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NEEDS OF PATIENT'S FAMILIES IN THE HOSPITAL TELE- INTENSIVE CARE UNIT

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NEEDS OF PATIENT'S FAMILIES
IN THE HOSPITAL TELE-INTENSIVE CARE UNIT

A Dissertation Presented

By

MARY L. JAHRSDOERFER

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

September 2014

School of Nursing

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IN THE HOSPITAL TELE-INTENSIVE CARE UNIT

A Dissertation Presented
By
MARY L. JAHRSDOERFER

Approved as to style and content by:

Linda A. Lewandowski, Chair

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DEDICATION

This dissertation is lovingly dedicated to my son James, whose unyielding faith in my ability to accomplish this work, has sustained me through to fruition. Through his teenage years, his maturity, patience, and expansive perspective, far surpassed his young lifespan. He persistently and enthusiastically cheered me on throughout the entire process. From his encouraging words, to the many cups of hot tea he would voluntarily bring me as I was writing late into the night, have brought both a smile to my face and propelled me to keep going. My hope is that this long, arduous work will serve as an example of what can be accomplished if you set your mind to it.

As I write this dedication, James is flourishing in his own college goals. It is with a spirit of celebration, pride, gratitude, and eternal love that I devote this work to him. Thank you, James.

Thank you too, to my entire family for their unending love and support.

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Lastly, I would like to extend a debt of gratitude to Rebecca Ready who served as my outside chair-person. I thank Becky for her perspective, comments and suggestions with all stages of chapter iterations throughout this project.

ABSTRACT
NEEDS OF PATIENT'S FAMILIES
IN THE HOSPITAL TELE-INTENSIVE CARE UNIT
SEPTEMBER 2014

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Directed by: Associate Dean for Academic Affairs and Professor Linda Lewandowski

Purpose: To explore, identify and describe the perceptions and needs of family members of a patient admitted to a telemedicine intensive care unit (tele-ICU); and to determine if these needs differ from those established by the Critical Care Family Needs Inventory (CCFNI) in the traditional ICU setting.

Background: The tele-ICU is a new care modality in which offsite nurses, intensivists, and other critical care specialists to provide consultation to bedside clinical staff at geographically-dispersed ICUs. The last decade demonstrates a growing existence of tele-ICU's in our healthcare culture. 'Information', 'close proximity', 'assurance', 'support' and 'comfort' have been identified as the top five needs of family members in the traditional ICU setting as reported in a study using the (CCFNI) by (Leske, 1986b; N. Molter, 1979b). Yet, we do not know what the family needs are within the tele-ICU context.

Significance: The complexity of the tele-ICU adds another dimension to patient-family care, requiring nurses to have appropriate knowledge of family member experiences in order to meet these needs. This necessitates knowing what the family's

perceived needs are within the novel tele-ICU environment. The focus of this study was to bridge the gap in nursing knowledge by identifying family needs in the tele-ICU environment through exploratory inquiry. This study was the first of its kind using face-to-face interviews to focus on the unique perceptions and needs of family members in this new care modality; and a follow-up to the published pilot study by this author.

Methods: This was a descriptive study that used exploratory inquiry. A semi-structured recorded interview method was used with a convenience sample of family-members/significant-others to assess their experiences, needs, and perceptions while patients received care in a tele-ICU at a large teaching hospital and mid-size community hospital, to expound upon the existing CCFNI findings in the traditional ICU. The interview format served as a follow-up to the pilot study by this author which utilized a questionnaire format across 3 health systems.

Conclusion: This study demonstrated significant gaps in communication about the tele-ICU between staff and patients' family. This finding is consistent with the pilot study. Although once informed about the tele-ICU existence and purpose by the investigator, perceptions of the tele-ICU model of care were generally favorable. The fact that 11 of the 16 family-participants interviewed (68.75%) indicated that they had not been informed that the patient was receiving care in a tele-ICU, as well as all 16 (100%) of the respondents never having been introduced to the remote staff, suggests the need for more timely, organized, and proactive communication strategies to inform patients' family members about this novel technology. Improved comprehension of the families' understanding of the role of the tele-ICU in the care of critically ill patient may support their informational needs.

TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS.....	v
ABSTRACT.....	vi
LIST OF TABLES.....	xxvii
LIST OF FIGURES.....	xxviii
CHAPTER	
1. STUDY OVERVIEW.....	1
1.1 Introduction	1
1.2 Background and Significance	2
1.3 General context of critical care needs in the United States.....	3
1.4 Statement of Problem.....	5
1.5 Research Question.....	7
1.6 Statement of Research Purpose.....	7
1.7 Operational Definitions.....	8
1.8 Summary.....	10
2. REVIEW OF THE LITERATURE.....	11
2.1 Introduction to Literature Search.....	11
2.2 Literature Search Methods.....	12
2.3 The Family.....	14
2.3.1 Family-Centered/Family-Focused care.....	14
2.3.2 Family in the Context of the Traditional ICU.....	16
2.3.2.1 Family response to critical illness.....	18
2.3.2.2 Family experience of stress.....	26
2.3.2.2.1 Family comprehension.....	31

2.3.2.2.2	Family satisfaction	32
2.3.2.2.3	Family anxiety and depression.....	33
2.3.2.2.4	Family post traumatic stress.....	34
2.3.2.3	Family Participation in Care.....	35
2.3.3	Evidence of Family Needs in the Critical Care Environment...	39
2.3.3.1	Need for assurance	40
2.3.3.2	Need for close proximity.....	44
2.3.3.3	Need for information.....	49
2.3.3.4	Need for comfort.....	54
2.3.3.5	Need for support	58
2.3.4	Meeting and Measuring Family Needs: Quality & Safety.....	60
2.3.4.1	Respect and dignity.....	62
2.3.4.2	Information sharing.....	62
2.3.4.3	Participation.....	63
2.3.4.4	Collaboration.....	63
2.3.5	Patient-family outcomes in the ICU.....	63
2.4	The Traditional Intensive Care Unit (ICU).....	70
2.4.1	Physical Environment and Characteristics of the ICU.....	70
2.4.2	Psychological Environment and Human Factors of the ICU	76
2.4.3	Complexity and Workload in the ICU.....	79
2.5	The Tele-Intensive Care Unit (ICU)	80
2.5.1	Introduction to Telemedicine	80
2.5.2	Organizational Context of the Telemedicine.....	82
2.5.3	Applications of Telemedicine.....	85
2.5.4	Tele-ICU and the Virtual Team.....	86
2.5.5	Communication Methods in the Tele-ICU.....	93

2.5.6 Impact of the Tele-ICU.....	96
2.5.7 Environment, Characteristics and Human Factors of the Tele-ICU.....	99
2.5.8 Knowledge of family needs and perceptions in the tele-ICU	101
2.6 Theoretical Framework.....	103
2.6.1 Overview of Family Stress and Adaptation Model.....	103
2.6.2 Paradigm Perspective	104
2.6.3 Metaparadigm Assumptions.....	104
2.6.3.1 Person-Family.....	105
2.6.3.2 Health.....	105
2.6.3.3 Nursing.....	105
2.6.3.4 Environment.....	105
2.6.4 Theory Development..	106
2.6.5 Concept of early family stress and adaptation model.....	108
2.6.5.1A Stressor.....	108
2.6.5.2 B Resources.....	108
2.6.5.3C How family defines event.....	109
2.6.5.4D Crisis.....	109
2.6.6 Concept of current family stress and adaptation model.....	110
2.6.6.1 Pile-up of stressor.....	110
2.6.6.2 Existing resources.....	110
2.6.6.3 Perception of stressor.....	111
2.6.6.4 Adaptation.....	111
2.6.7 Concept delineation.....	113
2.6.7.1 Antecedents.....	113
2.6.7.2 Consequences.....	114

2.6.8 Theory Evaluation	114
2.6.8.1 Congruence.....	114
2.6.8.2 Clarity.....	114
2.6.8.3 Simplicity.....	114
2.6.8.4 Complexity.....	115
2.6.8.5 Usefulness.....	115
2.6.9 Assumptions	115
2.6.9.1 Explicit assumptions.....	115
2.6.9.1.1 Natural life changes.....	115
2.6.9.1.2 Normative functional patterns.....	115
2.6.9.1.3 Non-normative functional patterns.....	115
2.6.9.1.4 Relationships and resources.....	115
2.6.9.1.5 Harmony and balance.....	115
2.6.9.2 Implicit assumptions.....	116
2.6.9.2.1 Coping with stress.....	116
2.6.9.2.2 Variables.....	116
2.6.10 Theory Strengths Weaknesses	116
2.6.10.1 Strengths.....	116
2.6.10.2 Weaknesses.....	117
2.6.11 Application to Family Needs in tele-ICU.....	117
2.6.12 Summary of Theoretical Model.....	118
2.7 Chapter Summary.....	119

3. METHODS.....	120
3.1 Introduction.....	120
3.2 Research Design.....	121
3.3 Setting.....	122
3.3.1 Gaining Access.....	122
3.3.2 Description of interview environment.....	123
3.4 Sample.....	123
3.4.1 Sample Size.....	123
3.4.2 Subject Recruitment.....	124
3.4.3 Inclusion Criteria.....	124
3.5 Data Sources.....	125
3.5.1 Data Collection Plan.....	125
3.5.2 CCFNI & Pilot Domain Correlation to Interview Schedule...126	
3.5.3 Data Recording Strategy.....	128
3.6 Data Collection Procedures.....	128
3.6.1 Interview Protocol -Sequential Steps.....	128
3.7 Establishment of Validity.....	130
3.7.1 Goodness Criteria and Trustworthiness.....	131
3.7.2 Measures of Trustworthiness, Validity and Reliability.....	132
3.7.3 Study Strengths and Weaknesses.....	135
3.7.3.1 Study strengths.....	135
3.7.3.2 Study weakness.....	136
3.8 Protection of Human Subjects/Ethics.....	136
3.8.1 Privacy and Confidentiality.....	137

4.4 Findings.....	154
4.4.1 Description of Methods for Interview Content Organization.....	154
4.4.1.1 Transcription Process.....	155
4.4.1.2 Coding Process.....	155
4.4.2 Key Themes used to Guide Family Interviews; Associated with CCFNI.....	155
4.4.2.1 Need for information.....	155
4.4.2.2 Need for close proximity.....	156
4.4.2.3 Need for assurance.....	156
4.4.2.4 Need for comfort.....	156
4.4.2.5 Need for support.....	156
4.4.3 Key Themes used to Guide Family Interviews; Associated with tele-ICU.....	156
4.4.3.1 Understanding of tele-ICU Function.....	156
4.4.3.2 Need for privacy	157
4.4.4 Interview Findings.....	157
4.4.4.1 Family source of general information about tele-ICU.....	157
4.4.4.2 How families receive their need for information.....	161
4.4.4.3 Need for close proximity to patient in tele-ICU.....	165
4.4.4.4 Family need for assurance in tele-ICU.....	167
4.4.4.5 Family need for comfort in tele-ICU.....	171
4.4.4.6 Family need for support in tele-ICU.....	176
4.4.4.7 Family need for privacy in tele-ICU.....	178
4.4.4.8 Additional participant thoughts.....	180
4.5 Summary.....	182

5: DISSCUSSION.....	185
5.1 Introduction.....	185
5.2 Discussion study outcomes within the family stress theoretical model...	185
5.2.1 Discussion of findings related to family informational needs..	188
5.2.1.1 American Association of Critical Care Nurses (AACN) tele-ICU Guidelines.....	189
5.2.2 Discussion of findings to family need for close proximity....	192
5.2.3 Discussion of findings to family need for assurance.....	193
5.2.4 Discussion of findings to family need for comfort.....	194
5.2.5 Discussion of findings to family need for support.....	196
5.2.6 Discussion of findings to family need for privacy.....	197
5.3 Summary of implication of findings.....	198
5.4 Implications to nursing practice and future research.....	199
5.5 Implications to policy.....	200
5.6 Study limitations.....	202
5.7 Conclusion.....	204

APPENDICES

A. LETTER OF INTRODUCTION TO PARTICIPANTS..	206
B. CONSENT FORM FOR INTERVIEW.....	207
C. INSTRUMENT PART I: DEMOGRAPHIC SURVEY.....	210
D. INSTRUMENT PART II: INTERVIEW SCHEDULE.....	211
E. POSTER & VERBAL SCRIPT.....	213
F. MOLTER’S ORIGINAL CCFNI.....	214
G. INTERNAL REVIEW BOARD (IRB) APPROVAL LETTER.....	215
H. CONSENT FROM UMASS WORCESTER.....	216
I. DATA MANAGEMENT & ANALYSIS PLAN.....	217
J. AUDIT TRAIL.....	219

BIBLIOGRAPHY.....	220
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LIST OF TABLES

TABLE	Page
2.1 Evolution of ICUs.....	75
2.2 Quality and Safety Design Recommendations.....	77
2.3 Main phases of telecommunication technology.....	82
2.4 Essential Attributes of Tele-ICU.....	87
3.1 Data Collection Phases.....	125
3.2 Interview Schedule correlation to CCFNI findings and Pilot Study.....	126
3.3 Study Timeline.....	141
4.1 Characteristics of tele-ICU by Interview Schedule Subjects.....	145
4.2 Family-participant and Patient Demographics.....	147
4.3 Participant Relationship to Patient and Unit Type.....	150
4.4 Participants Prior Experience in tele-ICU.....	154
4.5a Family Source of General Information.....	160
4.5b How Family Receives Need for Information.....	164
4.5c Family Need for Close Proximity.....	167
4.5d Family Need for Assurance.....	170
4.5e Family Need for Comfort.....	175
4.5f Family Need for Support.....	177
4.5g Family Need for Privacy.....	179
4.5h Participants Additional Thoughts.....	181

LIST OF FIGURES

Figure	Page
2. 1 Triangle of literature search.....	14
2. 2 High resolution camera.....	90
2.3 Family Stress Model	112
3.1 Data Analysis and Interpretation Plan.....	139
4.1 Sample accrual process.....	144
4.2 Participant sample age and gender.....	148
4.3 Participant age according to ICU type.....	151
4.4 Family participant according to patient length of stay and unit type.....	153
5.1 Association of outcomes within the family stress theoretical model.....	187

CHAPTER 1

STUDY OVERVIEW

1.1 Introduction

Families have specific needs when a loved one is critically ill in the intensive care unit (ICU). The complexity of the tele-ICU adds another dimension to patient-family care, requiring nurses to have appropriate knowledge of family member experiences in order to meet these needs. This necessitates knowing what the family's perceived needs are within the novel tele-ICU environment. The focus of this study was to bridge this gap in nursing knowledge by identifying family needs in the tele-ICU environment through exploratory inquiry.

As the population of the United States (US) ages, increasing numbers of individuals will be diagnosed with chronic, serious health conditions that will require treatment in ICUs (Goran, 2010; Milbrandt, 2008; Schumaker, 2006). One response to the growing scarcity of expert clinical resources and anticipated increased demand for critical care services has been development of a remote model of care or telemedicine, known as the tele-ICU; which utilizes technology that allows offsite nurses, intensivists (physicians with special training in critical care medicine), and other critical care specialists to provide consultations to bedside clinical staff at geographically-dispersed ICUs. While the needs of family members in the traditional ICU setting are well-documented, little is known about the needs and reactions of family members to care provided in the tele-ICU. To better understand the needs of family members and significant-others in the tele-ICU model of patient care, research and analysis must focus

on how this model of care is defined, what processes are involved, how nursing interventions are measured and how patient-family outcomes are used to effect change. This study began this process with a focus on family members' perceptions and needs.

1.2 Background and Significance of Problem

For most patients, admission to the ICU is preceded by a sudden illness or trauma that does not allow families time to prepare. (Fridh, Frosberg, & Bergbom, 2009; Hughes, Robbins, & Bryan, 2004). This observation was supported by (Pryzby, 2005) who noted that most families were caught off-guard when a critical illness strikes, which resulted in life disruptions and disorganization. There were more than two million admissions and approximately 200,000 deaths in ICUs each year in the US. (Lwin, 2008). It is estimated that as many as 75% of these patients were incapable of participating in the process of decision-making about treatment and treatment goals. (Curtis & Rubenfeld, 2001). Therefore, the family frequently was required to make important treatment decisions on behalf of critically-ill patients who could not speak for themselves (Orcutt, 2010). A frequent concern however, was that family members may be experience high levels of anxiety and difficulty coping, which may prevent them from making sound medical decisions on behalf of the patient (Mendonca & Warren, 1998; Pochard, Azoulay, Chevret, Lemaire, Hubert, Canoui, Grassin, Zittoun, le Gall, Dhainaut, Schlemmer, 2001; Takman & Severinsson, 2005).

Critical care nurses, because they spend by far the most time at the bedside, were in the best position to establish partnerships with patients and families to help them identify their needs, assess their perceptions, and provide continuity of care (Roland, Russell, Richards, & Sullivan, 2001). However, critical care nurses have not always

accurately assessed the needs of family members due to varying factors such as their own time constraints, willingness, or appreciation that a family participation is of vital importance in the overall care plan for the patient (Maxwell, Stunekel, & Saylor, 2007). In such situations where the family needs were not filtered into the overall care, families drew on their strength and ability both during and after the ICU stay in order to “facilitate changes in patterns of family functioning that allow the family to adapt to the new situation” (Soderstrom, Saveman, Hagberg, & Benzein, 2009). Families that struggled with adapting to the critical illness of their family member, often felt their own needs were not supported by those who were caring for the patient. Strategies for addressing family-centered care required “embracing a new philosophy” which included the family as an extension of the patient, and acknowledging the value of a pro-active approach to ensuring those needs were consistently met (Henneman & Cardin, 2002).

1.3. General Context of Critical Care Needs in the United States

Current estimates by the U.S. Census Bureau suggest that the demand for intensive care services among adults aged 65 and older will increase by 50% from 2000 to 2020 (Joint-Commission-Resources, 2004). Multidisciplinary care teams comprised of trained, knowledgeable, and skilled critical care nurses, intensivists, nurse practitioners, pharmacists, physician assistants, physician specialists, primary care physicians, respiratory therapists, and other critical care specialists will be needed to ensure optimal outcomes for the growing number of patients anticipated to require critical care services (Carayon & Gurses, 2008; SCCM, 2006 and 2004). A multidisciplinary approach to family-centered care means that all members of the health care team who have contact with the patient, will partner with the family to assure that the needs of the patient-

family unit are being met (Dowling, Vender, & Giulianelli, 2005; Henneman & Cardin, 2002). Multidisciplinary care is becoming more of an issue as today's healthcare workforce as we experiencing a shortage of expert critical-care clinicians; subsequently, alternative models of care are being considered.

The provision of professional critical care resources of nurses and medical-intensivists, over widespread geographical areas, specifically rural areas, is becoming more challenging in healthcare today (Breslow, 2007). The reason for this nationwide professional critical care shortage in outlying care areas is fourfold; 1) there is an increased demand for expert nurses and doctors as our technology becomes more advanced in the hospital critical care setting, 2) there is an inadequate supply of critical care nurses and doctors as more baby-boomers retire and non-expert personnel take over, 3) over the last two decades hospitals have experienced a reduction in overall critical care staffing and increased overtime, and 4) the reduction of patient length of stay has posed an higher patient turn-over rate, resulting in an increase in patient admissions to the ICU, therefore surpassing the supply of expert care providers (Carayon & Gurses, 2008). Consequently, access to critical care resources for those patients' residing outside urban tertiary centers are being met through the inception of remote care, better termed as the tele-ICU. This scarcity of qualified critical care personnel and increased workload, may subsequently affect perceived quality and safety of patient care. The remote model of care, the tele-ICU, is a practical solution to meet the issues that have been identified (Carayon & Gurses, 2008). The goal of healthcare leaders has been to level the playing ground to provide critical care access to all patients who need it, as well as to improve the quality of patient-care given by these providers (Aiken, Sochalski, & Lake, 1997).

Delivery of critical care expertise from afar is one way to address the evident need in the U.S. today.

Since the identified critical care staffing shortage, certain challenges have arisen that are associated with outcomes for which nurses are directly responsible (Irvine, Sidani, & Hall, 1998b). One challenge is to determine how nursing-sensitive patient outcomes in the tele-ICU may be affected as a result of this deficit. While warranted as a future study, identification of how nurses may directly affect patient-family needs in this new environment is at this time premature; as the needs of the family must be fundamentally identified. What we know thus far is that there have been a number of studies of how family members and significant-others endure and adapt in the traditional ICU setting, as will be discussed in Chapter 2. However, to date there have been no reported studies of family needs in the tele-ICU, outside of the pilot study that this researcher has conducted. Herein lays the gap in nursing knowledge.

The literature review will demonstrate that the normal pattern of family behavior is challenged in the face of critical illness of one of its members, therefore affecting their needs. (Hill, 1958; McCubbin & Patterson, 1983; Pryzby, 2005). Exploration of family perceptions and needs within the tele-ICU construct will close the existing knowledge gap will pave the road for future research related to nursing sensitive outcomes of patient-family in the tele-ICU.

1.4 Statement of the Problem

There was an existing gap in nursing knowledge related to family needs in the tele-ICU. Admission to an intensive care unit creates a state of crisis not only for the patient, but for his or her family as well. The family is a unit. Crisis-producing events are

those “normative and non-normative life events that disrupt the family system and that precipitate changes in, or the necessity for changes in, the family’s patterns of functioning”, thus placing the family system at risk for continued decline in functioning leading to dysfunction. (McCubbin, 1997). Although only the patient is critically ill, the entire family unit is affected (McCubbin & McCubbin, 1996). The gap in knowledge existed because we did not know how the complex structure of the tele-ICU affected these family perceptions and needs; perhaps in ways that were different than in traditional ICU’s where the staff making decisions are present at the bedside, not via a video screen or audio –only communication. While it was essential to pursue aggressive care for critically ill patients, nurses also needed to address family needs as part of their overall care plan. These family needs are well-established and documented in the traditional ICU setting as indicated by the seminal study conducted by Molter in 1979, the finding of which she later developed into the Critical Care Family Needs Inventory (CCFNI) by (Molter & Leske, 1983). Many subsequent research studies utilizing the CCFNI have confirmed the family need for information, assurance, support, closeness or proximity, and comfort to ease their sense of anxiety (Lee & Lau, 2002; Maxwell, Stunekel, & Saylor, 2007). Yet little is known about family needs in the tele-ICU setting.

Rather than recreating an entirely new research tool for the tele-ICU, the goal was to build upon existing science, garnering knowledge from previous research. Past research has shown that the need for information, assurance, support, proximity, and comfort are important to family members in the traditional ICU. We also know (from this researcher’s pilot study) that patient privacy (such as a camera in the patient room), and technology (knowing that doctor’s and nurses’ from afar are assessing their clinical

data), may be of vital importance to the family in the tele-ICU. Before a validated research tool for the tele-ICU can be developed and implemented however, a fundamental knowledge of family perceptions and needs in this setting needed to be determined. This objective was established by going directly to the source, that being the family members themselves, and asking them. That was the intent of this research study.

The core theoretical framework utilized to help support the underlying principles and guide the direction of questions asked of the family was the ‘The Family Stress Theory’; with the goal to generate further nursing knowledge in this unique setting. The Family Stress Theory provided a framework in which to integrate the CCFNI, and the family-needs pilot study, allowing a meaningful lens through which to view the experience of families undergoing stressful events such as the critical illness of a loved one in a tele-ICU. The aim was to answer the overall research question, as well as to set the stage for further studies that may aid in supporting families.

1.5 Research Question

This study was undertaken to answer the following research question:
What are the perceptions and needs of the family members of patients admitted to a tele-medicine intensive care unit (tele-ICU) relative to those identified by family members of a patient in the traditional ICU?

1.6 Statement of Research Purpose

The Critical Care Family Needs Inventory, referred to as CCFNI, was developed with families in the traditional ICUs. In addition, the pilot study (by this researcher) served as an initial family needs exploration in the tele-ICU. For purposes here, the goal

was to determine if family needs in the tele-ICU are similar to those in a traditional ICU; to establish if the CCFNI needed to be modified and refined; and to identify any emerging themes for this new care model. This was completed through exploration of family members perceived needs in the tele-ICU setting using descriptive, exploratory inquiry via semi-structured in-person interviews.

1.7 Operational Definitions

Nurse: a professional with delineated therapeutic expertise who is able to identify and define human problems, using a degree of skill in clinical situations that is conducive to the wellbeing of the patient (Peplau, 1992).

Critical care nurse also referred to as **intensive care nurse:** a nurse who is qualified to work in an expanded practice role in the critical care setting of the hospital and deal with human responses to life-threatening conditions (Alspach, 2006).

Nursing sensitive patient outcomes: measurable changes in a patient's state of health or condition as a result of nursing interventions and for which nurses are responsible (Johnson, Bulechek, Butcher, Dochterman, Maas, Moorehead, & Swanson, 2006; Maas, Johnson, & Moorhead, 1996).

Intensive care unit also referred to as the **critical care unit:** highly specialized unit within hospitals dedicated to providing care to critically ill patients requiring complex assessment, vigilance, continuous monitoring, and specialized interventions by critical care nurses and an interdisciplinary team of experts (Alspach, 2006). For the purpose of

this study, the ICU refers to the traditional ICU, to distinguish any difference from the tele-ICU.

Tele-ICU also referred to as the **remote-ICU** or the **e-ICU** ('e' standing for enhanced): 'Tele' is derived from the term telemedicine. **Tele**, short for telemetry, the science and technology of automatic measurement and transmission of data by radio or other means from remote sources to receiving stations for recording and analysis (telemetry. (n.d.). The American Heritage® Stedman's Medical Dictionary. Retrieved June 11). The classification 'tele-ICU' implies the presence of telemedicine technology in the delivery of care and exchange of medical information from one site to another via electronic communication to deliver optimal care to ICU patients (Breslow, Rosenfeld, & Doerfler, 2004).

Family member: The definition of family has evolved over the years. One traditional explanation of 'family' states when two or more people reside in the same house-hold and are related by marriage, birth or adoption, that constitutes family (Alspach, 2006; Census, 2010). A second, yet broader definition states family is a "group of people who love and care for each other" (Alspach, 2006; Seligmann, 1990). A different perspective defines family as whomever a communicating patient defines as his or her family (Schell & Puntillo, 2006). For the purpose of this study, a family member is anyone delegated by the patient to represent their best interest; specifically, an individual or group of individuals with a continuing legal, genetic and/or an emotional relationship to the patient (American Academy of Family Physicians, 2009).

Critical Care Family Needs Inventory (CCFNI): A research tool based upon a seminal study conducted by (Molter, 1979b), evaluating family needs of those who have a loved-one in a critical care. Several years later the tool was revised by (Leske, 1986a, 1986b) and became known as the Critical Care Family Needs Inventory (CCFNI). This is a widely used validated evaluation instrument that identifies the needs of families with a patient admitted to the intensive care unit.

1.8 Summary

The first chapter of this research investigation has provided an overview and background of the study. In this chapter a statement of the problem and proposed research question have been presented. The background and significance, the purpose of the study, and objectives have been stated. The next chapter examines and synthesizes the pertinent literature and identifies what is a known and existing gap in the literature.

CHAPTER 2

REVIEW OF THE LITERATURE

2.1 Introduction to Literature Search

The literature review addressed three primary topics including the 1) the impact of the experience and needs on the family members of patients generated by the traditional ICU experience, 2) environment, design, and structure of the traditional ICU, and 3) the environment, design, and structure of the tele-ICU and family needs related to the tele-ICU experience. The rationale for the literature search was threefold: to identify family needs in traditional ICU setting; to characterize existing knowledge about the strengths and limitations of traditional ICUs; and lastly to identify the impact of the tele-ICU on family perception of needs. This study summarizes results of the search in each of the respective categories; family needs in the ICU, human factors in the ICU environment, and finally current knowledge about the tele-ICU. To date, there is only one study on the perceived needs of the family in the tele-ICU, which was written by this author; with the intent to capture the family experiences with care delivery in a telemedicine intensive care unit (tele-ICU) (Jahrsdoerfer & Goran, 2013). A mixed-methods study design was used to describe family member's knowledge and perceptions of care given in the tele-ICU. A convenience sample of family members of patients admitted to 6 tele-ICUs in three hospital systems in the North-East United States, were considered the most appropriate to answer the research question: What is the family member's experience in a Tele-ICU? Three hundred-six family members were invited to participate in the study; 196 completed the survey (64 % response rate). Of these 196 family members, about two-thirds (66%) reported never receiving any form of information about the Tele-ICU.

Of the 66 (34%) family members who did receive information, 62 (95%) reported having received it via a brochure. Three-fourths of the respondents (n= 127; 77%) reported that their preferred method of receiving knowledge would be to speak directly to a nurse. Information reported to be important to the family members were; protection of patient privacy; effect of remote-team on patient-care; and how the remote technology works. Eighty-eight (45%) participant response comments to open-ended questions about remote ICU care were clustered into 3 themes: safety-quality, patient-comfort, and the remote technology. The majority of family members (79%; n=69) reported positive experiences with the tele-ICU care; 2% (n=2) reported negative experiences, and 19% (n=19) had neutral responses. In conclusion, it was evident that new care-delivery models such as Tele-ICUs present new opportunities and new challenges to providing patient and family centered-care. The findings of this study suggest that the family's unique information needs may not be consistently met, and will most likely require a change in the way that information is disseminated.

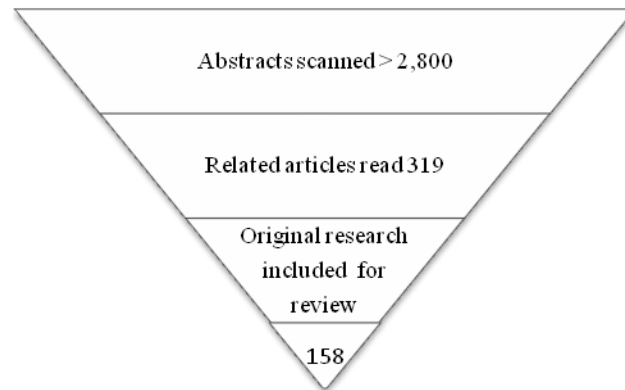
2.2 Literature Search Methods

An initial literature search was performed to identify publications relevant to the needs of family members with a loved one in the tele-ICU. Electronic database searches included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline Plus, and Google Scholar. In addition, the University of Massachusetts Library was also used as an ancillary source to access research relevant to family needs in the tele-ICU. Individual search terms included “family,” “intensive care,” “stress,” “telemedicine,” “adaptation,” and “nursing.” These search terms were chosen as they contain key attributes that describe the research question regarding family needs in the

ICU environment. The search was then expanded to identify and include systematic peer-reviewed studies related to family needs in the tele-ICU, using the PubMed, National Center for Biotechnology Information (NCBI), and the Medical Subject Headings (MeSH) database. The MeSH searches included various combinations of the following terms: “family needs,” “critical illness,” “intensive care,” “critical care environment,” “adult ICU environment,” “ICU structure,” ICU process,” “patient-family outcomes,” “nurse-sensitive patient-family outcomes,” “family-centered care,” “remote-ICU,” “tele-ICU,” “e-ICU,” “family presence,” “family stress,” “family adaptation to illness,” “family adaptation to crisis,” “nursing role independent function,” “nursing role interdependent function,” “organizational design,” “complex work system,” and “socio-technical system.” The advanced search using a combination of these terms in the MeSH database provided higher sensitivity to identify literature relevant to a complex topic.

The initial search was limited to articles published in English for the period 1998-2014. Review of these search results revealed that the foundation of relevant research was published in the 1970s. Consequently, a second search was conducted to include articles published in English during the years 1965-2014. This included all the terms used in the initial literature search as well as combination search terms used in the MeSH searches. A total of 158 articles with relevance to one or more of the three primary topics were identified and included in this literature review.

Figure 2.1 Triangle of Literature Search



2.3 The Family

2.3.1 Family-centered/Family-focused Care

The Institute of Medicine (IOM) recommended that hospitals become more patient-centered and encourage family members to be active participants in decision-making and self-management of the patient (Institute of Medicine, 2001). The IOM also recommended that both patients and their families be provided with comfort and emotional support.

The IOM has recognized family presence and involvement for patient's of all ages based upon demonstrated history. Originating in the 1980s in response to the need in pediatrics for parental involvement in the care of hospitalized children, family centered care was becoming more acceptable. This was accomplished, in part, by extending visitation rights and increasing parental participation in activities and communication regarding the child's plan of care. A decade later, in 1992, the Institute for Family-Centered Care was formed as a non-profit organization. Subsequently, the Institute broadened its scope to include the families of adult and geriatric patients based on the

assumption that it would foster mutually beneficial partnerships among health care providers, patients, and family members (Family-Centered-Care, 2011). Most adult patients have some form of connection to family members or a social support system and the Institute asserted that it was important for health care systems to encourage these natural support systems. Molter corroborated the principles put forth by the IOM and proposed that the uniqueness of the individual patient as a member of a family unit is a “baseline rather than an impediment to care” (Molter, 2003, p. 296). Specifically, Molter’s message asserts that clinicians should fundamentally presume that all patients are part of some sort of family unit or support system. Furthermore, this family unit should not be seen as an impediment to patient care, but rather, an integral part of patient care.

In 2010, the Institute changed its name to the Institute for Patient and Family Centered Care in order to include patients in the development of treatment plans. The distinction between “family-centered care” and “family-focused care” is that the latter approaches the patient and the family as the “unit of intervention” (Family-Centered-Care, 2011) with a plan of care developed by the clinician that includes the immediate family unit. “The whole family is greater than the sum of its parts” (Bond, Draeger, Mandleco, & Donnelly, 2003, p. 64). While this is a very good start, family-centered care moves beyond this initial concept to include the family as active participants in patient care. Family-centered care is a more dynamic and mutual approach to care-giving and decision-making which involves clinicians, patients, and key family members. Family-centered care moves conjointly to family-focused care, whereas the family and health care team assess the patient’s needs and collaboratively develop a treatment plan

(Henneman & Cardin, 2002). Both models have redefined relationships between clinicians, patients, and family members. In practice, the focus in care delivery began to shift to include the family in communication, visitation rights, and involvement in patient care, education, and counseling. Since the primary focus of the ICU is to restore health and well-being to patients; one method to accomplish this is through recognition of the family as a constant in the patient's life with a key role to play in delivery of care and support.

Family-centered care is based on the concept that the patient is part of a larger 'whole' and recommends that critical care nurses include the family in the circle of patient care (Morton, Fontaine, & China, 2009). Henneman and Cardin stated that family-centered care is "not a singular intervention but rather a philosophical approach to care that recognizes the needs of patients' family members as well as the important role that family members play during a patient's illness" (Henneman & Cardin, 2002, p. 13). The author's further emphasized that the fundamental concept of patient-centered care does not mean that patients lose their rights, but rather realizes that the family's involvement is a conscious choice (Henneman & Cardin, 2002).

2.3.2 The Family in the Context of the Traditional ICU

For nearly three decades, nursing research has demonstrated that the presence of the family at patients' bedside in the ICU promotes the physical and emotional well-being of both patients and family members (Bijttbier, Vanoost, & Delva, 2001; Daley, 1984; Leske, 1986a; O'Malley, Favaloror, & Anderson, 1991; Verhaeghe, vanZuuren, Defloor, Duijnste, & Grypdonck, 2007). Both patient and family feel it is important to

have a representative from the family act as a primary intercessor or intermediary between the patient and doctor (Davidson, 2009; Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Hickey & Leske, 1992; Leske, 1986b; Molter, 1979a; Titler & Cohen, 1991). However, the family of patients in traditional ICU settings typically experienced increased levels of stress, anxiety, and depression and required support to help them cope with these emotional reactions (Hinkle, 2009; Karlsson, 2011).

Most families are psychologically unprepared for the patient's admission to ICU because the majority of admissions were urgent and unexpected (Hughes, Robbins, & Bryan, 2004; Kentish-Barnes, Lemaile, Chaize, Pochard, & Azoulay, 2009). When families visit their loved ones in the ICU, they are confronted by unfamiliar and potentially frightening sights and sounds; the ICU is not a quiet environment with alarms routinely indicating changes in patients' clinical status and mechanical sounds associated with assistive devices such as ventilators. Hay and Oken (1972) described the ICU environment as a source of sensory overload for the family and "not unlike the atmosphere of the tension charged strategic war bunker" (Hay & Oken, 1972, p. 110). They described the feelings experienced by the family in response to the "intricate machinery, flashing lights, buzzing and beeping monitors, gurgling suction pumps and whooshing respirators, as being both frightening and stressful" (Hay & Oken, 1972, p.110).

The ICU also provided little opportunity for privacy between patients and family members. Nurses and other members of the health care team are a constant presence in the patient's room even in well-designed ICUs. This made it difficult for the family to have periods of private time with their loved one. In addition, family members were often

confronted by significant changes in the appearance of the patient who was usually confined to bed, reliant on an oxygen mask or cannula, subject to continuous vital sign monitoring, and frequently receiving intravenous medications and supplemental nutrition. Furthermore, the patient at times was in an altered state of consciousness and required life-support. Consequently, the family was frightened and overwhelmed at the sight of the incapacitated patient (Hupcey, 1999; Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996; O'Malley, Favaloror, & Anderson, 1991; Soderstrom, Saveman, Hagberg, & Benzein, 2009). A series of interactive, unstructured, individual interviews with 20 relatives of patients in a surgical trauma ICU revealed that family would benefit by brief explanation of what to expect when they walk into the ICU (Chavez & Faber, 1987). Upon admission, family members should be reassured that due to the nature of the patient's illness or injury, it behooves the patient to be in the ICU so that constant observation and immediate treatment of the clinical symptoms can be managed in a timely manner. Furthermore, it would be appropriate to be honest with the family member regarding the acuity, severity, and expected patient outcomes if known at the time (Chavez & Faber, 1987).

2.3.2.1 Family Response to Critical Illness

The response of family to the critical illness of a loved one admitted to the traditional ICU has been widely examined in nursing research (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001; Burr, 1998; Davidson, Powers, & Hedayat, 2007; Dowling, Vender, & Giulianelli, 2005; Hupcey, 2001; Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996; Leske & Pasquale, 2003, 2007; McCubbin & Olsen, 1980; Molter, 1979b; Patterson, 2002). Some of the earlier research

studies, though born out of Molter's (1979) classification of 45 identified family needs, centered attention on the relationship that the nurse held with the family (Daley, 1984; Leske, 1986b); while others were conducted from the subjective perspective of the nurse alone (Hickey & Lewandowski, 1988; O'Malley, Favaloror, & Anderson, 1991) examined beliefs that critical care nurses held concerning the extent of participation and role that the family should have in the ICU; as well as some of the reasons which may influence a nurses own engagement with family (which is discussed in more detail at the end of this section). Furthermore, other studies have demonstrated how ICU nurses may at times discourage family participation and keep them at a distance from the patient (Chesla & Stannard, 1997; Hupcey, 1998) discovered that families as well, may display behaviors that discourage the development of a relationship with the nurse, and possibly their own participation in the ICU. It was both of these realizations; the classification of family needs, as well as nursing perception and action that served as fundamental steps to assist in the family's understanding and adaptation to the stress level associated with their loved-one's critical illness, and to the ICU environment.

Jamerson (1998) conducted a retrospective analysis using a qualitative, descriptive design to elucidate the experience of family members with a relative in the ICU. The setting was a large tertiary surgical trauma ICU located in the mid-west, and the participants consisted of 18 women and 2 men who had a loved-one in the ICU. Utilizing both focus groups and unstructured interviews, four categorical themes of experiences were discovered; hovering state, information seeking, tracking, and garnering of resources. When the family first encountered the ICU, they expressed feeling a sense of confusion, uncertainty and stress, and found themselves 'hovering' about. Moving on

from the hovering state, the family began to 'seek information' about the patient's diagnosis. Their natural next step was to 'track' the progress that the patient was making, by observing, analyzing, and evaluating their own satisfaction with the environment and care that their loved-one was receiving. Lastly, the family member expressed a need to garner 'resources' available for themselves, in order to allay their own anxiety by addressing needs such as; rest, nutrition, diversionary activities, privacy, support, and bonding with other family members. Jamerson concluded that in responding to the needs of families who have a loved-one in the ICU can significantly help these families at a time when they need it most. Family members found themselves in a precarious position of confusion and stress. Furthermore, these families articulated their needs and made suggestions for intervention. Some of these suggestions included the need to be near the patient, for the waiting room to be well lit with access to vending machines, rest rooms, telephone, diversionary activities, television, private or solitary area, as well as blankets and pillows if they needed to sleep. These interventions were quite simple for nurses to implement. Jamerson also discussed the need for further research to corroborate this study (Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996).

