

An Integrative Literature Review on Patient and Family Centred Care in  
Adult Intensive Care Units

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### **Acknowledgements**

To my Mom and Dad,  
You grant me peace each and every day.  
And for that, I am grateful.

I also want to acknowledge the support provided to me by my supervisor, Rosalie Starzomski, and committee member, Lenora Marcellus. You kept me anchored to the larger picture at hand and I am grateful for the support that both of you provided.

### **Abstract**

Patients admitted into the Intensive Care Unit (ICU) face severe medical emergencies that are associated with complex interventions and high mortality rates (Angus et al., 2004). As patient acuity increases, the patient's ability to interact with health care providers often declines as patients face intubation, mechanical ventilation, sedation, and other interventions and medical circumstances that limit communication. With a patient's limited ability to communicate needs and wishes, health care providers increasingly depend upon family members to make difficult decisions. Nurses are often in the best position to act as liaisons between patients and their families as families are faced with making treatment decisions for their family members who are receiving care in the ICU.

My purpose, in this project, was to locate the most evidence informed methods for integrating patient and family centred care in adult ICU's. An integrative literature review was completed to determine recommendations for nursing practice for family inclusion in the ICU. My analysis revealed four themes; consultation, collaboration, presence, and communication. These themes, derived from the literature review, were then considered from a relational inquiry perspective and recommendations were formulated for best practice nursing in adult ICU's.

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The inclusion of family in the Intensive Care Unit (ICU) has become an expectation of nursing care and is noted in national and provincial guidelines that direct best practice (Canadian Association of Critical Care Nurses, 2009; College of Registered Nurses Association of British Columbia, 2012). Despite these national and provincial guidelines, many families of ICU patients continue to experience inconsistent practice in regard to their inclusion and support in Canadian ICU's (Davidson et al., 2007).

Researchers, examining family satisfaction in the ICU, support the idea that further work is needed to improve the satisfaction of families exposed to critical care environments (Bailey, Sabbagh, Loiselle, Boileau, & McVey, 2009; Nelson et al., 2010; Wall, Curtis, Cooke, & Engelberg, 2007).

This gap in family satisfaction in the ICU, and increased pressure from regulatory bodies on ICU providers, has garnered growing attention as health care organizations attempt to become progressively more patient and family centred in their delivery of care. Given this need to increase patient and family satisfaction, as well as the requirement of regulatory bodies for patient and family centred care, nurses practicing in the ICU are under increasing pressure to practice using a patient and family centred care model.

While there is a growing body of research on patient and family centered care in the ICU, as well as an increasing emphasis on the need for this culture of care in health care organizations, there is little consensus on the most effective methods that registered nurses can use to best include families in Intensive Care Units. In other words, multiple methods exist in which to practice patient and family centred care in the ICU, but just what are the most evidence informed methods to bring this growing expectation to life?

Examples of patient and family centred care can range from the benefits of families being present for cardiopulmonary resuscitation (Halm 2005; Meyers et al. 2000), to family presence on interdisciplinary rounds (Cypress, 2012; Davidson 2013; Jacobowski, Girard, Mulder & Ely, 2010) and even family presence during invasive procedures, such as line insertion (Hodge & Marshall, 2009). While many evidence-based recommendations exist on how best to integrate families in the intensive care environments to improve care and satisfaction, to my knowledge no consolidation of research currently exists to guide best practice for nurses in the inclusion of families in the ICU. Therefore, I have completed an integrative literature review to answer the question of how best to integrate patient and family centred care in the adult ICU.

In what follows, I provide an extensive review of research where methods for providing family involvement in the ICU are described and reflect upon the research using a relational lens. Further, I make recommendations for nursing practice on how to include families in the intensive care environment so nurses can best provide patient and family centred care. I also provide a brief historical review of patient and family centred care, and a working definition of the concept in which to anchor the use of the term throughout my project. I discuss the methods used in my integrative review and the theoretical underpinnings that guide the analysis of the literature. Finally, the 14 articles located as result of this integrative review are discussed, and a summary of findings and recommendations for best practice are offered.

## **Background**

In this section, I provide a definition of patient and family centred care (PFCC). I also explore the origins of the term, patient and family centred care, and describe the

brief history of the movement in order to provide context for the integrative literature review. I also provide an outline of the four core concepts of patient and family centred care and a working definition of the term ‘family’. I briefly outline the current state of PFCC as it exists in my own clinical practice site, a reality that is similar to many other clinical practice sites across North America. Finally, I review the philosophical underpinning selected for this project, relational inquiry.

