care, medical and technical tasks were considered to be the most important nursing duties and that they considered themselves as experts, having little time for family members. Nurses also did not want interference in their work by the family members and felt disturbed by the presence of family members.

The healthcare providers' setting, age, sex, level of education, years of professional experience and experience living in Saudi Arabia did not appear to influence their attitudes towards family involvement during routine care. This is in contrast to research where ICU staff attitudes were influenced by the length of working experience (Schiller & Anderson 2003). It was found that the nurses with less experience held more positive attitudes than the more experienced nurses towards family involvement, and there was a statistically significant difference in attitude in relation to nationality ( $p = 0.006$ ). In the current study, Saudi healthcare providers supported family involvement during routine care more than did expatriate healthcare providers. This finding suggests that the Saudi medical team appreciated the need for family members of critically ill adults to be involved in the care of their loved one. The Saudi healthcare workers would better understand the needs of Saudi families as they share with them the same culture, values and norms.

Another statistical significant difference was found in this study, in which physicians expressed opposition to family involvement during routine care ( $p = 0.04$ ) more than did nurses and respiratory therapists. This may be because physicians spend less time at the bedside, less time engaging with families and have less time to observe the benefits to patient and family than nurses and respiratory therapists.

Nurses and respiratory therapists in turn have a more holistic view of the patient care and so acknowledge the needs of families; accordingly, they may engage family members to provide some fundamental care for the patient.

#### Healthcare providers' attitude towards family presence during resuscitation and other invasive procedures

The mean score for the multidisciplinary ICU staff who participated in this study indicated a negative attitude towards family presence during resuscitation and other invasive procedures. Nearly 80% of the sample in this study, which incorporated physicians, nurses and respiratory therapists, did not favour the practice of family presence during resuscitation. This is similar to studies conducted in Turkey, Iran, Germany and Hong Kong which also showed a high percentage of opposition to family presence during resuscitation (Cunes & Zaybak 2009, Kianmehr *et al.* 2010, Koberich *et al.* 2010, Leung & Chow 2012). In these studies, medical staff displayed negative attitudes towards the practice of family presence and disagreed that family members should be present during resuscitation or any other invasive procedures. Whether or not to allow family presence remains a matter of current controversy among healthcare providers in many settings including Saudi Arabia (Al-Mutair *et al.* 2012).

The majority of healthcare providers (78.8%) denied the relatives' right to request to stay during resuscitation or any other invasive procedure. They also did not believe that family presence would assist the staff to obtain a timely medical history. In a recent study conducted by Al-Mutair *et al.* (2012), a similar result was reported, and 74.9% of ICU nurses denied the relatives' right to stay during resuscitation. Al-Mutair *et al.* (2012) commented that healthcare providers may fear emotional disturbance and traumatic experience when families witness the procedures. Healthcare providers may fear also that their performance will be affected by family presence.

In this study, the findings were similar to McClenathan *et al.* (2002), Knott and Kee (2005) and Badir and Sepit (2007), in that the most common reason for opposing the practice was healthcare providers' fear of a traumatic experience for the family members. However, in Meyers *et al.*'s study (2004), which surveyed family members to investigate their attitudes towards family presence during resuscitation and other invasive procedures, it was found that family members thought it was their right to be present with their loved one, and follow-up did not show they suffered from traumatic effects. Similarly, Holzhauser *et al.* (2006) in their study showed that none of the participating family

members felt pressured or traumatised and the majority preferred to be present. Meyers *et al.* (2000) had very similar findings where they surveyed a total of 96 medical staff; 14 physicians, 22 residents and 60 nurses, who had participated in resuscitation or an invasive procedure with family members. The majority (95% of the nurses, 77% of physicians and 64% of the residents) were comfortable with family presence, and 84% believed that their performance was not affected by the family's presence.