Although Jamerson (1998) shifted the focus to examine the family experience, via qualitative research in the ICU setting; it was Hupcey (1998) that examined how families became integrated into the ICU, assuming the role of supporter or caregiver. This important study elucidated the complexity and stress that families endured in this situation. The study measured the nurse perception of family needs and found that the family plays an important role in helping the patient through the traditional ICU experience, and in doing so feel comforted (Hupcey, 1999). Particularly, this study

examined how families and nurses interacted to a decrease or an increase in the family participation in the ICU, and how family endured to find their niche in the ICU. Using a method of grounded theory, a series of in-depth unstructured interviews of 10 nurses, 11 family members, and 30 patients were conducted in a large tertiary medical center. The nurse-experience ranged from 2 years to 20 years, and the participants consisted of adult patients with a varied range of medical, surgical and trauma diagnoses. The findings were broken down into two main categories; the first focused on the role of the family as it was perceived overall by the nurse, patient and family member; and the second finding focused on family integration into the ICU from the individual perspective of the nurse, the patient and then the family member. In the first category, the general consensus was that the family played an important role in the ICU, yet all differed as to what that role should be. Nurses felt that the family played an important role in encouraging, comforting and helping the patient to endure the ICU experience. Family members described their role as being both supportive and care-giving. Family members mainly felt however that their role was to “protect” and “watch out for” the patient’s best interest because the patient was unable to do that for them self. From the patient perspective, the overwhelming need expressed was to have their family member nearby, as this made them feel safe. When results were reported back to the nurses, data helped nurses to reevaluate and enhance their practice.

Hupcey’s second finding, regarding family integration into the ICU, had two opposing viewpoints; that of the nurse and the other of the family member. Despite the opposition, their goal was the same, and that was to see the patient through the ICU experience. The nurses’ goal was to, a) maintain control over the family member,

knowing that the primary nurse goal was to meet the needs of the patient first and that of the family member second; and b) to control the family perception of the care that the family member was able to provide to the patient. For the family member, their concern was focused on how they themselves would endure this stressful situation and adapt to the ICU environment. Throughout the interview process a common thread arose, and that was use of the word 'interaction'. Hupcey refers to this usage of the word to mean an active exchange of discussion, questions, concerns and information between the family member and the nurse. This study reinforces other studies such as (Dracup & Clark, 1993) and (Carr & Fogarty, 1997) that have determined that family members with a loved-one in the ICU undergo an extremely stressful experience, and should therefore be supported so that they too may endure the process. The following example underscores the struggle of the family member, self-expressed by feeling the need to “protect” and “watch out for” their loved-one while in the ICU, as described by Hupcey (1998) earlier in the literature review.

While the family often play an invaluable ombudsman-like role in the care of the critically ill patient, there are instances when the struggle to cope by the family member may result in an high levels of anxiety (Davidson, 2009; Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Dracup & Clark, 1993; Hickey & Leske, 1992; Leske, 1986b; Molter, 1979a; Titler & Cohen, 1991). One way to honor the family member’s perceived need to “protect” and “watch out for” their loved one in ICU, and therefore reduce their level of stress can be met by a set of simple, yet practical processes on the part of the clinician. The 3 main categories which have been identified by the family members that would satisfy their perceived needs for the watchfulness, protection and vigilance are; the

need for reassurance from the nurse and/or doctor that their loved-one is receiving optimal care; secondly, the family needs to be in close proximity to the patient so that they may observe the care that is being given and to provide comfort to the patient; and lastly the need for information so that they can experience a sense of understanding of the situation. Family members further explain that without this information, they feel an extreme sense of heightened stress (Dracup, 2002; Dracup & Breu, 1978; Hickey, 1990; Leske, 1991). High levels of anxiety in family members can at times effect the patient's therapeutic outcome and have other repercussions for the patient and his/her entire social network and members of the patient's health care team (Maxwell, Stunekel, & Saylor, 2007; McAdam, Arai, & Puntillo, 2008). McAdam and colleagues (2008) discussed the cognitive state of the critically ill patient as often being confused, resulting in family members substituting as their voice in the decision making process. Efforts by bedside nursing staff to assess and intervene to ensure optimal functioning of the family were found to benefit all involved with the patient (Leske, 1986b)

In a separate study by Lee and Lau (2002), that corroborated the findings previously discussed; they conducted semi-structured interviews with 131 family members of patients non-electively admitted to one of four general ICUs, with the goal undertaken to identify the needs of family members during hospitalization of their loved one. The qualitative interview data were correlated with findings on the CCFNI in an effort to further confirm the needs of family members in the ICU setting. The most frequently mentioned themes in the qualitative interviews were maintaining physical proximity to the patient and the need for information (Lee & Lau, 2002).

As part of a phenomenological study, Titler and Cohen (1991) examined the perceptions of family members, their children, patients and nurses, and asked them to describe the effect that the patient hospitalization has had on each of them. Tape recorded interviews were conducted with 12 family members (patient spouse), 11 children, 9 patients and 12 nurses. Certain themes emerged which included; the overall family unit (spouse, child, patient) feeling of lack of communication; protecting children from anxiety provoking news of the patient; an overriding threat of vulnerability, uncertainty and intense emotions; an interruption in home routines; changes in relationships; and role conflict. Conversely, the nurse perception of the impact of the patient-family event in the ICU demonstrated incongruence with the family member perception of the same event. The implications for nursing practice determined from this study are as follows: to obtain more detailed information about relationships among family members; promote communication; make appropriate referrals for family members to community resources such as social work, counseling, chaplains; and lastly, teach nurses and parents ways in which to help children deal with their parent being in the ICU (Titler & Cohen, 1991) .

Many other studies have substantiated the family member need for accurate and consistent information about the patient provided by caregivers, physical proximity to the patient, a personal alliance with members of the health care team, and support of health care providers (Hinkle, 2009; Karlsson, 2011; Linnarsson, 2010; Prachar, 2010). In a qualitative, phenomenological study using the design of the family systems theory, Eggenberger & Nelms (2007) endeavored to understand and interpret the experience of the family member with an adult loved one in the ICU. A series of 41 ‘family as a group’ semi-structured interviews were conducted from 11 different family members who had a

loved one who is a critically ill patient in the ICU. Findings demonstrate that gathering family together opens dialogue among family, and has therapeutic effect to help manage critical illness of their loved one (Eggenberger & Nelms, 2007). An interesting finding in a study conducted by Hickey and Lewandowski (1988) who examined the perspective of the nurse from four hospitals across New England and the Midwest, served as an indicator that the nurse must engage other members of the health care team in the total care of the ICU patient. Using a descriptive approach they found in their study of 226 critical care nurses that over 75% became involved with the families need for emotional support, yet the remainder of the nurses felt that they did not have adequate knowledge to meet the family's psycho-social needs. In particular, the situations that influenced those most were impending death of the patient and the nurses' subjective feelings for both patient and family member (Hickey & Lewandowski, 1988). This finding was later corroborated by Titler and Cohen (1991); 'the nurse must utilize all beneficial resources available to meet the needs of the ICU patient' (Titler & Cohen, 1991).

In closing this section, we know through the review of the literature on this topic that family presence in the ICU is extremely important to both the family member and the patient in order to relieve their own sense of anxiety. Additionally, we have learned that the nurse must incorporate the family member in the patient plan of care, as well as to reach out for other resources that may therapeutically assist the family to cope and adjust to the critical situation in the ICU.

The following section will review what is known about family member experience of anxiety and stressors. The longer the patient remains in the ICU, the family's sense of crisis grows (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002).

Consequently, the family members often experience psychological exhaustion and desperation (Forrester, Murphy, Price, & Managhan, 1990).

2.3.2.2 Family Member Experience of Stress

It is the family's experience of the 'unknown' or the 'not knowing' what the outcome of the patients' illness may be, or the feeling of 'uncertainty' that has been linked to the stress of the family member (Wong & Bramwell, 1992; Wong, 1995). The experience of stress has been stated as having two components; the first being an underlying anxiety trait, which is an inherent characteristic of the individual that predisposes them to respond a certain way, and the second element is an individual's transient reaction to a particular situation, which changes as the situation changes and their method of managing it changes (Chavez & Faber, 1987).

The term stressor (not the same as the response of feeling stressed) refers to the actual event that triggers the stress state (Merriam-Webster, 2012d). Germane to this study, the stressor refers to the patient in the ICU, the environment of the ICU and the resources available in the ICU and at home; while stress is the family member response to the stressor event. Each family member will respond with a different level of stress to the actual event of their loved one in ICU, dependent upon their own coping skills. In 1936, Hans Selye defined "stress" as "the non-specific response of the body to any demand for change" (Selye, 1950). Selye reported results from animal studies demonstrating that persistent stress could cause these animals to develop a variety of diseases comparable to those seen in humans, such as heart attacks, stroke, kidney disease and rheumatoid arthritis (Rosch, 1998; Selye, 1950).

Stressors and the subsequent outcomes are characterized in numerous ways. Boss (1992) defines stress as an interruption in the steady state of the family. Change provokes disturbance, which results in stress (Boss, 1992). Hill (1949) describes family stress as a course of adjustment that evolves from a phase of disorganization, to a position of healing, to a new stage of organization (Hill, 1949). Leske (2000) addresses the effects of both stressors and strengths, suggesting that previous stress, rather than the actual stressor episode, predict difficult psychosocial adaptation. Conversely, the family that has a certain 'hardiness', experienced decreased levels of stress and adapts in a positive manner. (Leske, 2000; Soderstrom, Saveman, Hagberg, & Benzein, 2009). A qualitative study of N=31 family members, was designed to measure how these family members adapted to life following a loved one's hospitalization in the ICU. The findings of this hermeneutical analysis resulted in 3 main themes that the family member experienced; striving for endurance, striving for consolation, and striving to rebuild life under new conditions (Soderstrom, Saveman, Hagberg, & Benzein, 2009).

The ICU experience for both the patient and family members creates a crisis situation within the family as a unit. When a family crisis occurs it can sometimes lead to confusion and helplessness among family members (Kotkamp-Mothes, Slawinsky, Hinderman, & Stauss, 2005). A crisis can be defined as an unstable or crucial time or state of affairs in which a decisive change is impending, *especially* one with the distinct possibility of a highly undesirable outcome (Merriam-Webster, 2012b). A further definition of crisis is a psychological or social condition characterized by unusual instability that is caused by excessive stress and is perceived as a source of danger or threat in security to the continuity of an individual or group (Merriam-Webster, 2012c).

People have diverse experiences of a crisis and generally rely on the mechanisms they have used to cope with prior crises to deal with current crises (Turner & Avison, 1992). Relevant here is when persistent exposure to stress may have a conditioning response on the person experiencing excessive stress. When able to draw understanding or meaning from the current crisis encounter it may in turn result in endurance and resilience (Avison & Turner, 1988; Turner & Avison, 1989). Much of the essential propositions noted here can be traced back to the crisis theory work of (Erikson, Paul, Heider, & Gardner, 1959), who proposed that those who successfully resolve problems or crises in previous developmental stages achieve lasting solution to the present crisis. Although it is not the nurse role to calibrate the family response to a loved one's illness, it is their role to recognize certain coping responses and seek assistance where appropriate (Erikson, Paul, Heider, & Gardner, 1959).

The following studies are highlighted to exemplify the legitimate stress that family members with a loved one in ICU are under, as well as their subsequent coping reactions. The purpose of this overview is to document that family, as the extension of the patient must be acknowledged as a vital component of the nursing care plan.

In a prospective study of caregivers of hospital survivors with prolonged (>72 hours) mechanical ventilation, the caregivers were interviewed at admission to the intensive care unit (ICU) and 2 months post-discharge. The study aim was to describe the characteristics of caregivers of chronically critically ill (CCI) patients and delineate key outcomes such as depression and physical health (Hickman, Daly, & Douglas, 2010). Patients discharged from ICU to a lower level of care had a high risk of post-hospital mortality (odds ratio, 8.61; $P = .01$). Caregivers of patients residing in interim care 2

months post ICU discharge had greater odds of being depressed than caregivers of patients residing at home (odds ratio, 2.75; $P = .001$). There was a significant reduction in caregiver physical health status over time ($P = .001$). The study concluded that caregivers of chronically critically ill patients are at risk for depression post-hospital discharge.

Kentish-Barnes and colleagues (2009) believe that burden on ICU member families should be assessed routinely (Kentish-Barnes, Lemaile, Chaize, Pochard, & Azoulay, 2009). In a comprehensive retrospective review of quantitative studies examined over 3 decades (1979-2009) that used a validated instrument both inside and outside of the traditional ICU to assess the burden of families of critical care patients, researchers Kentish-Barnes and colleagues (2009) determined that family burden during and following critical illness can be identified accurately and requires a preventive approach with specific treatment (Kentish-Barnes, Lemaile, Chaize, Pochard, & Azoulay, 2009). Awareness of the distress that families of ICU patients experience has been formidable since the importance of family-centered care has incited such interest (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001; Curtis & Rubenfeld, 2001; Heyland, Cook, Rocker, Dodek, Kutsogiannis, Peters, & O'Callaghan, 2003). Manifestation of anxiety and depression were assessed sequentially from ICU admission to 3 months after ICU discharge (Azoulay, Pochard, Kentish-Barnes, Chevret, Aboab, Adrie, & Schlemmer, 2005; Lautrette, Darmon, Megarbane, Joly, Chevret, Adrie, & Azoulay, 2007; Pochard, Azoulay, Chevret, Lemaire, Hubert, & Canoui, 2001; Pochard Damon, Fassier, Bollaert, Cheval, Coloigner, & Azoulay, 2005). Other benchmarks were measured on an individual basis: poor comprehension was measured 3

to 5 days after patient admission to the ICU (Azoulay, Pochard, Chevret, Jourdain, Bornstain, Wernet, & Lemaire, 2002); Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001; Rodriguez, Carlos, & Dominguez-Cherit, 2008); satisfaction after a family consultation, at ICU discharge, or within 1 month after ICU discharge (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001; Heyland, Cook, Rocker, Dodek, Kutsogiannis, Peters, & O'Callaghan, 2003; Johnson, Wilson, Cavanaugh, Bryden, Gudmundson, & Moodley, 1998); and lastly, risk factors for posttraumatic stress disorder (PTSD) 3 months after patient discharge or death (Azoulay, Pochard, Kentish-Barnes, Chevret, Aboab, Adrie, & Schlemmer, 2005; Jones, Skirrow, Griffiths, Humphris, Ingleby, Eddleston, & Gager, 2004).

The entire purpose of this extensive cumulative review of literature was to provide clinicians with a better understanding of the tools used to evaluate the anxiety and stress experienced by family members of ICU patients. As many as 80% of family members experienced deleterious effects, according to this retrospective analysis (Kentish-Barnes, Lemaile, Chaize, Pochard, & Azoulay, 2009). Findings extrapolated from the decades of original research have led Kentish-Barnes and colleagues to make a major claim that family burden should be measured at 3 different intervals; First, within 48 hours following ICU admission, the family comprehension, satisfaction, and signs of anxiety or depression should be assessed to, a) achieve better insight into specific family needs, b) to improve the likelihood that timely information is provided, and c) note any symptoms that may be present which would affect family participation in the clinical decision-making process. Second, after the third day of ICU admission, a scheduled family meeting should be held with designated clinical team members. The objective of

this meeting should be to determine and agree upon the best communication strategy to meet the family's needs. Family understanding can be evaluated by discussing the medical facts relevant to the patient's condition, agree upon a care plan, and have any family questions answered during this time. Third, if there is an alteration in the patient clinical status from therapeutic care to comfort care, a formal end-of life family conference is vital for reducing family burden and subsequent complicated grief (Kentish-Barnes, Lemaile, Chaize, Pochard, & Azoulay, 2009). Additionally, as a fourth recommendation, not a claim; a preventative assessment may be conducted for post traumatic stress disorder (PTSD) following discharge or death of a loved one when possible.

2.3.2.2.1 Findings #1 (Kentish-Barnes): Assessment of family comprehension (3-5 days post ICU admission) was essentially subjective on the part of the clinical team which intuitively determined (without the use of a validated tool) if the family minimally understood what was happening with their loved which would enable them to participate in decision-making process for the patient. The empirical data points used to measure family member comprehension were discussion and understanding of a) diagnosis, b) prognosis, and c) treatment (Kentish-Barnes, Lemaile, Chaize, Pochard, & Azoulay, 2009). A multicenter, randomized, controlled study confirmed the beneficial effect of providing family with a leaflet (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001). Another key finding from studies of comprehension was that family members who had a good understanding of the circumstances were less likely to share in the decision making process. Subsequently, useful information is a prerequisite when applying the shared decision making model (White, Braddock, Bereknei, & Curtis,

2007). Rodriguez and colleagues (2008) used an interview instrument containing 29 yes/no/do not know questions. Poor understanding of ICU care was noted in 19% of family members and poor comprehension of the patient's care was noted by 47% of the subjects. Overall, poor comprehension was correlated with lack of fluency of the English language. The subject matter with the highest rates of poor comprehension was mechanical ventilation, medications for pain or anxiety, and vasoactive agents. Family member perspective asserted that they received insufficient information from the staff and that the information was too complex (Rodriguez, Carlos, & Dominguez-Cherit, 2008).

2.3.2.2.2 Findings #2 (Kentish-Barnes): Family member satisfaction was measured while the patient was still in the ICU, upon discharge and/or 3 months post discharge.

Although several validated tools were utilized over the years, the most frequent was the Critical Care Family Needs Inventory (CCFNI). The studies that used the CCFNI emphasized the strong leverage that family satisfaction has on the delivery of care. Another tool used to measure family satisfaction was the family satisfaction ICU questionnaire (FS-ICU). This differs from the CCFNI in that half the items pertain to the satisfaction with clinical decisions that have been made. The FS-ICU was qualitatively validated with 22 family members of patients who died in the ICU (Heyland, Cook, Rucker, Dodek, Kutsogiannis, Peters, & O'Callaghan, 2003). The correlation between satisfaction with overall care and satisfaction with decision-making was 0.64. Reliability of test-retest, as determined in 25 family members, was 0.85. The FS-ICU takes approximately 15 minutes to complete and is intended to be self-administered.

2.3.2.2.3 Findings #3 (Kentish-Barnes): Family symptoms of anxiety and depression were measured sequentially, beginning at the ICU admission through 3 months following ICU discharge. The Hospital Anxiety and Depression Scale (HADS) developed by (Zigmond & Snaith, 1983) is a 14 item self-screening questionnaire designed to identify anxiety (7 questions) and depression (7 questions) was a common instrument utilized during the hospital stay. Although the tool has hospital in the title, many studies conducted around the world have confirmed its validity in the community setting as well. Of those studies that used HADS in families of ICU patients, a high prevalence of anxiety and depression were noted (Pochard, Azoulay, Chevret, Lemaire, Hubert, & Canoui, 2001; Pochard, Damon, Fassier, Bollaert, Cheval, Coloigner, & Azoulay, 2005). Signs and symptoms of anxiety were present in 69.1% of 836 family members, 73.4% of 544 family members respectively. Signs and symptoms of depression were noted in 35.4% and 35.3% respectively. When both anxiety and depression were found in family members, the outcome rose to 84% and 82.7%. In an important study by Siegel and colleagues measured the incidence of psychiatric illness in 41 next-of-kin who had acted as the main surrogate decision maker prior to the death of a relative in a medical ICU (Siegal, Hayes, Vanderwerker, Loseth, & Prigerson, 2008). Using the Inventory of Complicated Grief-Revised tool during structured clinical interviews (Silverman, Jacobs, Kasl, Shear, Maciejewski, Noaghiul, & Prigerson, 2000), they found that of 41 relatives, 34% met the criterion for at least one psychiatric disorder: depressive disorder (27%); general anxiety disorder (10%); panic disorder (10%); or complicated grief disorder (5%). These stress disorders were higher in spouses (63% vs. 16%) than of other relatives.

2.3.2.2.4 Finding #4 (Kentish-Barnes): In the Kentish-Barnes review, she and colleagues recommend testing for stress symptoms and risk for post traumatic stress disorder (PTSD). Using the Impact Event Scale (IES), (Sundin & Horowitz, 2003) listed difficulties people sometimes experience following stressful life events; 15 points were presented to family members as follows: 1) Any reminder brought back feelings, 2) I had trouble staying asleep, 3) Other things make me think of it, 4) I feel irritable and angry, 5) I avoid letting myself get upset when I am reminded, 6) I thought about it when I do not mean to, 7) I feel as though it didn't happen or it wasn't real, 8) I stay away from reminders, 9) Pictures about it pop into my mind, 10) I am jumpy and easily startled, 11) I try not to think about it, 12) I do not deal with my feelings, 13) I feel numb, 14) I feel like I am acting back at that time, 15) I have trouble falling asleep. These 15 points were separated into two subscale categories: a) the intrusion of thoughts related to the event (n=7 items); and b) avoidance of people or activities connected with the event (n=8 items). Family subjects were asked to rate the 15 items according to the frequency of their experience (0= not at all, 1= rarely, 3 = sometimes, 5 = often). A score over 30 is a high predictor for PTSD. Findings demonstrate that 33% of 284 family members of an ICU patient have had symptoms of PTSD 3 months following discharge or death of their loved one. The burdens experienced by family members are primarily due to the level uncertainty related to the illness and its meaning (Mishel, 1988). The comprehensive amount of testing and treatment, the way in which the family interprets the information they are receiving, and inadequate knowledge about the prognosis or severity of the illness lead to anxiety and uncertainty among family members. (Mishel, 1988).

2.3.2.3 Family Participation in Care

Family, at times, has had an influential positive effect on the patient's response to care, therefore decreasing their own stress response (Williams, 2005). An initial transition in the process of adapting to the situation occurs when the family of a critically ill patient see themselves as having an important role in the ICU (Hupcey, 1999 2001).

This section addresses the importance of family member involvement with basic patient care. Data employs the use of both qualitative and quantitative research. Williams conducted a study of the nurses in an 11 bedded ICU of a general hospital in the UK; with the precept to go beyond casual observation to obtain the feelings and experiences of their interaction with patient and family members. In an applied naturalistic approach, data were collected through direct observation, in-depth interviewing and video recording to explore the dynamics underpinning families' contribution to patient care. Findings indicated three major themes: a) getting to know the patient through the family, b) family contribution to care, and c) the nurses' role in supporting families of ICU patients (Williams, 2005). It is important for both family and clinician to acknowledge that at times the patient may not be cognitively available to weigh in on their own care, therefore placing more of a burden on the family member. Valuable interaction between staff members and family becomes essential at this point (Daley, 1984). Researchers, Price (2004), and Zainal and Scholes (1997) have identified the emotional effort involved in supporting a family member (Price, 2004; Zainal & Scholes, 1997). There is a great deal of evidence in the literature to suggest that nurses feel unprepared for this role (Benner, Tanner, & Chesla, 1997; Holden, Harrison, & Johnson, 2002; Plowright 1998; Price, 2004; Williams, 2005).

As part of a qualitative grounded-theory study, Jacelon explored the behavioral role of family members in relation to their hospitalized relative. The study participants included 5 older adult patients (≥ 75 years), a family member and a nurse for each patient. Using a semi-structured interview process, family members were asked to characterize their role in the care process. Prior research delineates that family and patient were viewed as one. Findings of this study are distinctive in that the family was regarded as a 'modifier' of the hospitalization. The family perceived as modifier affects the patient's hospital experience, yet is not the focus of care. As a result, family find themselves advocating for their loved one's personal integrity during this challenging period. Findings showed that family had two scopes of action: 1) directive role (ranging from an advisor role to a passive role), and 2) support role (presence through visiting, and keeping patient connected to the routine outside the hospital).

Using a grounded theory technique with in-depth unstructured interviews, Hupcey (1998) examined the process of integrating the family into the ICU. This study was part of a larger project that focused on social support and critically ill patients. The specific intent here was to evaluate the family role as supporter and/or caregiver in order to promote an optimal outcome for the patient. The effect had strong implications for family satisfaction as well. The sample was chosen from a large rural tertiary care medical center, with a varied population, and consisted of 11 ICU family members, 10 ICU nurses and 30 ICU patients. The interview focus was on the experiences of patient and the family while the patient was in the ICU, as well as the experiences that the nurses had with the patients' family and their perceived role that the family played (Hupcey, 1999). Data were analyzed using a constant comparative process by Glaser, B. G. A. L. (Glaser

& Strauss, 1967). Three key roles of family were identified including supporter, caregiver, and protector. The family offered emotional support, physical care, and advocacy. An example of support was the act of a family member listening to the patient's fears and concerns. The role of caregiver (family) was exemplified by providing basic care to the patient, such as brushing their hair or teeth. In the instance of the protector role, the family may advocate on behalf of the patient when the patient is incapable of speaking for them self (Hupcey, 1999).

In a quantitative descriptive study conducted by (Koller, 1991), research was designed to explore family needs and coping behaviors when faced with the stress of a loved one's critical illness. Employing the family systems, crisis, and coping theories a conceptual framework was developed for this study, using a convenience sample of 30 family members of 22 ICU patients. Subjects completed the Critical Care Family Needs Inventory (CCFNI) and the Jaloweic Coping Scale (JCS) and were given a 7 item semi-structured questionnaire. Identified as the most important item, based upon mean scores was the need to know the patient's prognosis. Overall, the top ten needs focused around the need for assurance, information, and proximity. Hope was identified as the most commonly used method of coping. Acknowledged by family members as the 5 highest most valuable coping mechanisms were continual hope, talking problems over with other family members, the use of positive thinking, prayer, and thankfulness for the good things in their life (Koller, 1991).

In a qualitative study, Soderstrom and colleagues (2009) interviewed 8 families, totally 31 family members, to describe and interpret their adaptation to ICU (Soderstrom, Saveman, Hagberg, & Benzein, 2009). Using a hermeneutical analysis, paradigm cases

were constructed. Results identified three main themes as the family adapted to a loved one's illness. The first was striving to endure when the demands of the situation influence the way in which the family perceives reality. It is as though "time stops and their map and compass are gone" (p.254). One way in which to endure is through family cohesiveness by staying close to the ill family member and drawing strength from other family members, as identified by other researchers as well (Boss, 2002; Engstrom & Soderberg, 2004; Lam & Beaulieu, 2004).

The second theme was striving for consolation, which can be accomplished by one of two means including 1) the freedom to share feelings of confusion and anguish and 2) the acquisition of as much information as possible regarding the illness. The first method of sharing feelings serves as a source of consolation in the overall adaptation process; while the acquisition of information helped to bring order to the situation (Soderstrom, Saveman, Hagberg, & Benzein, 2009). Family members, with an in-depth history of their loved one, often acted as a crucial intermediary between the patient and clinical staff. The third and last theme highlighted by Soderstrom and colleagues was the ability to rebuild life under new conditions, either while the patient was in ICU, after discharge or upon death. Family members expressed their struggle of feeling a heavy burden that life had changed. The study also revealed that families that had different beliefs, did not adapt well overall compared to those who had shared beliefs and 'facilitated' the situation well. Even if one member of the family held a strong 'facilitating' belief, it helped the family to overcome the stress and adapt to their new situation. The family had to find new physical, psychological and very practical solutions to cope (Soderstrom, Saveman, Hagberg, & Benzein, 2009).

2.3.3 Evidence of Family Needs in the Critical Care Environment

In the later decade of the 1970s, researchers Dracup and Breu (1978) encouraged nurses to utilize the research findings from Hampe (1975), which acknowledged the implications and importance of addressing the needs of family members who had an acutely ill or terminally ill loved one (Dracup & Breu, 1978; Hampe, 1975). The following year, Molter published her work on the needs of families of critically ill patients (Molter, 1979b). Several years later, Leske and Molter refined Molter's original work of 45 family needs, to form the Critical Care Family Need Inventory (CCFNI) (Leske, 1986b). The 45 needs identified on the inventory were then aggregated into 5 main need categories; assurance, proximity, information, comfort, and support.

The CCFNI was tested throughout the 1980's and 1990's to quantify those needs of family members of a patient in the ICU (Bernstein, 1990; Bouman, 1984; Daley, 1984; Engli & Kirsivali-Farmer, 1993; McIvor & Thompson, 1988; Mendonca & Warren, 1998; Miracle & Hovekamp, 1994)

The American Association of Critical-Care Nurses (AACN) published national guidelines for family-centered care, with the premise of creating a healing environment (Leske & Pasquale, 2007). These guidelines address the needs, assessment, and interventions for patients' families, compiled with an annotated bibliography of 24 original research studies, and a list of 122 references all related to the focus of family needs. This documentation provides evidence that the needs of family members who have had a loved one in the ICU have been examined across a broad body of research studies (Leske & Pasquale, 2007). These guidelines provide central principles and recommendations for nursing interventions that align with the 5 family needs identified

as “universally experienced by most family members” of patients in the ICU including: 1) assurance, 2) physical proximity to the patient, 3) information, 4) comfort, and 5) support (Leske & Pasquale, 2007). These expressed needs were adopted from Molter and Leske’s (1979, 1986) CCFNI work and validated many times over by other researchers (Bouman, 1984; Daley, 1984; Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Lee & Lau, 2003; Leske, 1986b; Leske & Pasquale, 2003 ; Maxwell, Stunekel, & Saylor, 2007; Stockdale & Hughes, 1988). Specifically, the CCFNI is a 45-item questionnaire that utilizes the perceived needs of family members of ICU patients. Items are answered on a 4-point rating scale, ranging from 1 (not important) to 4 (very important). The CCFNI instrument will be discussed in more detail at the end of the ‘needs’ section, as the actual identified family needs warrant discussion and substantiation prior to discourse of instrument utilization. The five recommendations for nursing intervention that are universally accepted are addressed in the following five subsections.

2.3.3.1 Need for Assurance in the Traditional ICU

Assurance regarding the ICU patient’s condition was associated with reduced feelings of anxiety and fear among the family (Chien, Chiu, & Lam, 2006; Maxwell, Stunekel, & Saylor, 2007; Molter, 2003), and also promoted a sense of trust in caregivers (Morton, Fontaine, & China, 2009).

The need for family assurance was exhibited a hermeneutic study of 15 female family members of critically ill patients in an ICU located in Sydney, Australia (Walters, 1995). The randomly chosen participants were interviewed and recorded for approximately 20 minutes in a private room just outside the ICU. Walter’s commented on the previous quantitative works of his colleagues (Leske, 1986b; Molter, 1979b;

O'Malley, Favaloro, & Anderson, 1991) maintained that although their works provided a large contribution to our knowledge of family needs, it omitted the 'life-world' of the family-participants, which is largely composed of the social, practical, experimental elements. Taking an ontological approach, Walter's positioned the study to examine the family experience of 'being' in the world at the same time that their loved-one was in ICU. The primary question asked of the participants was; 'When you see your loved one in the ICU, what kind of things go through your mind?' Any unanswered portion of the question was clarified with a follow-up of; 'Can you tell me more about that?' and 'What do you think is the meaning of...?' The results disclosed the family experience and need to "be with" and "see" the patient. The first identified element, "being with" centered more on the physical and emotional needs to be by their loved one's side and sharing their space; while "seeing" underscored the importance of just seeing their loved one and feeling 'in-tune' with them. Analogous to findings in earlier studies, Walters established that simply "being with" patients enabled family members to remain connected with their loved one, through the historical, personal ties and special affinities that bind them as family (Taylor, 1994; Walters, 1995).

In another study out of Australia, regarding family needs and experiences in an ICU, Burr (1998) contextualized family needs through triangulated qualitative and quantitative methods (Burr, 1998). Burr too, was mindful of how the quality of quantitative research on family needs using the CCFNI Molter (1979) has generated valuable outcomes through nursing interventions and processes, yet acknowledged that at no time did the family members themselves collaborate on the construction of the CCFNI instrument (Burr 1998) (Molter, 1979b). For that reason, Burr designed a needs analysis

to include variables that captured the contextual representation an individual's reality; with an ideology that it is the very essence of their experience that supports their own perception of need. The basis for the study used methodological triangulation to establish the degree of confirmation between a convenience sample of family members participating in CCFNI survey (n = 105) and the interview process (n = 26). Five major themes were identified; a) 'maintaining the vigil' or the need to be close to the patient and sustain contact, b) 'patient takes precedence' or the circumstantial need in which families direct all their energy and attention toward the patient, c) 'not knowing was the worst part' or the need for information, d) 'network rallies' or the need for family support, and e) 'protecting' or the need to protect certain members of the family from anxiety-provoking news. The findings of this study supported other research utilizing Molter's (1979) CCFNI instrument; particularly the needs for information and proximity. Conversely, the results of the semi-structured interviews revealed two major family needs not reflected with the CCFNI tool. These outcomes included the need for family members to support and reassure the patient, and the family member need to protect the patient. These particular needs were also found in previous qualitative studies (Johnson, Craft, Titler, Halm, Kleiber, Montgomery, & Buckwalter, 1995).

Lam and Beaulieu reported that families of patients in the traditional ICU consistently ranked the need for assurance, proximity, and information as more important than the need for support and comfort (Lam & Beaulieu, 2004). Using participant observation and a semi-structured interview, a convenience sample of 13 family members of patients admitted to the neurological ICU were recruited, with a study duration of 6 months at 3 shifts per week (during the patient ICU stay). A tape recorder was not used as

the researchers felt this was outside the realm of natural conversation. Instead, detailed field notes were documented to obtain an accurate history of what was discussed during the interview process. Over the study progression, Lam and Beaulieu captured two main insights that motivated family: first is to be at the bedside to ensure that the patient is receiving the best possible care; and secondly to fulfill a need to connect with the patient.

The need for assurance has been clearly stated and referenced here in this literature search. To close this section there was a powerful statement from a patient that came out of the Bond and colleagues study at Brigham Young University College of Nursing, Provo, Utah. The study used a qualitative descriptive design with a convenience sample of family members of patients who experienced a severe traumatic brain disorder with a Glasgow Coma Scale (GCS) score of 8 or less when admitted to an 11-bed neurological ICU in a level I trauma center. Using an exploratory interview process, researchers aimed to examine the family experience. Along with the need to know, the need for consistent information, the need for involvement, and the need to make sense of the experience, family members expressed the need for assurance. Family wanted to hear the truth about their loved one, which in turn made them feel assured that everything possible was being done for them. As one family member stated; “I can take the bad news. Don’t sugarcoat! I can take it. Please give me some reality. If there is no hope, tell me there is no hope!”

2.3.3.2 Need for Close Proximity in the Traditional ICU

The families of critically ill patients have consistently ranked the ability to be in close proximity to the patient as extremely important (Bijttbier, Vanoost, & Delva, 2001; Hupcey, 2001; Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996; Kleinpell & Powers, 1992; Maxwell, Stunekel, & Saylor, 2007). Specifically, family has noted that when they cannot physically see the patient it is a major source of stress for them (Duran, Oman, Abel, Koziel, & Szymanski, 2007). The family wanted to be near the patient's bedside whenever possible to offer support, obtain information, and observe the actions of caregivers. (Agard & Harder, 2007; Engstrom & Soderberg, 2004; Henneman & Cardin, 2002).

Referencing an original landmark survey conducted in 1988 by Stockdale and Hughes for the American Association of Critical Care Nurses (AACN) National Teaching Institute (NTI), (Stockdale & Hughes, 1988) collected data from 240 critical care nurses regarding visitation policies in the ICU. Results revealed that most ICUs (73.1%) had restrictions regarding the number of visits allowed each day as well as limits regarding the number and type of visitors (94.4%) with most (87.3%) permitting no more than two visitors at one time. Restrictions on the length of time per visit (84.8%) and minimum age of visitors (89.3%) were also reported (Stockdale & Hughes, 1988). Notably, 38% of respondents to the survey stated that the ideal number of visits per day should be unlimited and nearly 27% indicated that no limits should be imposed on the visit length. (Stockdale & Hughes, 1988).

A more current landmark study published in *Intensive Care Medicine* (2007), found that although families expressed the need to be near the patient, nurses expressed a

potential clinical safety concern for the patient, cautioning that the patient experienced a decrease in sleep when the family members stayed all day. (Berti, Ferdinand, & Moons, 2007; Halm & Titler, 1990; Henneman, Cardin, & Papillo, 1989; Kirchhoff, Pugh, & Reynolds, 1993; Lewandowski, 1994; Roland, Russell, Richards, & Sullivan, 2001).

Consistent with these results is a qualitative study by (Olsen, Dysvik, & Hansen, 2009) from Norway, which focused on the meaning of family members' presence during a loved one's intensive care stay. A semi-structured interview process was conducted with 11 patients in the ICU, and researchers found that visits have mutual importance to both the family member and the patient. However, their findings did demonstrate that some patients expressed a desire for some limitation in visiting hours knowing that their family member may become stressed in the process. The researchers suggest the nurse assist in negotiating a balance between social support and stress caused by family visits (Eriksson & Bergbom, 2007; Olsen, Dysvik, & Hansen, 2009).

In a study that examined the perceptions of family member needs and nurse perception of their needs, Maxwell and colleagues (2007) used a descriptive, exploratory design with a convenient sampling of 50 subjects; 20 family members of critically ill patients and 30 critical care nurses in a 16-bed CCU in a community hospital in northern California. Instruments used were the Norris and Grove 30-item version of Molter and Leske's CCFNI, as well as a 30-item version of Warren's Needs Met Inventory (NMI). (Maxwell, Stunekel, & Saylor, 2007; Warren, 1993) The investigator's added 2 additional research questions at the end of the modified versions of the CCFNI and NMI instruments. The main questions added were as follows: 1) 'Is there a difference in the perceived needs of family members of critically ill adults and critical care nurses at this

facility?’ and 2) ‘To what extent are these needs perceived as met by family members and critical care nurses?’ A ‘*t* test’ was used to compare both the family member and critical care nurse group means for CCFNI and NMI. Statistically significant differences ($p \leq 0.5$) between groups were noted for 9 of the items on the CCFNI, and for 22 items on the NMI instruments. These findings were found to be similar to that of earlier studies. There was general agreement from both nurse-group and family-group on most all of the needs. The findings were grouped into Molter and Leske’s 5 main themes; the need for information, assurance, proximity, support, and comfort (Leske, 1991). Although the need for information and assurance were rated high, the theme of proximity, need “to see the patient frequently” was ranked number one by family members on the NMI. The major strategy listed by family members regarding proximity was to have access to the patient in ICU through flexible visiting hours. Overall, findings demonstrate that family members rated all needs (listed on the survey tools) as being more important than did the nurses. Family ($n=20$) mean 3.95, nurses ($n=30$) mean 3.07, $t = 7.14$, ($p \leq 00$). McAdams and colleagues (2008) reported that patients felt safer, protected and more at ease when the family were present at the bedside, thus making the closeness an important need for the family member as well (McAdam, Arai, & Puntillo, 2008).

In a Swedish study conducted by Engstrom and Soderberg (2004), using a qualitative, narrative interview process of 11 partners (family members) with a loved one in ICU, the sole aim was to describe the family experience (Engstrom & Soderberg, 2004). The study outcome reflected three themes; ‘being present’, ‘putting oneself in second place’, and ‘living in uncertainty’. The primary need reported was the need to be near the patient (proximity); “It was important to be able to be present, nothing else

mattered”. Other findings regarding the need to be in close proximity to the patient was to show respect, which family perceived as a confirmation of integrity and dignity for their critically ill loved one (Engstrom & Soderberg, 2004).

The need to be in close proximity to the patient is directly tied to the ICU visitation policy has been identified as a priority for family members (Engstrom & Soderberg, 2004; Lee & Lau, 2003; Leske & Pasquale, 2003 ; Molter & Leske, 1983; Molter, 1979b; Olsen, Dysvik, & Hansen, 2009) visitation policies for critically ill patient’s differ between hospitals as well as within the same hospital. These variations of staff members appear to be a considerable source of stress for families. (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002) . Researchers, using the critical care family needs inventory (CCFNI) and the State Trait Anxiety Inventory, conclude that family needs and anxiety levels are significantly related to demographic variables and type of kinship with the patient (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002).