### **Defining Family**

For the purpose of my project, I used the definition located in my healthcare organization’s corporate policy manual, specifically the “Family Presence (Visitation) Corporate Policy” which is also consistent with the Institute for Patient and Family Centred Care (IPFCC) definition:

Family is defined by the patient/resident. When the patient/resident is unable to define family, the patient/resident’s next of kin or substitute decision maker provides the definition. Family members are the people who provide the primary physical, psychological, or emotional support for the patient or resident. Family is not necessarily blood relatives. Family members are encouraged to be involved and supportive of the patient/resident and are integral to the overall well being of the patient/resident. (Providence Health Care, 2013).

The key message in this definition of family is the understanding that the *patient* defines what family means to him/her. Within this understanding, family is not necessarily a blood relative, rather family is someone who provides support for the patient and contributes to his/her sense of well being. As ICU patients are often not capable of providing information about the definition of their family due to such

interventions as mechanical ventilation and intubation, the above definition provides guidelines as to who can be considered the patient's next of kin or legal decision maker until further clarification can be made directly with the patient.

As robust as the above definition of family is, I hesitate to provide such a static definition of family when the very term represents such complexity in this day and age. The complexity of identifying, defining, and collaborating with family is probably best understood by Hartrick Doane (2003) who writes that an ontological understanding of self is the best method to understand the fluid nature of family. While there is not room to examine my own understandings of the term family within the constraints of this project, I rely heavily on Hartrick Doane's work on family nursing as well as relational inquiry, and consider myself much aligned to the belief that no one voice is privileged over the other in this definition of family.

I recognize the multitude of definitions of the term family and very much welcome the dialogue as to what the term means to each of us. As Hartrick Doane (2005) suggests, challenging the need for certainty may very well be nursing's best resource when it comes to family nursing and the effort to define family.

### **Patient and Family Centred Care Defined**

Much like the term family, multiple definitions exist for PFCC. The most robust definition of PFCC can be found on the Institute for Patient and Family Centered Care website. For the purposes of this project, I have chosen this definition provided by the IPFCC:

Patient and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships

among health care providers, patients, and families. It redefines the relationships in health care...Patient and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction. (Institute for Patient and Family Centered Care, retrieved from: <http://www.ipfcc.org/faq.html> June 23, 2014).

This definition has become the working guideline for many health care organizations that aim to provide patient and family centred care, including the organization where I am currently employed, Providence Health Care, located in Vancouver, British Columbia, and where I hope to implement recommendations resulting from the integrative review. It is also a definition that is commonly referred to in the literature on patient and family centered care.

### **The Four Core Components of Patient and Family Centred Care**

In addition to the definition for patient and family centred care, the IPFCC outlines four core concepts that create the foundation for the definition: dignity and respect, information sharing, participation, and collaboration.

*Dignity and Respect:* Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

*Information Sharing:* Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

*Participation:* Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

*Collaboration:* Patients, families, health care practitioners, and leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

(Institute for Patient and Family Centered Care, retrieved from:

<http://www.ipfcc.org/pdf/CoreConcepts.pdf> June 15, 2014).

The origin of these four core concepts of patient and family centred care can be traced to Shelton, Jeppson, and Johnson's (1987) work entitled "Family-Centred Care for Children with Special Healthcare Needs". Shelton et al. (1987) originally identified eight key components of patient and family centred care that were later narrowed to four key components in 1996 during a meeting hosted by the Nathan Cummings Foundation (Johnson, 2000). These resulting four core concepts of patient and family centred care: dignity and respect, information sharing, participation, and collaboration, remain valid and in use to this day.

### **A Brief History of Patient and Family Centred Care**

Long before the origin of the four core concepts, PFCC had a rich beginning in pediatric care where families petitioned to be directly involved in the care of their infants or children. A far cry from today's hospitals, where 24 hour visiting is permitted by a large numbers of hospitals and facilities, as early as the 1920's, children were separated from their families and hospitalized for as long as two years with once weekly visits allowed for only 30 minutes by family members (Jolley & Shields, 2009). During this

time, policy makers and practitioners were driven by fear of infection, and the priority of family presence was taken over by the need for asepsis. By the 1940's, researchers began to learn more about infection as well as the traumatic effects of isolating children from their families, and by the beginning of the Second World War, families began to question the need for isolating their loved ones in hospitals (Jolley & Shields, 2009).

Post World War II, consumers (patients and families) began to drive health care reform in a way that they had never done before and forums, such as, 'The Citizen's Committee on Children of New York City,' held in 1955 helped to bring a collective voice to the growing need of patients and families. The American group, the Association for the Care of Children's Health was formed in 1965 and increased numbers of consumers began to question traditional biomedical models of health that did not include families (Jolley & Shields, 2009). In 1992, the Institute for Patient and Family Centered Care was formed by Beverley Johnson, the current CEO, who has helped not only mold the four core concepts of patient and family centred care outlined above, but become a model for innumerable changes in health care today. While the origins of patient and family centred care may have been formed in the pediatric world, it has very much spread to all corners of health care. As Beverley Johnson herself states: "patient and family centred care is not *new* work, it *is* the work" (personal communication, August 8, 2014).