The current study demonstrated that staff had positive attitudes if family members were well informed and signed a consent form. In a study by Leung and Chow (2012), there was an agreement by healthcare providers to allow family presence only if the family was well informed and was accompanied by a facilitator. The facilitator member should assess the families for coping abilities and for the absence of any psychological and emotional disturbance. According to Leung and Chow (2012), the facilitator member is to be selected from the resuscitation team and has an important role to follow up and explain to the family throughout the procedure. The need for signed consent was also endorsed by ICU healthcare providers for safe implementation of family presence during resuscitation or other invasive procedures. Al-Mutair *et al.* (2012) noted that the practice constitutes a breach of confidentiality without prior consent by patient and family.

In the present study, no real differences in terms of positive or negative attitudes were evident among healthcare providers in relation to hospital, age, level of education, years of working experience and experience in Saudi Arabia. Kianmehr *et al.* (2010) similarly noted that staff participants' age did not correlate with staff attitudes. For family presence and level of education, Ellison (2003) found a statistically significant relationship between education level and positive attitudes ( $p < 0.01$ ).

An interesting and significant finding in the present study ( $p < 0.0005$ ) was found between healthcare providers' sex and attitudes. Male healthcare providers opposed family presence more than female healthcare providers. Most of the nurse respondents were women, and most of the physician respondents were men. This was surprising as women may be thought to have high sensitivity to stressors and to be more likely than men to develop emotional disorders when exposed to traumatic experiences (McDonough & Walters 2001). Possibly one might argue that the attitudes of male healthcare providers were dominated by their professional role, whereas the women were conscious of the emotional element in care. This emotional element might help female healthcare providers to understand the distressing impact on relatives if they were not present during

resuscitation or other invasive procedures and thus may explain why female healthcare providers were more positive regarding family presence.

One statistically significant finding inconsistent with the literature was detected between nationality and attitudes ( $p = 0.001$ ). The results show that Saudi healthcare providers agreed that family members should have the option to be with the patient during resuscitation or other invasive procedures, more than did the non-Saudi. It is possible that Saudi healthcare providers are more liberal in their viewpoints, and they share strong cultural values with family members. Although healthcare providers often work as a team in the ICU environment, they develop different thoughts towards family presence during resuscitation or other invasive procedures. Physicians were found to oppose the rights of patients to have their families present during resuscitation or other invasive procedures more than their nurses and respiratory therapist colleagues ( $p < 0.0005$ ). As reported in Meyers *et al.* (2000), McClenathan *et al.* (2002), Maclean *et al.* (2003) and Moreland and Manor (2005), this difference of opinions may be related to nurses' more holistic view of the patient. According to Moreland and Manor (2005), physicians are patient-focused; however, nursing places more emphasis on the patient's role within the family system, recognising the importance of the family to the physical and emotional well-being of the patient.

Despite the fact that healthcare providers held negative attitudes towards family presence, they reported a need for training programmes to support the family when they attend resuscitation or other invasive procedures, a finding congruent with other work (Al-Mutairi *et al.* 2012). A number of studies including Fullbrook *et al.* (2005), Mian *et al.* (2007) and Koberich *et al.* (2010) also emphasised the need to develop educational programmes for medical staff on the safe implementation and practice of family presence. According to Koberich *et al.* (2010), the training programme would assist staff to increase their confidence, overcome any fears and support the family during the situation; such topics were planned to be introduced within the nursing curricula and other healthcare programmes.

In addition, almost half (49.4%) of the healthcare providers expressed the need to develop guidelines to support family involvement and give family the option to attend resuscitation or other invasive procedures. This concern seems to be consistent with Maclean *et al.* (2003), Meyers *et al.* (2004), Mian *et al.* (2007) and Al-Mutairi *et al.* (2012). This should focus the attention of the healthcare authorities in Saudi Arabia to develop guidelines and policies which give the family the opportunity to remain with

their relative during such times. The policies should also lay stress on the facilitator responsibilities and interventions to follow up and explain to the family throughout the resuscitation or any other invasive procedures.