In the first prospective quantitative multi-site trial of 43 ICU’s in France, with a total of 920 family members and 637 patients, Azoulay and colleagues used a modified version of Molter’s CCFNI 14 item questionnaire and found that: family ranked proximity of the waiting room to the patient and easy access to the patient as being very important ($p=0.0002$). The next highest ranking need was the need for information, specifically ‘written protocol available for interacting with families’ ($p= 0.0233$). The patient-nurse ratio was also an important finding ($p=0.0008$), where family felt they were not satisfied. In addition, a demographic survey was used to determine length of stay, age, gender, geographical origin, marital status, plus the clinical status at admission including the Simplified Acute Physiological Score II (SAPS II). A Poisson regression

model was used to compute the expected percentage change in the satisfaction score with each one-unit decrease in the dependent variable. Family satisfaction was not correlated with SAPSII score, length of stay or mortality (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001). However, most ICUs have visitation policies that limit family access to patients, although current U.S. policies are more liberal compared with decades earlier when family members were restricted to a few minutes of patient visitation time. (Berwick & Kotagal, 2004).

Research by Berwick et al revealed that patients in the ICU were often calmer and had clinically favorable decreases in blood pressure and heart rate when the family was in close proximity (Berwick & Kotagal, 2004). A quantitative, time series analysis (TSA) was conducted by (Hepworth, Hendrickson, & Lopez, 1994) regarding the presence of visiting family in the Neuro ICU. TSA of the effect of family on the patient's intracranial pressure (ICP) suggested that family presence was associated with a decrease in ICP; as the interrelated effect demonstrated that when family was not present, the patient heart rate and blood pressure were inconsistent. Marsden asserts that if the presence of family is beneficial to the patient's well-being and physical condition, nurses should support their presence at the bedside (Marsden, 1992). Other investigators have also concluded that the ability for the family to be at the patient's bedside through the course of a critical illness and hospitalization enhances coping responses by the family (Patterson, 2002; Soderstrom, Saveman, Hagberg, & Benzein, 2009).

The literature is expansive related to family need to be close to their loved one during their critical illness in the ICU. Although many of the researchers have incorporated the CCFNI instrument into their studies, the majority have elaborated upon

their quantitative investigations by adding qualitative inquiry, with the attempt to zero in on why the family feels this way.

2.3.3.3 Need for Information in the Traditional ICU

The technical environment of the ICU, coupled with the complexity of patients' physiological status are often major obstacles to successful communication between the patient, family, and members of the nursing staff (Daley, 1984; Johnson, Craft, Titler, Halm, Kleiber, Montgomery, & Buckwalter, 1995; Mendonca & Warren, 1998). Communication barriers may be related to the patient being intubated, mechanically ventilated, or neurologically compromised due to trauma, sedation, or stroke. Thus, both nurses and physicians turn to the family to speak on behalf of the patient to help in the decision-making process. Respectively, the family has informational needs they require to help them understand why the patient is in critical condition, to understand the patient's current status, and to understand the long-term patient prognosis (Agard & Harder, 2007; Lee & Lau, 2002; Verhaeghe, vanZuuren, Defloor, Duijnste, & Grypdonck, 2007). In fact, the most important need expressed by the family, has been information concerning their loved one (Bijttbier, Vanoost, & Delva, 2001; Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996; Leske, 1986a, 1986b).

The need for general information about the patient is typically not enough for the family. The family needs accurate, comprehensible information that leaves room for hope (Verhaeghe, Defloor, & VanZuuren, 2005). Using a grounded theory, qualitative approach, Verhaeghe and colleagues conducted in-depth interviews with 22 family members of 16 patients who were in a traumatic coma. The study aim was to assess the interplay amongst hope and information provided to the family by the clinical staff. The

data was analyzed using a constant comparative approach. Findings were validated through researcher triangulation, where the second researcher assessed the same themes, followed by an independent third party who was not involved with the study process. Researchers found that hope was a central theme in every single interview with family. In fact, they found that hope was dependent on information about their loved one. They described a concrete hope that is a step-wise process in which the family maintains hope at a certain level, and then when new information is received from the staff, the family member either steps up or steps down their hope accordingly. During the interview process, family members made it clear to the researchers that there is a distinct need for realistic hope; which is based directly on received information which must be as clear, concise and complete as possible. Researchers characterized 4 different stages common to all family members as they learned to handle the information that was given to them. First, they passively tried to absorb fragments of information brought to them. Secondly, after they saw the patient, they tried to grasp their new reality. In the third stage, as they began to take in the strangeness of the ICU environment, they sought help to cope with the information and the environment around them. Lastly, they began to develop their own method to filter and understand the information that they were receiving, in order to establish realistic hope.

Azoulay and colleagues (2001) (study specifics addressed in previous section) contended that the time allotted for family members to receive patient information and clinical status updates was not sufficient, finding that the family would prefer more time to talk with clinicians, ask questions, and absorb what is being conveyed to them (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001). Notably,

it is estimated that approximately 50% of the clinical information provided to the family is not retained or comprehended (Pochard, Azoulay, Chevret, Lemaire, Hubert, Canoui, 2001). In a quantitative study regarding communication with family, specifically when delivering bad news, Jurkovich and colleagues (2000) used a self-designed 14 item survey tool (scale 1-6; 1=least and 6= most) to assess 54 family members perceptions concerning feelings of how they received news of their loved one's death (n=48). Deceased patients ranged in age from 12-91 years (with a mean age of 51 years). The most essential elements of delivering bad news were summarized as; 'attitude' of the clinician providing the news ranked most important (72%), 'clarity' of the message (70%), privacy of the conversation (65%), and the ability and knowledge to answer family questions (57%). The attire of the clinician ranked as least important (3%). Throughout, communication with the family must be meaningful and presented in simple, clear language in order to increase comprehension and retention (Jurkovich, Pierce, Pananen, & Rivara, 2000).

As family needs were first examined and identified, Leske and Molter estimated that approximately 75% of patients in an ICU may be unable to participate in the process of decision-making regarding their own treatment goals (Leske, 1986b; Molter, 1979a). Over two decades later, researchers from Canada conducted a prospective multi-center cohort study of six University affiliated ICU's to examine the substitute (family) decision-makers perception related to their adopted role in the ICU on behalf of their loved one (Heyland, Cook, Rocker, Dodek, Kutsogiannis, Peters, & O'Callaghan, 2003). The validated self-administered instrument consisted of 21 questions that targeted family perception of surrogate decision-making and communication of those who have a loved

one in the ICU receiving mechanical ventilation for over 48 hours. A total of 1,123 surveys were distributed and 739 were completed (70.3%). In overall satisfaction terms 560 participants (70.9%) were satisfied with the amount of communication and information that they were receiving from the ICU staff. Yet, the majority (81.2%) felt stressed and preferred some sort of shared decision-making process. Findings identified 3 major factors; 1) approval with the level of care the patient received, 2) the comprehensive level of information they received enabling them to make a sound decision, and 3) the feeling of support from the staff during the decision-making process. (Heyland, Cook, Rocker, Dodek, Kutsogiannis, Peters, & O'Callaghan, 2003)

Consistent across both U.S. and international studies (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001; Bijttbier, Vanoost, & Delva, 2001; Bouman, 1984; Henneman, McKenzie, & Dewa 1992 ; Heyland, Cook, Rocker, Dodek, Kutsogiannis, Peters, & O'Callaghan, 2003; Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996; Leske, 1986a, 1986b; Verhaeghe, Defloor, & VanZuuren, 2005), researchers from China corroborate findings that the need for information ranks high on the list of perceived family needs. Using a descriptive, cross-sectional study set in an 18 bed ICU in Hong Kong, researchers used a convenience sampling of 40 adult family members to conduct the Chinese version of the Critical Care Family Needs Inventory (CCFNI) and demonstrated that the need for information was ranked as most important (Lee & Lau, 2003).

Auerbach and colleagues (2005) concluded that what family members primarily required during a patient's ICU stay was access to understandable, and truthful information about the patient's medical condition (Auerbach, Kiesler, Wartella, Rausch,

Ward, & Ivatury, 2005). The aim of the Auerbach study was to assess ‘family satisfaction with needs met’, ‘signs and symptoms of acute stress disorder’, ‘interpersonal perception of healthcare staff’, ‘level of optimism’, and the ‘relationships among these variables in patients' family members’, which was measured during the patient ICU stay or shortly after discharge. Five instruments were used in this study; the ‘Critical Care Family Needs Inventory’, the ‘Acute Stress Disorder Scale’, the ‘Brief Symptom Inventory’, the ‘Impact Message Inventory’, and the ‘Life Orientation Test’. Results demonstrated that needs the families thought were least satisfactorily met, involved the lack of information they were receiving. Another finding pertinent to family overall needs, revealed that signs of isolation correlated with acute stress disorder was elevated in family members immediately after admission, however decreased appreciably after discharge (Auerbach, Kiesler, Wartella, Rausch, Ward, & Ivatury, 2005).

Studies conducted in Sweden by Takman and Severinsson (2005) reported on the perspective of the nurse (n=236), with the aim to identify the needs of critically ill adult patients’ family members, using the Critical Care Family Needs Inventory (CCFNI). Data were analyzed using descriptive and inferential statistics, with a significant outcome similar to that of the Auerbach study; including that 1) nurses felt family member’s should be kept informed and treated with concern and respect ($p < 0.01$); 2) nurses have a specific competence and aside from the high-tech care, they should be providing supportive care in existential crisis ($p < 0.001$); 3) nurses can assist family to cope by listening and being responsive ($p < 0.001$) (Takman & Severinsson, 2005). From the perspective of the patient however, a qualitative study by Bergbom et al state that the

presence of those family member's closest to them have sustained their humanity by sharing memories of life outside the ICU (Bergbom & Askwall, 2000).

On the basis of the findings of those investigations reviewed in this section, it is evident that there is a consensus regarding the importance of 'information' as a primary need for the patients' family in the ICU. The next section will review the literature on the family need for comfort. Although families tend to rate this need below their need for information, need to be in close proximity to the patient, and the need for assurance, it has been identified as one of the five 'need' themes borne from Molter and Leske's CCFNI work (Leske and Molter 1987).

2.3.3.4 Need for Comfort in the Traditional ICU

Throughout the 20th century, comfort was the central goal of nursing and medicine. Comfort was the nurse's first consideration. During the later part of the 1980's a modern query of comfort began to evolve, as Kolcaba built upon the century work of theorists before her (Harmer, 1926; Orlando, 1961; Watson, 1979). Kolcaba, considered a mid-range theorist, focused on the patient-family experience in a multidisciplinary sense. As comfort activities were observed, the meaning of comfort was explored. Application of comfort as an intervention in the ICU came later as the theory was accepted as a need and incorporated into the CCFNI. The fundamental principle held by Kolcaba was that there are benefits of incorporating 'comfort' into nursing practice (Kolcaba, 1991). Kolcaba identified 3 types of comfort; relief, ease and transcendence. She further delineated that these experiences can take place within one of four contexts; physical, psycho-spiritual, socio-cultural, and environmental. To operationalize these concepts,

she developed the General Comfort Questionnaire (GCQ) which was later tested and analyzed for validity (Kolcaba & Fisher, 1996; Kolcaba, Tilton, & Drouin, 2006).

Although the focus in this dissertation is not central to the concept of comfort, it is necessary to draw upon its assumptions, so that this fundamental ‘need’ for both the patient and family is recognized. Kolcaba defines comfort as the “immediate experience of being strengthened through having the needs for relief, ease, and transcendence met in four contexts of experience (physical, psycho-spiritual, social, and environmental)” page 6, (Kolcaba, 1992) When the patient experiences a sense of comfort, the family too experiences relief and a feeling of comfort.

In a retrospective, descriptive study using a qualitative approach, Jamerson and colleagues aimed to examine the experiences of families with a relative in the ICU. The research took place in an adult surgical trauma ICU of a university affiliated medical center, whose subjects included 18 women and 2 men who were family of an ICU patient. Methodology consisted of a twofold approach, using a focus group and unstructured interviews with individual family members. Their findings revealed 3 stages of sequential behavior: first was the theme of hovering, which meant that until such time family could move past their own anxiety and uncertainty, they found themselves in a cursory movement of hovering around the ICU; secondly was the stage of information-seeking (importance discussed in the previous section); and the last stage in the process involved an awareness of their own needs which the researchers called resource-gathering. After the initial shock subsided, the family became aware of their surroundings in the ICU, and therefore of their own comfort needs. It is this last finding that will be addressed here. Within the context of comfort, family specifically identified their

physical need to have a quiet space, a bathroom nearby the ICU, some personal space to rest their head, access to nutritional food items, a place to make phone calls, a place to cry, perhaps even a cot, blanket or pillow, and diversionary activities such as a television, books and magazines. These physical items lessen the family member overall level of stress (Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996).

The issue of comfort for the family has been corroborated by many other researchers (Leske, 1992; Leske & Pasquale, 2007; Soderstrom, 2003; Soderstrom, Saveman, Hagberg, & Benzein, 2009) (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, le Gall, & Schlemmer, 2001; Daley, 1984; Johnson, Wilson, Cavanaugh, Bryden, Gudmundson, & Moodley, 1998 ; Maxwell, Stunekel, & Saylor, 2007; Mendonca & Warren, 1998; Norris & Grove, 1986; D. Price, Forrester, Murphy, & Monaghan, 1991). Frequently, the family spends countless hours in the vicinity of the ICU and there is a need for physical and environmental comforts such as a separate waiting room, telephone access, comfortable ambient temperature and lighting, and restful furniture (Leske, 1992; Leske & Pasquale, 2007).

Comfort related to perceived safety needs of the patient has been identified as an issue for family members (Hupcey, 2000). Hupcey described the psychosocial needs of the ICU patient (and family): when the patient encounters an adverse, painful, or frightening experience in the ICU, their perceived safety is often questioned. Subsequently, the family response is one of discord and anxiety, insofar as they want their loved one to be comfortable. Hupcey studied 45 adult ICU patients (20 men, 25 women) in a large tertiary care center, using a direct recorded interview technique when the patient was able to speak or was discharged from the ICU. The rationale for this

qualitative study was to examine the patient psychosocial needs, which included the following two questions; a) 'what are patients' experiences when their needs are not met', and b) 'what do families and ICU staff do that either helps to meet or does not meet patients' needs. (Hupcey, 2000).

The overarching discovery expressed in this study was the patient's need to feel safe. Findings demonstrated 4 subcategories of the patient's perceived safety needs; knowing, regaining control, hoping, and trusting. If for example, the patient felt confused, it made them feel unsafe. If they did not trust their nurse, it made them feel unsafe. However, once these needs were met, patients communicated to the researcher that they felt safe. Patient's expressed that family provided a great source of comfort for them and the fact that just their presence or "being there" made patients feel safe. Many patient-subjects described having family present at their bedside, as giving them a sense of comfort, even if they weren't talking. The patient-family psycho-social needs must be taken into account when addressing the need for comfort (Hupcey, 2000).

Conversely, a Korean study adopted a triangulation mixed methods design of 85 family members designated as the primary caregiver to their loved one, now in ICU (Yang, 2008). Using the CCFNI and direct semi-structured interviews, 25 family members of the 85 invited, participated. The study aim was to capture the family needs and experience in the ICU. All interviews were recorded and transcribed verbatim. Regarding the socio-cultural and psycho-spiritual comfort needs of the family, they ranked low as the family is most concerned about their loved one's comfort needs being met over their own. Of the CCFNI quantitative results, the highest need of the participants was the need for assurance ($M=3.67$, $SD=0.41$); followed in priority were the

need for information (M=3.49, SD=0.40), proximity (M=3.23, SD=0.50), comfort (M=2.93, SD=0.60), and support (M=2.63, SD=0.55) (Yang, 2008). The family response in ranking the need for comfort as low on the scale indicated that either it was unimportant in the scope of the situation or that the hospital facilities were adequately comfortable. This low priority need for comfort was reflected in the qualitative data set as well. The study participants reported that they did not expect much from the hospital relevant to the convenience of facilities for the ICU families; instead accepted the perceived notion that ICU families would have to endure inconveniences and discomforts. One wife put in plain words: “Inconvenience doesn’t matter. I came here because my husband is critically ill. There is nothing I can do except wait”, (Yang, 2008, p. 84).

2.3.3.5 Need for Support in the Traditional ICU

Between 2004 and 2005, the American College of Critical Care Medicine Task Force, composed of the American College of Critical Care Medicine (ACCM) and the Society of Critical Care Medicine (SCCM) released clinical practice guidelines for support of the family in a patient-centered ICU (Davidson, Powers, & Hedayat, 2007). The single goal was to develop standardized practice guidelines for all hospitals that provide intensive care to any adult, pediatric or neonatal patient population and their respective families. The panel reviewed approximately 300 published research studies between 1980 and 2003; and made 43 recommendations based upon the research. The advisement was as follows: a shared family decision-making model, early and repeated care conferencing to reduce family stress and improve communication, honor culturally appropriate requests from family, informed refusal, spiritual support, debriefing to

minimize family impact of interactions on staff health, family presence on grand rounds and during resuscitation, open family visitation to patient, family-friendly signage and family support during the patient ICU stay, and before and after patient death. These practice guidelines were made public and shared with U.S. hospitals in a comprehensive multidisciplinary effort to support both patient and family.

In the same Hupcey study referenced in the above section on comfort, her findings also disclosed that patients' stated that family and close friends provided a great source of support to them. The findings further revealed that the quality of support, rather than the quantity of social support from family is more meaningful (Hupcey, 2001).

In a qualitative investigation to understand and interpret the experience of family members with a loved one hospitalized in an ICU, researchers Eggenberger and colleague (2007) conducted semi-structured 'family as a group' interviews with 11 families. Study design incorporated the family systems theory and existential phenomenology as a framework. Data were analyzed using Van Manen's hermeneutic framework of 'lived space, lived relation, lived body and lived time'. Researchers concluded that family bonds make them remarkably strong during the ICU experience. 'Being a family unit' is the essence of what allows most families the capacity to tolerate the emotional turmoil and suffering that is a repercussion of the critical illness experience. A constitutive pattern of being family was revealed. (Eggenberger & Nelms, 2007, Van Manen, 1990).

Vandall-Walker and colleagues (2007) examined the value family support from the perspective of the nurse. Using a grounded theory approach to delineate nursing support of family members, researchers (Vandall-Walker, Jensen, & Oberle, 2007)

concluded that the most frequent theme that surfaced was “support” to get through the crisis experience.

A heightened awareness of the need for family presence has prompted U.S. hospital decision makers to support basic needs of visitors and especially close family by creating an environment that is safe, clean and meets essential biological comfort requirements (Davidson, Powers, & Hedayat, 2007). Paradoxically, the importance of cleanliness, ventilation, lighting, color, and noise constraints were legendary standards set by Florence Nightingale in the mid-1800s (Nightingale, 1860) and are influencing the design of current critical care environments (Rubert, Long, & Hutchinson, 2007). The designs current ICUs often take into consideration are environmental noise, light, landscape, color, air quality, therapeutic-sound, music-therapy, art, aromatherapy, does not fit here under “design” and, what does this mean? Issue of visiting/family presence has a whole literature base of its own (Rubert, Long, & Hutchinson, 2007); all of which support the family experience in the critical care setting.

2.3.4 Meeting and Measuring Family Needs in ICU: Quality and Patient Safety

The Institute of Medicine (IOM) acknowledges that patient safety is “indistinguishable from the delivery of quality health care.” (Aspden, Corrigan, & Wolcott, 2004, p. 5). So, what defines quality health care in the context of family presence? The American Academy of Nursing Expert Panel on Quality Health targeted the following positive benchmarks which support nurses in achieving high-quality patient care; ‘appropriate self-care’, ‘demonstration of health-promoting behaviors’, ‘health-related quality of life’, ‘perception of being well cared for’, and ‘symptom management’ (Mitchell & Lang, 2004)

The most vital role in nursing is patient safety, which must advocate and incorporate a care-plan to assure that quality is delivered by all disciplines caring for the patient, including family members. Two important components of this integrative care, includes; interception of errors by others, otherwise known as near misses, and surveillance that identifies hazards and patient deterioration before they become errors and adverse events (Mitchell, 2008). The steadfast presence of family often allows them to notice subtle changes in their loved one, or peculiar alterations in the patient's immediate environment. At times asked to weigh-in on decisions, or to in fact serve as surrogate decision-maker, family shares a role in the process of patient care. The patient's well-being is at the forefront of the family objective.

Significant changes have occurred during the past several decades in the way nursing staff perceive the family of patients, with a transition from an intrusive presence with restrictive visitation privileges to an integral element of the care process (Dockter, Black, Hovell, Engleberg, Amick, Neimier, & Sheets, 1988; Maxwell, Stunekel, & Saylor, 2007; Warren, 1993). These changes are largely due to a conceptual shift in the perception of patients as individuals, often voiced as a need by the patients themselves, as part of a family system, rather than forsaken entity in the bed (Williams, 2005). In qualitative investigations that directly sought the ICU patients' viewpoint, patients expressed that having the awareness of a family member present at their bedside was highly valued, providing a sense of comfort as well as an active reduction in their anxiety level (Granberg, Engberg, & Lundberg, 1998, 1999).

Another indication of process change that incorporates family into the equation of patient care was the guidelines discussed earlier set forth by the American College of

Critical Care Medicine Task Force, (2007). However, the presence of family at patients' bedsides has added to the complexity of care for nursing staff, who may not feel adequately prepared to meet the needs of the family (Bouman, 1984; Chartier & Coutu-Wakulczyk, 1989; Daley, 1984; Maxwell, Stunekel, & Saylor, 2007). Yet, the importance of the family homeostatic structure cannot be understated, as exemplified in influential root psychosocial and behavioral studies (Bouman, 1984; McCubbin & McCubbin, 1993; Olsen, 1970; Volicer, 1973).

Family members have certain rights beyond the aforementioned needs. The American Nurses Association (ANA) Code of Ethics for Nurses (2000) states that addressing patient-family needs requires nurses to recognize the patient's place in the family or other networks of relationship, as well as the family member's place in the care of the patient. The ANA designated four guidelines for nurses to incorporate when caring for patient and family; they are as follows:

2.3.4.1 Respect and Dignity: It is the innate right of all human beings to be treated with respect and dignity. According to Immanuel Kant, "free will" and the "ability for humans to choose their own actions" are the essential attributes of dignity (Kant, 1724-1804). When applied to this belief as a core value of health care, the family has the right (if the patient consents) to be an active participant in the patient plan of care.

2.3.4.2 Information Sharing: The health care team provides the patient and the family with unbiased, timely, accurate, and useful information that enables them to participate in the decision-making process (Institute-for-Patient-and-Family-Centered-Care, 2011).

2.3.4.3 Participation: Both the patient and the family are encouraged to participate in the clinical decision-making process at a level that is comfortable for them (Institute-for-Patient-and-Family-Centered-Care, 2011).

2.3.4.4 Collaboration: Many institutions today encourage certain volunteer family members to become involved at many levels of policy and program development, education, and health care facility design (Institute-for-Patient-and-Family-Centered-Care, 2011).

2.3.5 Patient-Family Outcomes in the Traditional ICU

In 1979, a seminal descriptive study by Molter revealed that the family members of patients in the ICU had their own set of unresolved needs related to the care, processes, and environment that might have affected patient outcomes (Molter, 1979b). Using crisis theory as a foundation for this research, Molter first determined the family's perceptions of their needs prior to including them in the care process. This was accomplished by asking the following 3 questions: 1) what personal needs do relatives of critically ill patients identify, 2) what is the importance of these needs to relatives, and 3) are those needs being met, and if so by whom? Following an extensive and methodical review of the literature, and surveying 23 graduate nursing students who chronicled the needs of family members corresponding to observations and experiences throughout their own practice, a 45 item needs inventory was developed. The incongruous factor here however, is that the instrument held restricted content validity since it was not derived from family members, but rather from nursing students. Approximately a decade later, the content of the inventory tool was validated and deemed reliable by Macey and Bouman, using a panel of experts comprised of 5 critical care nurse managers and 11 nursing faculty

members (Macey & Bouman, 1991). Subsequent studies have established internal consistency of the instrument with test-retest reliability (Leske, 1986a; Norris & Grove, 1986). Molter (1979) conducted a structured interview with 40 family members of relatives in the ICU using this 45-item list of needs. The family members were asked to rate each of the need statements on a scale of one to four (one = not important to four = very important).

The results of Molter's seminal study identified 10 prominent needs that family members rated as very important including the need to: 1) feel hope, 2) have questions answered honestly, 3) receive reassurance that the best possible care was given to the patient, 4) receive explanations using understandable language and terminology, 5) feel that hospital personnel cared about them, 6) know the patient's prognosis and chance of recovery, 7) be called at least once a day, 8) be called at home in the event of any changes in the patient's status, 9) receive specific facts about the patient's progress, 10) know why things are being done to the patient (Molter, 1979b). Replications of Molter's original study have been conducted numerous times (Bouman, 1984; Daley, 1984; Leske, 1986b; Molter & Leske, 1983; Norris & Grove, 1986; Price, Forrester, Murphy, & Monaghan, 1991)

Additional research was subsequently performed to revise and improve the content validity of the original 45-item needs assessment developed by Molter. Norris and Grove (1986) scaled back the original 45 item inventory using a method called 'Q sort'; creating fewer categories in which similar needs were sorted (Polit & Hungler, 1997). The instrument was reduced to 30 items following a conclave of 5 family members of an ICU patient and 5 graduate nursing students working in ICU, who were

asked to sort through each of the 45 items and rank them according to importance. A median score was generated and 15 items were removed from the original instrument. The revised instrument was then implemented and needs of 20 family members were investigated. Findings rated as very important showed that family members need to 'feel there is hope', 'have their questions answered honestly', 'be assured the patient is receiving the best possible care', and to feel that the patient is genuinely being cared for by hospital personnel'. An ensuing study using the Norris and Grove (1986) instrument of perceived needs of families of critically ill patients in 2 ICU's of two community hospitals, both family members (n=25) and ICU nurses (n=24) completed the 30 item questionnaire. Findings suggest that nurses' perceptions of family needs are congruent between the 2 ICU's, however, family members collectively and by unit ranked their needs consistently higher than did nurses (Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990).

Molter's original 45 item instrument was also revised by Leske (1986) who randomly reorganized the question sequence, as well as inserting an open-ended question at the end of the instrument that would allow for a family member to post a subjective comment. The modification of this tool was called the Critical Care Family Needs Inventory (CCFNI) (Leske, 1986b). Further evaluation of the CCFI was conducted by Leske in 1991 to determine construct validity and internal consistency by performing a factor analysis (Leske, 1991). An aggregate data base of family needs was constructed over a 9 year period from 1980 to 1988 on 677 subjects, in 14 states collected by 21 nurse investigators. The results defined by Leske and later published in the AACN national protocols for practice focused on 5 primary dimensions of family needs including: 1)

support, 2) comfort, 3) proximity, 4) information, and 5) assurance. The total CCFNI internal consistency alpha coefficient was 0.92. Internal consistency was also established for the 5 identified dimensions, with Cronbach's alphas between 0.61 and 0.88. Adequate psychometric properties merit continuation of the tool both in research and clinical practice (Leske, 1997).

Not only have there have been numerous studies using the CCFNI to evaluate family needs in the U.S., the instrument has been translated into many languages and continues to be used worldwide. Johnson and colleagues (1998) shortened the original version to 14 items, which was validated for internal consistency and stability. At a university hospital in Saskatoon, Canada, investigators used the modified CCFNI conjointly with the Acute Physiology and Chronic Health Evaluation (APACHE) II score, and the Therapeutic Intervention Scoring System (TISS) score. Study criteria deemed the patient must have been in the ICU for at least 48 hours. Of the 470 patients that were admitted during the study time (October to December 1994 and January to June 1995), only 149 respective family members were eligible for inclusion having met the patient 48 hour rule, and 99 ultimately composed the cohort group (those who completed the questionnaire). Next, for every fifth patient, researchers chose a second family member to participate in the study (n=16) to test for concordance within the family. Principle components for the factor analysis used a varimax rotation which revealed four distinct factors. Factor 1 comprised of questions 1, 2, 6, and 7 (Cronbach alpha 0.7885); this field was termed 'attitude' which explored family perception of nurse and physician behavior, such as including family in overall patient plan. Factor 2 comprised of questions 3, 4, 5, 12, and 13 (Cronbach alpha 0.6963); this field was termed

‘communication’ which dealt with family perception of the information they were receiving and their physical adaptation to the ICU surroundings. The third factor comprised of questions 7, 8, and 9 (Cronbach alpha 0.5526) and was termed as ‘comforting skill.’ This factor explored family perception of clarification and reassurance from the staff. Finally, the fourth factor, question 14, which was open-ended, addressed the family experience in general; as an example, isolation. The Cronbach alpha for the entire scale was 0.7617. The additive sum score of all questions was then calculated and used as the dependent variable. There was increased family dissatisfaction (higher score) if there were more than two ICU attending physicians for the patient ($p = .048$), and if the same nurse was not assigned to the patient, providing care for two consecutive days ($p = .044$). There was decreased dissatisfaction if the family participant was female ($p = .006$), and if the relationship to the patient was that of brother/sister ($p = .012$). The independent variables were demographic features concerning the patients, the ICU, and the respondents. The 3 most vital issues identified by family members concerning the care providers were 1) the attitude of the staff, 2) communication, and 3) comforting skills (Johnson, Wilson, Cavanaugh, Bryden, Gudmundson, & Moodley, 1998). The content of this instrument has since been validated for reliability by hundreds of family members, and clinical experts in the field in numerous separate studies (e.g., (Auerbach, Kiesler, Wartella, Rausch, Ward, & Ivatury, 2005; Bijttebier, Delva, Vanoost, Bobbaers, Lauwers, & Vertommen, 2000; Burr, 1998; Coutu-Wakulczyk & Chartier, 1990; Norris & Grove, 1986). It is this tool that was used to guide the survey schedule for this research study (*see Appendix D, p. VI*).

The CCFNI has been criticized despite its usefulness, largely due to the fact that it does not allow family members to express needs that may not be included on the survey instrument (Yang, 2008). Furthermore, the quantitative format of the CCFNI may not capture the full impact of the crisis event (Forrester, Murphy, Price, & Managhan, 1990). Researcher, Yang (2008) conducted a mixed method study, using a combination of the CCFNI (n=80) and in-depth family interviews (n=25) with the aim to achieve knowledge of family needs and experiences in a Korean ICU. Results of the CCFNI revealed that ICU Korean families expressed the need for assurance foremost, followed by the need for information, proximity, comfort, and support. The qualitative findings demonstrated greater insight into how and if these needs were met by both hospital and family systems. Participants expressed concern and expectation that other family members would visit the patient, to offer practical help and support for the primary caregiver. There is a cultural aspect within Korean families that have certain expectations for each member to be an integral component of the family; the premise being that if these expectations were fulfilled, the structure of the family system was fortified; if not, it resulted in dispute, blame, or avoidance within the family (Yang, 2008).

In a quantitative study using the CCFNI, in a large teaching hospital in New Jersey, researchers conducted a comparative study of family needs in the ICU, between nurse (n=49) and family (n=92) response used paired t tests (two tailed) to calculate Family members' perceptions and ICU nurses' evaluation of the most and least important critical care family needs were identified. Significant ($p < 0.001$ - $p < 0.05$) differences were identified between close family members' perceptions and that of the ICU nurses' judgments of how important family needs were being met in ICU in 50% of the results.

This indicates that nurses only moderately comprehended what families perceive as important (Forrester, Murphy, Price, & Managhan, 1990).

While replication of the CCFNI has promoted a consensus amongst investigators regarding the overall needs of ICU family members, a purely quantitative approach has been criticized for falling short of acknowledging the less tangible or subjective perspective of families' experiences (Zainal & Scholes, 1997) A focus group was conducted with 20 family members of surgical-trauma ICU patients who gathered two to six months post-discharge and were asked to recount their experiences during the time their loved one was in the ICU (Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996). Results identified four main shared experiences; 1) an initial period of "hovering" as a state of confusion, 2) "information seeking" as a means to move forward, 3) "tracking" as a process of observing and analyzing the care that is provided, and 4) "garnering resources" as a means of self-preservation and adaptation (Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996).

In a phenomenological study, Titler and Cohen (1991) reported that families experience disturbances in intra-family relationships which force undue strain on individual family roles; as perceived by patients, spouses, children of the patient, and nurses. Interviews were conducted and recorded with patients (n=9), spouses (n=12), children (n=11), and nurses (n=12), with the aim was to garner a better understanding of family needs through qualitative inquiry. Certain themes emerged with regard to how this crisis influenced the family as a unit, as well as the individual family member; findings included: 1) inadequate communication between family members, 2) safe-guarding the children from information that may cause apprehension and fear, 3) underlying threat,

manifested by feelings of uncertainty, intense emotional swings, and physical illness in children, 4) interruption of typical home routines, 5) altered relationships, and 6) role conflict. Findings demonstrated a divergence of opinion between nurse perception of family needs with that of patients and family members (Titler & Cohen, 1991).

2.4 The Traditional Intensive Care Unit

2.4.1 Physical Environment and Characteristics of the ICU

The intensive care unit began as a simple concept to congregate the most acutely ill patients so that they could be closely observed by the health care team (Knaus, Draper, & Zimmerman, 1986). The current equipment and devices in an ICU make it the most technologically sophisticated environment in the hospital. (Almerud, Alapack, Frilund, & Eckbergh, 2007; Hoonakker, McGuire, & Carayon, 2011).

Admission to the ICU is experienced as a crisis for both patients and their family members/significant others (Fridh, Frosberg, & Bergbom, 2009; Lee & Lau, 2003; Meert, Briller, Myers-Schim, & Thurston, 2008). Using a phenomenological-hermeneutic method, Fridh and colleagues (2009) interviewed 17 close relatives following recent deaths of their loved one. The interviews resulted in seven themes, two of which related to their feelings about the ICU environment; maintaining vigil and the need for privacy, both expressed by the family as difficult to accomplish in a strange environment with frightening unfamiliar technology (Fridh, Frosberg, & Bergbom, 2009).

In a different study conducted in a pediatric intensive care unit, environmental needs of 33 parents experiencing a child's hospitalization and death were examined. The

purpose of this qualitative descriptive analysis was to determine if family environmental needs were met. Through in-depth videotaped interviews the main findings identified six themes: 1) the physical place remembered; 2) special characteristics, such as privacy, proximity, space, temperature, lighting, noise, safety and cleanliness; 3) services for family for daily living, such as facilities that allow the parent to shower and care for themselves, food, and a place to rest; 4) parent care-giving, such as facilities to allow the parent to continue their caregiver role (for the chronically ill patient); 5) access to their child at all times; and 6) presence of people (reassurance and information from staff and environmental space for visitors) was identified as important both in the waiting room and the patient room (Meert, Briller, Myers-Schim, & Thurston, 2008).

A third study demonstrates a quantitative descriptive design, using the Chinese version of the Critical Care Family Need Inventory (CCFNI) to investigate the needs of 40 adult family members of a 1285 bed hospital, 18 bed adult ICU in Hong Kong (Lee & Lau, 2003). Ranked on a four-point Likert scale from 1= not important to 4= very important, 55.5% of the subjects ranked the 45 need items as ≥ 3 (important to very important). Overall, 58.4% of the subjects considered that their needs were met. Findings reflected that most of the families 'unmet' needs related to the hospital facilities and the unit environment (waiting room, furniture, good food, telephone, and toilet). The two highest needs that were not met were; a) to have a toilet near the waiting room, ranked 3.2 (important) with only 12.5% of the subjects stating this need was met, and b) to have a telephone in or near the waiting room, ranked 3.0 (important), with 25% of the subjects stating this need was met (Lee & Lau, 2003). Elements of the ICU environment that contribute to the stress experienced by family members include: 1) monitoring by various

devices; 2) exposure to noise, lighting, temperature, and odors; 3) observing other patients as recipients of care; 4) restricted movement; 5) disorientation to time and place; 6) invasive and possibly painful procedures; 7) lack of information; 8) changes in staff; 8) communication difficulties; and 9) limited access to family (Almerud, Alapack, Frilund, & Eckbergh, 2007; Fontaine, Briggs, & Pope-Smith, 2001; Hoonakker, McGuire, & Carayon, 2011; Ozer & Akyil, 2008; Stichler, 2001). Research has shown that the ICU environment, including noise, disruptions to day and night rhythms, and the emphasis on technology can cause physical and mental stress for patient which in turn upsets the family member (Merilainen, Kyngas, & Ala-Kokko, 2010). In this non-participative observational study by Merilainen and colleagues (2010), using continuous recording of 4 ICU patients and families for a 96 hour timeframe, the authors concluded that the ICU environment can be broken down into the physical, social and symbolic environment, of which all influence the patient and family. In the 12-bed open concept ICU in a large teaching hospital, bed spaces were small with a plastic curtain separating one patient from the next, leaving the family little room to move or for privacy (Merilainen, Kyngas, & Ala-Kokko, 2010). This research corroborated an earlier study by Stremler, Wong, & Parshuram (2008), who conducted a cross-sectional survey of 135 Canadian and American Hospitals; 65 (48%) free standing pediatric hospitals and 70 (52%) adult hospitals with a pediatric unit, measured the provisions for the family. Using a validated 37 question telephone survey tool, with a 77% response rate, Stremler and colleagues reported that 117 (87%) of the hospitals had access to no cost accommodations for immediate family (shared or private sleeping room or off-site), but requests are in high demand and not guaranteed. Adult hospitals with pediatric units were more likely than

free standing pediatric hospitals to allow a parent or close family member to stay overnight in the intensive care unit (ICU) (77% vs. 53%, $p \leq .01$). Hospitals that provided a free meal and provision for self-care to immediate family members was low at 19 of the 135 sites (14%). Future studies are warranted for evidence of sleep disruption and the effects of insomnia on family members (Halm, Titler, Kleiber, Johnson, Montgomery, Craft, & Megern, 1993; Stremler, Wong, & Parshuram, 2008).

While the ICU environment is beginning to undergo considerable changes, most are still dominated by high noise levels from alarms, equipment, monitors, telephones, intercoms, constant staff activity, and conversation; which minimizes the chance for normal rhythms of sleep or rest for the patient as well as causing distress for the family (Rubert, Long, & Hutchinson, 2007). A different perspective measured the noise level in two different ICUs, which resulted in a peak noise level of 80 decibels and approximately 50% of the noxious noise generated in the ICU was directly from human behavior (Kahn Cook, Carlisle, Nelson, Kramer, & Millman, 1998). Patients and families have since been included on some of the clinical teams when new unit design is in the planning phase (Cooper-Marcus & Barnes, 1999; Samuels, 2009)

Research has identified that people interact with their environmental surroundings, and when applied to the surroundings of a critical care area of a hospital, the environment may have adverse effects on therapeutic outcomes (Malkin, 2003; Ulrich, 1984, 1992, 1999). Studies conducted in the late 1980's and 1990's surveyed discharged hospital patients, differing in age, gender and diagnosis, about the hospital environment. Results consistently found that they shared a common request to include more natural elements such as nature pictures, in-door plants, and small gardens to offset

the intimidating critical care area of a hospital (Cooper-Marcus & Barnes, 1999; MacRae, 1997; Ulrich, 1981). Research further demonstrates that views of nature are important in the hospital setting: patients who have the benefit of natural views heal faster than control groups that look onto blank walls (Ulrich, 2000b; Ulrich, 2000a). Hospitals today are attempting to create a healing environment in the ICU by making the patient room more welcoming with natural lighting, increased space, window view, nature-artwork, reduced noise, improved air-quality, and the addition of color (Malkin, 2003). The physical ICU environment effects the physiology, psychology, and sociology of all those who experience it, including the patient's family (Hamilton & McCuskey-Shepley, 2010). Table 2.1 highlights the evolution of the ICU. It was not until the 4th generation of ICU's that inclusion of family was noted.