While the evolution of patient and family centred care has been occurring over numerous decades (Cliff, 2012), health care providers, patients, and families have yet to see the *consistent* implementation of Beverley Johnson's wise words. In the next section, I illuminate what gains have been made in current clinical practice in regard to PFCC and what changes still need to be made.

**PFCC in Clinical Practice**

Today, patient and family centered care has been deemed a basic need, and in some areas, a legislated necessity in health care organizations across the world (Obama, 2010). Unlike trends and temporary recommendations for evidence based practice that change with time, renewed interest, and expertise – patient and family centred care can be seen as a permanent texture of our health care fabric (Institute for Medicine, 2001; Johnson, 2005). However, this ideal state is not often the clinical practice in current ICU's (Ciufu, Hader, & Holly 2011). For example, whereas the tenets of patient and family centred care can be seen on occasion in the ICU where I currently practice, *consistency* of staff actions to fully embrace patient and family centred care is not present.

The current state of the ICU where I practice is not unlike many other organizations and ICU's across the developed world. Authors such as Ciufu, Hader, and Holly (2011), in their systematic review of literature on adult ICU visitation models, revealed that nurses see visiting policies as guidelines and not rules. Ciufu et al. (2011) examined research on visitation policies from the United States of America (US), Norway, Denmark, Belgium, Spain, and the United Kingdom (UK), which represents an analysis of 35 different hospitals, and more than 1000 nurses patients and families. The authors demonstrated that nurses see benefit to visitation only if it is in line with the patients and their own (the nurses) needs. Despite being aware of the principles of patient and family centred care, nurses' decisions around visitation in the ICU were centred on patient and self. Similar to what Ciufu et al. (2011) identified, the nurses in the

ICU where I practice identify with the ideals of patient and family centred care, however, staff face difficulty in translating these ideals into day-to-day practice.

This current state of patient family centred care is in stark contrast to position statements from the American Critical Care Nurses Association (Bell, 2008), as well as the Canadian Standards for Critical Care Nursing Practice that are published by the Canadian Association of Critical Care Nurses (2009). For example, within the third standard of the Canadian Standards for Critical Care Nursing is the statement: “[c]ritical care nurses foster mutually beneficial partnerships with patients and families based on trust, dignity, respect, communication and collaboration. Family is defined by the patient” (Canadian Association of Critical Care Nurses, 2009, p. 5). Acknowledging the contrast between the current state, and the reality of care for families and patients in an adult ICU, creates a definite need for changes in practice and merits efforts such as this integrative literature review to identify the most evidence informed practices.

### **Mutually Beneficial Partnerships**

The core concepts, and the definition of PFCC, provide the key foundation for this integrative literature review as I seek to locate the most evidence informed methods for integrating patient and family centred care in adult ICU’s. In addition to the core concepts and definition of PFCC, a particular emphasis must be placed on the definition of PFCC, and, in particular, the phrase: *mutually beneficial partnership*. This is important, as when examining the evolution of care from a biomedical model, traditional ‘expert’ voices have taken precedence over other voices such as patients and families. A biomedical model can be seen as a definite barrier to patient and family centred care (Barrier, Li, & Jensen, 2003).

When considering a theoretical underpinning to this project, the core concepts of PFCC and a mutually beneficial partnership became very important. Examining literature to improve care of patients and families in adult ICU's *without* a lens of partnership and respect seemed counterintuitive. Framing this literature review from a relational lens then became a key component of this project as I sought to find the most evidence informed methods for integrating patient and family centred care in adult ICU's. Having a lens of relational inquiry to locate evidence informed methods for patient and family centred care helped me to strip away the traditional biomedical model and put in place a theoretical perspective very much in line with the core concepts and definition of patient and family centred care itself.

### **Relational Inquiry – Theoretical Underpinnings**

The theoretical underpinning selected to frame the findings of my integrative literature review is relational inquiry. For the purposes of my project, the understanding of relational inquiry is derived from the work of Hartrick Doane and Varcoe, noted in their book: “Family Nursing as Relational Inquiry: Developing Health-Promoting Practice” (2005) as well as in their later book “How to Nurse: Relational Inquiry with Individuals and Family in Changing Health and Health Care Contexts” (2013).