### Qualitative interpretive synthesis

The healthcare providers in the open-ended item confirmed that families could be involved during routine nursing care in activities such as *feeding the patient or applying lotion to their loved one's body*. A healthcare provider also stated that:

Including families on the patient's care and explaining to them honestly, can prepare them for any further development of the patient condition. (ID: 55)

The issue of the resources needed to involve the family was raised by the healthcare providers. Thus, the comment *hospital administration should prepare a specific room/area intended for family members in the ICU to ease their access and involvement* (ID: 59). This finding is consistent with Takman and Severinsson (2006) who suggested that the hospital or ICU has to provide resources to help families with issues connected to the patient's stay in the ICU. This is particularly highly significant as there is no waiting room in most ICUs in Saudi Arabia. The need to stay overnight could arise also because some families may travel a long distance to visit the patient.

Healthcare providers expressed fear that family presence during resuscitation or other invasive procedures would be traumatic and hazardous. They also believed that it might worsen the patient's condition, upset the family and interfere with the staff performance. These attitudes were supported by personal experiences of a healthcare provider that *Saudi families come to visit in groups most of the time and cry in groups* (ID: 140). However, participants suggested that family presence during resuscitation could be implemented if key environmental conditions were met such as *families do not interfere or affect performance and were well educated before attending any invasive procedure or resuscitation*. This concern was reported by healthcare providers in Meyers *et al.* (2000) and Knott and Kee (2005), in which they argued that the implementation of family presence should be well prepared for decision at hospital and healthcare provider levels. Furthermore, healthcare providers endorsed the need for public education regarding family presence:

There should be extensive family education, so they understand the procedures, why these procedures are being done for the patient. (ID: 356)

Another healthcare provider summarised how safe implementation of ICU family presence in Saudi Arabia would play:

a significant role to recognise that everything possible was done to save their loved one and more easily accept any further development. (ID: 139)

The healthcare providers advocated that involving family during routine care and resuscitation and other invasive procedures is the hospital administration's responsibility through developing guidelines, protocols and written policies. One participant claimed that:

it is the responsibility of the hospital administration to shift the rules and regulations. (ID: 206)

They similarly confirmed that for safe implementation of the practice. One provider stating a *clear and well established protocols and guidelines* should be implemented in advance and in consultation with patients', families' and staff's preference.

The study has a number of limitations; first, the nonprobability convenience sample limits the generalisability of the findings. Also, the low response rate of physicians and respiratory therapists compared with nurses could result in a biased sample comparison. It would be interesting to replicate the study to investigate whether the families would like to be involved and present during routine care and resuscitation or other invasive procedures.

## Conclusion

Healthcare providers showed positive attitudes towards family involvement during routine care and negative attitudes towards family presence during resuscitation or other invasive procedures. In previous studies and in this study, it has been evident that family participation in the ICU may benefit patients and families physically and psychologically and may reduce the stress of medical staff. Clinical barriers may prevent the practice including resources, hospital policies and guidelines and staff and public education.

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## Relevance to clinical practice

The involvement of family in the care of patients in the ICU has implications for several important issues for healthcare providers. They include workplace satisfaction, standards of practice and quality of care delivered to the patient. A family-centred model of care is recommended and will necessarily include these issues. Also embedded in these are enhanced communications between families and the ICU team. The results of this study will inform intensive care nursing, the hospital authorities in Saudi Arabia and critical care services internationally about the contemporary attitudes of health providers on this topic.

Policy and procedure development or modernization could be supported by education and facilitators and introduction of the concept into staff orientation modules and ongoing clinical interprofessional education. Those policies may also include flexible visiting practices and waiting rooms with comfortable, welcoming furniture in the ICU for the family members. The study has raised a question about the nursing and other medical curricula standard in Saudi Arabia requiring more emphasis on the family need for involvement with a critically ill family member. The findings can also influence the development of integrated and consistent education for the public regarding their contributions during the care of their loved one in the ICU.

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## Disclosure

The authors have confirmed that all authors meet the ICMJE criteria for authorship credit ([www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

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