Table 2.1

Evolution of ICU's

	First Generation 1950's	Second Generation 1970's	Third Generation 1980's - Present	Fourth Generation Present- Future
Characteristics	<ul style="list-style-type: none"> *Open unit/ward *No partitions except for screens *Nurses desk at foot of bed or in corner *Unit lighting control, one switch 	<ul style="list-style-type: none"> *Individual rooms or walled cubicles *Rooms often on either side of the hall with open nursing station in the middle *Central monitoring *Some units without external patient room windows leading to increased incidence of delirium *Patient room lighting with separate switch(s) from nursing station *Calendars and clocks in patient rooms 	<ul style="list-style-type: none"> *Individual rooms/folding or sliding doors *Rooms often arranged in semi-circle or circle with nursing station in center *Some units configured with decentralized nursing stations *Patient room windows with external views/lighting *Increased control patient room lighting levels 	<ul style="list-style-type: none"> *Individual rooms *Folding or sliding doors with privacy curtains/blinds *Circular/pod shaped floor plan *Increased noise reduction design *Patient windows with a view of outdoors (natural or contrived) *Patient controlled lighting (artificial and natural) *Planned areas for family in patient rooms *Increased use of color and texture on wall, floor and ceiling
Advantages	<ul style="list-style-type: none"> *Increased nurse proximity to patients 	<ul style="list-style-type: none"> *Increased patient privacy *Better control of lighting noise and infection 	<ul style="list-style-type: none"> *Increased nursing access during high-intensity activities 	<ul style="list-style-type: none"> *Nursing access and availability of high-tech care in a more homelike environment
Disadvantages	<ul style="list-style-type: none"> *Lack of privacy *Inability to control noise or light *Infection control issues 	<ul style="list-style-type: none"> *Less direct patient access/observation *Less than optimal control of noise and lighting 	<ul style="list-style-type: none"> *Glass doors reduce patient privacy 	

From Fontaine DK, Prinkey Briggs L, Pope-Smith B: Designing humanistic critical care environments. Crit Care Nurs Q 24(3):21-34, 2001, with permission.

2.4.2 Psychological Environment and Human Factors of the ICU

Human factors research has identified the physical environment as having an important impact on safety and human performance (Leape, 1994; Reason, 1997; Reiling, Hughes, & Murphy, 2008). In an existing data sets of hospital patient and population, using a prospective analysis of the ICU environment current workforce, n=393 critical care directors, n=421, critical care specialists (1996-1999), it is estimated that by the year 2020 there will be a 22% decrease in specialized care providers. The demand for critical care experts will outweigh the available resources, due to health care reform initiatives, disease prevalence with complex management, and changes in training and retirement (Angus, 2000). As the ICU environment becomes increasingly complex, it is paramount that the interrelationships are understood between human roles, technology, the environment in which clinician's work, the environment in which patients receive care, and the environment in which family members experience the crisis of the illness (Weinger, 1998).

Critical design elements to ensure hospital safety and quality care for both patients and family members are included in the recommendations of the Institute of Medicine's report, *Crossing the Quality Chasm: A New Health for the 21st Century* (Institute of Medicine, 2001). These recommendations include the following:

Table 2.2

Quality and Safety Design Recommendations

(Institute of Medicine)

A	Patient-family centeredness:	Use of variable acuity (resource utilization based upon patient acuity severity (Walczak, Pofahl, & Scorpio, 2003)) rooms, single bedrooms, adequate space for family members to sit or rest, patient and family access to healthcare information, and clearly marked signage
B	Safety:	Use of design elements such as assistive devices to prevent patient falls, proper ventilation and filtration systems to prevent spread of infections, surfaces that can be easily decontaminated, signage to promote hand washing and prevent patient and provider injury, address interdependencies of care such as work spaces and processes
C	Effectiveness:	Use of good lighting to increase visual performance, natural lighting, noise control elements
D	Efficiency:	Standardization of the room layout and the location of medical equipment and supplies
E	Timeliness	Rapid response to patient needs, eliminate inefficiencies in processes of care delivery, facilitate clinical work of nurses
F	Equity:	Ensure the design size, layout, and functionality meet the diverse needs of patients and their families

The psychological impact of the ICU environment on patients and their family members has been well documented. The most important or frequently mentioned stressor by patients was ‘fear of death’ (Pang & Suen, 2008). This was directly related to environmental stressors in the ICU, which generated a flight or fight response.(Pang & Suen, 2008). Additional stressors frequently mentioned by patients were ‘feeling

pressured to consent to treatment’, ‘the experience of pain’, and ‘not knowing the duration of admission to the ICU’. (Pang & Suen, 2008). These stressors combined with the environmental stimulation of the ICU and the physiology of critical illness creates a non-normative stress condition for both patients and family.

In a prospective cohort study of 150 adult ICU patients who survived mechanical ventilation and were oriented to person, place, and situation, two thirds of patients “remembered the endotracheal tube and/or being in an intensive care unit, and expressed pain, fear, anxiety, lack of sleep, feeling tense, inability to speak/communicate, lack of control, nightmares, and loneliness” (Rotondi Lakshmi, Sirio, Mendelsohn, Schulz, Belle, & Pinsky, 2002). This study recommended better symptom management, which could reduce the stressors associated with ICU hospitalization and improve patient outcomes.

A qualitative study of patients (n=30), families (n=11), and nurses (n=10), (Hupcey, 1999) examined how families and nurses interact to evaluate the involvement of family in patient care. Using a grounded theory approach and unstructured interviews, findings demonstrate that the patient’s primary wish was for the family to be continuously present at the bedside; the family expressed a strong need to ‘look out for’ and ‘protect’ the patient; while the nursing perspective was to understand what the family was experiencing in order to include them in the plan of care. Moreover, research demonstrated that the family experienced levels of stress comparable to the amount of stress experienced by patients (Kotkamp-Mothes, Slawinsky, Hinderman, & Stauss, 2005). Supporting this concept of family enduring psychological distress comparable with the patient, (Hodges, Humphris, & Macfarlane, 2005) conducted a meta analysis on

21 independent samples of cancer patients and their care givers. Findings confirm that there is a positive association between patients and their family caregiver regarding psychological distress, ($r = 0.35$, $p < 0.0001$). Furthermore, results did not demonstrate that there was more or less distress in one or the other ($p = 0.64$). Exacerbating family stress is the prolonged duration of stay in the ICU, as disruptions in sleeping and eating patterns as well as the experience of feelings of exhaustion, disorientation, and helplessness continue (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002). However, the constant presence of the family provides patients with a sense of security, comfort, and safety (Takman & Severinsson, 2005). A quantitative study by (Swoboda & Lipsett, 2002) looking at the impact of prolonged critical illness on a patient family (N=128); findings reveal that approximately 60% of the time a family member provided a large amount of the care giving one to nine months post hospital discharge. Of this these family member's, >36.7% lost savings, some moved to a less expensive home, delayed educational plans, or delayed medical care for another family member (Swoboda & Lipsett, 2002).

2.4.3 Complexity of the Workload in the Traditional ICU

A heavy workload and high levels of stress have been reported for ICU nurses (Goodfellow, Varnam, Rees, & Shelly, 1997; Gurses, Carayon, & Wall, 2009; Hay & Oken, 1977; LeBlanc & Leidner, 2001). In an effort to explore the impact of performance obstacles on ICU nurses and the effect of patient safety outcomes, (Gurses, Carayon, & Wall, 2009) conducted a cross-sectional study of nurses (N=265) in 17 different ICU's. Data from the structured questionnaire showed that performance obstacles in the ICU negatively affected the perceived quality of care. Health care in the 1990's introduced

the diagnosis related group (DRG) to hospitals, which reduced the patient length of stay (LOS), raised health care costs, and led to reductions in nursing staff (Aiken, Sochalski, & Anderson, 1996). Despite reductions in staffing levels, today's nurses provide care to patients who have a much higher acuity compared with patients hospitalized during previous decades (Aiken, Sochalski, & Anderson, 1996). The demand for nurses has escalated as the baby boomer population has entered retirement and nursing schools are unable to meet the growing need for education (Kuehn, 2007). A nursing shortage has resulted in an increased workload for those nurses who continue to practice in clinical settings. (Baumann Giovanetti, O'Brien-Pallas, Mallette, Deber, & Blythe, 2001). With expanding technology and shrinking resources, the ICU has become a complex environment in which to work.

2.5 The Tele-intensive Care Unit (ICU)

2.5.1 Introduction to Telemedicine

Although the ICU imposes significant stressors on the patient, their family members, and the staff, the overall environmental trend is transitioning to a more esthetic, familial, functional, and healing atmosphere. The principal infrastructure of the ICU however, continues to operate as a highly complex, technical, coordinated, regulated, and fast-paced unit of acute critical care. During the last two decades, the traditional configuration of the ICU has been conceptually and literally transformed into a new model of care called the tele-ICU in order to meet resource demands, improve patient outcomes, reduce length of stay (LOS) and reduce costs.

The word telemedicine is derived from the Greek word *tele*, meaning far, at a distance, and remote, and the Latin word *mederi*, meaning to heal (Hoonakker, 2012). Therefore, the meaning of telemedicine is to heal at a distance. Remote medicine or telemedicine is not a new development. In medieval times, during the bubonic plague, some European countries used smoke signals as a danger signal as a primitive method to warn distant villages to keep away (Hoonakker, McGuire, & Carayon, 2011).

Telemedicine has made great progress due to the evolution of telecommunication technology from the early days of telegrams via telegraphy (*Table 2.3, pg 82*). One of the first uses of telegraphy occurred during the Civil War from 1861-1865 to provide field updates, order supplies, and transmit casualty lists (Wootton, Craig, & Patterson, 2006). Telegraphy was introduced to the medical world by William Einthoven in 1905, the Nobel Prize winner and inventor of the electrocardiogram (ECG) when he transmitted the first electrocardiogram (ECG) from the hospital to his laboratory (Einthoven, 1906). Soon thereafter, the use of radio transmission was used for governmental application aboard ships, as well as by physicians to broadcast health alerts, and entertainment purposes (Hoonakker, McGuire, & Carayon, 2011).

Telecommunication has evolved to a broad spectrum of functionality since its inception. Application to patient care does not infer that telemedicine is separate from the traditional medical specialties, but rather it is an extension of health care services as an element of a larger investment by health care institutions in the delivery of clinical care (Telemedicine Association).

Table 2.3 Main Phases of Tele-communication Technology

Type of Technology	Period
• Telegraphy	1830's – 1920's
• Telephone	1870's - current
• Radio	1920's - current
• Television	1950's - current
• Space technologies • (<i>satellite-based communications</i>)	1960's - current
• Digital technologies	1990's - current

Hoonakker, P. from textbook: Carayon, P (2012) Handbook of Human Factors and Ergonomics in Health Care and Patient Safety. Used with permission.

2.5.2 Organizational Context of Telemedicine

ICU length of stay (LOS) has decreased with the inception of the tele-ICU. While overall, the number of critical care beds in the US has increased by 26.2% between 1985-2000, the ability for US hospitals to offer 24-hour critical care staffing by qualified clinicians has decreased 13.7% (Halpern & Pastores, 2010; Pronovost, Angus, Dorman, Robinson, Dremsizov, & Young, 2002). Various studies have demonstrated that inadequate clinical staffing of ICUs is associated with higher rates of medication errors, pneumonia, intubation, complications, readmissions, longer LOS, and higher mortality rates (Aiken, Sochalski, & Lake, 1997; Breslow, Rosenfeld, & Doerfler, 2004; Camire, 2009; Cho, Hwang, & Kim, 2008; Cho & Yun, 2009; Gaijic, 2008; Netzger, 2011; Penoyer, 2010).

To determine if an increase in clinical staffing would have an effect on patient mortality, Netzger and associates conducted a retrospective 2 year observational study in

a medical intensive care unit (MICU) at a major tertiary medical center. This comparative analysis of 1,263 ICU patients admitted between April 2004 and April 2006 (prior to organizational change) were compared with 2,424 ICU patients between September 2006 and September 2008 (after initiation of full-time critical care intensivists). Acuity of patient illness was measured by the case mix index (3.0 ± 3.7 vs. 3.1 ± 3.8 , $p = .69$). The unadjusted MICU mortality decreased from 18.4% to 14.9% ($p=.006$) as did in-hospital mortality (from 25.8% to 21.7%, $p = .005$). Researchers concluded that sustained and significant changes in clinical patient outcomes may be acquired from organizational changes, indicating that those hospitals that do not have an intensivists staffed in their ICU may benefit from a remote expertise (Netzger, 2011).

In a comparative study by Breslow and colleagues (2004) of two adult ICU and tele-ICU between 1999 and 2001 (N=1,240 patients), ventured to examine patient mortality and length of stay before and after implementation of the remote care model. Prior to tele-ICU implementation, n= 1396 post tele-ICU implementation n=744 to measure patient. ICU patient mortality was lower with the implementation of remote care (9.4% vs. 12.9%, relative risk, 0.73; 95% confidence level [CI], 0.55-0.95), and ICU LOS was shorter (3.63 days [95% CI, 3.21-4.04] vs. 4.35 days [95% CI, 3.93-4.78]). Lower variable costs were also noted, resulting in higher hospital revenues (Breslow, Rosenfeld, & Doerfler, 2004).

Elderly patients (> 65 years) accounted for 60% of all ICU days and comprised up to 52% of the overall ICU population in 2030 (Marik, 2006). The population of older Americans over the age of 65 is expected to double by the year 2030 to 72 million (Administration-on-Aging, 2011). In a comparison study measuring the number of

adverse effects between patient populations over 65 and under 65 years of age, elderly patients have a significantly higher incidence of preventable events (0.28% vs. 0.14%) respectively ($P = 0.001$) (Thomas & Brennan, 2000). Paradoxically, studies demonstrate that adequate numbers of staff trained to provide critical care improves clinical outcomes and decreases costs (Aiken, Smith, & Lake, 1994; Breslow, Rosenfeld, & Doerfler, 2004).

However, at a time when the need for ICU services is expected to increase, the US health care system faces a shortage of providers, including critical care nurses. This is primarily attributed to aging of the workforce and decreases in the number of new, trained providers.(Amaral, 2009; Cohen, 2009; Goran, 2010; Krell, 2008). The Society of Critical Care Medicine projects that the increase in need for providers of critical care services will result in 22% and 35% staffing shortfalls by 2020 and 2030, respectively, while other estimates suggest that the demand for ICU clinicians will be 129% above supply by 2020 (Angus, 2000; Manthous, 2004; Popely, 2009; SCCM, 2006 and 2004). The shortages in critical care nurses and physicians are expected to exacerbate the problem of providing quality, cost-effective care to critically ill patients (Kuehn, 2007; Popely, 2009; SCCM, 2006 and 2004).

As the US health care system adapted to meet the changing needs of patients and their family members, traditional health care delivery has undergone a transformation. Current telecommunication technologies address professional clinical shortages within a broad geographical scope including both rural and urban areas (Breslow, 2007; Goran, 2010; Hengehold, 2007). The expansion of local and national health care delivery systems has opened new opportunities for linking patients with specialized medical

experts (National Council of State Boards of Nursing, 1998). Today, thanks to modern technology and telemedicine, patients and expert providers do not need to be in the same location in order for patients to benefit from the providers' critical care expertise.

2.5.3 Applications of Telemedicine

The five overarching applications for telemedicine include 1) tele-consultation, 2) tele-education, 3) tele-monitoring, 4) tele-surgery, and 5) tele-homecare (Hoonakker, 2012; Norris, 2002). Tele-consultation services are the most widely used application and are often used to connect remote rural areas with an urban center, and at times, to connect remote parts of the world with a large medical center for consultative purposes (Hoonakker, 2012). Tele-surgery that was developed by the National Aeronautics and Space Administration (NASA), and is used for repair aboard the International Space Station, and is currently used during war-time for remote battlefield surgery (Hoonakker, 2012).

Tele-monitoring, which is the technical basis for the tele-ICU, refers to the use of telecommunications to gather real-time routine or repetitive data concerning a patient's condition of health (Norris, 2002). In a large investigation across 15 hospitals and multiple states, over a two and half year period, tele-ICU programs were tracked for acute physiology, age, chronic health evaluation (APACHE III) scores, mortality rates, and length of stay. N=5,146 patients across of 15 hospital facilities. Hospitals were categorized according to size and acuity; tertiary, regional medical centers, and small access or community hospitals. Findings show: 1) tertiary hospitals (n= 2,445 patients) mortality 0.63 vs. 0.26, $p < .01$, length of stay 1.05 vs. 0.58, $p = 0.001$; 2) regional hospitals (n=2,285 patients), low mortality rates precluded accurate estimation of baseline severity-

adjusted mortality, length of stay 1.28 vs. 0.88, $p=0.001$; and 3) community access hospitals ($n=416$ patients) reported the major enhancement for them was being able to care for patients in their own hospitals as the patient transfer rate decreased by 37.5%. Additionally, the cost per one patient transfer (by helicopter) ranges from \$5,800-\$10,900 (Zawada, Herr, Larson, Fromm, & Kapaska, 2009).

2.5.4 Tele-ICU and the Virtual Team

The impact of information technology has been widely studied and integrated into health care delivery systems to improve patient safety and outcomes (Bates & Gawande, 2003; Karsh, 2004; Toofany, 2006). Information technology is an essential component in the virtual world of the tele-ICU, with its roots highly documented in the Institute of Medicine (Kohn, Corrigan, & Donaldson, 2000) report, *To Err Is Human, that* recommended increased efforts to integrate information technology into the delivery of patient care in order to prevent human errors. (Rothschild Landrigan, Cronin, Kaushal, Lockley, Burdick, & Bates, 2005). The vital message of this reform effort is inherent in the acceptance of the tele-ICU model, stating that information technology should be used to 1) prevent errors and adverse events, 2) facilitate more rapid responses after adverse events have occurred, and 3) track and provide feedback about adverse events (Kohn, Corrigan, & Donaldson, 2000). Data now demonstrate that information technology can reduce the frequency of errors of different types and probably the frequency of associated adverse events (Osheroff, Teich, Middleton, Steen, Wright, & Detmer, 2007; Petersen, Orav, Teich, O'Neil, & Brennan, 1998; Rind, Safran, Phillips, Wang, Calkins, Delbanco, & Slack, 1994; Rosenfeld, Dorman, Breslow, Jenckes, Zhang, Anderson, & Rubin, 2000; Shabot, LoBue, & Chen, 2000). Enhanced ICU care was created to help transform ICU

performance by bringing scarce critical care expertise to ICU patients via telemedicine (Breslow, Rosenfeld, & Doerfler, 2004). The preceding paragraph explains why the tele-ICU brings value thus far to overall healthcare delivery. When placed into practical boundaries however, it holds little meaning until its function can be further elucidated.

The following describes the tele-ICU in practical terms of structure in a clinical setting. The tele-ICU, also known as a virtual or remote ICU, refers to the use of a centralized or remotely located team of critical care clinicians who collaborate with bedside clinical staff through the use of two-way audiovisual communication and computer systems to coordinate the care of large numbers of patients at multiple hospitals located in diverse geographic regions (Goran, 2010; Myers & Reed, 2008). The tele-ICU model consists of three essential attributes including:(Myers & Reed, 2008; Zapotochny-Rufo, 2008)

Table 2.4 Essential Attributes of the Tele-ICU

1	A centralized staff of remotely located expert clinicians who simultaneously provide remote oversight of patients in multiple ICUs by monitoring vital signs and tracking clinical trends
2	Utilization of information technologies via continuous surveillance that permits remote monitoring of patient information, laboratory, medication, and chart data as information is entered into the bedside clinical information system
3	Goal-directed guidance and instructions provided by intensivists and experienced critical care nurses to support the care provided by sometimes less experienced or expert onsite caregivers.

The literature further defines the virtual team as having certain compulsory characteristics such as being “geographically dispersed, electronically dependent, dynamic and comprising diverse members working remotely” (Gibson & Cohen, 2003; Gibson & Gibbs, 2006; Hoonakker, McGuire, & Carayon, 2011; O’Leary & Cummings, 2007).

The offsite support hub (or center) of the tele-ICU is comprised of a virtual team of both clinical and nonclinical staff. This team usually includes one intensivist (a physician who specializes in critical care), critical care nurses, administrative personnel, and in some programs, an ICU pharmacist. The team has two main functions to: 1) detect and respond to evolving physiological instability, and 2) screen and monitor patients for preventable events (Lilly & Thomas, 2009). Continuous monitoring by the remote (off-site) experts at the hub allows for early detection of preventive events, as these clinicians are observing more information about the patients than is possible by the onsite clinician (Lilly & Thomas, 2009). This process permits tele-ICU programs to provide real-time oversight for a wide range of critically ill patients.

The main function of the remote clinical providers is to intervene for the benefit of patient and to provide information, reassurance, and education to the onsite staff. (Goran, 2010; Reynolds, Rogove, Bander, McCambridge, Cowboy, & Niemeier, 2011; Willmitch, Golembeski, Kim, Nelson, & Gidel, 2012). The remote clinical experts working round the clock rely on computerized clinical decision support and an intricate technological infrastructure that facilitates automated assessments of patient outcomes as well as enhanced workflow, efficiency, and effectiveness (Celi, Hassan, Marquardt, Breslow, & Rosenfeld, 2001). Practitioners in the remote hub monitor patients via a

command center, which has real-time access to patient physiological data (i.e. heart rate, respiration, blood pressure, ventilator trending, etc.), laboratory data, treatment plan, and medical records. Remote tele-ICU clinicians use an arrangement of roughly six computer screens configured to each user's precise needs in order to monitor patients. One site may configure a screen to watch 8 patients at a time, while another facility may have the clinician configure the monitor screen to visualize 16 patients at a time. This ratio is flexible and dependent upon the policies and procedures for the individual institution (Rosenfeld, Dorman, Breslow, Jenckes, Zhang, Anderson, & Rubin, 2000). In addition, patient monitoring by the remote team is facilitated by remote two-way audio and either one-way or two-way video cameras that are located in each patient's room.

The cameras provide multiple views of the patient and the room and also provide automated fixed-zoom capabilities to easily view critical bedside data sources. These high-resolution digital cameras (*figure 2.2, p. 90*) allow members of the virtual team to assess patients' physical status such as neurologic function (Larner, 2011), respiration, facial expressions, diaphoresis, and skin color. The digital cameras can even assist onsite staff with invasive bedside procedures (e.g., pulmonary artery catheter insertion) by coaching the on-site clinician through the procedure (Breslow, 2005). In addition to the individual real-time patient data, the control system has 'smart alerts' that monitor trends in various alarms and characterize the meaning of the trend data based on temporal changes in vital sign information. (Breslow, 2005; Rosenfeld, Dorman, Breslow, Jenckes, Zhang, Anderson, & Rubin, 2000).

Figure 2.2 High-resolution camera
(in patient room)



The size of the virtual team is likely to vary depending upon the number of patients who require virtual management. For example, Breslow suggests that 40-50 patients may be effectively managed with one intensivist, one critical care nurse, and one clerical functioning staff member (Breslow, 2005). A more recent and much larger estimate suggests that the average ratio of patients to virtual health care provider is more likely to be 60-125 patients per intensivist, 30-40 per nurse and 50-125 per clerical assistant (Ries, 2009). Continuous tele-vigilance (remote watchfulness) is operationalized by means of ‘virtual rounding’ with tele-ICU clinicians assessing patients for early signs of clinical decompensation, and assisting with the implementation of care plans as delineated by the bedside clinicians. Some tele-ICU clinical staff collaboratively define the severity of patients by a color code system with red being the most critical, yellow referring to those who are less acutely ill, and green referring to those patients who are the most stable (Ries, 2009). Tele-ICU rounding is prioritized based on level of acuity, with highest acuity patients assessed at least hourly, and lower acuity patients reviewed less frequently (Lilly & Thomas, 2009; Pronovost, Thompson, Holzmueller, & Morlock, 2007; Ries, 2009; Rosenfeld, Dorman, Breslow, Jenckes, Zhang, Anderson, & Rubin,

2000). When the virtual team conducts rounds, it is done in real-time collaboration with the onsite staff. This virtual process entails teleconferencing into each patient's room which allows the staff to visually assess the patient, present clinical information, and review or modify the current plan of care (Breslow, 2005; Ellison Pinto, Kim, Ong, Patriciu, Stoianovici, & Kavoussi, 2004).

Nursing report and virtual rounds, similar to that of traditional nursing report and rounding, often reveal an opportunity for staff education regarding specific patient care issues (Goran, 2010, 2011). Throughout the course of an ordinary shift, many informal discussions ensue, providing support to onsite staff. The ability for the virtual intensivist to observe house staff performing bedside procedures is invaluable for education and can eliminate variability and reduce errors (Breslow, 2005).

The remote model for the ICU setting is analogous to that of air traffic control, which uses technology and expertise to keep pilots and passengers safe (Breslow, 2007; Myers & Reed, 2008). The tele-ICU center is separately located from the hospital and does not provide bedside care to patients or replace hospital ICUs. The level of staff coverage varies with nurses available 24 hours every day and intensivists providing different levels of support such as daytime hours, off-shift hours when onsite physicians are on call and ensuring timely response to pages (Goran, 2010; Rosenfeld, Dorman, Breslow, Jenckes, Zhang, Anderson, & Rubin, 2000; Rosenfeld & Breslow, 2004). The offsite team oversees multiple, geographically-dispersed hospital sites around-the-clock from a centralized location. A powerful technological infrastructure provides staff with real time electronic access to patient bedside data, plans of care, and visual access to patients that enables them to provide decision support to onsite staff (Gracias, 2007).

The effectiveness of the remote team is directly related to the amount of time and expertise required to identify and to work with bedside clinicians to identify opportunities to improve patient care (Lilly, Cody, Zhao, Landry, Baker, McIlwaine, & Irwin, 2011). In a pre/post step-wedge design of a traditional vs. the tele-ICU, electronically monitored processes of ICU interventions (N=6,290 patients) were measure over a 2 year period: hospital mortality pre-intervention group 13.6% vs. 11.8% for the tele-ICU group; mean ICU LOS 6.4 days for the pre-intervention group vs. 4.5 days for the tele-ICU group; also affected was best practices, adherence to deep vein thrombosis 85% (pre) vs. 99% (post); prevention of stress ulcers 83% (pre) vs. 96% (post); prevention of ventilator assist pneumonia (VAP) 33% (pre) vs. 52% (post) (Lilly, Cody, Zhao, Landry, Baker, McIlwaine, & Irwin, 2011). The primary focus of the remote care model is on two-way communication between onsite bedside clinicians and the virtual team (Breslow, Rosenfeld, & Doerfler, 2004; Goran, 2010; Lilly & Thomas, 2009; Zawada, Herr, Larson Fromm, & Kapaska 2009). The ways in which the remote clinical support team interacts with bedside providers can influence program satisfaction and acceptance (Lilly & Thomas, 2009).

Research regarding virtual teams and the remote care model has evolved over the last decade. One important step toward the goal of successful communication and integration between the two teams is to have the same individuals who work at the bedside also provide the remote support (Goran, 2010; Lilly & Thomas, 2009). Some tele-ICUs require that nurses and intensivists divide their time between the bedside and the remote unit (Goran, 2010). Additionally, virtual clinicians must have a high level of clinical expertise in order to coach the onsite staff at the bedside (Reynolds, et al., 2011).

Research suggests that tele-ICU programs that include seasoned and respected bedside nurses in the remote support center facilities acceptance and more effective usage of tele-ICU virtual resources by the bedside nurses. In contrast, tele-ICU programs that involved clinicians who were still in training programs or the use of remote intensivists who were not part of the community of bedside providers were associated with lack of acceptance or support for the tele-ICU model by the on-site staff (Reynolds, Rogove, Bander, McCambridge, Cowboy, & Niemeier, 2011).

2.5.5 Communication in the Tele-ICU

The widespread attributes addressed earlier, are applied within an operationalized context here; 1) a centralized staff of remotely located expert clinicians who provide remote oversight of patients in multiple ICU's, 2) utilization of information technologies, and 3) goal-directed support and guidance. Inherent in the tele-ICU model are tele-consultation, tele-education, and tele-monitoring. The tele-consultation application allows experts (nurses and physicians) located in remote central operations rooms (COR) or the hub provide coaching and instruction to onsite staff. Tele-education consists of scheduled in-services between remotely located and onsite staff, as well as provision of training for onsite staff by the remote staff. Tele-monitoring relies on technology to provide continuous real-time patient data that is transmitted back to the hub where the remotely located staff monitor trends and alert onsite staff to any changes of concern (Anders, Patterson, Woods, & Ebright, 2007; Hoonakker, McGuire, & Carayon, 2011).

The first study of telemedicine in the ICU (Grundy, Jones, & Lovitt, 1982) evaluated the impact of intensivists located at a university-based hospital who provided consultations for 395 ICU patients located at an inner city hospital with no onsite

intensivist over an 18-month period (Breslow, 2005). Tele-consultation also was used to support the care of critically ill patients in other settings, such as the neonatal ICU for low birth weight infants (Rendina, 1998), or the management and transfer of trauma patients (Kirkpatrick, Brenneman, & McCallum, 1999), and inpatient pediatric critical care consultations (Breslow, 2005; Dimand, Marcin, & Kallas, 2000). The study by (Rendina, 1998) evaluated the use of telemedicine for the rapid interpretation of echocardiograms for the neonatal intensive care unit (NICU) regional level III trauma center. All infants born during the first six months of the system were compared those infants during the same time period the previous year. Findings were non-significant (5.4 day reduction LOS) of low birth weight infants was reported ($p=0.37$). The cost of the electronically transmitted echocardiogram was approximately \$33.00 compared to the former method of sending a videotape by overnight courier.

Clinical research demonstrates that patient outcomes in traditional ICUs are correlated with nurse workload and nurse staffing. In addition, heavy nurse workloads and reduced nurse-patient ratios are associated with significantly higher severity-adjusted mortality rates among ICU patients (Aiken, Clarke, Sloane, Lake, & Cheney, 2008; Aiken, Sochalski, & Anderson, 1996; Aiken, Clarke, S., Sloane, Lake, & Cheney, 1997; Shortell, 1994; Tarnow-Mordi, Hau, Warden, & Shearer, 2000). In a large quantitative study by Cho and Yung (2009), 185 Korean hospitals using a cross-sectional design to determine the effects of nurse staffing on mortality were evaluated. Researchers examined basic care (i.e. bathing, feeding assistance) in patients who experienced hemorrhagic and ischemic stroke and were admitted to the ICU. The average nurse-patient ratio fluctuated widely at 2 to 8 patients per nurse. Findings demonstrate that one

fifth of the nurses believed that there were an adequate amount of nurses to provide quality care, one third were frustrated and dissatisfied with the patient load they carried, half of the nurses claimed to feel burnt out, and one quarter of the nurses had intentions of quitting their job within the next year. Moreover, nurses were more apt to rank quality of patient care as high when they cared for 1 to 2 ICU patients (odds ratio, 3.26; 95% confidence interval, 1.14–9.31) or 2.0–2.5 patients (odds ratio, 2.44; 95% confidence interval, 1.32–4.52), compared with having more than three patients. The bed-to-nurse ratio was measured between groups, those for whom who were assisted in basic care also by family members or ancillary staff. Over a 30 day period (N=6,957 patients), staffing ratios that were at full capacity compared to those that had a lower staff ratio (basic patient care provided completely by the nurse), mortality rates were 21.9% and 25.4% respectively (Cho & Yun, 2009).

A study at Johns Hopkins Hospital Center in Baltimore, evaluated whether a telemedicine (tele-ICU) and information technology system could improve clinical and economic proficiency across various ICUs. The study took place in a 650 bed tertiary care teaching hospital, between 1999 and 2001 in two adult ICUs with a total of 2,140 patients (n=1396 pre implementation and n=744 post implementation). Findings reveal that ICU hospital mortality was lower during the phase of remote ICU care (9.4% vs. 12.9%; relative risk, 0.73; 95% confidence interval [CI], 0.55–0.95), and the ICU length of stay was shorter at (3.63 days [95% CI, 3.21–4.04] vs. 4.35 days [95% CI, 3.93–4.78]). The tele-ICU care model is based upon previously proven methods of advanced health care, while responding to shortages in critical care staff with the goal of to increased efficiency improved patient outcomes (Breslow, 2005).

2.5.6 Impact of the Tele-ICU

While the inception of the tele-ICU in the mid 1990's has proliferated, its economic and clinical impact is just beginning to be realized. Several years ago, research to evaluate the clinical outcomes and cost-effectiveness of the tele-ICU model was a fairly new concept; yet initial reports showed favorable effects on ICU and hospital mortality rates, decreased length of stay in the ICU and hospital, and reductions in cost of care, although not consistently demonstrated (Lilly & Thomas, 2009). An analysis of the impact and cost-effectiveness of a tele-ICU program implemented in six ICUs in a large health care system demonstrated decreased mortality rates for the highest acuity patients and no significant increase in costs of care per patient (Franzini, 2011). An ICU telemedicine program implemented at 15 rural hospitals located in multiple states resulted in lower mortality rates and decreased length of stay at some regional hospitals and decreased ICU and hospital mortality rates and length of stay ratios at a tertiary care center (Zawada, Herr, Larson D, Fromm, & Kapaska, 2009). (Data reported in previous section). A meta-analysis of 13 studies involving 35 ICUs and 41,375 patients with each study using a before-and-after design demonstrated significant decreases in both ICU mortality and length of stay. Specifically, the pooled odds ratio (OR) for ICU mortality was 0.80 (95% CI, 0.66, 0.97; P = 0.02) and there was a trend for decreased inpatient mortality that approached statistical significance (OR, 0.82; 95% CI, 0.065, 1.03; P = 0.08). There was a mean decrease of 1.26 days (95% CI, -2.1, -0.30; P = 0.01) for ICU length of stay (Young, 2000). These results suggest that the tele-ICU has the potential to significantly improve patients' clinical outcomes.

The clinical impact of the tele-ICU is far reaching. The tele-ICU model has important advantages for people living in remote and rural areas with limited access to state-of-the-art critical care (Nesbitt, Hilty, Kuenneth, & Siefkin, 2000; Norton, Burdick, Phillips, & Berman, 1997). Introduction of the tele-ICU to a rural community in 2004 involved 18 hospitals, including three large tertiary care facility, three rural regional hospitals, two community hospitals, and nine critical access hospitals and 5,146 patients (Zawada, Herr, Larson, Fromm, & Kapaska, 2009). Participating community and critical access hospitals experienced a 37.5% decrease in patient transfers to facilities providing higher levels of care with an estimated savings of \$1.25 million. Mortality rates were unchanged in two of the three regional hospitals while the third hospital achieved a 4.5% reduction in mortality. Severity-adjusted length of stay was reduced in all three regional facilities. Within the tertiary care facility, the tele-ICU was associated with a reduction in severity-adjusted ICU mortality (odds ratio, 0.35; $P = .07$), decreased ICU length of stay (3.79 vs. 2.08 days; $P = .001$), and reduced hospital length of stay (10.08 vs. 7.81 days; $P = .001$). Tele-ICU implementation was associated with a reduction in length of stay 6,825 ICU days and 821 hospital days when combining results from the community hospitals and the tertiary facility. (Jarrah & Van der Kloot, 2010; Zawada, Herr, Larson, Fromm, & Kapaska, 2009).

An observational study by evaluated clinical outcomes one year before and one, two, and three years following implementation of a tele-ICU in a hospital health care system. (Willmitch, et al., 2012) The study involved 10 adult ICUs with 114 beds in five community hospitals located in south Florida and included the medical records of 24,656 adult patients. Hospital length of stay, ICU length of stay, hospital mortality, and Case

Mix Index (CMI) were measured. Severity of illness using all patient refined-DRG scores was used as a covariate. From baseline to year three post implementation, the severity-adjusted hospital length of stay decreased 11.86 days (95% confidence interval [CI] 11.55–12.21) to 10.16 days (95% CI 9.80–10.53; $p < .001$), severity-adjusted ICU length of stay decreased 4.35 days (95% CI 4.22–4.49) to 3.80 days (95% CI 3.65–3.94; $p < .001$), and the relative risk of hospital mortality decreased to 0.77 (95% CI 0.69–0.87; $p < .001$) (Willmitch, Golembeski, Kim, Nelson, & Gidel, 2012).

Researchers from rural Kansas evaluated the amount of resources saved by reducing travel-related costs following implementation of a tele-ICU (Cowboy, Simmons, Nygaard, & Simmons, 2009). In a remote region of the state, family members of critically ill patients frequently must travel hundreds of miles in order to be near their loved ones while they are hospitalized in an urban tertiary care center. Cowboy states that barriers to travel by family members to the tertiary care facilities include financial limitations, job restrictions, childcare or physical limitations (Cowboy, Simmons, Nygaard, & Simmons, 2009). Using a very conservative LOS estimate of two days, the researchers determined that 203 patients were able to remain in their local hospital under the direct care of their primary physician in collaboration with the tele-ICU physicians and nurses. In addition, the families collectively saved 127,000 miles of travel, 55.9 tons of carbon dioxide emissions, \$23,495 in gasoline costs, \$36,540 for lodging, and \$12,180 for meals, for a total savings of \$72,215 (Cowboy, Simmons, Nygaard, & Simmons, 2009).

2.5.7 Environment, Characteristics, and Human Factors of the Tele-ICU

Naturalistic studies in diverse areas of practice have focused on the implications of technological changes and reported differences between anticipated and actual effects on human performance following the introduction of new devices and/or systems (Woods & Dekker, 2000; Woods & Hollnagel, 2006). Adaptation of new technology is accomplished through repeated use that results in eventual changes in practice, new strategies, interactions, and changes in performance expectations (Cook & Woods, 1996a). The end user modifies the process and/or mechanism to meet their particular needs. The introduction of the remote model of intensive care requires us to examine the delivery of care, with its inherent heterogeneous attributes of technology, communication, management, and performance issues related to the staff, patients and family.

Although it has been said that changes in technology transform the nature of practice (Cook & Woods, 1996a), only time and patience implementing this novel dimension of remote care are warranted, and demand a level of support where cognitively stressful situations arise (Winograd & Flores, 1986). Additionally, the remote team is under tremendous pressure with temporal demands, and consequently it is vital to the organization to anticipate where error and system failures could possibly emerge (Corker, 2000; Woods & Dekker, 2000; Woods & Hollnagel, 2006). It would be both challenging and meaningful to facilitate an understanding and level of expertise, while minimizing potential negative consequences prior to implementation (Woods & Hollnagel, 2006).

Hoonakker (2011) talks about the importance of ‘trust’ between the remote and on-site tele-ICU teams especially in light of the fact that there is no prior social-work

history to place the relationship within context(Hoonakker, 2012; Hoonakker, McGuire, & Carayon, 2011). Furthermore, the attributes of the virtual team affect the traditional means in which teams typically create trust (Aubert & Kelsey, 2003). Trust has been found to be influenced by its antecedents at different points in time While it is the technology interface that links the geographically dispersed teams in coordination of care, it is the frequent face-to-face communication between team members that serves as an impetus for trust to be built through sharing new norms (Jarvenpaa & Leidner, 1999). The level of cohesive trust between teams will grow as the relationship matures, which in-turn will allow an exchange of ideas to stream naturally without fear of repercussion (Mayer, Davis, & Schoorman, 1995).

In order to comprehend how the tele on-site and remote teams will act within the virtual, collaborative world around them, it is essential to understand what they are thinking and how they organize and structure information as they are executing complex tasks (Cook & Woods, 1996a). To support the growth of computer-based instruments intended to aid cognition and collaboration in the tele-ICU, (Potter, Roth, Woods, & Elm, 1998) have found that cognitive task analysis (CTA) is more than the application of any single cognitive task challenge. Cognitive task analysis has been defined as a process uncovering the cognitive activities necessary in the field of practice (hub of tele-ICU), and to identify further opportunities for valuable support to the on-site team (Potter, Roth, Woods, & Elm, 1998). This model has been used to improve human and team performance in the domain of training, user interfaces, collaboration or decision aids, as well as used across domains such as military intelligence analysis (Potter, McKee, & Elm, 1997), military command control (Shattuck & Woods, 1997), military aero-medical

evacuation planning (Cook, Woods, Walters, & Christoffersen, 1996), commercial aviation (Sarter & Woods, 2000), hospital operating rooms (Cook & Woods, 1996a), and the space shuttle mission control (Patterson, Watts-Perotti, & Woods, 1999).