Relational inquiry in family nursing, as outlined by Hartrick Doane and Varcoe (2005), is based on the views of pragmatism where it is understood that knowledge is central to the knower and is socially constructed. From the view that each person constructs their own matrix of understanding, Hartrick Doane and Varcoe (2005) suggest that no one universal truth can be constructed, and, therefore, our knowledge is relational to the world and experience that each of us hold. Pragmatism is in direct contrast to the

standardly held Cartesian view where boundaries are created between mind and body and it is assumed that one universal truth is understood by all. By examining the belief that knowledge is constructed, sustained, and carried in relation to knowers and their unique environments, in the context of family knowledge, Hartrick Doane and Varcoe (2005) provide the theoretical underpinning of family nursing as relational inquiry.

When it comes to defining the meaning of family nursing as relational inquiry, Hartrick Doane and Varcoe (2005) draw on a multitude of disciplines and theories in order to provide a rich definition. The very richness of family nursing as relational inquiry is underscored as Hartrick Doane and Varcoe (2005) explain that no one concept is used to shape the definition and no one method of understanding can explain its interconnectedness. Or, as Hartrick Doane and Varcoe explain: “[w]e attempt to explicitly show how families, nurses, and family nursing exist and occur within webs of interrelationality that integrally connect and shape people/families’ health and healing” (2005, p. 13). In this sense, relational inquiry becomes as much about the knower as it is about the family and they both must craft a web of understanding in order to apply that relational inquiry.

As expansive and robust as relational inquiry is, Hartrick Doane and Varcoe (2005) are explicit in their understanding that relational inquiry is not an *end point* in how to think about family nursing. Indeed, the authors identify that relational inquiry is not a flow diagram, or steps nurses take that provide black and white methods in becoming family orientated or ‘better nurses’. In fact, using relational inquiry is the very opposite for nurses as the authors suggest the theory as a “way to foster knowledgeable and competent family nursing practice [by] develop[ing] a more conscious, intentional and

responsive way of living knowledge” that can inform nursing practice on a much deeper and sustainable platform than a single grand theory (2005, p. 13). In other words, relational inquiry becomes a state of *being and understanding* rather than a prescribed call to action or theorem.

### **Constructing Views Within Relational Context**

Relational inquiry is the theoretical underpinning for my project on ICU patient and family centred care as it provides a cornerstone of philosophy similar to the constructs of patient and family centred care that have been outlined previously. Respect, dignity, information sharing, collaboration, and participation all fall under the same constructs of relational inquiry as described by Hartrick Doane and Varcoe. At its heart, Hartrick Doane and Varcoe identify relational being as a process that “involves walking alongside people/families to facilitate responsive, safe, and health promoting care” (2005, p. 255) – a concept that is at the very soul of patient and family centred care as defined by the IPFCC outlined previously. To care with respect and dignity, to share information for more fruitful participation and collaboration, nurses must place themselves alongside the patient and family and understand their ways of being.

Hartrick Doane and Varcoe (2005) create a visual metaphor of ‘walking alongside’ the patient and family to illustrate the need for no one story or individual to take precedence, rather, a mutually beneficial partnership occurs between the individual caring and the individual requiring care. This mutual beneficial relationship is at the centre of patient and family centred care and thus is fitting as a theoretical underpinning for my project.

### **Methodological Approach**

Whittemore and Knafl's five-step process was used to conduct an integrative review and thorough analysis of the literature on the topic of guiding patient and family centred care in adult ICU's. Whittemore and Knafl defined an integrative literature review as a "specific review method that summarizes past empirical or theoretical literature to provide a more comprehensive understanding of a particular phenomenon or health care problem" (Whittemore & Knafl, 2005, p. 546). Or, as Torraco (2005) identified, an integrative literature review is "a form of research that reviews, critiques, and synthesizes representative literature on a topic in an integrated way as such that new frameworks and perspectives on the topic are generated" (p. 356). Whittemore and Knafl's five-step process includes the following stages; problem identification stage, literature search stage, data evaluation stage, data analysis stage (including data reduction, data display, and data comparison sub stages), and finally a presentation stage.

Whittemore and Knafl's (2005) method for integrative research review was adapted from Cooper's (1998) literature review process that was intended for systematic reviews or meta-analysis. Whittemore and Knafl expanded the method beyond systematic review and meta-analysis in order to integrate different origins of research based on specified criteria.

This integrative literature review process was chosen as a method for this project for its particular strengths in helping the reviewer with analysis and practical application to nursing research. Whittemore and Knafl (2005) also outlined tools for incorporating multiple styles of research, with the emphasis being on the rigor of research versus the style of research. In other words, the integrative literature review does not require an

exclusion of either qualitative or quantitative methods, but rather a thorough and rigorous examination of varied research based on the research question at hand and the strength of the individual study design. The strength of each study is extracted and coded to create robust and succinct recommendations for practice, research, and even policy design. By procuring this stratified review of literature based on the strength of each sample of research, and its match with the search review criteria, I was able to provide a much more in depth analysis of the literature in order to determine my findings. For these reasons, Whitemore and Knafel's framework for integrative literature reviews was used as the methodological process for this project.