Anders (2007) conducted a 40-hour observational human-computer interaction study of eight tele-ICU nurses and one tele-intensivist in a single tele-ICU; and concluded that there are three main functions of the remote team: 1) anomaly response: tele-nurse processed information related to alerts and contacted the on-site nurse, 2) access to specialized expertise: tele-nurse observed to mentor junior or novice nurses that are on-site, and 3) sense-making: tele-nurse is able to make sense and bring meaning to about what is happening with the patient because they have the expertise and data resources (Anders, Patterson, Woods, & Ebright, 2007).

2.5.8 Knowledge of Family Needs in the Tele-ICU

The tele-ICU program networks multiple hospital ICUs together into a central facility (tele-ICU center or hub), to provide a 24 hour, 7 days a week (24x7) expert safety net (Breslow, 2007; Breslow, Rosenfeld, & Doerfler, 2004). As health care systems implement new technologies such as the tele-ICU to meet the needs of increased patient demand in an environment of diminishing resources, it will be important to determine the impact of these new technologies and care models on the needs of patients and their families.

Family Needs in the Tele-ICU. A literature review conducted by (Foley, Kee, & Minick, 2002) identified collaboration as a key factor in limiting error and improving patient outcomes. They went on to say that an essential element of care is to utilize the

capabilities of the tele-ICU to facilitate proactive and consistent assessment of patient and family needs. This is the only reference identified in the literature review to discuss the issue of family needs of patients receiving care in a tele-ICU. The article went on to list the strategies in which this could be accomplished such as use of the video assessment capabilities in each room to encourage communication between the family members with the remote staff. They concluded that these pioneering communication tools can support the efforts of staff to achieve greater satisfaction among patients and family by addressing real-time concerns and reducing anxieties associated with hospitalization. (Foley, Kee, & Minick, 2002).

An exploratory pilot study was conducted by this researcher with the family members of tele-ICU patients at a tertiary medical center in the north-east U.S. Since no research with family members in the tele-ICU setting had previously been conducted, effort was made to explore the perceptions and needs of family in this unique situation. Details discussed at beginning of chapter (Jahrsdoerfer & Goran, 2013).

According to the pilot study, results indicate that family members of patients receiving care in a tele-ICU have the need to know more about a) the technology involved in this new environment, b) how the technology works, c) how patient privacy is protected, and d) patient safety in the tele-ICU environment. Additionally, some of the well documented themes studied in the traditional ICU, such as need for information, the need for close proximity, the need for comfort, and the need for support and assurance were also needs expressed by family members in the pilot study. Using exploratory semi-structured interview questions will provide more in depth insight to the concerns, experiences and needs of family members with a loved-one in the tele-ICU.

2.6 Theoretical Framework

The theoretical framework used to guide this research was the Family Stress Model from McCubbin and Patterson (1983). In order to make this theoretical model meaningful to this study, the use of the CCFNI tool and the tele-ICU pilot study (by this researcher) were interlinked to strengthen the structure. This model was chosen because the family's ability to adapt to a stressful event depends upon resources available to them as well as their past experience with stressors in their life.

2.6.1 Overview of Family Stress Theory

When considering families of patients in the context of the tele-ICU, the application of a theoretical model is useful in understanding the collective dynamic of the family within the structural processes of remote care. To elucidate the experience of families, the theory of family stress was examined (McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). In this section, the researcher explained the definition of relevant terms; presented the paradigm perspective of Family Stress Model; the relational propositions; examined the theory development and its assumptions.

The use of family stress theory in clinical practice is especially relevant in promoting health during normal family transitions, as well as to assess family change during a family member's acute or chronic illness (Tomlinson, 1986).

A family member or significant-other's personal experience of stress, crises is an ongoing and dynamic process. Adjustment is influenced by the family's response to a stressful event, their available resources, and presence or absence of effective coping-

strategies. As related to the tele-ICU setting, family resources, needs, and resolved-needs are unknown. Communication between family members and the health care team is essential. If the patient-family experiences of the tele-ICU admission has been perceived as overwhelming, or produces a hardship or has depleted family resources, interdisciplinary assistance is available. Reduction in family stress to the patient's critical illness depends upon resolution of their needs that have been met. (McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). Therefore, these needs must be identified prior to potential resolution.

2.6.2 Paradigm Perspective

The term 'paradigm' exists as a common philosophical orientation that serves to describe the nature of a system (Peterson & Bredow, 2004). Similarly, Cody (2006) refers to a paradigm as a pattern, example or model of effectiveness in explaining a complex process (Cody, 2006). Kuhn (1977, 1996) established the term paradigm and defined it as a symbolic generalization, shared commitments to beliefs in particular models, values and exemplars (Kuhn, 1977, 1996). It is to this end that a consensus of family needs in the tele-ICU needs to be established.

The family stress theory grew from the basic systems theory which is a holism approach subject to the universal laws of nature. To apply this theory to the care of the critically ill patient is to understand the importance of including family as part of the larger care plan and the need to observe the patient as an open and living system.

2.6.3 Metaparadigm Assumptions

Assumptions are fundamental principles or statements that are taken for granted or believed to be true even without being scientifically tested (Burns & Grove, 2009).

The researcher accepts the Family Stress Theory (Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983) from which the following assumptions were made:

2.6.3.1 Person- Family is viewed as encountering hardship and transition as an unavoidable part of family over the lifecycle (Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983) .

2.6.3.2 Health: Family's state of balance is determined by resiliency or the ability of the family to respond to and ultimately adapt to the circumstances and crises-events encountered (Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983)

2.6.3.3 Nursing: The function of nursing moves beyond promotion of family health, to improving and sustaining family strengths, to supporting and maintaining family associations with community support-system, and to help families in arriving at a realistic expectation of what the best "fit" for them in their situation (Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983) .

2.6.3.4 Environment: Viewed as an open system and a component of the larger community and society. This constitutes both internal and external factors of the community network that positively influence or threaten the well being of the family (Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983).

2.6.4 Theory Development

From his original work on “family-dismemberment”, Hill (1949) developed the family crisis/stress theory and studied families’ responses to WWII, separation, and ultimate reunion (Hill, 1949) (McCubbin & Patterson, 1981; McCubbin & Patterson, 1983). Working for the U.S. Army, as a social scientist, Hill was charged with assessment and impact of war casualties on American families (Hill, 1949; Friedman, 1998). In the original model of Family Crisis Theory in which Hill called the ABC-X model, representing the event; family resources; family perception; and crisis, Hill made the following four social science assumptions: 1) unexpected or unplanned events are usually perceived as stressful; 2) events within the families, such as serious illness, and defined as stressful, are more disruptive than stressors that occur outside the family, such as war, flood, or depression; 3) lack of previous experience with stressor events leads to increased perceptions of stress, and 4) ambiguous stressor events are more stressful than non-ambiguous events (Hill, 1949; Friedman, 1998).

Based upon the original work by Hill, sociologists (McCubbin & Patterson, 1983) developed the Double ABC-X Model, which added a phase addressing the post-crisis variables or coping mechanisms of the family. This phase is addressed simply to highlight the spectrum of theory. It is the crisis part of the theory that was the focus of this study; the component in which family identified what they are experiencing. This gap in knowledge had to be identified prior to recommending resolution of family needs in response to their experience of the crisis. The premise was based on the assumption that families experience a ‘pile-up’ stress effect, such as a loved one in the ICU. The added dimension of the tele-ICU presented an unprecedented exploration of family stress and

subsequent needs. As previously discussed, there was an initial shock that the family experienced upon learning their loved one has been admitted to the ICU. It was this critical phase while the patient is still in the tele-ICU that was examined related to family 'needs'. Families faced a range of processes in which the variables of the initial stressor, existing resources, family perception, and the reality of the crisis interact (McCubbin & Patterson, 1983).

The Double ABC-X Model specifies three factors (the aA, bB, cC components): Where 'A' used to refer to the stressor, 'a' now refers to the accumulation or 'pile-up' of stressors; where 'B' used to refer to the crisis meeting resource or precipitating event, 'b' now equals existing resources; and where 'C' used to equal the meaning or interpretation of the event, 'c' now equals the family's perception of that stressor that led up to the event as well as the event itself. Some family member's perceive the event as a learning experience or growth opportunity. Although the fourth factor X was not examined, it refers to the family's adjustment, adaptation and coping ability with the crisis. This study reflects the family perception of the stressor event.

McCubbin and Patterson (1982, 1983a, 1983b) incorporated Hill's theory yet augmented the term 'resources' to include psychological and social resources as well as intra-family resources first considered by Hill (McCubbin and Patterson, 1982, 1983a, 1983b). The pre-crisis phase or initial model that Hill described was integrated into the Double ABC-X model, yet the difference lies in the fact that family perceptions of the event mechanisms were addressed in the revised Double ABCX model (*See figure 2.2, pg 112*). The following is a breakdown and progression of the early Hill 'ABCX model' elements to the revised McCubbin and Patterson 'Double ABCX model'.

2.6.5 Concepts of the Early ABC-X Model Elements

2.6.5.1 A = Stressor

The critical life event, adversity or transition causing discord in the family unit that has the potential for altering the family and/or social system (Hill, 1949). The concept of stress is often studied within the construct of an event (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980). Stressors can be normative or non-normative in nature, internal or external to the family, and are typically not equal, therefore may produce different effects (Patterson, 1988). In this study, the stressor is non-normative in nature and internal to the family unit.

2.6.5.2 B = Crisis Meeting Resources of Precipitating Event

Families all have some level of resources. The concept of crisis-meeting resources is the family relationship to their community services, whether it is extended family, friends, church, school, governmental agency, an out-reach program, child day-care, elder-care, ride-services, and their own problem solving ability. Depending upon the extent of the stressor itself, the individual-family-member resources, the family-system resources often determines the outcome of the family ability to cope (Hill, 1949). Hill defined family crisis-meeting resources as issues in family organization that, “by their presence, kept the family from crisis or, by their absence, urged a family into crisis”. An example may include a neighbor coordinating care for the school-aged children in the family with the grandparents who are staying at the house but are unable to drive; while one parent keeps vigil at the hospital for the other parent. Hill states that the use of resources helps to establish the adequacy (crisis-proofness) or inadequacy (crisis-proneness) of the family. Finally, Hill summarized the family’s crisis-meeting resources

such as family integration and family adaptability, from (Angell, 1936). The crisis-precipitating event and the family's resources interacted with the family's actual experience of the event determines family coping of the ICU crisis.

2.6.5.3 C = Definition the Family Makes of the Event

Stress according to Reiss (1981), is compiled of two levels of reality; one being the family construct and the other, the family paradigm. The family construct refers to more specific and situational experiences than the paradigm (Reiss, 1981), and is pertinent for intentions of this study. Whereas, the family paradigm refers to the interaction between the family unit and its social world which in fact shapes the characteristics of the family network. The family construct is comprised firstly of ordinary day-to-day family interactions, and secondly of the crisis construct (examined in this study) in which the family reacts to and perceives a specific event (Hill, 1958). It is the crisis (or event) that triggers the family response to the event and the stressors they associate with it. The individual member and/or family unit attach experience to the crisis which determines the magnitude they believe the situation to be (Patterson, 1988).

2.6.5.4 X = Crisis

A family crisis is defined as a disruption in family routine patterns, resulting in incapacity to maintain family stability. In such an event, change is inevitable whether or not the family conforms to this change (Burr, 1973; Patterson, 1988). Conversely, if the family has the capability of dealing with the stressors, the crisis may be suppressed.

2.6.6 Concepts of the Double ABCX Model Elements (Revised from Hill Model)

The family is recognized as a 'system', where experiences of one family member in turn affect the experiences of other family members.

2.6.6.1 aA = Pile-up of Stressors

Family demands, stressors accumulate or pile-up over time. Most families deal with more than one stressor at a time. The effect of coping with various degrees of stressors at one time may on occasion mean that demand-load outweighs the family management threshold (Patterson, 1988). Gather an image in your mind of the justice scale; if you add an object it may not tip the scale at first. As a matter of fact, you may be able to place numerous objects on the scale until its weight is finally outbalanced. As the concept pertains to this study, it may be the patient admission to the ICU that finally tips the family stress scale of coping.

2.6.6.2 bB = Existing Resources and New Family Role

The 'b' factor takes into consideration the family ability to meet crisis demands by consciously including expanded resources. In the original ABC-X model by Hill, existing resources refers to typical means of support (family and community); in the Double ABC-X model, accounts for the addition of newly expanded resources (social service, chaplain, speech therapy, physical therapy, occupational therapy, home care, as well as community resources), which strengthen the response to the crisis (Hill, 1958; R Hill, 1949) (McCubbin, 1983b).

2.6.6.3 cC = Family Perception of the Stressor

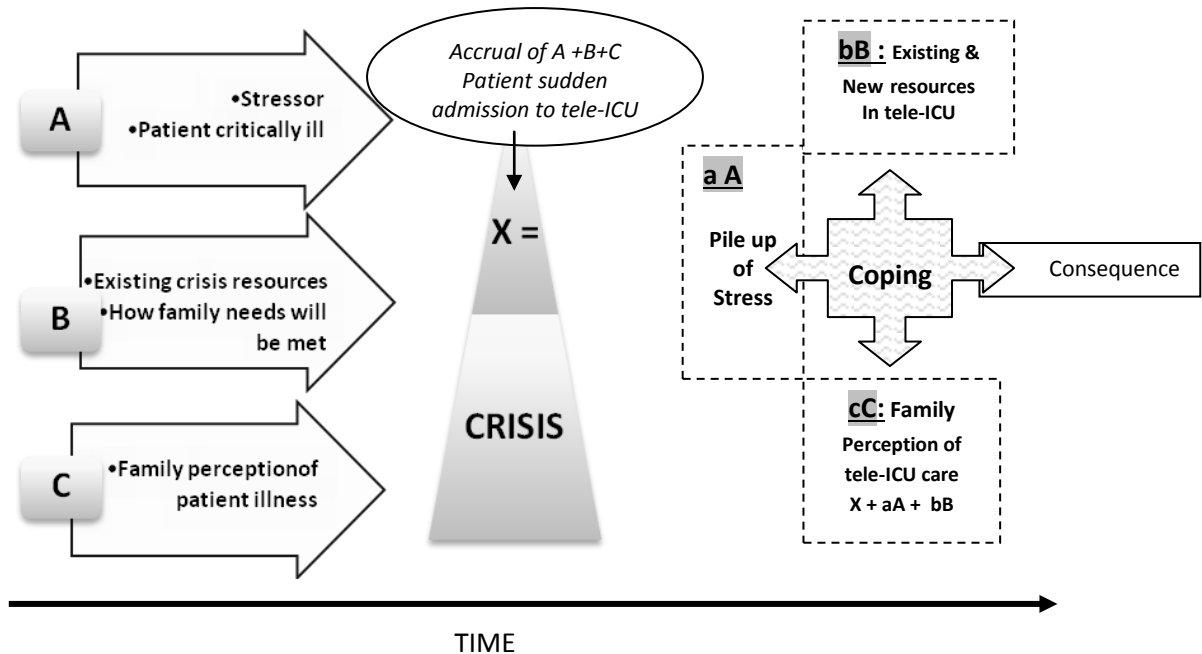
It is the crisis (or event) that triggers the family response to the event and the stressors they associate with it. The individual member and/or family-unit attach experience and significance to the crisis which determines the magnitude they believe the situation to be (Patterson, 1988). As the family attempts to realistically comprehend the experience of the crisis situation, it facilitates overall family management of the situation. Perception is central to coping. These concepts are the essence of this study in that the researchers' goal is to examine the family perception of their stress experience within the construct of the tele-ICU. To date, there is no research that explores family perception of those who have a loved one as a patient in the sophisticated environment of the tele-ICU.

2.6.6.4 xX = Adaptation

Not measured in this study. The family focuses on restoring balance to the system, which is accomplished by 'broadening the experience to acknowledge and accept changed circumstances', by 'decreasing the pile-up demands', by 'cultivating adaptive resources', and to 'enhance coping strategies' (Patterson, 1988). The previous components of the model had to be examined, and were the focuses of this study, prior to making suggesting interventions for families to adapt.

Figure 2.3

Family Stress Model
(ABC-X Model & Double aA bB cC-xX Model)



The ABC-X Model and Double ABC-X Model included the following propositions used to describe relationships within the model itself. Applied to the situation that prompted this study, these propositions explain that in family crisis:

1. There was a *positive* relationship between identification of family *stress* in the tele-ICU by family level of relief/ease/transcendence of *needs* met.
2. There was a *positive relationship* between the *intervention of allowing the family close proximity to the patient* and the family level of *stress*.
3. There was a *positive* relationship between the effective *interventions of delivering information in a caring manner* with family level of *stress*.

4. There was a *positive* relationship between *family perception of stress* and the *health-seeking behaviors (HSB) of the family* (as he/she engages consciously or subconsciously, moving them toward *assurance, support*).

5. There was a positive relationship between the ethical quality of health care or *provision of stress resources* and the level of *holistic comfort* that the family experiences.

The above propositions are; logical, low level of abstraction, easily defined, reasonable. Therefore, this is inductive reasoning which simply translates to a practical ‘bottom-up’ approach for the researcher, beginning with a broad spectrum of information (what is known about family needs in the traditional ICU) and filter up to a specific conclusion (what is currently unknown about family needs in the tele-ICU) through semi-structured interviews garnering family perceptions of the tele-ICU.

2.6.7 Concept Delineation: Antecedents and Consequences

2.6.7.1 Antecedents

Antecedents are experiences that must occur for a concept to take place (Walker & Avant, 2005). This study emphasized several concepts (i.e. crisis, stressor, perception). Therefore, hardship and adversity must take place before adaptation or resiliency can be demonstrated. Without the crisis or adversity (loved-one in ICU), adjustment, rebounding, self-efficacy, effectiveness, energy, positive-relationships or a positive outlook on life are no longer related to adaptation or resilience. There must be a disruption in the normal pattern of life in which the family member / significant-other can employ coping techniques.

2.6.7.2 Consequences

There was an important outcome that transpired as a result of the stress continuum. Family members were able to express their perceptions of their personal tragedy. The double 'Xx' was not measured as it would entail a separate study to measure family adaptation.

2.6.8 Theory Evaluation

2.6.8.1 Congruence

The theory was internally consistent and makes logical sense. The characteristics of the concepts have been operationally defined with reliable instruments (McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). Various concepts may be limited in description, such as the full experience of crises-event or stressor-event. Examinations of later use of the theory developmental phase's show that the theory when appended or altered expands conceptually, which in turn may make practical use of the model unmanageable.

2.6.8.2 Clarity

The theory was parsimonious (reads easily). Relationship between the concepts was simply stated and could easily be demonstrated and visually illustrated. The causes (ABC) and consequences (X) are carefully separated. The theory offers both content and constructs validity. Multiple applications are available in the literature.

2.6.8.3 Simplicity

The theory was straightforward as presented by (McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). However, the addition of this phase did not provide all the

answers about *perception*, which was a multi-faceted concept on its own accord. ABC-X presents a solid framework for generating a study hypothesis that could be empirically tested.

2.6.8.4 Complexity

This was a multidimensional theory. Concepts of stressors and crisis vary according to family perception of the event and the resources that were available to them during the stressful period.

2.6.8.5 Usefulness

This theory was directly applicable to nursing practice in critical-care with the intent of measuring family needs and perceptions within the realm of the tele-ICU model of care.

2.6.9 Assumptions

Assumptions are basic principles or statements that are taken for granted or understood to be true even without being scientifically tested (Burns & Grove, 2009). Based upon the principle and the theory of family stress (McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983), the researcher acknowledges the following assumptions:

2.6.9.1 Explicit Assumptions of Family Stress

2.6.9.1.1 Families experience many natural life-changes over the years that result in varying degrees of stress, from predictable and life-giving through difficult hardships.

2.6.9.1.2 Families build functional patterns of competencies, and practical knowledge to promote growth and development of the family unit, in addition to guarding the family from major disruptions amidst transitional events.

2.6.9.1.3 Families build functional patterns of competencies, and practical knowledge intended to guard the family from unpredicted or non-normative stressors and to promote the family's recovery following a family crisis or a major transitional event.

2.6.9.1.4 Families' are part of a dynamic network of relationships and resources within their community that are characterized by traditions and cultural customs, from which they contribute and to rely on particularly during periods of family stress and crises.

2.6.9.1.5 Families demand a change in their family function when faced with crisis situations in order to restore order, harmony and balance even in the midst of change.

(McCubbin & McCubbin, 1996)

2.6.9.2 Implicit Assumptions of Family Stress and Adaptation

2.6.9.2.1 Families have a desire to live orderly and balanced lives and are therefore necessitate coping with the stress.

2.6.9.2.2 Family variables are present prior to and independent of their connections to each other and these variables can be clearly distinguished

2.6.10 Theory Strengths and Weaknesses

2.6.10.1 Strengths

The theory strengths were easy to understand (parsimonious); translated well into therapy and intervention: when applied to family needs in the tele-ICU the measurement tool used will be the Critical Care Family Needs Inventory (CCFNI) within the framework of the Family Stress model; the theory explained the progression entailed in

dealing with stress and adaptation; it has multiple applications of the theory is demonstrated in the literature lending to efficacy; and it provides both content and construct validity through the correlational relationship of ABC-X model and use of CCNFI instrument in the study of family needs in the tele-ICU.

2.6.10.2 Weaknesses

The theory weakness is limited to discussion of those aspects in the family dealing with stress. The findings may not generalize to family members or other tele-ICU settings. It will be difficult to draw a quantitative judgment based upon the subjective findings of this study. It will most likely take more time to collect the exploratory data, if compared to quantitative data collection. Analysis of the findings may be quite time consuming.

2.6.11 Application to family needs in the tele-ICU

The Family Stress and Adaptation Model is a developmental theory derived from social-science and family-sciences which examines why some family-systems are able to adapt and thrive when faced with situational stressors or transitional events, while other family units deteriorate and disintegrate in comparable circumstances (McCubbin & McCubbin, 1993). The theory is defined in nursing's Metaparadigm of person, environment, and health. When applied to nursing, the theory is useful in guiding nursing practice in critical care settings wherein the family is an essential part of the intervention.

Current nursing research regarding the family ability to adapt to general illness emphasizes that nurses need to understand the phases of illness and how families act in response to the variables of the illness process. Theory assumptions facilitate nursing-

practice to recognize that family needs may reach a far broader context than the isolated stressor event of patient admission to the ICU; meaning that other compelling life stressors may augment the ‘pile-up’ effect for the family member.

The Family Stress model was useful as an initial step in identifying family needs in the tele-ICU by categorizing the structural components of the ABC-X theory: the patient, the family resources, the function of the off-site and on-site nurse responsibilities, the family perception of the critical event (crisis), and the illness itself. The Double ABC-X theory adds another dimension to the model of care. Current utilization of this theory in the critical care setting, if practiced correctly, takes into account the family needs and existing resources as well as being cognizant of patient/family needs beyond the walls of the intensive care unit. Within the tele-ICU model of care, the ‘B’ factor is exponentially supported by virtue of the extra team of clinical expertise overseeing and participating in the care given. What we do not know at this point is if the family perception of care diverges from perceptions and needs in the traditional ICU. The intent of this study is to determine if family needs are met in the tele-ICU.

2.6.12 Summary of Theoretical Framework

This section has provided a theoretical framework for this study. The Family Stress Model was introduced to help identify existing peer reviewed research about family needs in the traditional ICU, why it is important, and how the primary concepts, along with the CCFNI and tele-ICU pilot study can be applied in the tele-ICU setting. When applied to nursing, the theory was useful in guiding nursing practice in the traditional ICU setting wherein the family is an essential part of the intervention. Using

the analysis of the stress theory construct, including paradigm perspective, assumptions, concepts, antecedents and consequences, theory development and theory evaluation have been fully examined and have been applied to exploration of family needs in the tele-ICU.

2.7 Chapter Summary

The structural model of the contemporary tele-ICU has been evolving in order to meet the demand for skilled critical care nurses and a growing demand for critical care services (Kettering-Murray, 2002). In the tele-ICU model, a group of critical care nurses and intensivists provide clinical expert knowledge to the on-site staff caring for the patient. This stratified process, while associated with positive clinical outcomes, may raise questions for the patient and family. A review of the literature demonstrates a lack of research on the needs of family in this unique acute care setting. The purpose of this study is to examine the needs of family in the tele-ICU. The next chapter will address the methodology of the study.

CHAPTER 3

METHODS

3.1 Introduction

This research project used a descriptive, exploratory inquiry. By means of a holistic approach of interpretive inquiry (bottom-up or inductive reasoning), semi-structured interviews took place with family members' of a patient in the tele-ICU. This study took place in a natural environment, meaning in the hospital, close to the actual ICU. From the raw data gathered from the spoken word of the participants, interpretations and inferences were then classified into broader categories or themes. This directed content analysis, in which coded themes were based on relevant research findings, such as Molter's work and her Critical Care Family Needs Inventory (CCFNI) instrument as described below. The goal was to base the data collection on previous work, yet also allow emerging data (new information) to surface as a result of the interview process. All information from the participants were incorporated in the findings and synthesized to offer multiple perspectives (Creswell 2009).

In addition to the CCFNI, the tele-ICU pilot study was used to build a structure for the interview question design. This pilot study (as discussed in chapter 2) served as the initial published research to examine the family needs and viewpoints of patient care in the tele-ICU (Jahrsdoerfer & Goran, 2013). The findings of this study suggested that the family's unique information needs may not have been consistently met, and would most likely require a change in the way that information is disseminated.

The researcher used several components of the Critical Care Family Needs Inventory (CCFNI) instrument (Molter, 1979b) to begin to look at the needs of families

in the tele-ICU. The results however, did not provide the type of in-depth information needed to determine the meaning of the family member's experience in the tele-ICU setting. In order to further understand the family member's experience in this setting, exploratory face-to-face interviews were conducted to elicit perceptions and needs from the participants in the tele-ICU situation. The CCFNI served as a fundamental tool to guide the semi-structured / open ended questions during the interview process.

3.2 Research Design

This study incorporated a descriptive, exploratory research design. This design was chosen to assist the investigator in discovering any new meaning in the family situation, to describe what exists in the tele-ICU, to describe the frequency in which something occurred, and to categorize information (Burns & Grove, 2009) . Creswell (2007, 2009) characterized a descriptive study as one that has emerging questions, and in which analysis of data is inductively built from details offered by the participants to draw certain conclusions that may potentially be applied in similar situations.

This study used an exploratory semi-structured interview schedule that was organized into seven main themes. The first five themes were taken from the factor analysis of Molter's original work and Johnson's modified version of the CCFNI; which are the family member's need for 1) information, 2) close proximity, 3) assurance, 4) comfort and 5) support. The final two themes of inquiry were taken from two additional factor analyses of this author's pilot study, which were the need for 6) privacy and the need to 7) understand the tele-ICU model of care. Participants were also invited to comment freely on any matter they wished to add.

Semi-structured interviews allowed the investigator to not only assess the participants' viewpoint through guided questioning, but allowed participants to voluntarily discuss narratives about their actual experiences (Nohl, 2009). Open-ended questions allowed the participants to freely voice their experiences and minimize the influence of the researcher's attitudes and previous findings (Creswell 2005).

3.3 Setting

A total of 4 tele-ICUs at 2 separate academic campuses within the UMass Worcester Memorial Medical Center System were utilized for this study. Specifically, these included the Neuro-Trauma ICU and Medical-Surgical ICU at the University Campus, as well as the Coronary ICU and Surgical ICU at the Memorial Campus. The Worcester Health System was chosen and approved in lieu of the Maine Vital Health Networks recent closing due to financial constraints.

The interview process was conducted in the setting of the 'on-site' tele-intensive care unit, in a private room off of the family waiting area. The remote clinical hub was located off-site approximately 4 miles from both hospital campuses, at the UMass Hahnemann site. There was no interaction with the off-site personnel.

3.3.1 Gaining access

The sequential plan included successfully obtaining approval from the 1) UMass Memorial Medical Center, Worcester, MA internal review board (IRB); 2) Associate Chief Nursing Officer for Critical Care in charge of the tele- ICUs at Worcester, in conjunction with the Critical Care Operations Committee (CCOC); and 3) IRB at UMass

Amherst. A schedule of interview times was coordinated with the Nurse Manager for the tele-ICU.

3.3.2 Description of interview environment

The context in which the interviews took place were real-time or naturally occurring in one of the 'on-site' tele-intensive care units, in a private room off of the family waiting area. The interviews were face-to-face with the researcher and family member. The plan was carried out that when and if a family member requested that someone else be by their side for a comfort reason, it was fully acceptable, although questioning was still directed towards the intended participant.

3.4 Sample

For the explicit purposes of this study, the targeted population consisted of a convenience sample of one or more adult family member(s) or a significant other of a patient in the tele-ICU and must meet the inclusion criteria.

3.4.1 Sample size

At a minimum, approximately 12-15 persons from at least 10 families were sought to participate, or until saturation of all themes had occurred. This is a debatable topic with many differing opinions. Although this particular recommendation was made with the dissertation committee, the investigator explored the topic further to discover the following guidelines: 1) Creswell recommends 5 - 25 participants for phenomenology studies (Creswell, 1997). 2) Morse recommends at least 6 participants for phenomenology studies (Morse, 1994). 3) Bertaux recommends that 15 is the smallest acceptable sample in all qualitative (Bertaux, 1981). 4) Atran recommends as few as 10

subjects are needed to reliably establish a consensus (Atran, Medin, & Ross, 2005). 6) Guest suggests a sample of 6 interviews may be sufficient to enable development of meaningful themes (Guest, Bunce, & Johnson, 2006).

Although the sampling size chosen falls within these guidelines, it was the following statement by Creswell that made the most sense while deciding sample size. Creswell (2009) noted that for qualitative research, purposeful sampling of participants is used to “best help the researcher understand the problem and the research question” (Creswell, 2009, p. 178). It was useful to this investigator to conduct an in-depth exploration with family participants to understand the central phenomenon. Interviews were conducted until saturation was reached and the investigator felt comfortable that all themes were exhausted.

3.4.2 Subject Recruitment

Participants were selected on a purely voluntary basis. Recruitment strategies used included: 1) poster signage in ICU family waiting room, 2) informational letters on tables in ICU family waiting area, and 3) a scripted verbal invitation will be utilized. (Appendix E)

3.4.3 Inclusion Criteria

The inclusion criteria included the following: a) Eligible participants must have had a family member who is a patient in the tele-ICU; b) Participants must have been at least 18 years of age, able to read and write in English, and be able to give informed consent; c) The patient must have been in the tele-ICU a minimum of 24 hours prior to family being asked to participate in the study; d) Up to two persons per family (from at least 10 families) were required to be eligible for participation to gather as many

perspectives as possible. Additionally, the both males and females were invited and participation was completely voluntary.

3.5 Data Sources

All sources of data (excluding hospital/unit descriptives) were planned and obtained explicitly from the family participant. The following tables contain the data collection plan (Table 3.1), and the interview schedule in its totality, as it correlates to the CCFNI and Pilot domains (Table 3.2).

3.5.1 Data Collection Plan

Phase I	Phase II	Phase III
<ul style="list-style-type: none"> • Submission of research proposal to UMass University Medical Center, Worcester MA IRB • Garner general process knowledge of UMC and their particular tele-ICU via phone interview with 3 tele-ICU Nurse Managers • Meet with Nursing Director and Nurse Manager(s) tele-ICU to review study plan 	<ul style="list-style-type: none"> • Be present on-site for as long as it takes to reach saturation • Explain purpose of study to participant • Have participant read and sign consent • Conduct interview following approved Interview Schedule 	<ul style="list-style-type: none"> • Code answers according to as many themes as necessary (i.e. need for information, need for comfort, need for privacy, plus whatever other information is discovered. • Analyze themes • Report findings

3.5.2 CCFNI & Pilot Study Domains that Correlate to Interview Schedule

Table 3.2 reflects the interview schedule which was divided into the five main domains that came from the CCFNI and the two domains from the Pilot Study. Each question was related to the context of the tele-ICU and its subsequent implications. Additionally, there was an open-ended section that allowed family participants to candidly comment in any way meaningful to them.

Table 3 .2 Interview Schedule correlation to CCFNI and Pilot Study

General Information -- Need to understand basics of tele-ICU model of care

1. The tele-ICU is a new model of care that some hospitals are now using like they are here at Worcester Memorial Medical Center. What do you think about the idea of a tele-ICU?
2. What is your understanding of how a tele-ICU works?
3. What is it like for you having a family member in the tele-ICU?
4. Are there advantages to this type of care?
5. Are there any disadvantages or concerns you have about this model of care?

Need for Information

6. Who gives you the most information about your family member in the ICU, someone from the local staff or the remote staff?
7. Who is the person who usually answers your questions? Who provides updates on how your family member is doing?
8. Are you given an opportunity to be introduced to the nurse or other staff at the remote hub at Worcester Medical Center? Do you get to talk to them or ask them questions?
9. What is the communication like between the bedside nurse and the remote nurse at the hub?
10. Do you get to listen in on communications between the on-site nurse or doctor and the nurse or doctor from the remote hub?
11. Do you feel like you have the opportunity to get all the information you want from both staffs—here at Worcester Memorial and from the remote hub?

Need for Close Proximity

12. Are you able to be present at the bedside of your family member more or less, since he/she is a patient here and may not have had to be transferred to another hospital further from your home?
 13. What kind of access do you have to see your family member? Are you able to be with him/her as much as you would like to be?
 14. What kinds of things are you able to do to participate in your family member's care? Is this level of participation what you would like? Would you prefer more of less participation than
-

you have now?

Need for Assurance

15. What is the experience like for you when you hear a voice from the remote center come over the intercom?
 16. Can you see who is talking? Do you think being able to see the staff person from the remote site when they are talking makes/would make a difference in your comfort level?
 17. Do you feel confident that you will be notified of any changes in your family member's condition? How are you notified about any changes?
 18. When you feel you need reassurance, do you feel that you get it? (Who from? How does this happen?-- If it doesn't happen, do you have thoughts on how things could be done better in this area?)
-

Need for Comfort

19. What comforts you most about this type of care that the patient is receiving?
 20. What concerns you the most?
 21. How comfortable do you feel while visiting or being present with your family member in the Tele-ICU unit?
 22. Are there things that could be done to make you more comfortable in this environment?
-

Need for Support

23. Please tell me about any type of support or encouragement that you receive.
 24. Who provides you with the most support during this difficult time?
 25. Do you receive support from staff here? Is there a difference in the level of support you feel from the onsite staff and the remote staff?
 26. Do you have some ideas on how staff could help you feel more supported?
-

Need for Privacy

27. How do you feel about the level of privacy of your family member in the tele-ICU?
 28. Tell me about the camera in the patient's room and how that makes you feel.
 29. Do you feel like your privacy is respected?
 30. Do you have any additional thoughts on privacy?
-

Summary thoughts

31. Would you recommend the tele-ICU model of care to other family or friends who may have the need for ICU care? Why or why not?
 32. Are there any other thoughts you have about your family member being a patient in the tele-ICU that we have not discussed?
-

3.5.3 Data Recording Strategy

The entire interview schedule between the researcher and family participant was audio recorded, using 2 separate recorders for the purpose of gathering all verbatim information exchanged during this period. The family participants were informed of the planned recording, both in the letter of introduction and through the verbal script. *See Appendix 'A' for Letter of Introduction.* Note that the second recorder was used for the sole purpose of back-up in case the first one failed.

3.6 Data Collection Procedures

The data collection procedure had 4 components. First, was a letter of introduction (*Appendix A*). The second component was a letter of consent, stating the purpose of the study description of study steps, confirming the confidentiality of the family responses, and acknowledging consent (*Appendix B*). The third element was a brief Demographic Data Tool consisting of family demographics (*Appendix C*) and the fourth and last section was the actual interview process formatted in a semi-structured question style, to explore the family perception and needs related to the tele-ICU (*Appendix D*).

3.6.1 Interview Protocol - Sequential Steps

All interviews were one-on-one (researcher and participant) to increase the likelihood of obtaining an individual's true feelings and eliminating any extraneous persuasion that may affect a response. All participants of this study were encouraged to have an active role in the interview process, thus allowing each participant to express their unique experience related to the tele-ICU.

The goal was to follow a standard procedure for interviewing from one interview to another. The researcher invited one or more family-member(s) to voluntarily participate in an interview lasting approximately 45-50 minutes. Upon agreeing to do so, the family-subject signed a consent form (*Appendix B*) for the interview process. A semi-structured interview schedule was used consisting of a series of 32 open ended questions (*Appendix D*).

After the participant's written consent had been obtained, the investigator escorted the participant to a quiet room close to the waiting room and sat, facing the family-participant (see *Appendix B*). The investigator thanked them, asked if they would like a drink of water, and asked if they are comfortable to begin. The investigator then proceeded with the planned dialog, and let them know that she would be turning on the audio-recorder (following written consent) at that time and would be taking some field notes. The questioning then continued, taking the necessary time that the participant needed.

In the unlikely event that answering the interview questions had elicited a significant stress response, the subject would be asked if she/he needed a moment or wished to take a break. This did not happen. Additionally, if needed, the investigator would have suggested that there are resources in place for them at the hospital, such as social workers and pastoral care staff. The subject would be asked if he/she would like one of these support persons to be called to talk with them or if they would like a family member or friend to be called. The subject would also be offered the opportunity to stop the interview if he/she wished. When the interview was over, the investigator thanked the participants for their participation.

All data obtained therefore, consisted of direct accounts of perspectives and experiences by the participants as documented via audio-recording. Once the family participant left the room, the researcher wrote any other field notes immediately following every interview while they remained fresh in her mind. An example was that the participant appeared to be upset, or any other observation noteworthy. All information relayed by the participant was incorporated in the field notes, such as, key ideas; if the information represented primary experiences or secondary hear-say; bullets of important information that have been conveyed (Creswell, 2011).

3.7 Research Validity

An exploratory descriptive approach to research is thought by some to leave an open door to interpretation, extraneous information, questionable value, rigor and incompleteness (Guba & Lincoln, 1988a). Thus, the methods took into account reliability, validity, and replicability for the study to be a truthful inquiry in which the researcher found consensus and clarification (Marshall, 1990). Clarification refers to information that may be meaningful to the participant, which was not captured in the questions asked. This refers to comments and insights the participant voluntarily offered in addition to the questions being asked. Although we have established that we know the family needs in a traditional ICU setting, these themes were not explored in the tele-ICU environment. Thus, a deeper understanding of the essence and inferences of the family experience was hoped for and welcomed in this exploratory study, which cannot be solely obtained through quantitative measures.

To maintain the validity of this study the investigator has described and interpreted findings according to the direct expressed needs of each participant. These interpretive findings have been related in a theoretical framework that makes sense for this population. This framework consists of the stress theory, the CCFNI, and the family needs pilot study in which this research has applied to the tele-ICU setting.

The threat to this study was its generalizability, as the tele-ICU policies and procedures for remote staff communication with the family participants appears to be unique. Please see discussion section.

3.7.1 Goodness Criteria and Trustworthiness of Interview Questions

In approaching the descriptive design of this study, the ‘goodness’ of the research question must be phrased in a manner that supports the discovery and exploration of various viewpoints and perceptions. The goal of questions in this study was that they were useful, ethical, unbiased, concise and clear.

Marshall (1990) notes that there is common agreement regarding the criteria for determining what constitutes good descriptive research. These goodness criteria encompass 20 different assumptions. They are listed in brief as follows: 1) the method must be described in detail, 2) assumptions and biases are stated, 3) avoid value judgment, 4) present data in readable form, 5) the study should answer the research question and generate further questions, 6) the relationship between the current study and previous studies is explicit, 7) the study report must be accessible to other researchers, practitioners and policy makers, 8) researcher must be tolerant of ambiguity and search for alternative explanations, 9) report should acknowledge limitations and generalizability, 10) an exploration to identify new information, 11) observations are

made of a full range of activities, 12) data are preserved and available for reanalysis, 13) methods are devised for checking data quality such as participant knowledge, concealed motives and truthfulness, 14) in-field work is documented, 15) meaning is elicited from cross-cultural perspectives, 16) researcher must be sensitive to those being researched, 17) participants benefit in some way such as having someone listen to them, 18) researcher is careful to recognize if they are getting too subjective, 19) the study must be tied to the big-picture, 20) the researcher traces historical context to determine how roles have evolved. All of these criteria will be adhered to, to the fullest extent possible in this study.

3.7.2 Measures of Trustworthiness, Validity and Reliability

Although various researchers hold distinct principles that direct them to a good and trustworthy research study, a common thread is Guba's (1981) model, which was based on the identification of four aspects of trustworthiness, relevant to both quantitative and qualitative studies: a) truth value (truth or falsity of a proposition statement), b) applicability, c) consistency, and d) neutrality. In qualitative research, “truth value is typically acquired through the discovery of human experiences as they are lived and perceived by informants”, (Lincoln & Guba, 1985, p. 172). Truth value may sometimes be referred to as logical value. In relationship to this study, it meant that there was a consensus among the participants regarding their perception of care in the tele-ICU, and therefore it was logical to say that there was truth in their statements. Truth value also establishes whether the researcher is assured the truth of the findings is consistent with the research design itself (Lincoln & Guba, 1985). It is the very ‘discovery’ process in which this researcher used to establish true findings.

Applicability or transferability refers to the degree to which the findings can be applied in a different setting (Lincoln & Guba, 1985). In this research study, the generalizability could plausibly apply to similar tele-ICU type health care settings, in which the structural, environmental, and personnel processes are parallel throughout hospital systems for the sole reason that it strengthened findings from the family-needs pilot study in which the outcomes of this study are similar. To further test for generalizability, a broader multisite trial using a validated tool may be warranted in the future, especially in light of some of the findings regarding family information.

The third measure of trustworthiness was consistency, which was accomplished through participant checking. Pertaining to this study, the researcher confirmed participant answers during the interview.

The fourth principle of trustworthiness is neutrality (Lincoln & Guba, 1985). Neutrality indicates there are freedom from bias within the research procedures itself, as well as the data results (Sandelowski, 1986). In quantitative analysis, objectivity is the principle for which neutrality is established and is obtained through rigor of methodology; for example, a randomized trial. In a qualitative or exploratory research approach, Guba suggests there is a shift from objectivity of the researcher, to objectivity of the data. By decreasing the distance between the researcher and participants, the data are apt to be richer. This was accomplished through prolonged engagement between the researcher and participants, which in turn allowed the participant to become accustomed to the investigator, therefore opening up to share their perceptions and needs. This investigator accomplished neutrality by, 1) spending large amounts of time on site every day during the study, 2) making myself available when convenient for the family

participant without time constraints, and 3) sitting face-to-face and making eye contact with the participant and engaging in light conversation prior to questioning, as well as opening myself so they could get to know a little bit about me.

Yet, the question is raised, if the investigator has established truth value, how do we know that the study is valid? Verification methods were used that provided both reliability and validity of data to address coherence (consistency); dynamic relationship between sampling (participants who have familiarity of the research topic and for researcher to reach saturation among the sampling); data collection and analysis (synergy between what is already known and that which one needs to know), thinking theoretically (any new data was used to build upon the existing knowledge base of family needs and perceptions), and theory development (where the family stress theory and CCFNI were expanded upon in the tele-ICU setting) (Creswell, 2011). These strategies established rigor by shifting responsibility from external reviewers' judgments to the researcher themselves. Also meaningful were the attributes of the research investigator, who was receptive, adaptable, sensitive, holistic, and possessed the ability to clarify and summarize the information (Guba & Lincoln, 1981). Specific strategies for demonstrating rigor in this study included an audit trail of 1) raw data, consisting of auditory recordings, field notes, written and signed participant consents, and a participant demographic sheet; 2) data reduction outcomes, that include analysis, tables, and condensed notes; 3) data reconstruction and synthesis was done by creation of categories and themes, reported findings, used existing literature and concepts to integrate findings and draw conclusions; 4) used process methodology by use of an interview schedule, so that every interview followed the same format; 5) used materials

that related investigator intentions, such as formal request and approval from UMass Worcester research site, IRB approval from UMass Amherst, outlining intentions in formal proposal, developed a strategy, and timeline; 6) utilized recent published family-needs pilot study to guide face-to-face exploratory study, developed instrument/interview schedule; 7) conducted informant feedback (member-check) during each interview, confirmed all answers with each participant (Guba & Lincoln, 1981; Lincoln & Guba, 1985; Guba & Lincoln, 1982).

3.7.3 Strengths and Weakness of the Study Design

3.7.3.1 Strengths of the Design

The major strength of these face to face interviews was that the investigator received first hand (single-subject) historical information as experienced directly from the participant. There were several other strengths to note; the audio-recording appeared to be an unobtrusive method of collecting data; the face to face interviews provided an opportunity for each participant to directly share their reality with me; the synchronous communication allowed the participant to appear more natural; the investigator had control over the line of questioning, even though it was a semi-structured, open-ended interview schedule (Creswell 2009; Opdenakker 2006; Wengraf, 2001). This was also the first known face-to-face exploration of the tele-ICU experience with family members. Thus, it brings and important added knowledge regarding this new emerging model of care.

3.7.3.2 Weaknesses of the Design

Several weaknesses may have occurred during the interview process that included: the researcher's presence which potentially may have biased responses; not all of the family participants were equally articulate and perceptive; and the recordings, although fairly clear to interpret, were lengthy to transcribe (Bryman, 2001). In an effort to reduce these adverse effects, the researcher tried to make the participant comfortable by summoning light conversation prior to questioning. For example, by addressing such things as the weather or their comfort level, or offering water, or assuring them that their responses and identity were completely confidential, it seemed to put them at greater ease. Additionally, to optimize the voice recording, attention was paid to the interview room to ensure that it was as quiet as possible. Another issue may be that given the sample actually obtained and the nature of a face-to-face interview, the findings may not necessarily be compared to family members in other tele-ICU settings. A last issue with the study design is that these analysis of the findings of a descriptive study has been quite time consuming.

3.8 Protection of Human Subjects / Ethics

Institutional Review Board (IRB) approval was obtained from the University of Massachusetts Amherst (Appendix G). While UMass Worcester did not require their own IRB approval in lieu of the UMass Amherst approval, they did require verbal approval from the Associate Chief Nursing Officer for Critical Care in charge of the all Worcester tele-ICUs. (Appendix H)

3.8.1 Privacy & Confidentiality

All patient identifiers have remained confidential. During the interview process and the transcription of the voice recording, no participant identifiers were used. Once the research study analysis has been totally completed, the participant voice recordings will be deleted. Any written notations and/or paper trail were locked in a file cabinet in the researcher's office, to which no one else holds the key. Additionally, as this researcher has taken an ethical oath as a nurse, she was ethically bound to abide by these same ethical standards. No participant identifying information was shared outside of the private rooms in which the interview took place.

3.8.2 Risk(s)

It was determined that there would be negligible associated risk to the family participant. As the researcher was unable to pre-determine how a certain question would make a family-participant feel at any given point or if certain questions would invoke an emotional response, participants were informed that they could stop the interview without recrimination at any time during the interview process. Plans were made as discussed earlier that if at any point the participant appeared to be upset, the researcher would offer an opportunity for him/her to stop for awhile, or if warranted may contact a staff member of the hospital social service or pastoral care department who would be enlisted to provide additional support. This did not occur. Additionally, this investigator is a licensed registered nurse with expert knowledge and experience of cardiac emergencies, and therefore has the training and ability to assess the magnitude of a stress reaction and whether additional support should be summoned, based on participant input.

Interviews were conducted on a purely voluntary basis, with English speaking subjects only. Answers were kept confidential by placing any notes taken during the audio-taped interview in a sealed envelope, hand-carried and opened only by this researcher. No identifying information about either the patient or family was recorded during the interview or disclosed to the ICU staff caring for the patient.

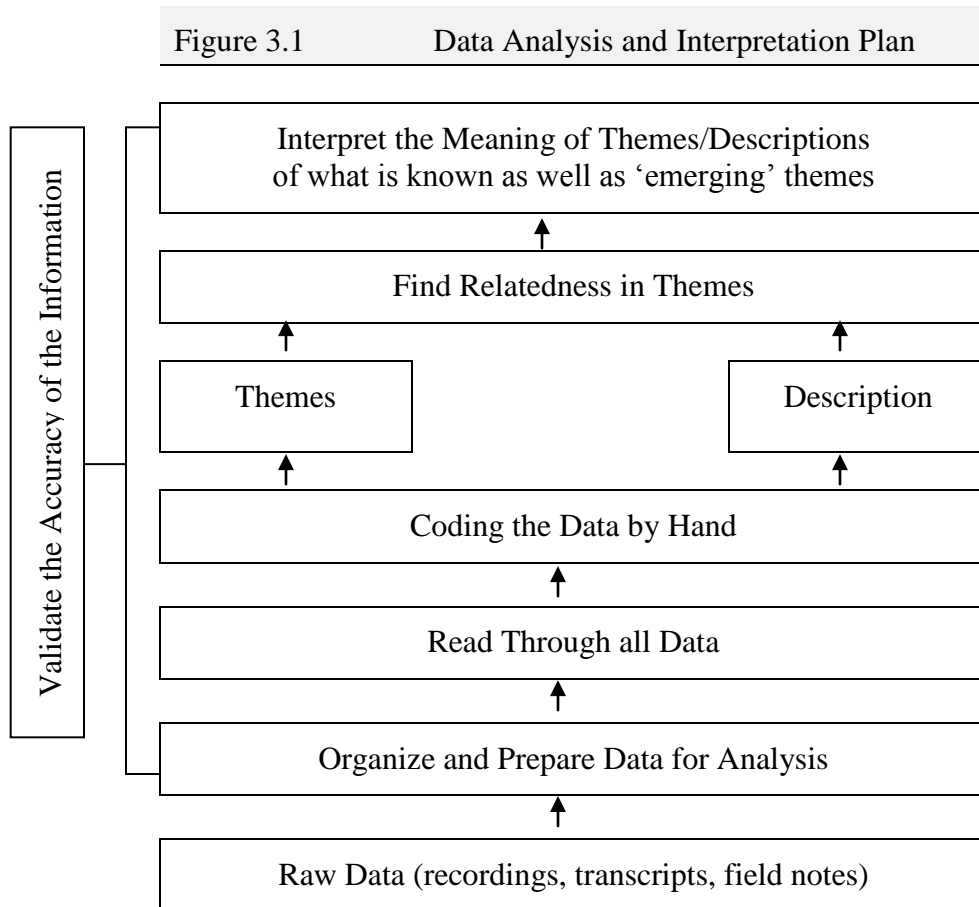
3.9 Data Management and Analysis Strategies

The data management and analysis plan used a systematic process and technique that helped to demonstrate, describe, summarize and evaluate data. Iterative practices were used to clarify the spoken word of the family participant, to formulate themes, categories and inferences. Refer to APPENDIX I.

The goal was for data collection to continue until a minimum of 12-15 family members (from at least 10 families) had been interviewed or further if saturation had not been reached. Saturation refers to the recurrence of information that is discovered during the interview process as well as evidence based upon previously collected data (Morse, 2003). Therefore, there was no pre-determined number of interviews in order to gather statistical significance, but rather the intent was to recognize the repetitive nature of the data (where no new information is discovered) and therefore when the point of saturation had been reached. All data collected were coded into themes based upon the factor analysis of Molter's CCFNI; Johnson's modified CCFNI, and Jahrsdoerfer's pilot study. Although the identified seven themes would serve as a liberal guide for questioning, the intent was to seek emerging information regarding the family experience in the tele-ICU that may actually provide expansion or a different dimension to the identified themes as

well as the possible addition of categories or themes not seen in previous research based on traditional ICUs.

Analysis was therefore based upon field notes and transcriptions of the recorded interviews. Coding of the data was accomplished by reading the participant text line by line and placing the main premise of that text into the appropriate category (Creswell, 2011). Information was distributed into the appropriate categories as they were discovered throughout the process. Coding is a procedure that is used to symbolically assign a collective summary or prominent attribute for a portion of language-based transcription, which may hold both superficial and deep meaning, depending upon new discoveries (Creswell, 2011).



Adapted from Creswell, Research Design 3rd Ed., page 185

According to Creswell (2009), when interpreting the meaning of the themes in qualitative research, the research itself is interpretative research” (Creswell, 2009). This researcher believes this implication was to interpret the meanings of the coded data within the realm of his/her own belief system, history culture, and experience.

There are varied computer software programs that are available for coding purposes, such as ATLAS.ti, NVivo, and MAXQDA for example. Yet, in order for the investigator to authentically engage with the subjective nature of quotes that were elicited from the family participants, manual coding was conducted for this study. With 16 participant interviews to analyze, this investigator was compelled to take the information transcribed from Dragon-Nuance and enter all data into a Microsoft Excel database using the Microsoft calculator format. Using this format, themes were reconstructed forming a secondary text next to the original resulting in a narrative that is better-quality to the original (Mulkay, 1985). People do not always speak in complete sentences, often using filler words such as ‘c’mon’, ‘uhm’, ‘ya’know’. These words will remain in the original recordings and raw themes, but were not reflected in the final results. The drawbacks to eliminating these non-verbal sounds in the final reporting of the results may have been a loss of feeling the participant was trying to get across, whether that was anxiety, sadness, or exhaustion for example. The upside to excluding these non-verbal sounds was that the data was easier to follow, to understand and to interpret. Data that cannot be coded to the existing seven theme framework were placed into a category labeled ‘emerging information’. These data were later analyzed to synthesize possible new themes or findings.

3.9.1 Timeline

Table 3.3 Study Timeline

Month	Activity
April 2014	Submit to UMass Amherst IRB , then UMass Univ. Hosp IRB
May 2014	Data collection (face-to-face interviews)
May-June 2014	Data analysis
June – July 2014	Complete write-up & submission
August 4, 2014	Final Defense

3.10 Summary

This chapter of the study has presented the methodology, to include: the study objectives; study design; study setting; sample; data collection including procedure and instrument used; instrument validity and reliability; ethical considerations, and the data analysis plan.

CHAPTER 4

RESULTS and ANALYSIS

4.1 Introduction

This chapter reported findings from the family interviews that took place in the tele-ICUs at Worcester Memorial Medical Center. The experiences of patients' family, as expressed directly from the family-participants were presented along with an analysis of these findings. Specifically, the chapter was divided into subsections addressing the research question; study approval, sample, and setting; findings associated with family need for information, close proximity, assurance, comfort, support, privacy, basic knowledge of tele-ICU, and any emerging themes that were identified. Lastly, an analysis of these findings was reported.

4.1.1 Research Question

This study that was undertaken, answered the following research question:
What are the perceptions and needs of the family members of patients admitted to a tele-medicine intensive care unit (tele-ICU) relative to those identified by family member's of patient's in a traditional ICU?

4.2. Study Approval Process and Hospital Tele-ICU Site Description

Approval was granted by the University of Massachusetts Amherst, Internal Review Board (IRB), and the University of Massachusetts Worcester, Critical Care Operating Committee (CCOC) for this research study. A list of authorized tele-ICU's within the UMass Worcester Hospital System was identified and approved for this

research by the Associate Chief Nursing Officer for Critical Care at UMass Memorial Medical Center in Worcester, Massachusetts. (Appendix G; Appendix H)

4.2.1 Description of Hospital Campuses

A total 3 separate academic campuses at UMass Worcester Memorial Medical Center operate within the tele-ICU system. For the purposes of this research, necessitating direct family interaction, the 2 hospitals that have tele-ICUs within the UMass Worcester Memorial Medical Center System participated in this study. Each hospital campus, the University Campus and the Memorial Campus, were situated just 1.5 miles apart. The remote hub, also in Worcester and part of the UMass Worcester Memorial Medical Center System was located at the Hahnemann Campus. This remote hub did not house patients. (Figure 4.1)

4.2.2 Description of Tele-ICU Locations within the Hospital System

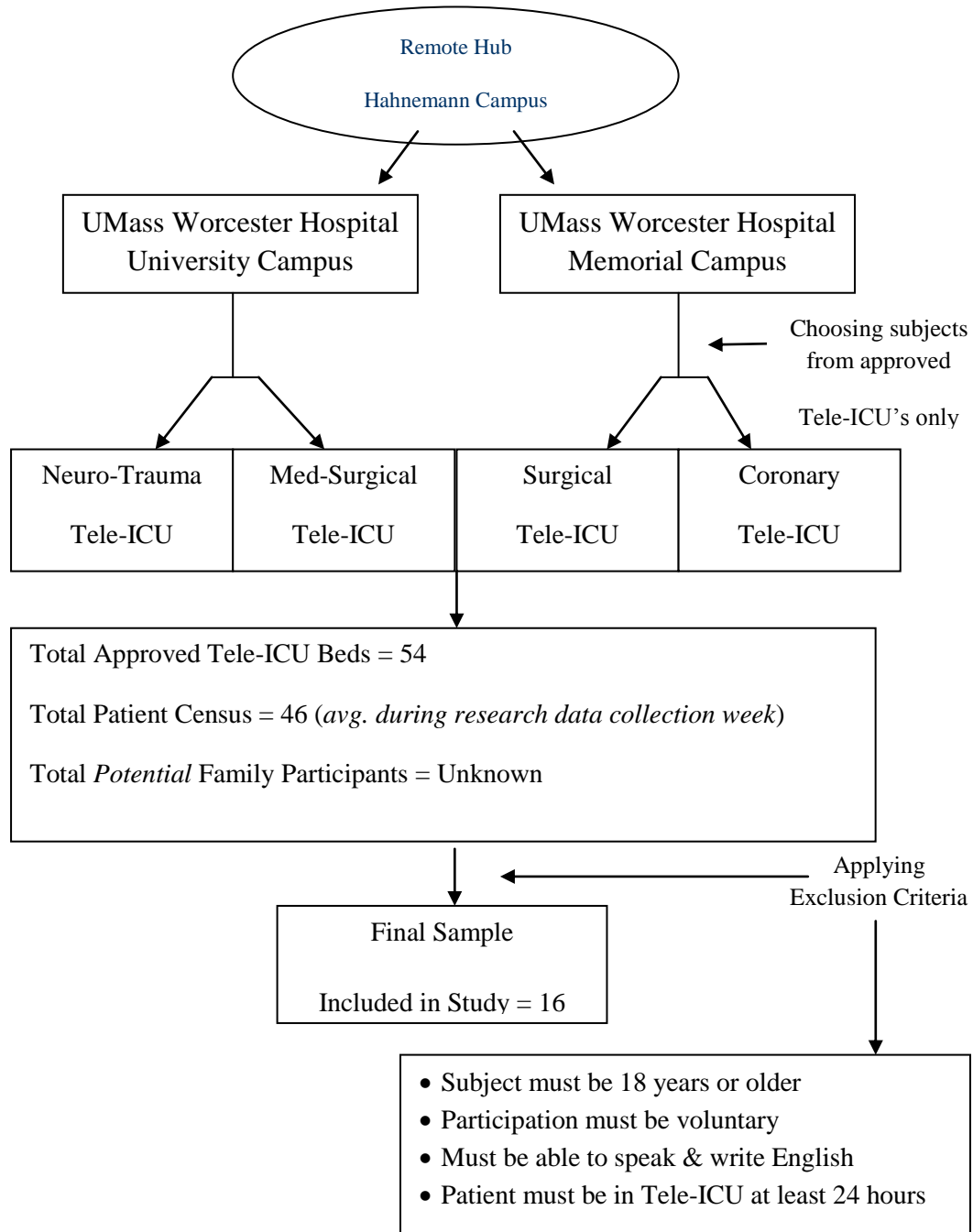
The Tele-ICUs included the Neuro-Trauma ICU (16 beds) and Medical -Surgical ICU (15 beds) at the University Campus, as well as the Coronary ICU (14 beds) and Surgical ICU (9 beds) at the Memorial Campus.

4.2.3 Description of Remote-Hub within the Hospital System

The remote-hub was comprised of a critical care physician (intensivist), several critical-care nurses, and monitoring equipment that provided live-stream clinical data from patients at the University and Memorial campuses. The camera's used at the hub were all one-way camera's, meaning that the staff at the remote hub at the Hahnemann Campus were able to see the patient, family and on-site staff from the University and

Memorial Campuses, but in return, the patient, family and on-site staff only had audio access to the remote staff. There was no two-way camera in place (Figure 4.1)

Figure: 4.1 Sample Accrual Process



4.2.4 Description of Tele-ICU Census Effect on Data Collection

Sunday, May 18th through Friday, May 23rd, 2014, this investigator spent 6 days on-site at Worcester Memorial Medical Center in central Massachusetts. Prior to beginning the research, it was noted (by the Associate Chief Nursing Officer for Critical Care) that the University Campus was the busier of the two campuses. This was evidenced by 15 out of 16 total interviews taking place at the University Campus. Although the investigator visited both campuses each day, the patient census at the Memorial Campus remained low, with only one family member volunteering to partake in the study. Subsequently, the majority of the interviews took place between two tele-ICUs at the University Campus. (Table 4.1)

Table 4.1 Characteristics of Tele-ICUs by Interview Schedule Subjects

UMass Worcester University Campus	UMass Worcester Memorial Campus
n=9 (Neuro-Trauma)	n=0 (CICU)
n=6 (ICU3)	n=1 (SICU)
TOTAL # Participants University Campus n=15	TOTAL # Participants Memorial Campus n=1

4.3 Sample

This study used a convenience sampling of participant's who were a family member of a tele-ICU patient, who were readily available, and who met the study criteria. The following section is a description of sample characteristics.

4.3.1 Description of Sample and Setting

A total of 18 family members were invited to participate in the study with 16 consenting and submitting completed demographic information and answering the interview schedule, for an overall response rate of 89%. Table 4.1 presents the percent of interviews that were completed at each of the 4 tele-ICU sites at UMass Worcester. The bulk of interviews occurred on the University Campus with 9 participants from the Neuro-Trauma ICU and 6 participants from the Medical Surgical ICU. The Memorial Campus had a quiet patient census during the schedule time, with only one participant from the Surgical ICU. One family member interested in the study participation was excluded because his wife was admitted less than 24 hours.

4.3.1.1 Sample Age, Gender, and Ethnicity Distribution

The mean age of the study participants was 49.75 years, with a range of 28 to 69 years. The majority of the participants, 14 were female and 2 were male. The skewed response of female to male subjects was not purposeful. The only rationale for the large majority of women participants appeared to be twofold; their openness to volunteer, and the fact that over half (n=10) of the patients were male, with a female visiting family member. Note that two men were excluded from the study; one being unable to speak

English and the other because his wife was admitted less than 24 hours to the tele-ICU.

The ethnicity of the study participants were 100% Caucasian. (Figure 4.2)

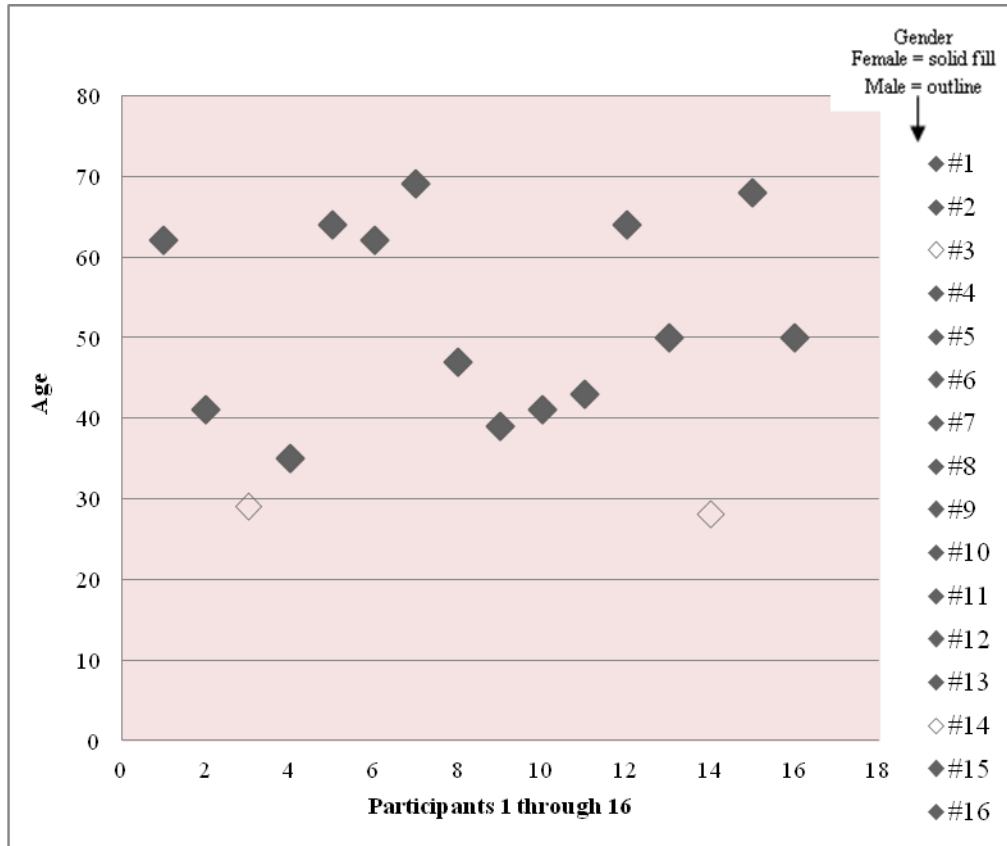
Table 4.2 Family Participant & Patient Demographics

	Mean/Avg. Age	Median	Range (Age)	Gender Female	Gender Male	Ethnicity	Comment
Family Participant N=16	49.75 yrs.	(47+50)/2 = 48.5	28-69 yrs.	14	2	Caucasian	Convenience Sample
Patient N=14	60.71 yrs.	(59+64)/2 = 61.5	25-90 yrs.	2	12	Caucasian	Convenience Sample
Participant Exclusion	-	-	-	-	2	-	#1-Pt. < 24hrs in ICU #2-Non-English speaking

4.3.1.2 Study Setting

A total of 16 subjects volunteered to partake in the study. Each audio-recorded face-to-face interview was conducted in a private room just off the tele-ICU waiting area. Field notes were taken during the interview. The average time spent interviewing each family-participant lasted approximately 40-90 minutes, with a mean of 65 minutes. There were 2 outliers however, with one interview lasting just 25 minutes and the other lasting 130 minutes. Common trends and themes were noted around the 7th or 8th participant interview. Saturation was reached with 16 participant interviews. All interviews took place between 8 o'clock in the morning and 11 o'clock at night.

Figure 4.2 Participant sample age and gender



4.3.2 Characteristics of Participant Relationship to Patient

The relationship of family member participants to the patient is presented in Figure 4.3 with 81.2% (n = 13) respondents identified as an immediate family member, a spouse, parent, child, or sibling. Of these immediate family members one quarter (n=4) are spouses. Of the total spouses, all are female, with a husband whose mean age is 66.25 years, with a range of 59 to 74 years. One family member (6.25%) is parent and mother of our youngest patient. The largest population 37.5% (n=6) are grown children who have a parent in the tele-ICU. Of these grown children 25% (n=4) are daughters and 12.5% (n=2) are sons. There are 2 grown siblings (12.5%) in the immediate family group, both female.

Participants responding as an extended family member 12.5% (n = 2) were comprised of one grandmother (6.25%) and one Aunt (6.25%). Lastly, there is one female participant responding as a life-long friend (6.25%). Of the 16 participants who took part in the study, two families had more than one member consent to participate (specifically 1 extra participant each), for a total of 14 patients. (Figure 4.3)

Most of these participants were eager to speak about the care their loved one was receiving; specifically the families of a 25 year old male patient and a 41 year old female patient. Each of these 2 families' has spent over 3 weeks in and around the tele-ICU area. It was not surprising that these 2 families requested more than one member of the family participate in the interview process. See table 4.3 for participant relationship to patient and unit type.

Table 4.3 Participant Relationship to Patient and Unit Type

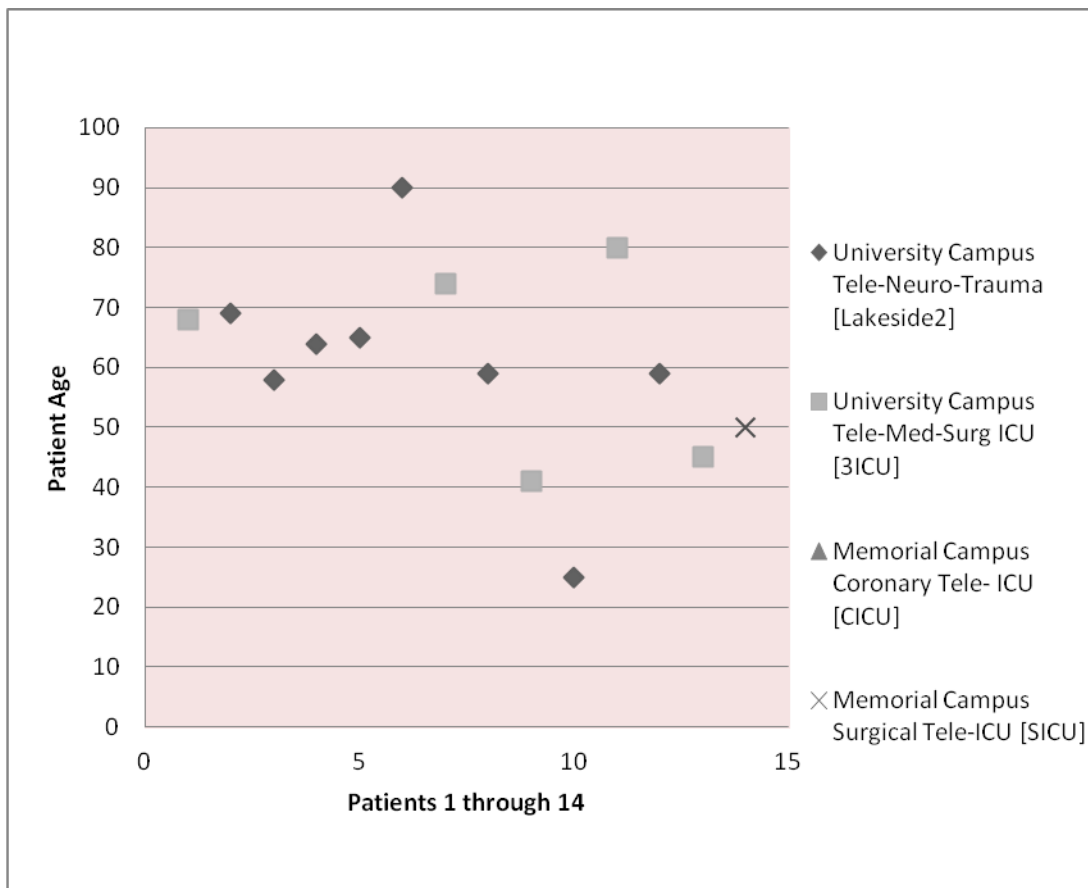
	Number	Percent	Female	Male	Patient Unit
Spouse	4	25%	4	-	2 participants/ Med-Surg ICU 2 participants/Neuro-Trauma ICU
Parent of Patient	1	6.25%	1	-	1 participant/Neuro-Trauma ICU
(Grown) Child of Patient	6	37.5%	4	2	5 participants/ Neuro-Trauma ICU (2 sons & 3 daughters) 1 daughter Med-Surg ICU
Grandparent	1	6.25%	1	-	1 participant/Neuro-Trauma ICU
Sibling	2	12.5%	2	-	1 participant /Med-Surg ICU 1 participant/ SICU
Aunt/Uncle	1	6.25%	1	-	1 participant /Med-Surg ICU
Close Friend	1	6.25%	1	-	1 participant/Med-Surg ICU

4.3.3 Characteristics of Patient Age according to Unit Type

The mean patient age across all ICUs that were linked to a participant interview was 60.50 years, ranging from 25 years to 90 years, for a total of 14 patients'. Over half (n=9) of the patients fell in the parameter of 50-70 years of age, while 4 participants rendered above this range and 4 others fell below this range (with 1 outlier patient in this lower range at 25 years old). Of this patient group, more than a third (n=6) were the father of one of the participants; almost a third (n=4) were husbands; one brother, and the

youngest male patient was the son and grandson of the participant mix. Of the total patient group there were 2 females; one the niece and best friend of two of the participants, and the other a sister. At the time of this research, the total ICU combined patient days equaled 86, for an average length of stay (LOS) of 6.61 days.

Figure 4.3 Patient age according to ICU type

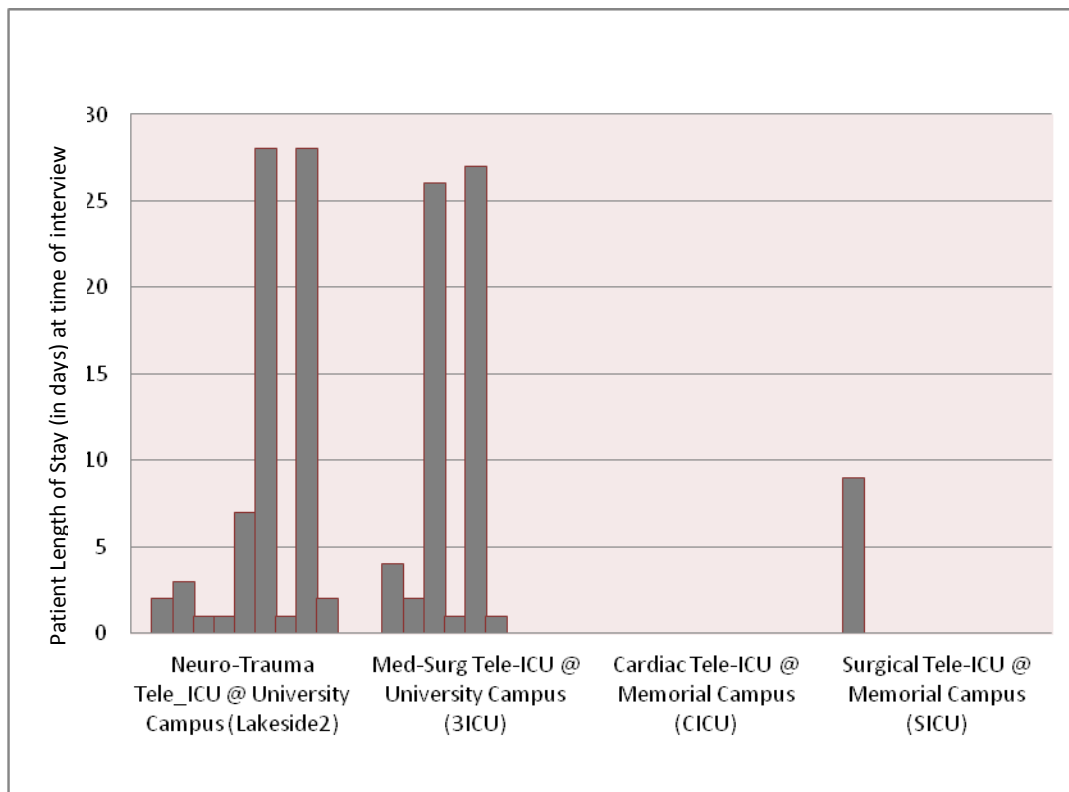


4.3.4 Characteristics of Participant to Patient Length of Stay and Unit Type

The following figure 4.5 illustrates sample characteristics by tele-ICU, in relation to the patient length of stay at the time of the interview. The purpose was to determine if there was an effect of the participant responses according to the length of time (at time of interview) the patient has been in the tele-ICU. Two families' were identified (each with

two participants), with a patient whose length of stay was five times higher (LOS >27 days) than the majority 71.4% (LOS 1-3 days). There were 2 other participants where the patient LOS fell just over the week-long mark at 7-9 days. Of the first two family-outliers mentioned, with a patient admission to the tele-ICU over 27 days, one a medical trauma patient (25 year old male) and the other a surgical patient (41 year old female), there was no correlation between these two participants to the patient length of stay and unit type. There was however a strong common denominator shared by these 2 family's (4 participants), although they never met. This was their familiarity with the everydayness of the tele-ICU; the patient routine, the staff, and the environment. Each family commented on their favorite nurse, who to approach for information, the most comfortable position for the patient, which families were new to the unit, the cleanliness of the waiting areas, the comfort or lack of comfort of the chairs, where to get good coffee. More will be presented in the results section.

Figure 4.4 Family participants according to patient length of stay and unit type



4.3.5 Participant Prior Experience with the Tele-ICU

In terms of whether the participants had any past experience with a tele-ICU, over two-thirds (n=11) stated that they had never been a visitor in a tele-ICU setting while (n=5) had had previous visiting experience with this type of unit. When asked if they themselves had ever been a patient in a tele-ICU, 100% stated that they had not. A small portion of the respondents (n=3) had, however, had the patient they are now visiting have a prior admission to the tele-ICU, while the vast majority (n=13) claimed that their family-member has never been a patient in this setting. *See Table 4.4 for more detailing of the responses.*

Table: 4.4 Participant Prior Experience with the Tele-ICU

	Yes	No
Have you ever been a visitor in a Tele-ICU before this?	n=5	n=11
Have you ever been a patient in the Tele-ICU environment?	n=0	N=16
Has your loved one ever been a patient in the Tele-ICU?	n=3	n=13

4.4 Findings

The following key themes were examined (based upon Molter’s original work and the pilot study of this researcher) in order to guide the questions: The seven family needs for information, close proximity, assurance, comfort, support, privacy and the need to have a basic understanding of how the tele-ICU functions. Additionally, all emerging themes that resulted from this inquiry have been described.

4.4.1 Description of Methods Used for Interview Content Organization

This section presents how the investigator transcribed the participant interviews and categorized them into meaningful themes.

4.4.1.1 Transcription Process

Utilizing the ‘Dragon Home Version 12’ software for transcription by Nuance (2012), all interviews were transcribed into the 7 categories introduced at the beginning of this section, plus into a separate category for all emerging themes.

This was a very lengthy process, as this software was only able to pick up one voice. Therefore, this investigator listened to the interview recordings and word for word dictated them into the computer software. This allowed the sole voice of the investigator to initiate the transcription process. The pros to using the Dragon software is that it allowed the investigator to have all recordings in one file and be able to easily access a individual recording at any point. The cons to using this type of software was that it was extremely time consuming to learn how to properly use the software for the first time, as well as the fact that it only picks up one voice at a time.

4.4.1.2 Coding Process

Next, participant responses were coded according to a short word or phrase that symbolically captured what the participant was communicating. While it was the original intention of using ATLAS.ti software to aide in this process, this investigator found the transition more effective to manually code the themes. These codes were then placed into common themes according to the category in which the question was asked.

4.4.2 Key Themes Used to Guide the Family Interview; Associated with CCFNI

4.4.2.1 Theme 1: The need for information: Participants reported their strong need to receive information; what staff members answered family questions and provided clinical

updates; the lack of observed communication between onsite staff and remote staff; the lack of family opportunity to receive information from both on-site and remote staff.

4.4.2.2 Theme 2: The need for close proximity: Participants reported positive factors concerning family presence at the patient bedside; patient access; and care participation.

4.4.2.3 Theme 3: The need for assurance: Participants reported factors concerning absence of hearing the voice over the intercom from the remote site; visualizing the remote clinician; questionable confidence in receiving status updates when there is a change in the patient condition; and who the assurance came from on the clinical staff.

4.4.2.4 Theme 4: The need for comfort: Participants reported factors concerning comfort receiving this type of care; concerns over this type of care; overall comfort and/or changes that were perceived and warranted with this type of care.

4.4.2.5 Theme 5: The need for support: Participants reported factors concerning where family support and encouragement came from; whether or not staff offered family support; and a discussion on how the staff may have helped the family member to feel more supported.

4.4.3 Key Themes Used to Guide the Family Interview; Associated with Pilot Study

4.4.3.1 Theme 6: The need for basic understanding of how the tele-ICU model works: Questions determined factors concerning family perception of the tele-ICU; knowledge of model function; feelings about having a family member as recipient of this type of care; and the advantages and/or disadvantages to this type of care.