### **Stage 1.0: Problem Identification Stage**

The first stage of the integrative literature review requires that a problem is clearly identified and the variables of interest are narrowed. In my clinical area of practice, an adult intensive care unit, a need for provision of patient and family centred care has been identified, however, an exact method to develop this culture of care has not been located. With this clinical need, the question that I sought to answer was: *what are the most evidence informed methods for integrating patient and family centred care in an adult ICU?* The population of interest for the purposes of my review was identified as *adult ICU patients and families*. The guiding concepts chosen for the integrative review were ICU, *family inclusion*, and *patient and family centered care* with a theoretical perspective of *relational inquiry* providing the theoretical underpinning.

### **Stage 2.0: Literature Search Stage**

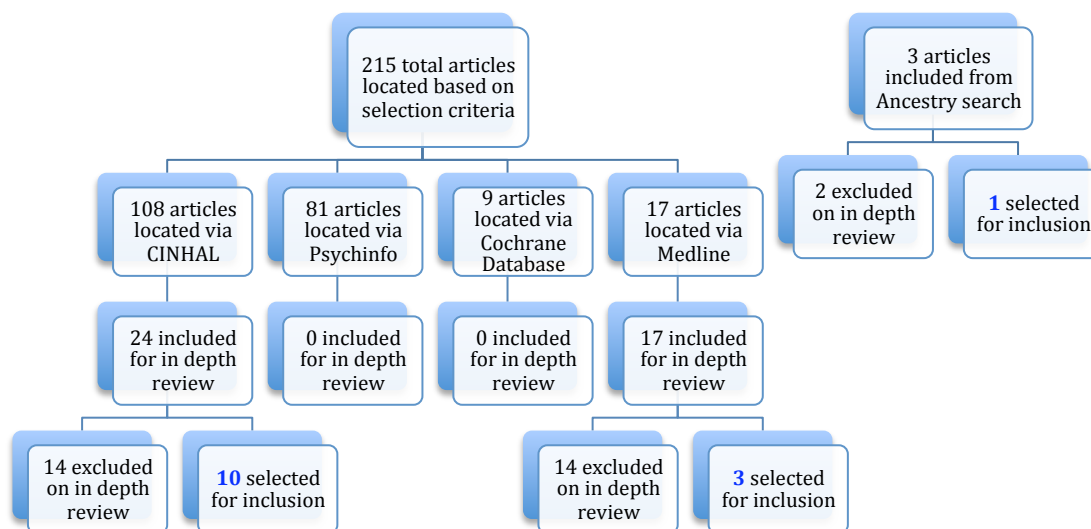
The literature search stage was completed using electronic database search and ancestry searching. The selected databases for the search included the Cumulative Index

for Nursing and Allied Health Literature (CINAHL), Medical Literature On-line (MEDLINE), PsycINFO, and the Cochrane Database of Systematic Reviews. As part of the second stage of Whittmore and Knaf's (2005) integrated literature review model titles, key words, and abstracts were first screened in order to judge eligibility for inclusion into the integrative review.

Inclusion guidelines for the integrative review included; materials that were written in the English language, materials that passed ethical approval, materials that were published in peer reviewed sources, and materials that were published from the year 1990 and later. The publication inclusion date of 1990 and later was selected as this is recognized as the start of the patient and family centred care movement in North American (Johnson, 2000), as well as when patient and family centred care research begins to show more rigor. Exclusion criteria included unpublished manuscripts, interviews, case reports, opinion articles, books, and book reviews, materials written outside the English language, and material published in the year 1989 or earlier. All adult ICU's were included in my review with no exclusion/inclusion criteria for the specific type or field of adult ICU, such as neurological, trauma, or a medical ICU. Research generated from pediatric or neonatal ICU's was not used in the integrative literature review as my population of interest was selected as adult ICU patients and their families. These exclusion guidelines were chosen in an effort to obtain the most rigorous and evidence informed data possible, as well as to best fit the needs of adult ICU's, patients, and their families. The search words *ICU, family inclusion, and patient and family centered care* were used.

A total of 215 articles were located using the above listed databases. Three articles were located via an ancestry search, one of which met the inclusion criteria. Of the total 218 articles located via databases and ancestry searches, 42 articles were selected for more detailed review. All 42 of these articles were reviewed in depth and were either included or excluded based on the criteria detailed above. 28 articles were eliminated after this more in-depth analysis resulting in a final number of 14 articles included for the integrative literature review (see *Figure 1.0*).