4.4.3.2 Theme 7: The need for privacy: Questions determined factors concerning the level of privacy the patient is receiving; feelings regarding the camera in the patient room; whether or not privacy is respected; and any additional thoughts regarding privacy.

4.4.4 Interview Findings

Prior to plunging into association of existing themes with the participants, the interview questioning first sort to explore the participant basic understanding and general knowledge of the tele-ICU. It was not meant to disorient the reader here, but used rather to organize the interview schedule, as well as to provide an answer for the participant if needed. Therefore, this finding from the pilot study was placed as the first theme, followed by the CCFNI themes (information, close proximity, assurance, comfort, and support), then the privacy theme (from pilot study) was addressed on the interview schedule. All emerging data were discussed and documented as associated with each theme or as it is independently stated.

It should be noted that the findings related to the first theme, family basic understanding of tele-ICU, have many places overlapped with their need for information (second theme). Findings described in next section.

4.4.4.1 Family Source of General Information about the Tele-ICU

Among the 16 family participants who responded to the interview schedule, the first series of 5 questions focused on their basic understanding and general knowledge of the tele-ICU. This was presented prior to exploration of existing needs as associated with

the tele-ICU. When asked what they thought about the tele-ICU, all of the participants liked the idea, but the majority had never heard about it prior to this point. Remarkably, over two-thirds (n =11) had no understanding the tele-ICU (model, purpose & function), but did comment on the concept of it once explained to them. Responses to this category of general tele-ICU knowledge may be found in table 4.3.1

Only a quarter (n=4) of family members indicated that they had been informed of this care model upon admission of the tele-ICU. Yet this minority reported the only explanation provided by the staff upon patient admission to the tele-ICU, was a simple statement verbalized as ‘there is a camera in the room in which a physician will check in on you from time to time’. Not one of the participants reported an explanation beyond the boundaries of this statement initiated by the on-site nurse. Additionally, of those family members who were offered a brief explanation, they were unaware that a nurse was also part of the remote team, as well as the fact that real time clinical data was being collected on the patient.

As a result of this finding, the investigator followed-up with a question to the nurse managers regarding hospital policy on disclosing this information to the patient and family. The shared response was that the patient and family ‘are not routinely told because there is a brief tele-ICU program description mentioned in the ICU admission packet when the patient enters the hospital’ (as per nurse managers). One family members commented that,

“It would have been nice to have had a verbal explanation, or to have been handed an informational brochure”. (Interviewee #8, female)

When asked what it is like to have a family member in the tele-ICU, half of the respondents (n=8) commented that it feels good to know the patient is receiving extra care. The other half (n=8), though, stated that they could not comment claiming they lacked sufficient information. Note participant comment below. No one opposed having a family member in this setting.

“How can I be expected to describe what it is like to have this kind of care if I don’t have the facts about it? I don’t see any differences, but I suppose it must be special or why would they go to all the trouble to put it in place?” (Interviewee #1, female)

When asked to comment on the advantages to this type of care, three-fourths (n = 12) of the total participants stated that there are advantages to this type of care model. Here is one of their comments,

“My brother gets very agitated on the ventilator and sometimes he knocks the breathing tube off, and then these loud, crazy noises go off that sound almost like a fire engine. Now knowing that he is watched 24/7 puts me at ease. Maybe they’ll notice his breathing tube is off before the nurse here.” (Interviewee #16, female)

When asked about the disadvantages to this type of care, a significant number (n = 7) still had too many questions about the tele-ICU to know if there would be any disadvantages. Almost a third (n = 5) could not identify any disadvantages to this type of care. A few participants did voice some issues including concerns over patient/family privacy (n = 2) and one participant expressed worries over why the tele-ICU exists in the first place, stating the following,

“I can’t be sure, but I just wonder if it is because the nurse here may be less experienced or you know....not a critical thinker, and they have to bring someone on board to make up for that. Maybe it is just to help out with timing and scheduling”
(Interviewee #2, female)

See Table 4.5.1 for results associated with questions 1-5 concerning family general tele-ICU understanding.

Table 4.5a Family Source of General Information about the Tele-ICU
 (Questions 1 – 5 of the Interview Schedule)

	n (%)
Q#1 What do you think about the tele-ICU?	
i) ever heard of the Tele-ICU	11 (68.7)
ii) like the concept once explained	16 (100.0)
Q#2 What is your understanding of how tele-ICU works?	
ii) new about this model prior to the patients’ admission	1(6.3)
ii) Have a basic understanding because it was explained to them upon ICU admission	4 25.0)
iii) Have no understanding of the Tele-ICU, nor was it ever explained upon admission to the ICU	11 (68.8)
Q#3 What is it like having a family member in the tele-ICU?	
i) feel good knowing patient in tele-ICU getting extra care	8 (50.0)
ii) could not comment because they didn't have enough information about the Tele-ICU	8 (50.0)
iii) opposed	0 (0.0)

Q#4 Are there advantages to this type of care?	
i) From total (N=16) Agree that yes, there are advantages to this care model.	12 (75.0)
ii) From subtotal (n=11) that never heard of the Tele-ICU, now agree there are advantages to this model	8 (72.7)
iii) From subtotal (n=11) that never heard of Tele-ICU, still need more information before commenting	3 (27.7)
Q#5 Are there disadvantages to this type of care?	
i) Uncertain...still have too many questions about the Tele-ICU to know if there would be any disadvantages	7 (43.8)
iii) Feel there are no disadvantages to this type of care	5 (31.3)
iii) Have concerns over patient/family privacy	2 (12.5)
iv) Worried onsite staff may be less experienced or may lack the expertise/ therefore implementation of remote staff	1 (6.3)

4.4.4.2 How Family-Participants Receive their Need for Information

As stated earlier, there has been some overlap between the participant need for clinical information (this section) and need for information concerning basic tele-function (previous section). As the results are reported it will become evident that the family need for information in the tele-ICU takes on an entirely new dimension.

The next set of questions revolved around the family need for information in the tele-ICU setting. A set of 6 questions were posed to the participants regarding their own experience on this topic. The first question asked “who provides you the most

information about your family member in the ICU, someone from the local staff or the remote staff?” All of the participants (N=16) stated that they received all of their information from the local on-site staff. This is not surprising considering the majority (n=11) were unaware of its existence. See discussion section on this topic.

Next they were asked who is it that may answer any questions you may have and provide you with patient updates. The vast majority (n = 14) stated that they received their information from the nursing staff only; with only a few identifying other staff members, one identified receiving information from both the nurse and the resident doctor in ICU; one stated both the nurse and the attending physician. Not quite half (n =7) stated that they needed to ask the nurse for information regarding the patient. Over a third (n = 6) said that they have patient information volunteered to them by the clinical (on-site) staff. A quarter of the respondents (n = 4) stated they both ask for information and also have information voluntarily offered from the (on-site) staff regarding patient status.

When asked if they are given the opportunity to be introduced to the nurse (or other staff) at the remote hub, to talk to them or ask them any questions, 100% of the respondents stated that they have never been given the opportunity to speak to a clinician at the remote hub in any manner. There is a full patient comment under the assurance section verbalizing that “*it would have been nice to hear the remote voice*”.

Next the family-participant was asked what it is like to listen in on communication between the bedside nurse and the remote nurse. All (100%) of the respondents stated that they have never experienced any type of communication between the nurses onsite and remotely. Similarly, when asked if they get to listen in on

communications between the on-site nurse or doctor and the nurse or doctor from the remote hub, the unanimous response was (N = 16) that they have never had this opportunity. This finding demonstrates that implementation of educational processes is warranted for the clinical staff at both the on-site and remote units.

Lastly, the participants were asked if they feel like they have the opportunity to get all of the information they need from both staffs...here on-site at Worcester and at the remote hub. Once more, all of the respondents stated that all of the information that they receive comes from the on-site staff. And none of them had had the opportunity for any type of interaction with the remote staff. The following participant quote reflects the general group feeling about having no contact with the remote staff:

“I get all the information that I need from the staff here on-site, but now knowing the remote staff is able to look in on us at any time they want, it would be respectful if they would at least introduce themselves to us. Even to set some guidelines...that they are just checking and that the on-site staff will provide us with any patient updates”. (Interviewee #14, male)

The research interview process itself brought the tele-ICU entity to the forefront of our discussion as it relates to the participant need for information. Furthermore, over half of the participants (n=10) felt that not being informed of the tele-care use model at Worcester Hospital concerned them; and in their words, made them feel “*unsettled*”, “*uneasy*”, “*skeptical*”, and “*left with more questions*”.

Table 4.5b How the Family Receives their Need for Information in the Tele-ICU
(Questions 6 – 11 of the Interview Schedule)

	n (%)
Q#6 Who gives you the most information about your family member in the ICU, someone from the local staff or the remote staff?	
i) he onsite staff	16 100.0)
ii) remote staff at the hub	0 (0.0)
Q#7 Who is the person who usually answers your questions? Who provides updates on how your family member is doing?	
Answers questions....	-----
i) From on-site nursing staff only	14 (87.5)
ii) From on-site nurse and resident doctor	1 6.3)
iii) From on-site nurse and attending physician	1 6.3)
Provides updates....	-----
iv) Need to ask staff for updated information re: patient	7 43.8)
v) Have information volunteered from staff	6 37.5)
vi) Both have information volunteered as well as must ask	3 (18.7%)
Q#8 Are you given the opportunity to be introduced to the nurse or other staff at the remote hub or to ask them any questions?	
i) Have not had an opportunity to speak to a clinician at the remote hub in any manner	16 (100.0)
Q#9 What is the communication like between the bedside nurse and the remote nurse?	
i) Have never experienced communication between nurses	16 (100.0)

Q#10 Do you get to listen in on communications between the on-site nurse or doctor and the nurse or doctor from the remote hub?	
i) Have never experienced communication between both staff's in any capacity	16 100.0)
Q#11 Do you feel like you have the opportunity to get all of the information you want from both staff's...here at Worcester and the remote hub?	
i) es. Participants receive information from on-site staff	16 (100.0)
ii) articipants receive information from remote staff	0 (0.0)

4.4.4.3 The Need for Close Proximity to the Patient in the Tele-ICU

The results of this research corroborate previous research findings that the family has a strong need 'to be present' at the critical care bedside of the patient (Engstrom & Soderberg, 2004; Lee & Lau, 2003; Leske & Pasquale, 2003 ; Molter & Leske, 1983; Molter, 1979b; Olsen, Dysvik, & Hansen, 2009).

The first question in this next section has been eliminated since participants did not have to travel because the patient did not have to be transferred to a large tertiary care center to be treated for specialty care. All of the participants (N = 16) said that this situation has not affected their travel since this tele-ICU is fairly close to their home.

When asked to describe what kind of access they have to see the patient, all of the participants (N =16) all responded without hesitation that they have full access to the patient any time, day or night. Although progressive, this policy is not unique to a tele-ICU setting. One respondent characterized her need for close proximity as follows:

“My grandson is so sick, it is important to me to be close by his side. Being at home is horrible. I need to have that physical connection, to lay eyes on him, to touch him and to get information first hand.” (Interviewee #12, female)

The last question regarding the need for close proximity explored what types of care activities the participants get involved in with the patient and if they feel this time is sufficient. Over two-thirds (n = 11) stated that they actively take part in some of the basic care of the patient, such as bathing, oral care, brushing hair, and lotioning. A quarter (n = 4) stated that they are allowed to participate in basic patient care but choose not to do so. For some, this was a purposeful decision. As one spouse caretaker noted,

“I am a full-time caregiver to my husband when we are at home. I am taking a break while in the hospital and letting the nursing staff take care of him. I am content just being by his side”. (Interviewee #7, female)

The remaining participant was not allowed to partake in basic care since the patient was in a medical-induced coma, therefore restricted from undue tactile stimulation that touch may yield. The patient’s grandmother made the following remarks,

“I know I am not allowed to touch him, but it is so difficult to watch his muscles waste away and atrophy. You see, my grandson was very athletic before his accident. I am waiting to do some range of motion so that I can help him...I know that will help him, but I need to wait. As long as I can be with him and see him, I’ll try to have patience”. (Interviewee #12, female)

See Table 4.5.3 for a summary of responses to questions in this section.

Table 4.5c Family Need for Close Proximity (to the Patient in the Tele-ICU)
(Questions 12 – 14 of the Interview Schedule)

	n (%)
Q#12 Are you able to be present at the bedside of your family member since he/she may not have been transferred to another hospital further from your home?	
QUESTION EXCLUDED	----
Q#13 What kind of access do you have to see your family member? Are you able to be with them as much as you would like?	
i) Yes, have full access to patient and able to spend as much time as I would like	16 (100.0)
Q# 14 What kinds of things are you able to do to participate in your family member's care and is this time sufficient?	
i) Actively take part in some of the basic care of the patient, such as bathing, oral care, brushing hair, and lotioning	11 (68.8)
ii) Allowed to participant in basic patient care, but choose not to do so.	4 (25.0)
iii) Not allowed to partake in care for clinical reasons (as per staff)	1 (6.3)

4.4.4.4 The Family-Participant's Need for Assurance in the Tele-ICU

While the family need for assurance remains important, it has taken on additional meaning within the context of the tele-ICU. With the added dimension of the remote staff, it was important to determine the interaction (if any) between the staff and the patient/family. The following question asked the participant if they could see the person who is talking and if being able to see the staff person from the remote site when they are

talking would be reassuring. None of the participants have been able to see the remote staff member as all the camera's within the Worcester Medical System are currently one-way camera's only, meaning the remote staff can see the onsite team, but not vice versa. One participant who was aware of the camera responded,

“The onsite nurse was busy in a code with another patient, but after being interrupted by the remote staff, she came in to my best-friends’ room to address her oxygen saturation which was dangerously low.” (Interviewee #10, female)

The majority (n=15) of the family-participants stated that it would have been very reassuring to have been able to see the remote care provider (nurse and/or doctor) via a monitor in the patient room, while a quarter claimed it would be reassuring to hear their voice. The effect of a 2-way camera that would allow patients, family members, and remotely located staff to visualize and interact with each other has not yet been determined, although it is possible that this would clarify the location of the off-site staff. A 2-way camera would disclose the faces of off-site staff to patients and their family and would serve as a reminder that patient care was coordinated by both bedside and remotely located staff. One participant made the following comment,

“Being able to see the remote nurse would just be another way for me to know they are paying attention to my father. That would be very reassuring.”
(Interviewee #2, female)

The participants were then asked if they were confident that they would be notified of any changes in their family-member's condition and knew how they would be notified. A half of the respondents (n = 8) stated they are confident that they will be

notified if there is a change in the patient's clinical status, while two participants said that they were not confident that they would be called because of an experience they encountered during this admission. One participant's family member/patient had a GI bleed and was not told until she came in to visit him, see her comment below,

“No, I’m definitely not confident that I will be notified...that is why I am always here. I try to spend as much time as I can here so I don’t miss anything. My husband had a GI bleed in the middle of the night on Saturday and I didn’t find out until I came in to visit Sunday afternoon”. (Interviewee #1, female)

Over a third of the participants (n = 6) stated that they were unsure if they would be notified if there was a change in the patient's clinical status.

When questioned about the need for assurance, and if and who they receive it from, the majority (n = 14) felt that they did in fact receive assurance regarding their family member’s illness. One stated that they did not feel assured, and one participant shared that they were "too numb" to even notice if someone was trying to reassure them. A significant number (n = 7) stated that they are reassured by both the physician and the nurse on a consistent basis. Two participants said they received assurance from their family while three noted that they received assurance from both their family and the nurse. Sadly, one participant stated that she receives no assurance and one was uncertain. Table 4.5.4 below illustrates a summary of the family -participant responses regarding the need for assurance.

Table 4.5d Family Need for Assurance (in the Tele-ICU)
(Questions 15 – 18 of the Interview Schedule)

	n (%)
Q#15 What is it like when you hear a voice from the remote center come over the intercom?	
i) I have never heard a voice from the remote hub come over the intercom	16 100.0)
*** Although not a question, some volunteered that they would have liked to hear the remote nurse/doctor voice as it would be reassuring	4 (25.0)
Q#16 Can you see who is talking and do you think being able to see the staff person from the remote site would be reassuring to you?	
i) I could not see remote staff	16(100.0)
Q#17 Do you feel confident that you would be notified of any changes in your family-member's condition? How are you notified?	
i) Yes, confident	8(50.0)
ii) No, not confident	2(12.5)
iii) Unsure	6 (37.5)
Q#18 When you feel you need reassurance, do you feel that you get it? If so, who from? If, not, what suggestions do you have on how things could be done better in this area?	
i) Yes, feel they receive assurance.	14(87.5)
ii) No, do not feel they receive assurance	1(6.25)
iii) Unable to answer ***Stating “to numb to feel anything”	1 (6.25)

4.4.4.5 The Family-Participant Need for Comfort in the Tele-ICU

Although the majority of participants were concerned with their loved one's comfort first, the following set of 4 questions intentionally targeted their own needs. When asked what comforts them most about the type of care the patient is receiving, over two-thirds (n= 11) acknowledged that now that they were aware of the remote staff collaborating with the on-site clinical staff, the realization of the tele-ICU is very comforting to them, with several (n=5) stating that the extra set of eyes and knowledge is important. The below comment is reflective of the theme addressing comfort,

"The extra eyes looking out for him make me feel better" (Interviewee # 13, female)

Other participants did not see the tele-ICU model of care as a comfort to them. One noted that they were not comfortable with the tele-ICU type of care, but rather preferred care by the on-site nurses and their close proximity to the patient. And other one questioned the effectiveness of this type of care saying,

"Could this care really be effective if the nurse or doctor is not physically here? I don't really believe it". (Interviewee #3, male)

One participant mentioned feeling comforted by the consistent relationship with the hospital social worker. Although not specific to the tele-ICU she stated,

"I've developed a good rapport with the social worker that comes around. I didn't like the first person...I think she was just the weekend gal, but the regular one is so

nice. She stops by the room almost every day for just a couple of minutes. It's quite comforting, really". (Interviewee# 9, female)

Conversely, the next question asked what concerned them most about this type of care model. Over half (n = 9) stated that they feel comfortable with this type of care and have no real concerns, with one stating she *"will feel better when my husband is home"*. A small number (n = 3) noted their concerns over the level of privacy with this type of care, all using the same terminology, stating they feel as though 'big brother is watching'. Here is quote reflecting the sentiment,

"Knowing someone is watching is unsettling and quite eerie. It almost feels like big brother is watching...kind of creepy. We should be given a choice as to whether or not we want this type of care. Or at the very least we should be told if they are watching. My real concern is his dignity. I sure hope they don't leave the camera on while he is bathing" (Interviewee #8, female)

A couple participants were concerned about the potential of staff not receiving updated information, hoping that each team works together to provide updates regularly. One participant noted,

Now that I know there are different people taking care of my son, I'm thinking that there may be differing opinions. I just hope they update each other and they agree on treatment. I don't want the team here to do something and the other team has a different plan. (Interviewee #10, female)

The third question in this set, asked about the participant comfort level while visiting or being present with their family member in the tele-ICU. The large majority (n = 14) stated that they felt comfortable while visiting the patient in the tele-ICU, with just one added participant comment as follows,

“I am very comfortable, but would like to be notified of this type of care beforehand”. (Interviewee # 14, male)

The last question on family comfort focused on the participants’ own physical needs in their immediate environment and what could be done to make them feel more comfortable. Over half (n=9) of family participants expressed the need for more comfortable chairs (preferably reclining) as they spent countless hours in and around the patient bedside. Although not unique to the tele-ICU, the physical concerns of the family still exist in their immediate environment. Here are some direct quotes from participants,

“Oh dear let me tell you, we could certainly use a comfortable chair in that room....2 chairs. There should be 2 comfortable chairs in the patient room. We need to stay strong you know. My daughter and I have been camped out here at my grandson’s bedside since the accident. We are from Ohio. We are afraid to even get a hotel room, so we sleep in the waiting room on the couches and shower at the med-school....they don’t know it though. We went home once in 3 weeks to pick up clothing and came right back. We’re not going anywhere”. (Interviewee #12, female)

The availability of a reclining chair or couch in the patient room or in the tele-ICU waiting area would allow family the close proximity needed while fulfilling their own basic sleep needs. Their exhaustion was adding to their anxiety levels and the way in

which they perceived circumstances of patient events. Of the long-term family members (2 families, each > 3 weeks) also voiced the need for “*cleanliness in the waiting area and restrooms*”, and to have “*healthy snacks in vending machines in the waiting vicinity*”. They felt as though their own needs were compromised as they tried to adapt to the hospital surroundings and forced to choose between their own comfort and staying close to the patient.

My niece was rushed to the hospital in the middle of the night and placed in ICU. She has been here for 26 days now, and so have I. It would certainly be helpful if there were a couch, some coffee...even water. Other basic things that come to mind...since you asked...is to have a blanket or pillow available if family is spending countless hours, days and nights here.(Interviewee #9, female)

A significant number (n = 7) said that they are comfortable in the environment stating that it is more about the patient. *See table 4.5.5*

Table 4.5e

Family Need for Comfort (in the Tele-ICU)
(Questions 19 – 22 of the Interview Schedule)

	n (%)
Q#19 What comforts you most about the type of care the patient is receiving?	
i) knowing about collaboration between remote team and on-site team is comforting... 'an extra set of eyes'	11(68.7)
ii) Uncomfortable with Tele-ICU type of care/Prefer on-site nurse only	2 (12.5)
Q#20 What concerns you most?	
i) comfortable with this type of care, no real concerns	9 (56.3)
ii) concerned about the level of privacy for the patient	3 (18.7)
iii) concerned about potential for not receiving information, thinking one team may assume the other team is supposed to provide it.	2 (12.5)
iv) concerned that there may be too many opinions	1 (6.3)
v) concerned about the patient's pain level, hoping remote staff will recognize when there is a need for more.	1 (6.3)
Q#21 How comfortable do you feel while visiting or being present with your family member in the tele-ICU?	
i) yes, very comfortable with this type of care ***extra comment: great, but just notify us when you are watching***	14 87.5)
ii) no, not comfortable	1 (6.25)
iii) unsure	1 (6.25)

Q#22 Are there things that could be done to make you feel more comfortable in this environment?	
i) es, need for comfortable recliner chair (or couch)	9 56.3)
ii) o, comfortable as is	7 43.7)
***A percentage of respondents who have been here > 3 weeks, voiced the need for cleaner waiting area and rest rooms.	4 (25.0)

4.4.4.6 The Family-Participant Need for Support in the Tele-ICU

In chapter two, the literature revealed that the quality of support, rather than the quantity of social support from family is more meaningful (Hupcey, 2001). This section of questioning placed a focus on the participants' perception of support while their family member is a patient in the Tele-ICU. The first question asked about any type of support that the participant may be receiving. All (100%) of the respondents stated that emotional support is essential and that they receive this from family & friends.

To be more specific, the next question asked: who provides the most support during this difficult time?" A large majority (n = 14) explained that support comes from many different people, but mostly from family. Two participants identified receiving support from the nursing staff and two others identified that support for them comes from pastoral care & social work.

When asked if they received support from staff on-site, and if so is there a difference in the level of support between the on-site staff and the remote staff, the vast majority again (n = 14) felt that they received support from the on-site staff of nurses and doctors. Two family members also stated they found support from pastoral care as well; and one family found additional support from social work. Two participants felt that they

did not receive support from the staff. All of the participants said that they do not receive any type of support from the remote staff.

Participants were also asked if they could suggest any ideas on how staff could help them feel more supported. Over half (n = 9) had no further suggestions to offer regarding extra support from staff, while (n = 5) said they would feel more supported if the staff would provide more information regarding the patient status without the family having to seek them out to ask.

Table 4.5f Family Need for Support (in the Tele-ICU)
(Questions 23 – 26 of the Interview Schedule)

	n (%)
Q#23 Please tell me about any type of support that you receive	
i) Essential support from family and friends	16 (100.0)
Q#24 Who provides you with the most support during this difficult time?	
i) The most support comes from family	14 87.5)
ii) Support from nursing staff	2 12.5)
*** Of the total, additional support comes from pastoral care and social work.	2 (12.5)
Q#25 Do you receive support from staff here? Is there a difference in the level of support between the on-site staff and the remote staff?	
i) Yes, from the staff here, including nurses, doctors, pastoral care and social work	14 87.5)
ii) No	3 12.5)

	o, feel they do not receive support from the staff	
iii)	tate no support from remote team	16 (100.0)
Q#26 Do you have some ideas on how staff could help you feel more supported?		
i)	o, no further suggestions	9(56.3)
ii)	ould feel better supported if staff could volunteer patient updates without family having to interrupt them	5 (31.3)

4.4.4.7 The Family-Participant Need for Privacy in the Tele-ICU

This next section of interview questioning stemmed from what is known about family concerns regarding privacy in the Tele-ICU, derived from the pilot study conducted by this investigator. The first question asked the family- participants how they felt about the level of privacy of the patient in the tele-ICU. About two-thirds (n = 10) felt the level of the patient's privacy in the tele-ICU was acceptable while two did not feel the patient's privacy was adequate in this setting. A quarter (n = 4) were uncertain because they were still unsure regarding the circumstances in which the camera is utilized.

Next, they were asked to expand upon what they knew about the camera in the patient's room and to determine how it makes them feel. Over two –thirds said that (n = 11) felt good having the camera in the room as it enhanced the care of the patient. Two participants said that they felt uneasy about the camera. Three said they were unable to

answer the question claiming they did not have enough experience with the camera. One participant made the following comment regarding the camera in the patient’s room;

“I feel really good about the camera in the room. It makes me feel that it is safer for the patient. I think it is a good idea to be notified when the camera is being turned on tough.” (Interviewee # 7, female)

Participants were then asked if they thought their privacy has been respected. Over two-thirds (n = 11) said yes, they felt their privacy was respected, while two said no, they did not feel their privacy was respected with someone watching without their knowledge. Three participants said they were unsure how they felt at the time.

Lastly they were asked if they could suggest additional thoughts on privacy. Three-quarters (n = 12) had no further comments to add regarding privacy. One quarter (n = 4) said they would have liked/expected to be told about this type of care before hand, specifically the camera in the room. See table 4.5.7 for overall results of this section

Table 4.5g Family Need for Privacy (in the Tele-ICU)
(Questions 27 – 30 of the Interview Schedule)

	n (%)
Q#27 How do you feel about the level of privacy of your family member in the tele-ICU?	
i) feel level of privacy is adequate and respected	10 (62.5)
ii) do not feel privacy is adequate or respected	2 (12.5)
iii) uncertain because there is insufficient information	4 (25.0)

Q#28 Tell me about the camera in the patient's room and how that makes you feel	
i) like the camera/enhances patient care	10 (68.7)
ii) feel uneasy about the camera in the room	2(12.5)
iii) unable to answer the question because they had no knowledge of the camera until this point	3 (18.7)
Q#29 Do you feel your privacy is respected?	
i) yes, feel their privacy is respected	11(68.7)
ii) no, feel their privacy is not respected when someone turns a camera on without their knowledge	2(12.5)
iii) unsure how they feel	3 (18.7)
Q#30 Do you have any additional thoughts on privacy?	
i) no, no further comments on privacy	12 (75.0)
ii) would have liked to have been told ahead of time about this type of care, especially with a camera in the room	4 (25.0)

4.4.4.8 Additional Participant Thoughts on the Interview Schedule

When asked if family-participants would recommend the tele-ICU model of care to other family or friends, 100% of the participants said they would recommend this model of care to family or friends who may be in need of ICU care. As the final portion of the interview schedule, participants were asked to comment on any other thoughts

they may have about their family member being a patient in the tele-ICU that was not discussed. The following comments (although no themes were noted) are direct quotes from the study participants:

Table 4.5h Participants Additional Comments

The following individual comments vary widely, and are therefore written freely in no particular order.
There should be a sensitivity class for the nurses
Recommend 1:1 ratio of nurse to patient
Please tell other family members not to be afraid to ask questions of the staff
Family members could use a water cooler
The extra staff watching is a great idea. I'm so glad they are using it here
We need to be informed about it before hand. Maybe a hand-out of some sort
Need complimentary coffee for the visitors (we need help to get through our long nights & days)
Would like to see a case worker earlier on in the process
Patient/family should be given the option for tele-ICU care, it shouldn't be mandatory
Great care
No thoughts
Amazing staff
Need informational brochure
Posters should be in the waiting room describing purpose of tele-ICU & that it is being used here
Need pamphlets
Tell us how this Tele-ICU regulated. Tell us more about it.
Wonderful care, thank you to the staff

Really could use a comfortable chair so that family could fall asleep nearby the patient

I think the Tele-ICU must help to decrease malpractice

4.5 Summary

The results of the Interview questioning aimed at exploration of Family Needs in the tele-ICU have been presented in this chapter. The schedule was divided into 8 sections as follows: 1) need to understand basics of tele-ICU model of care, 2) need for information, 3) need for close proximity, 4) need for assurance, 5) need for comfort, 6) need for support, 7) need for privacy, and 8) any additional comments from the study subjects. All categories were answered as completely as possible by each participant.

While the need for information and close proximity continued to be of greatest importance to the family member-participants regarding the patient, almost 3/4 (n=11) of the sample was never informed of the tele-ICU model of care. They have never heard of the term tele-ICU, nor have any understanding at all pertaining to its basic function. This finding led to many discussions and additional questions, some of which this researcher could not answer. Once the basic concepts were explained, twelve of the subjects felt there were major advantages to this type of care, including enhanced staffing, increased patient safety and better quality of care. Many of the questions arose when it came time to comment on the care model disadvantages; as close to half (n=7) still had outstanding questions relevant to the tele-ICU purpose and function. A comment from one of the participants states the family feeling of conflict quite clearly;

“I have never heard of a tele-ICU. The technology doesn’t surprise me though. The surveillance of the patient is interesting and has so many good points for the patient. My father had a stroke and it is hard for him to call for help, so I like someone watching over him. At the same time though, I have so many concerns, like... we should have been told about this; we may be recorded and I’m not sure what happens to that information; and then of course there is the question of privacy. I think we should be better informed.”

(Interviewee #14, male)

Noteworthy finding concerns that fact that 100% of the participants were never introduced to, or spoke to a staff member at the remote hub, nor have they experienced any kind of conversation between both the on-site staff and the remote staff. A strong majority (n=14) of the subjects felt reassured of the level of care being provided, but this assurance stems 100% from the on-site staff.

The need for information was important, which was generally stated throughout participant comments (throughout this chapter) and exhibited in the family-participant demeanor, body posture and tone of voice. Participants stated that all 100% of their patient information comes from the on-site staff, while five of participants voiced the need to have staff volunteer patient information updates, rather than family having to seek out staff and interrupt them. The family need for close proximity to patient is being fully met as 100% of the respondents state they have 24 hour a day/ 7 days a week full access to the patient. Regarding the privacy factor, (n=11) felt good about having a camera in the room and felt that their privacy was respected, while (n=3) felt uncertain and (n=2) did not like the idea and felt their privacy has been compromised.

Many participants placed their own comfort needs below their need for information, close proximity and assurance (as referenced in the comments). However, they did articulate the need for more comfortable chairs and basic needs while they spend countless hours at the patient's bedside and waiting areas. In sum, 100% of the study participants said that they would recommend this type of tele-ICU care to someone else.

CHAPTER 5

DISCUSSION

5.1 Introduction

To date there are no known research studies related to the family perception of the tele-ICU outside of the pilot study by this investigator. Before nursing can consider family needs within this new model of care, it was necessary to explore and understand the importance of the family experience in this setting.

The context of this final chapter presents a discussion of all study findings, divided into the following sections: 1) a discussion of the findings within the framework of the family stress theoretical model using the association of study outcomes with each of the seven themes for family need to include, the need for information, close proximity, assurance, comfort, support, privacy and the need to understand basic tele-ICU function as determined by the CCFNI and the family-needs pilot study; 2) all emerging themes; 3) the implications for nursing practice, research, and policy; and lastly, 4) all study limitations.

5.2 Discussion of Study Outcomes within the Family Stress Theoretical Model

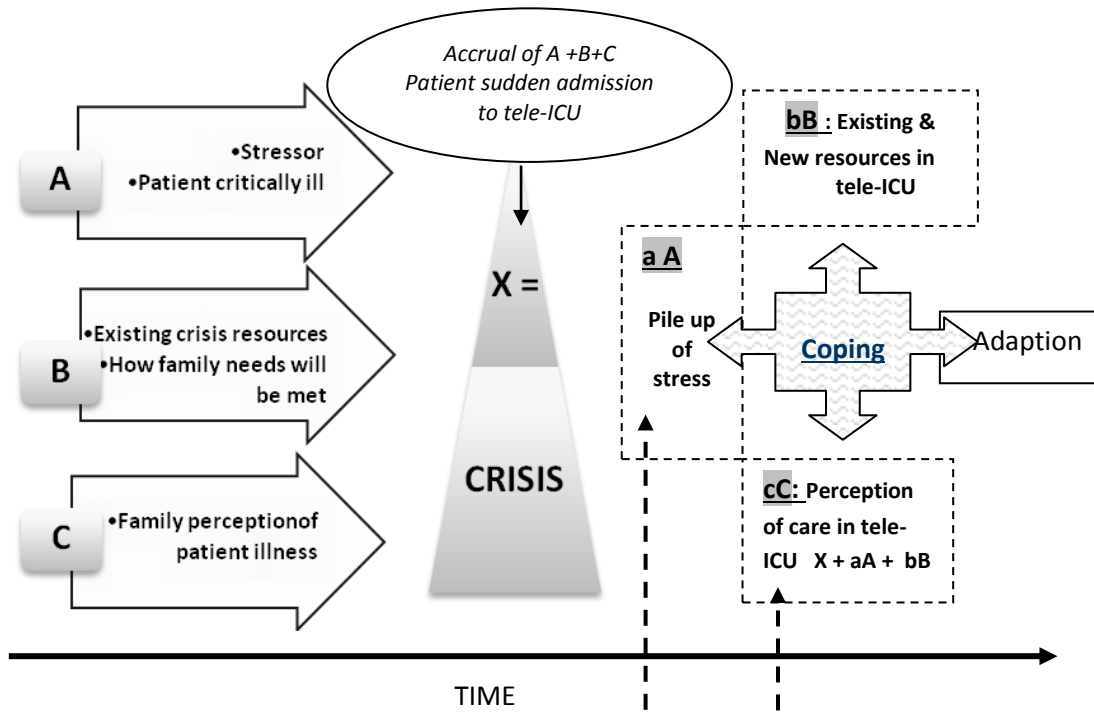
The family stress theoretical model was used in this study to guide the exploratory questioning of family members in the tele-ICU. Specifically, it was the hospital acute care phase within the healthcare continuum and subsequent family experience during this time (related to the family needs in the tele-ICU environment), that has been examined. Utilization of this theory helped to convey meaning to the participants expressed needs,

with the aim to identify and appreciate the tele-ICU family resources, needs, and resolved-needs that have been unknown until this point. The experiences expressed by the family provided insight that may potentially be used to guide mediation of future needs of family. Families facing a stressor event, such as critical hospitalization of a loved-one, experience various phases of adjustment; represented by a range of processes in which the variables of the initial stressor, existing resources, family perception, and the reality of the crisis interact. (Figure 5.1)

As a primary result of this study we have learned that improvements are needed in communication mechanisms, content, and frequency of information. This finding is inherent to the tele-ICU, as this need for information expands beyond the borders of solely the need for clinical information concerning the patient. Rather, it traverses several other categories affecting the family's perception of assurance, comfort, privacy and unit function. Subsequently, it is evident that communication is needed about the role of the tele-ICU in patient care in order to ensure that patients' family are informed about the tele-ICU in the most appropriate and timely manner.

Figure 5.1

Association of Study Outcomes within the Family Stress Theoretical Model



- Major findings of resources in tele-ICU that may affect family coping*
- 68.75% (n=11) have no understanding of tele-ICU model, purpose or function
 - 100% (N=16) family have not had been introduced nor have had any sort of communication with remote caregiver
 - 43.75% (n=7) family have many questions regarding this type of care
 - 100% (N=16) receive information from on-site staff only
 - 100% (N=16) able to be in close proximity to loved one, without restrictions
 - 68.75% (n=11) able to participate in patient care as desired
 - 94% (n=15) state would have been reassuring to hear voice from remote caregiver
 - 50% (n=8) said they were not assured nor confident they would be notified of a change in patient status
 - 56.25% (n=9) re: comfort; families are uncomfortable with physical environmental attributes while visiting patient
 - 87.5% (n=14) receive support from on-site nurses & doctors
 - 62.5% (n=10) feel patient privacy is protected
 - 68.75% (n=11) feel good about camera in patient room; enhances care
 - 31.25% (n=5) are uncomfortable or do not have enough information regarding camera in patient room

5.2.1 Discussion of Findings Related to Family Informational Needs

The previous work of Molter and Leske's CCFNI, and various other research studies which have validated the original findings using the CCFNI, that the need for information is paramount to the family member, are also corroborated in this study (Leske, 1986b; Molter, 1979b; O'Malley, Favaloror, & Anderson, 1991; Molter, 2003; Lee & Lau, 2003). While the family's primary need is for information, results from this exploratory study confirm that patients' family members have varied informational needs regarding the tele-ICU; with the primary concern focused on the lack of information directly related to how the remote monitoring system worked, and general communication with the remote staff. When asked to describe their basic understanding of the tele-ICU purpose, just over 2/3 of the participants 68.75% (n=11) responded that they were unaware of this existing model of care. This new piece of information for the family confounded their understanding of the type of care being provided. However, this finding is somewhat consistent with results from the pilot study in which 66.1% (n=127) family member's surveyed from six different hospital tele-ICU's indicated that they were not informed upon admission to the tele-ICU, and therefore unaware the patient was in a tele-ICU environment until they experienced the interaction between the on-site and remote staff (Jahrsdoerfer and Goran, 2013). The difference between this current study and the pilot study is the actual voice interaction of between, nurse, physician, patient, family, and the on-site nurse that occurred in the pilot study, as opposed to no interaction to report at the Worcester site.

One family-participant was familiar with the concept of care prior to her husband's admission to the tele-ICU. Only 1/4 (n=4) of family members indicated that

they had been informed upon admission of the tele-ICU. Yet this minority reported receiving a partial explanation by the staff stating ‘there is a camera in the room in which a physician will check in on you from time to time’, with no other follow-up reported.

As a result of this finding, the investigator followed-up with a question to the nurse managers regarding hospital policy on disclosing this information to the patient and family. The shared response was that the patient and family ‘are not routinely told because there is a brief tele-ICU program description mentioned in the ICU admission packet when the patient enters the hospital’ (as per nurse managers).

5.2.1.1 American Association of Critical Care Nurses (AACN) Tele-ICU Guidelines

According to the nursing practice guidelines established by the American Association for Critical Care Nurses (AACN) in 2013, there are essential elements of care that the remote nurse is responsible for. Guideline #1 specifically addresses that tele-ICU nurses and nurse-leaders “must establish and sustain an environment that promotes effective communication, collaboration, and collegiality to ensure optimal quality outcomes” (AACN, 2013). Pertaining to patients’ families, the remote nurse must create policies to standardize tele-ICU procedures. These include but are not limited to: virtual rounding; patient and family communication and education; monitoring and response to alerts and alarms; management of bedside emergency situations; and escalation process to address real-time care concerns (AACN, 2013).

Virtual-rounding and communication between the remote nurse, patient and family members has been identified as an essential practice guideline for nurses. It is the experience of this researcher, who has consulted in over different hospital¹⁰ tele-ICU’s,

to have witnessed firsthand the exchange of communication with the remote staff, the on-site team, the patient and the family members.

Regarding this study, the lack of awareness experienced by the family regarding the program operation, although listed in the fine print of a hospital admission packet, raises many questions concerning the patient-family rights to be informed, and the manner in which the information is presented, with sensitivity to family needs at this crucial, anxiety provoking period.

There was a remarkable consensus from all 16 respondents in which they had never been introduced to the remote staff, or experienced any exchange of communication themselves, or between the on-site and remote staff. This finding demonstrates that implementation of educational processes is warranted for the clinical staff at both the on-site and remote units. It also raises the possibility that family members may have been unaware that the tele-ICU staff were located off site and reflects a potential misunderstanding among family members about staffing related to the tele-ICU model of care. Notable however, is the fact that 100% of the participants did receive necessary clinical patient updates from the on-site staff. Of the total participants (N=16), not one interaction was initiated by the remote staff, nor did family-participants experience any communication between the on-site and remote teams. These findings regarding the family need for information suggests the need for more timely, organized, and proactive communication strategies to inform patients' family members about this novel technology. The promotion of open conversation and family interaction with members of the patient's health care team is crucial for a positive family experience (Soderstrom, Saveman, Hagberg, & Benzein, 2009).

The research interview process itself brought the tele-ICU entity to the forefront of our discussion. Furthermore, over half of the participants (n=10) felt that not being informed of the tele-care use model at Worcester Hospital concerned them. This added concern or 'pile-up' (figure 5.1) of stress may have a contrary effect of the family.

When meta-paradigm assumptions are applied to this situation of 'person-family', it is evident that the family has encountered hardship and transition as an unavoidable part of the patient's critical illness (R Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). The fact that the need for information concerning the full care model was not revealed to family members means that the person-family need was not fully realized by the staff. Concerning the meta-paradigm of 'health', the family's state of balance is determined by resiliency or the ability of the family to respond to and ultimately adapt to the circumstances and crises-events encountered (Hill, 1949, McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). Family adaption to the tele-ICU could have been simplified had an explanation been provided about its function. The meta-paradigm of 'nursing' moves beyond promotion of family health, to supporting arriving at a realistic expectation of how the family fits into the current critical situation (Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). Family adjustment to the environment could have been simplified if both on-site and remote team collaboration were explained. The meta-paradigm of 'environment' is viewed as an open system that constitutes both internal and external factors that positively influence or threaten the well being of the family (Hill, 1949; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983). Family adjustment could have been simplified had an explanation been provided about the function of the camera in the patient room.

An accurate understanding of the tele-ICU, including the role of the remotely located staff in the monitoring and care of the patient, might enhance family perceptions that patients are receiving enhanced care and also more effectively respond to family member informational needs. Therefore, we can conclude that communication between family members and the health care team is essential.

5.2.2 Discussion of Findings Related to the Family Need for Close Proximity

The family need for close proximity to the patient is important as documented in the literature (Bijttbier, et al., 2001; Hupcey, 2001; Jamerson, et al., 1996; Kleinpell & Powers, 1992; Maxwell, et al., 2007). This identified family need continues to be an essential need in the tele-ICU setting according to the results of this study. However, the construct of this tele-ICU as it relates to distance is somewhat different than described in the earlier chapters. The geographical coverage area does not span hundreds of miles, but rather several miles. The inherent use-model is the same in that expert staff is coaching and collaborating with the onsite staff to benefit positive patient outcomes. For the purposes of this study it means that the investigator was unable to elicit specific data regarding what it is like for families who receive this type of care in remote parts of the country. The American Telemedicine Association (ATA) is in the process of establishing 2014 guidelines for hospital administrators, physician and nursing leadership, as well as informatics/technical support. The concept of telemedicine in the ICUs is evolving to varied use models. The core concepts remain the same however.

Participants spoke of the importance to be close to their loved one. Of the family-participants, 100% reported that this need was being met, as they have had full access to be with the patient at any time of day or night. This consistent response resonated across

all tele-ICU's and family-participants. This need is fully being met and would constitute bonadaptation within the theoretical model.

The presence of family is beneficial to the patient's well-being and physical condition, and should be supported (Marsden, 1992). Other investigators have also concluded that the ability for the family to be at the patient's bedside through the course of a critical illness and hospitalization enhances coping responses by the family (Patterson, 2002; Soderstrom, Saveman, Hagberg, & Benzein, 2009). Over two-thirds of the family participants actively took part in some form of basic patient care, such as bathing, oral care, brushing hair, and lotioning, while a quarter of family member's although able, chose not to participate in basic patient care. This is an important fact to take notice of, as referenced in chapter 4, this particular respondent was the sole caregiver at home, so has decided to use her husband's hospitalization as a chance for her to rest, to regain her energy, and just be present with him.

Statements made by family members highlighted throughout these previous chapters, concur with research that has been established, asserting that simply 'being with' patients enabled family members to remain connected with their loved one, through the historical, personal ties and special affinities that bind them as family (Taylor, 1994; Walters, 1995). Therefore, the need for close proximity to the patient is being met and represents a theoretical level of adjustment.

5.2.3 Discussion of Findings Related to the Family Need for Assurance

While the family need for assurance remains important, it has taken on additional meaning within the context of the tele-ICU. The majority of the family-participants

stated that it would have been very reassuring to have been able to see the remote care provider (nurse and/or doctor) via a monitor in the patient room, while one quarter stated it would be reassuring to hear their voice. The effect of a 2-way camera that would allow patients, family members, and remotely located staff to visualize and interact with each other has not yet been determined, although it is possible that this would clarify the location of the off-site staff. A 2-way camera would disclose the faces of off-site staff to patients and their family and would serve as a reminder that patient care was coordinated by both bedside and remotely located staff. An accurate understanding of the tele-ICU, including the role of remotely located staff to provide patient care, might enhance family member perceptions that patients are receiving quality care and also more effectively respond to the families informational needs. Information provided by ICU staff about these issues at the time of admission and during patients' stay in the tele-ICU may address these informational needs and may also promote the development of a therapeutic alliance between caregivers and patients' significant others.

5.2.4 Discussion of Findings Related to the Family Need for Comfort

Family members generally rank their own need for comfort below their need for information, close proximity and assurance (Bouman, 1984; Daley, 1984; Leske, 1986; Norris & Grove, 1986; Price, Forrester, Murphy, & Monaghan, 1991). Even when family members spend extended periods of time in and around the ICU, they consistently regard information, assurance, and proximity needs as most necessary, putting off their own need for support and comfort (Freichels, 1991). A study by Jamerson and colleagues (1996) discovered that there are 3 stages of sequential behavior of family when a loved one is admitted to an ICU: first was the theme of hovering, which meant that until such

time family could move past their own anxiety and uncertainty, they found themselves in a cursory movement of hovering around the ICU; secondly was the stage of information-seeking (importance discussed in the previous section); and the last stage in the process involved an awareness of their own needs which the researchers called resource-gathering. After the initial shock subsided, the family became aware of their surroundings in the ICU, and therefore of their own comfort needs. It is this last finding that will be addressed here (Jamerson, Scheibmeir, Bott, Crighton, Ruthellyn, & Cobb, 1996).

Once the tele-ICU model was described to them by the investigator, over half of the participants felt like the extra clinical expertise brought them a whole new level of comfort. Some described it as ‘an extra set of eyes’. Less than a quarter of the family members though were concerned about the level of privacy with this type of care referring to the saying ‘big brother is watching’. When asked about their feelings, they felt they simply needed more information.

The interpretation of these results concludes that well over half of the respondents felt comforted knowing about the remote team working in conjunction with the on-site team to care for the patient. Therefore, this particular group of family participants has adjusted well to this factor variable within the theoretical model of tele-care in the ICU. However, the remaining family-participants (n=7) expressed some anxiety and discomfort regarding this type of care. Specifically identified were the feelings of “*not knowing enough about the tele-ICU*”, “*wondering if this kind of care is necessary*”, and “*question tele-ICU effectiveness*”. Therefore, their comfort needs were not fully being met within the theoretical model. This finding may be averted in the future, as clarification and education by the staff may be enough to comfort family members.

The other comfort need strongly expressed was more tangible as it involved the family's immediate environment. Over half of family participants expressed the need for more comfortable recliner chairs as they spent countless hours in and around the tele-ICU. While this concern is not unique to the tele-ICU, family concerns still exist in this environment. The availability of a reclining chair or couch in the patient room or in the tele-ICU waiting area would allow family the close proximity needed while fulfilling their own basic sleep needs. Their exhaustion was adding to their anxiety levels and the way in which they perceived circumstances of patient events. Of the long-term family members (2 families, each > 3 weeks) also voiced the need for cleanliness in the waiting area and restrooms, and to have healthy snacks in vending machines in the waiting vicinity. They felt as though their own needs were compromised as they tried to adapt to the hospital surroundings and forced to choose between their own comfort and staying close to the patient. Often times they compromised their own needs. While this tangible need can be met, the process would translate to an increased capital budget for the critical care areas of the hospital. Identification of this family experience is simply the first step in making the staff aware of the family expressed need for comfort in this area.

5.2.5 Discussion of Findings Related to the Family Need for Support

Family need for support remains essentially unchanged within the context of the tele-ICU. All family members stated the importance of support and the need to feel as though they are not facing this family crisis on their own. The vast majority (n=14) of respondents stated that support came mostly from their family, friends and community and that they received support from the on-site staff as well. For this population, their need for support has been met. As for the remaining 2 participants who did not feel

supported, their coping skills to this critical family situation may be compromised, yet may be reconciled simply by staff awareness. A clear example comes from almost 1/3 (n=5) of family participants who stated they would feel better supported if the staff would initiate a brief dialog with them concerning patient status, rather than feeling as though family is a burden to the staff. One participant stated that would have liked to have been asked if I would like to meet with pastoral care or social work early in the process. If the family experience in the tele-ICU has been perceived as overwhelming, or produces a personal and/or family hardship, interdisciplinary assistance is and must be made available. Family doesn't always reach out to staff. In the case of interviewee #10, this investigator encouraged her to tell the nurse of her need to meet with either pastoral care or social work so that she could share her concerns, in hopes to reduce her anxiety and help her to cope with the situation.

5.2.6 Discussion of Findings Related to the Family Need for Privacy in the tele-ICU

While about two-thirds (n=10) of family-participants felt their privacy has been respected and therefore benefited by this need being met. The remaining third (n=6) of families stated that they felt as though their privacy needs were not necessarily being met, as they were unaware when someone at the hub would periodically turn the camera on to watch the patient. As one participant verbalized her concerns,

“I like the concept. I just feel we should be notified when the camera is coming on. I think that is my husband's right, and my right too”. (Interviewee #8, female)

For the 6 family participants in this study, this added concern of the unknown or ‘pile-up’ of stress indicates that their privacy needs are not being met. As with the other factors studied, this need can be mitigated through process changes such as educational pamphlets, brochures, orientation, remote staff introductions, conversation, 2-way cameras, and the use of an alert or bell when the camera is going on.

5.3 Summary of Implications of Findings

The previous section presented the implication of findings of emerging data regarding the tele-ICU as it is associated with the existing family needs for information, close proximity, assurance, comfort, support, knowledge of tele-ICU function, and privacy. There is an overarching emerging theme from this study that is recurring through 4 out of 5 existing need factors (excluding close proximity). Most striking in the findings was the unexpected lack of knowledge by the family members of the existence of the tele-ICU and knowledge of its purposes or how it worked. This need for information is broader and more complex in nature than solely the family need for clinical patient information. Rather there is a fundamental need to understand this unique model of care, including its clinical providers (on-site team as well as remote team). This investigator is not certain whether to call this a theme or need for ‘awareness’ or ‘knowledge’ or even the need for ‘remote-communication’ in the tele-ICU. However, this observational finding is characteristic of a tele-ICU, and therefore warrants more detailed education with regard to the family informational needs. This need of awareness and function of the tele-ICU affects and permeates the family’s level assurance, their knowledge, comfort, support, and privacy needs. A factual understanding of the tele-ICU, including the role and collaboration of remote staff, might improve family perceptions that patients are

receiving quality care; therefore meeting family needs. In meeting these family needs, the level of assurance, comfort, support and questionable privacy, will be diminished.

5.4 Implications for Nursing Practice and Future Research

As the tele-ICU model of care is more broadly implemented, there will be a mounting need for nursing research to support the development of communication strategies and content to overcome barriers imposed by the remote model. Further research is needed to identify and evaluate strategies to inform and educate patients' families about the tele-ICU. Explicitly, studies are needed to clarify the appropriate types of information desired by family members about the tele-ICU, including information that addresses their right to know of its existence. In addition, a basic orientation of family members to the tele-ICU is warranted, so they understand the patient is being supervised via audio-visual remote monitoring; which was the topic mentioned most frequently by family in this study. Other future studies may examine the need for the remote nurse to introduce themselves to the patient and family, and to measure the family satisfaction with regard to their comfort and reassurance. The Joint Commission on 'Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care' suggests beginning the patient-provider relationship with an introduction. A simple introduction by all staff to the patient and their family can demonstrate sensitivity to the patient-family needs and preferences by explaining his or her role on the care team. Furthermore, JCAHO recommends that all members of the care team must in fact introduce themselves to the patient and explain their role in the care process (JCAHO, 2010).

Future studies might also examine variations in satisfaction with care between family members who have a loved one receiving critical care via remote monitoring compared with traditional models of ICU care to determine if the tele-ICU is associated with differences in satisfaction with quality of communication about such a system. Future research might also consider assessment of the demographic characteristics of study respondents and evaluate the effect of these variables on family member informational needs regarding the tele-ICU.

5.5 Implications for Policy

The American Telemedicine Association (ATA) is in the process of establishing 2014 guidelines for hospital administrators, physician and nursing leadership, and have included results of this researchers pilot study as practice guidelines for clinical education for families. The results of this current study concur with original findings that over two-thirds of families were unaware that the patient was in a tele-ICU. This finding strengthens the existing knowledge that there is an extensive need for patient-family education, and that standardization of tele-ICU policy is warranted.

The findings from this study may directly affect hospital reimbursement when related to new federal regulations. The Affordable Care Act, often referred to as ‘Obama Care’, is a pay-for-performance measure that ties hospital reimbursement to consumer satisfaction by measuring responses to a survey questionnaire regarding how well hospitals are serving their patients. This instrument is called the ‘Hospital Consumer Assessment of Healthcare Providers and Systems’ (HCAHPS), (Robinson and Cook, 2010). The objective of the HCAHPS initiative is to implement a standardized

instrument for data collection methodology which will measure the patient-family perspectives on hospital care. The scored results of this instrument determine the hospital's level of reimbursement. There are several factors on the questionnaire that reflect the patient-family perspectives on care, in which several of them directly relate to the factors measured and discussed in this study. Although this study found that there was no interaction of family with the remote staff, it is in fact this very finding that could affect the hospital HCAHPS outcome and diminish their level of reimbursement. These factors specifically encompass; patient-family communication with nurses, patient-family communication with doctors, responsiveness of hospital staff, cleanliness of the hospital environment, and explanation of care. HCAHPS provides a national standard for collecting and publicly reporting patient-family perspectives of care, enabling valid comparisons to be made across all hospitals. Mention of HCAHPS here is important, because it is an actual tool that the hospital in which this research study was conducted will be required to give their tele-ICU patient-families. This investigator does not know how or if the family participants will influence hospital outcomes in this area. Each patient-family in this study will be mailed an HCAHPS survey. If the family-participants, along with the patient were to answer the survey the same way in which they answered the interview schedule, that significant information was not transparently shared regarding the type of care the patient was receiving, the hospital would take a direct, measurable strike with implications for quality of care provided. The emphasis serves as one realistic measure of how this family experience in the tele-ICU may affect policy. Therefore, the incentive to implement processes, educate staff, and strengthen

communication policies between the on-site and remote staff with the patient and family are not only timely, but imperative.

5.6 Study Limitations

Several limitations should be considered when interpreting the results of this study. First, the study was conducted within one health system, with 3 units that utilized the same standard operating procedures. It would be helpful to broaden the scope of research to include multiple hospital systems in varied geographical locations to determine if the outcome would differ in significance.

Secondly, although a convenience sampling was utilized, the participant demographic mix was quite homogeneous; with the majority of participants being women, and the fact that all participants were Caucasian. Again, this was not planned, but rather the natural sampling during the data collection phase. It would be helpful to conduct a similar study in an urban area using a diverse cultural population to determine if responses would differ.

The third limitation noted was that interviews were conducted while patients were in the tele-ICU, and this action may have increased the likelihood that answers were influenced by the emotional state of the family member. It is feasible that higher levels of anxiety and distress were associated with a decreased ability to recall having been informed about the tele-ICU or may have affected family perceptions of the impact of the tele-ICU on the patient. Conversely, collection of this information while patients were receiving care in the ICU has the potential to yield more accurate assessments of family perceptions about the tele-ICU. However, the high acceptance rate to participate in the

study indicates that family members are willing to talk about their experiences, even at such a high anxiety time with a loved one in the ICU.

The fourth limitation noted was that formal efforts to establish the reliability and validity of a tele-ICU instrument were not undertaken because this was an exploratory study intended to elicit views and opinions from participants regarding care in the tele-ICU. However, the phenomenon of the family experience in the tele-ICU established from this study may serve as a basis for future investigations. It was not possible to use an existing survey because there are no known validated instruments that assess these issues among family members with loved ones receiving care in the tele-ICU. As research efforts expand to address issues of communication regarding the tele-ICU between on-site and off-site clinical staff with patients and their family, it will be essential to develop and evaluate reliable, valid assessment instruments.

Finally, this study excluded family members who were unable to read and speak English, and results cannot be generalized to those for whom English was not their primary language. At the conclusion of the study, only one family member declined to participate in the interview schedule because of a language barrier. Additionally, the level of participant education was not measured. It is conceivable that such variables could influence responses to the survey questions, particularly those associated with perceptions of the tele-ICU.

5.7 Conclusion

We know that families have specific needs when a loved one is critically ill in the intensive care unit (ICU). The complexity of the tele-ICU adds another dimension to patient-family care, requiring nurses to have appropriate knowledge of family member experiences in order to meet their needs. This study bridged the gap in nursing knowledge by identifying family needs in the tele-ICU environment through exploratory inquiry.

In particular, this study identified significant breaks in communication between the tele-ICU staff and patients' family. Although once informed about the tele-ICU existence and purpose (by this investigator), perceptions of the tele-ICU model of care were generally favorable, with 100% of participants stating they would certainly recommend this type of care to someone else. Yet a study limitation leaves us with the concern, asking if this break in communication is specific to this hospital, or common to all tele-ICUs? The pilot study offered a paradoxical finding regarding tele-communication strategy, as it was common practice or 'tele-etiquette' for the staff, patient and family to communicate with each other multiple times during each shift. Large scale inquiry is needed in this area, with sufficient quality nursing practices to be shared and implemented where needed. Improved comprehension of the families' understanding of the role of the tele-ICU in the care of critically ill patient may support their informational needs.

This study examined the hospital acute care phase within the healthcare continuum and subsequent family adaptation during this time (related to the family needs in the tele-ICU environment). Application of the Family Stress Theoretical Model

was used to determine the identified needs for information, close proximity, assurance, comfort, support; privacy and the need for basic understanding of tele-ICU function. Utilization of this theory helped to convey meaning to the participants expressed needs, with the aim to identify and appreciate the tele-ICU family resources, needs, and resolved-needs that have been unknown until this point. The experiences expressed by the families will provide insight that may potentially be used to guide future need-based interventions of family.

As a result of this study we have learned that improvements are needed in communication mechanisms, content, and frequency of information about the role of the tele-ICU in patient care in order to ensure that patients' family are informed about the tele-ICU in the most appropriate and timely manner.

APPENDIX A

LETTER OF INTRODUCTION

Dear Family Member or Significant Other,

Please allow me to introduce myself. My name is Mary Jahrsdoerfer and I am a student at the University Of Massachusetts Amherst College Of Nursing. I am currently completing requirements for my PhD, doctoral degree in nursing. I am inviting you to take part in a brief research interview which will take approximately 45-50 minutes (or as much as needed) of your time. The purpose of this study is to find out what your perceptions are as a family member with a patient/loved one in the ICU and to determine your understanding, feelings and needs about the tele-ICU arrangement and the remote care team who speak through the cameras in the patient room. I will use your feedback to better understand how to provide the best care for future families in the same situation. 'Family' can be defined in many ways, but for this study, 'family' is whomever the patient says is important to his/her getting better.

Please note that I will be using a tape-recorder so that I do not miss or misinterpret anything you say. All recordings will be erased once the data are transcribed.

I would like to offer my sincere thanks for your participation in this study. As you spend this time waiting, please remember to take care of yourself as well!

Sincerely, *Mary Jahrsdoerfer*

APPENDIX B

CONSENTFORM

Consent Form for (Audio-recorded) Participation in a Research Study University of Massachusetts Amherst

Faculty Sponsor: *Cynthia Jacelon*

Researcher: *Mary Jahrsdoerfer, Student Researcher*

Study Title: *Needs of the patient's family in the hospital Tele-ICU*

1. WHAT IS THIS FORM?

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate in a brief interview. We encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

2. WHO IS ELIGIBLE TO PARTICIPATE?

Any family member or significant-other of the hospitalized patient in the Tele-ICU may participate. Subjects must be at least 18 years old to participate and must speak English.

3. WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this research study is to gather more information from family members and significant others regarding their feelings, and perceived needs in the Tele-ICU setting, so that the clinical staff can better meet these needs for others in the future.

4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?

The interview process will be conducted in the ICU waiting area or a place nearby and will take approximately 45-50 minutes.

5. WHAT WILL I BE ASKED TO DO?

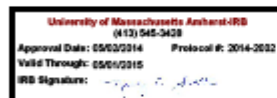
If you agree to take part in this study, you will be asked to answer approximately 40 questions related to your experience as a family member/significant other in the Tele-ICU. Your answers will be audio recorded. You may skip any question you feel uncomfortable answering.

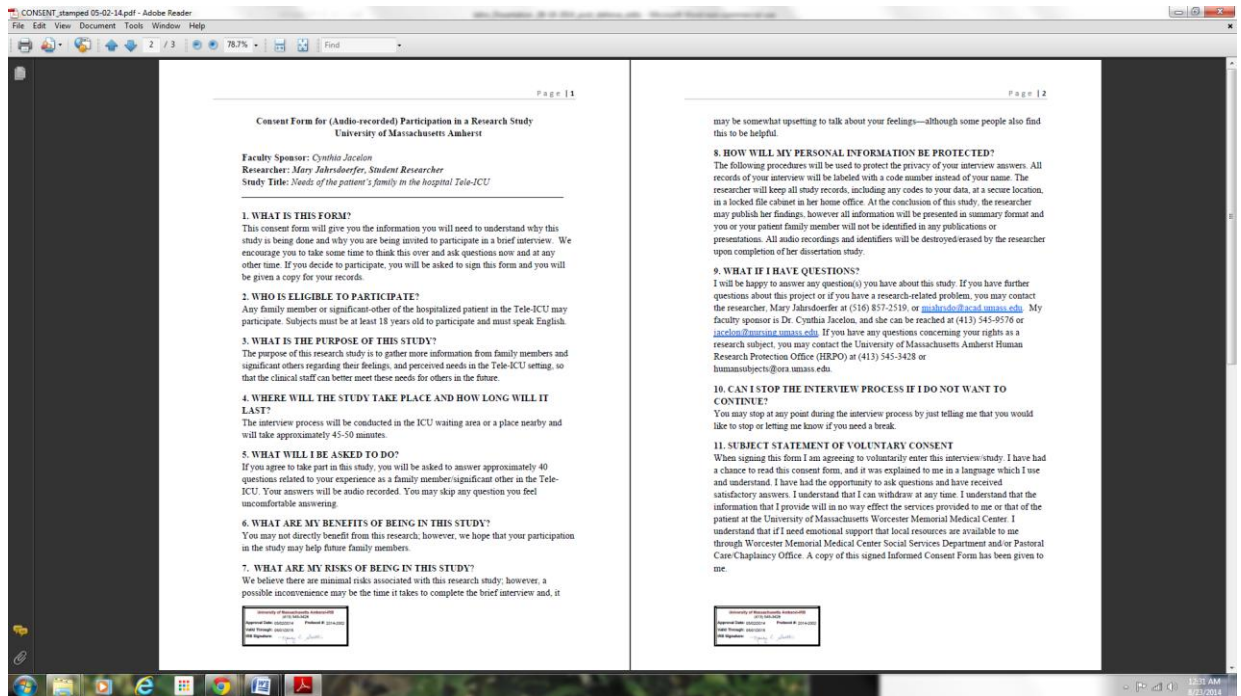
6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?

You may not directly benefit from this research; however, we hope that your participation in the study may help future family members.

7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?

We believe there are minimal risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the brief interview and, it





8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?

The following procedures will be used to protect the privacy of your interview answers. All records of your interview will be labeled with a code number instead of your name. The researcher will keep all study records, including any codes to your data, at a secure location, in a locked file cabinet in her home office. At the conclusion of this study, the researcher may publish her findings, however all information will be presented in summary format and you or your patient family member will not be identified in any publications or presentations.

9. WHAT IF I HAVE QUESTIONS?

I will be happy to answer any question(s) you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Mary Jahrsdoerfer at (516) 857-2519, or mjahrsdo@acad.umass.edu. If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

10. CAN I STOP THE INTERVIEW PROCESS IF I DO NOT WANT TO CONTINUE?

You may stop at any point during the interview process by just telling me that you would like to stop or letting me know if you need a break.

APPENDIX C

PARTICIPANT DEMOGRAPHICS

to be obtained at time of interview

Code # 000	
Instruction: Please indicate your response inside the box against each item.	
1. What is your age?	<input type="text"/> years old
2. Age of the patient?.....	<input type="text"/>
3. Your Gender.....	Male <input type="checkbox"/> Female <input type="checkbox"/>
4. Your Relationship to patient? _____	
5. How many days has the patient been in the ICU?	<input type="text"/>
6. Have you ever been a <i>visitor</i> in the tele-ICU environment before this?	Yes... <input type="checkbox"/> No <input type="checkbox"/>
7. Have you ever been a <i>patient</i> in the tele-ICU environment?	Yes... <input type="checkbox"/> No <input type="checkbox"/>
8. Has your loved one ever been a patient before in the tele-ICU?	Yes <input type="checkbox"/> No <input type="checkbox"/>

APPENDIX D

INTERVIEW SCHEDULE: CRITICAL CARE FAMILY NEEDS INVENTORY (MODIFIED) EXPLORATORY QUESTIONS

The Tele-ICU method of care is fairly new and as a result we would like to know what the families think and how you feel about this way of caring for very sick patients.

Table 3 .2

Interview Schedule Inter-relatedness with findings from CCFNI and Pilot Study

General Information -- Need to understand basics of tele-ICU model of care

1. The tele-ICU is a new model of care that some hospitals are now using like they are here at Worcester Memorial Medical Center. What do you think about the idea of a tele-ICU?
2. What is your understanding of how a tele-ICU works?
3. What is it like for you having a family member in the tele-ICU?
4. Are there advantages to this type of care?
5. Are there any disadvantages or concerns you have about this model of care?

Need for Information

6. Who gives you the most information about your family member in the ICU, someone from the local staff or the remote staff?
7. Who is the person who usually answers your questions? Who provides updates on how your family member is doing?
8. Are you given an opportunity to be introduced to the nurse or other staff at the remote hub at Worcester Medical Center? Do you get to talk to them or ask them questions?
9. What is the communication like between the bedside nurse and the remote nurse at the hub?
10. Do you get to listen in on communications between the on-site nurse or doctor and the nurse or doctor from the remote hub?
11. Do you feel like you have the opportunity to get all the information you want from both staffs—here at Worcester Memorial and from the remote hub?

Need for Close Proximity

- ~~12. Are you able to be present at the bedside of your family member more or less, since he/she is a patient here and may not have had to be transferred to another hospital further from your home? QUESTION #12 ELIMINATED~~
 13. What kind of access do you have to see your family member? Are you able to be with him/her as much as you would like to be?
 14. What kinds of things are you able to do to participate in your family member's care? Is this level of participation what you would like? Would you prefer more of less participation than
-

you have now?

Need for Assurance

15. What is the experience like for you when you hear a voice from the remote center come over the intercom?
16. Can you see who is talking? Do you think being able to see the staff person from the remote site when they are talking makes/would make a difference in your comfort level?
17. Do you feel confident that you will be notified of any changes in your family member's condition? How are you notified about any changes?
18. When you feel you need reassurance, do you feel that you get it? (Who from? How does this happen?-- If it doesn't happen, do you have thoughts on how things could be done better in this area?)

Need for Comfort

19. What comforts you most about this type of care that the patient is receiving?
20. What concerns you the most?
21. How comfortable do you feel while visiting or being present with your family member in the Tele-ICU unit?
22. Are there things that could be done to make you more comfortable in this environment?

Need for Support

23. Please tell me about any type of support or encouragement that you receive.
24. Who provides you with the most support during this difficult time?
25. Do you receive support from staff here? Is there a difference in the level of support you feel from the onsite staff and the remote staff?
26. Do you have some ideas on how staff could help you feel more supported?

Need for Privacy

27. How do you feel about the level of privacy of your family member in the tele-ICU?
28. Tell me about the camera in the patient's room and how that makes you feel.
29. Do you feel like your privacy is respected?
30. Do you have any additional thoughts on privacy?

Summary thoughts

31. Would you recommend the tele-ICU model of care to other family or friends who may have the need for ICU care? Why or why not?
 32. Are there any other thoughts you have about your family member being a patient in the tele-ICU that we have not discussed?
-

APPENDIX E

POSTER SCRIPT

PARTICIPATE IN A RESEARCH STUDY

(Week of May 18th -23rd)

Seeking family members or significant-other who has a patient/loved one in the tele-ICU to participate in a research interview.

My name is Mary Jahrsdoerfer and I am a student studying for my PhD at the University of Massachusetts Amherst, College of Nursing. I would like to know more about the family experience here in the tele-ICU. If you are willing to participate in a study, I would love to talk to you. Below (on this poster) are pull-off tabs with my contact information. Please take one and call me if you are interested in participating and we will meet at an agreed time. The interview should last approximately 45-50 minutes. With gratitude for your participation, please accept a \$10.⁰⁰ gift card to Dunkin Donuts.



I look forward to meeting you. **Thank you!**

Mary

VERBAL SCRIPT

To initiate the process, the investigator will respectfully approach people in the tele-ICU waiting area... I will introduce myself by saying, "Hello, my name is Mary Jahrsdoerfer. I am a student studying for my PhD at the University of Massachusetts Amherst, College of Nursing. As part of my school requirements I am conducting research on the family experience in the tele-ICU". Next I would ask if they are a family member of a patient in the tele-ICU, and if so would they care to voluntarily participate in a research study which would involve some discussion and interview questions.

APPENDIX F

MOLTER'S ORIGINAL 45 QUESTION CRITICAL CARE FAMILY NEEDS INVENTORY

Table I. Ranking of needs from most important to least important

<i>Needs</i>	<i>Categories of importance*</i>				
	<i>Not important (1)</i>	<i>Slightly important (2)</i>	<i>Important (3)</i>	<i>Very important (4)</i>	
1. To feel there is hope					40
2. To feel that hospital personnel care about the patient	1				39
3. To have the waiting room near the patient	1		5		34
4. To be called at home about changes in the condition of the patient	2	1	2		35
5. To know the prognosis	3		2		35
6. To have questions answered honestly	2		4		34
7. To know specific facts concerning the patients progress	2		7		31
8. To receive information about the patient once a day	4		1		35
9. To have explanations given in terms that are understandable	2	2	7		29
10. To see the patient frequently	2	3	7		28
11. To feel accepted by hospital staff	4	3	6		27
12. To have a bathroom near the waiting room	4	3	8		25
13. To be assured that the best care possible is being given to the patient	8		3		29
14. To know why things were done for the patient	8		4		28
15. To know exactly what is being done for the patient	6	3	4		27
16. To have comfortable furniture in the waiting room	5	3	10		22
17. To know how the patient is being treated medically	6	3	7		24
18. To have friends nearby for support	8	3	5		24
19. To be told about transfer plans while they are being made	5	2	16		17
20. To be assured it is alright to leave the hospital for a while	9	1	7		23
21. To visit at any time	10	3	7		20
22. To have a telephone near the waiting room	10	3	8		19
23. To have explanations of environment before going into ICU for the first time	13	1	5		21
24. To have good food available in the hospital	11	1	16		12
25. To have the pastor visit	16		4		20
26. To talk to the doctor every day	16	1	5		18
27. To have visiting hours start on time	18	2	5		15
28. To talk about the possibility of the patient's death	20	1	3		16
29. To help with the patient's physical care	20	3	3		14
30. To have directions as to what to do at the bedside	20	1	7		12
31. To know which staff members could give what type of information	18	2	13		7
32. To talk to the same nurse each day	21	2	6		11
33. To know about the types of staff members taking care of the patient	23	1	4		12
34. To have a specific person to call at the hospital when unable to visit	21	2	9		8
35. To be told about chaplain services	22	2	5		11
36. To be told about other people who could help with problems	23	2	7		8
37. To have someone be concerned with the relative's health	25	2	8		5
38. To have a place to be alone while in the hospital	28	4			8
39. To be alone at any time	28	4	3		5
40. To be told about someone to help with family problems	32	1	3		4
41. To be encouraged to cry	32	2	1		5
42. To have another person with the relative when visiting in ICU	32	2	1		5
43. To have visiting hours changed for special conditions	34		3		3
44. To have someone to help with financial problems	36	1			3
45. To talk about negative feelings such as guilt or anger	37	2			1

*The category values are 1, 2, 3, and 4, respectively. The numbers in the columns indicate the frequency of responses.

APPENDIX G

CERTIFICATE OF HUMAN SUBJECTS APPROVAL



University of Massachusetts Amherst
108 Research Administration Bldg.
70 Butterfield Terrace
Amherst, MA 01003-9242

Research Compliance
Human Research Protection Office (HRPO)
Telephone: (413) 545-3428
FAX: (413) 577-1728

Certification of Human Subjects Approval

Date: May 2, 2014
To: Mary Jahrsdoerfer, Nursing
Other Investigator: Cynthia Jacelon, Nursing
From: Lynnette Leidy Sievert, Chair, UMASS IRB

Protocol Title: NEEDS OF THE PATIENTS FAMILY IN THE HOSPITAL TELE-INTENSIVE CARE UNIT
Protocol ID: 2014-2002
Review Type: EXPEDITED - NEW
Paragraph ID: 7
Approval Date: 05/02/2014
Expiration Date: 05/01/2015
OGCA #:

This study has been reviewed and approved by the University of Massachusetts Amherst IRB, Federal Wide Assurance # 00003909. Approval is granted with the understanding that investigator(s) are responsible for:

Modifications - All changes to the study (e.g. protocol, recruitment materials, consent form, additional key personnel), must be submitted for approval in e-protocol before instituting the changes. New personnel must have completed CITI training.

Consent forms - A copy of the approved, validated, consent form (with the IRB stamp) must be used to consent each subject. Investigators must retain copies of signed consent documents for six (6) years after close of the grant, or three (3) years if unfunded.

Adverse Event Reporting - Adverse events occurring in the course of the protocol must be reported in e-protocol as soon as possible, but no later than five (5) working days.

Continuing Review - Studies that received Full Board or Expedited approval must be reviewed three weeks prior to expiration, or six weeks for Full Board. Renewal Reports are submitted through e-protocol.

Completion Reports - Notify the IRB when your study is complete by submitting a Final Report Form in e-protocol.

Consent form (when applicable) will be stamped and sent in a separate e-mail. Use only IRB approved copies of the consent forms, questionnaires, letters, advertisements etc. in your research.

Please contact the Human Research Protection Office if you have any further questions. Best wishes for a successful project.

M
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r
y
,

APPENDIX H

E-mail Approval

T
h
Cody, John (Shawn) <John.Cody@umassmemorial.org>

My request for pre-IRB approval is clear. You have permission to proceed with the research under the following conditions;

- ✓ 1. A copy of the Amherst IRB approval prior to starting data collection
- 2. Approval from the ICU research committee (CCOC), which in turn is requesting Amherst IRB approval and a copy of your outline questions.
- ✓ 3. Data collection will be carried out only in specified units as discussed.
- ✓ 4. Please forward a copy of your recruitment plan.

Thank you,
Shawn Cody, MSN/MBA, RN
Associate Chief Nursing Officer
Critical Care
UMassMemorialMedical Center
Worcester, MA

From: Mary Jahrsdoerfer [mailto:maryjahrs@gmail.com]
Sent: Tuesday, April 01, 2014 1:01 PM
To: Cody, John (Shawn)
Subject: Re: FW: dissertation work at UMass Worcester

On Mon, May 5, 2014 at 8:34 AM, Cody, John (Shawn)

- ✓ <John.Cody@umassmemorial.org> wrote:
Mary, The study was approved by CCOC pending your IRB approval. Now that you have that you are free to begin. Happy to discuss, Thanks Shawn

APPENDIX I

DATA MANAGEMENT & ANALYSIS PLAN

Step 1	<i>Organization</i> was key to the success of data collection, transcription, and written analysis of the study. This was done by having all study signage (to be hung in the units) ready; consent forms, demographic sheets and interview schedule printed on time. Planned an estimation of time needed for each step in the process. Spent time after each interview reviewing and editing field notes.
Step 2	A clear <i>file name</i> was chosen on the computer for organization of collected data, using an Excel Spreadsheet. Each page was clearly labeled according to participant (using a number system for distinction), demographics, categories, themes for page headers, and a section for emerging themes
Step 3	The <i>tracking system</i> was simple due to the fact there was no intermediary. The investigator gathered all of the data, compiled it first- hand, reviewed consent forms for completeness, uploaded audio files, developed Excel Spreadsheet, analyzed the data, and made a written report of the data.
Step 5	<i>Transcription</i> of data was conducted by the investigator using a software program called Dragon, Nuance 2012. The upside to using this was that it allowed the investigator to have control over the process (instead of subcontracting a professional). The down side was that there was a learning curve, plus the current version of the Dragon software only recognizes one voice. This made for labor-intensive, tedious work. All verbatim data was transcribed, including mispronunciations, non-verbal sounds, and any unusual extraneous or background noise that was evident. Lexicons were attempted, but because of user unfamiliarity and the fact that the sample size was somewhat manageable, free-hand notations were documented as well.
Step 6	<i>Confidentiality</i> of the family participant was maintained at all times, by password protection on the investigator computer and locked storage of paper files.
Step 7	<i>Quality</i> control of data was carried out by frequent comparison of transcription against the actual recording. This check was done over and over again with each recorded interview.

Step 8 *Timeline.* A realistic timeline was established with room for flexibility if warranted. Allocation of time was done by not placing constraints on the data collection (interview) process. The investigator allocated one weeks' time to conduct the interviews, and consciously was available any time day or night during this time (stayed in hotel directly across from hospital). Although all data was collected within this time frame, the week would have been extended until saturation was reached. Time management for analysis occurred at a natural pace without constraints.

APPENDIX J

AUDIT TRAIL

<p align="center">UMass Worcester IRB</p> <ul style="list-style-type: none"> • Informed that if going through UMass Amherst IRB, then Worcester would only require approval from their Critical Care Operating Committee (CCOC) 	3-19-2014
<p align="center">UMass Worcester CCOC</p> <ul style="list-style-type: none"> • Clinical approval given pending UMass Amherst IRB approval 	4-1-2014
<p align="center">UMass Amherst IRB submission</p> <ul style="list-style-type: none"> • Letter of Introduction • Interview schedule • Participant consent form • Participant demographic questionnaire • Verbal script • Poster script 	4-23-2014
<p align="center">UMass Amherst IRB approval</p> <ul style="list-style-type: none"> • Consent stamped 	5-2-2014
<p align="center">UMass Worcester approval</p>	5-8-2014
<p align="center">Data Collection</p> <ul style="list-style-type: none"> • On-site at UMass campuses for 6 days 	5-18-2014 to 5-23-2014
<p align="center">UMass Worcester: Interviews</p>	
• Sunday night (1)	5-18
• Monday (4)	5-19
• Tuesday (3)	5-20
• Wednesday (5)	5-21
• Thursday (2)	5-22
• Friday (1)	5-23
<p align="center">Analyzed data and wrote initial findings</p> <ul style="list-style-type: none"> • Transcription using Dragon (v.12) by Nuance • Clustered and coded themes manually • Muller over findings and best way to report them • Written analysis and discussion 	June 2014
<p align="center">Multiple edits with advisor</p>	July 2014
<p align="center">Final Dissertation Defense</p>	8-4-2014

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