*Figure 1.0: Articles located during literature search stage*



### Stage 3.0: Data Evaluation Stage

As part of the third stage of the integrative review, data evaluation, the Johns Hopkins Nursing Evidence Based Practice (JHNEBP) appraisal tool was used to help me examine the eligible articles as well as provide a method for tracking the research collection (See Appendix A for an example). The JHNEBP research appraisal tool was chosen specifically as it provides a basis for both qualitative and quantitative research

review and significance for practice is considered when the tool is used for analysis. The final question in the JHNEBP appraisal tool is of particular interest to me in my research process: “[w]ill the results help me in caring for my patients?” This question is very pertinent as my ultimate goal is to improve the care of patients and their identified family members in the ICU.

Questions on adequate sample size, ethical considerations, and limitations of the research are identified clearly in the JHNEBP research appraisal tool and these questions assisted me in the clear analysis of the articles chosen for review (Newhouse, Dearholt, Poe, Pugh, White, 2007). The JHNEBP research appraisal tool also offered specific criteria for dividing research versus non-research materials.

The 14 articles originated from a variety of geographical locations, a noted tribute to the spread of the movement of patient and family centred care in ICU’s. The 14 articles originated from authors in the US, France, Sweden, Australia, UK, and Hong Kong with one study being a joint effort between the US and Canada. The majority of the articles originated from the US at 7 articles, or 50%. France was the second highest contributor to my review with 2 articles included totaling 14%. Authors from the UK, Hong Kong, Sweden, and Australia each produced one article that met the set inclusion criteria with each country contributing 7% to the total. There was also an article written by authors from the US and Canada as a joint effort, which contributed to the last 7% of the articles considered for the integrative review.

All the research in the studies included was conducted in the clinical setting of an adult ICU. Seven (50%) of the studies were quasi-experimental, 4 (29%) of the studies were quantitative (randomized control studies) in design, and 3 (21%) of the studies used

qualitative methods (phenomenological, ethnographic, and phenomenological/hermeneutical) in the study design.

#### **Stage 4.0: Data Analysis Stage**

The data analysis stage included the detailed coding, ordering, categorizing, and summarizing of the selected articles. The articles that passed the first stages of the integrative review, and fit the criteria of my search intentions, were analyzed and reviewed in a much more detailed way than on the initial review for inclusion. I used the Johns Hopkins Nursing Evidence Based Practice: Research Evidence Appraisal Tool (Newhouse, Dearholt, Poe, Pugh, White, 2007) (see Appendix B) to track individual references once they were screened for inclusion. Information gathered using this grid included correct citation, authors, year published, evidence type (methodology), sample and sample size, results/recommendations, limitations, rating (strength/quality), theme, search database used, and finally a column to track where this research was generated. I chose not to have an ethics approval column on the grid, as one of the inclusion criteria for articles in my review was that ethics approval be completed. This tool was extremely helpful in both outlining the quality of the data as well as developing themes from the data that resulted from the data analysis stage. The grid also provided a useful pictorial representation of the analyzed data that was referred to on numerous occasions to confirm the comparative nature of each article and its fit to the overall intentions of the integrative review.

Research articles that had a quality rating of A (high) or B (good) were included in my integrative review; those that received a quality rating of C (low/major flaw) were not included. All strengths of evidence (Level I, II, and III) were included in my

analysis, as the strength of each article was reviewed on the basis of its individual merits according to particular style, versus prioritizing such categories of research as randomized controlled trials over a well designed phenomenological study.

Acknowledging the strengths of each type of evidence was a definite reason for my selection of the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal, as it allowed the analysis of a broad range of research basing the strengths on *merit* of research versus *type* of research design.

The data analysis stage includes four areas: data reduction, data display, data comparison, and conclusion drawing and verification. In the next section, I outline these stages of analysis as provided by Whitemore & Knafl (2005).

#### **Stage 4.1 Data Reduction**

Whitemore & Knafl (2005) describe the next phase of the integrative review, the data reduction phase, as a point where the selected references are grouped into subgroups. The authors recommend a manner of classification such as type of evidence, publication date, type of experimental sample used, or any other logical grouping in order to facilitate analysis. I chose to reduce the data into themes in order to assist in the presentation stage, as well as to strengthen the recommendations that would ultimately result in the completion of the integrative review.

In order to eliminate bias in the data reduction phase of my integrative review, I elected to use a mind-map (See Appendix C). A mind map can be defined as a “way of geographically representing ideas, concepts and sub-concepts, classifying and organizing a large number of items around a central concept” (Whiting & Sines, 2012, p. 22). A mind map provided a visual geography of the data and the themes that were emerging in

a non-biased manner so I could visually sort and understand the themes. Bias was reduced in this process as I reviewed all the articles selected for inclusion in one consolidated sitting and wrote a very brief summary for each article (see Appendix C). Words from each brief summary were reviewed again and a theme for each article was selected.

#### **Stage 4.2 Data Display**

The second stage of the overall data analysis portion of the integrative review that is outlined by Whitemore & Knafl (2005) is data display. I chose to complete the data display stage visually which can be seen in the Appendix B. This helped me to extract large amounts of data into a single primary source and ultimately helped in the data comparison stage and, eventually, in formulating the recommendations for practice.

#### **Stage 4.3 Data Comparison**

This process allowed for the consolidation of the original six themes into four major themes that helped me to formulate the implications for practice and research that are located at the end of this project description. The four themes that emerged were consultation, collaboration, presence, and communication and are discussed at a later point in this paper. In order to bring transparency to the data analysis stage, and particularly to the data comparison stage, I provide a summary of chosen references in the next section listed in alphabetical order according to lead author.

#### **Stage 5: Presentation**

The summary of chosen references, in combination with Appendix B, Appendix C, dissemination of findings, and conclusion are offered as the last phase of Whitemore and Knafl's (2005) integrative review process – presentation. The presentation stage can

be presented in a table or chart or in a written summary according to Whittemore and Knafl (2005). To bring depth to the integrative review process, I have chosen to present this stage using a combination of methods including the summary of chosen references below, as well as a table (Appendix B), and mind map (Appendix C).

### **Summary of Chosen References**

The summary of the chosen references brings to life the data reviewed and analyzed. In addition, I provide detailed recommendations for practice from the individual authors. Any limitations of the research that I observed upon review of the selected titles, or was noted by the authors themselves, were also outlined in the summary of the chosen references.

Azoulay, E., Pochard, F., Chevret, S., Jourdain, M., Bornstain, C., Wernet, A.,... Lemaire, F. (2002). Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients. *American Journal of Respiratory and Critical Care Medicine* 165, 438-442.

Azoulay et al. (2002) conducted a multi-centre prospective randomized control trial. The authors sought to discover if a standardized family information leaflet (FIL) improved comprehension and satisfaction in families of ICU patients who received the leaflet. The authors were able to recruit a statistically significant number of patients for both the control and experimental group with 102 patients in each group. A rating of I for the strength of this study, and B for quality, was allocated upon my review.

The only inclusion criterion identified by the authors was an expected length of stay of at least 48 hours. Exclusion criteria included if the patient died within 48 hours of admission to the ICU, no family was present five days post ICU admission, and if the

family refused to participate. Study data were collected from 175 family representatives, 87 in the control group and 88 from the intervention group. Characteristics of the ICU's were discussed and variability of diagnosis, care, and staff was deemed insignificant between the sites as to make the results generalizable to other ICU's.

The authors found that the family information leaflet was effective in improving comprehension overall with comprehension rising from 11.5% in the control group to 40% in the experimental group. In addition to increases in comprehension, family members' understanding of diagnosis and treatment of their loved ones was also seen to improve as a result of the intervention. Of note, no statistical significance was found in the comprehension of *prognosis* between the control and experimental group. Satisfaction, anxiety, and depression were not significantly different between the control and the experimental group.

Limitations for this study, mentioned by the authors, include the issue that only one family member was provided with the intervention or included in the control group, while it is widely recognized that most patients have more than one family member. This means that possible selection bias was introduced if a more favorable family member was involved in the intervention/control than a family member who was less appreciative of the care and thus more likely to comment in a positive light and skew findings. The authors recognized this as a limitation and, therefore, conducted a stratified randomization of the control and experimental group in order to attain the most statistically significant results despite this limitation. Because of the author's ability to recognize this limitation and control for it, the study was included in my integrative review. If the authors had failed to locate a control group to juxtapose any potential

selection bias in the experimental group, I would have eliminated this study because of this limitation. Ethical considerations were not directly addressed in this study; however, the authors did discuss that part of the exclusion criteria were persons who refused to participate, meaning that participation was a signal of implied consent. Azoulay et al. also mentioned that they were part of the French FAMIREA group who must adhere to strict federal/ethical guidelines to protect patients during the completion of any research. The authors' inclusion in the FAMIREA group, as well as the voluntary participation of persons included in the study, provided sufficient ethical support for me to include this study in my integrative review.

From this analysis, I concluded that a family information leaflet could improve comprehension. ICU clinicians should consider using this method to improve information provided to families of ICU patients. While the information leaflet can be seen as an effective tool in increasing comprehension and understanding of diagnosis and treatment, the authors underscored that the delivery of a family information leaflet alone cannot improve comprehension. Combining nurses' abilities to assess such things as emotional readiness of a family member to receive information, alongside a family information leaflet provided by a caring professional, has been demonstrated as a beneficial tool for family members with loved ones receiving care in the ICU.

In adapting the leaflet into my own practice, or clinical unit, attention to language, culture, and reading ability would need to be considered. While the authors show sufficient improvement in comprehension of the ICU setting by families using the leaflet, the diverse population served in my particular clinical setting might not find as great a

benefit unless multiple translations were available as well as an alternative for persons unable to read.

Chien, W. Chiu, Y.L., Lam, L., & Ip, W. (2006). Effects of a needs-based education programme for family carers with a relative in an intensive care unit: A quasi-experimental study. *International Journal of Nursing Studies*, 43, 39-50.

The authors conducted a quasi-experimental study using non-randomized control and intervention groups and a pre/post test design. The authors hypothesized that anxiety levels would *decrease* and satisfaction would *increase* in families who had experienced a needs based education program about different aspects of care in the ICU. Ethical approval for the study was granted from the internal institute where this study was conducted, and statistical power was demonstrated with 66 family members included in the sample (32 in the control and 34 for experimental group). Instead of calculating statistical power specific to their study, Chien et al. based their calculations on two prior studies where researchers also examined educational interventions for families with loved ones facing critical illnesses and used these same statistical criteria for their study. Although, I would have preferred an individual calculation of participants needed to demonstrate statistical power, the authors' ability to still maintain statistical power while using very similar studies (in terms of population, unit characteristics, and intervention), I believe this limitation is not significant enough to result in the exclusion of the study from my findings. A rating of II for the strength of this study, and A for quality, was allocated upon my review.

The needs based education program consisted of a three-day education program that was administered by the bedside ICU nurse. On day one of the patient's admission to ICU, a family member was identified and a pre-test was self administered and collected from both the control and experimental groups. The pre-test data also included demographic information from the family member and written consent to be involved in the study. Depending on bed assignment, (bed 1-10 for experimental and bed 11-20 as control), the patients were grouped into a control or experimental group. The routine ICU orientation was provided to both groups, but only the experimental group had two one-hour sessions delivered on day 2 and 3. The two one-hour sessions were held in an interview room at a time of convenience and completed by the same bedside nurse for each one-hour session. Each one-hour session was delivered according to the needs identified by the family in the pre-test record. Exclusion and inclusion criteria were clearly outlined by the authors of the study and language, age, and presence/specified relationship of the family member were considered.

The authors concluded that family members in the experimental group had a significant reduction in their anxiety levels and a significant increase in their satisfaction of care by reviewing the pre and post-tests that contained a Critical Care Family Needs Inventory – a validated tool that measured anxiety and satisfaction in this population. Despite the lack of randomization, the authors were still able to demonstrate a need for tailored, needs-based education and orientation for families of patients admitted to Intensive Care Units. The authors recognized that needs based assessment, and delivery of tailored orientation, is one way that nurses could provide a high level of patient and family centred care.

Daly, B.J., Douglas, S.L., O'Toole, E., Gordon, N.H., Hejal, R., Peerless, J., Rowbottom, J., Garland, A., Lilly, C., Wienczek, C., & Hickman R. (2010). Effectiveness trial of an intensive communication structure for families of long-stay ICU patients. *Critical Care Medicine*, 138(6), 1340-1348.

Daly et al. (2010) conducted an experimental study and aimed to test the ability of structured, intensive, family meetings conducted five days post admission and at least weekly thereafter, on the ICU length of stay (LOS). A large sample of 346 patients in the experimental group and 135 patients in the control group was included in five hospital ICU settings. Ethics approval for the study was granted by the appropriate bodies and noted by the authors. A variety of ICU's (medical, surgical, and neuroscience) that were university affiliated, non-university affiliated, or not for profit, in the same city, was used to conduct the research. Having this variety of settings was of particular interest in my analysis, as the authors' findings could be considered for use in settings similar to my own ICU. A rating of I for the strength of this study, and A for quality, was allocated upon my review.

The control and the experimental group arms were conducted in two separate phases with two Advanced Practice Nurses (APN's) hired for scheduling and assistance with the completion of the family meetings. The ICU staff conducted the family meetings and were provided a session on the intensive communication structure. The family meetings were held away from the bedside and 30% of the interviews were taped to ensure adherence to the methodology. The researchers determined that a reduction in LOS was not achieved by the implementation of the intensive communication structure.

Despite the authors' original hypothesis, that an intensive communication structure could reduce LOS not being supported by the findings, they found there was still a need for communication in the ICU with families. The authors suggested that this intensive communication structure needed to be tested against additional hypotheses and suggested more research on this topic was needed.

Inclusion of this article in my integrative literature review underscored the finding that reduced LOS is not an outcome of this style of communication but it does not negate the need for a method of communication in order to support patient and family centred care in the adult ICU. As more and more ICU processes become streamlined, such as with lean, processes (Davis, 2010), adapting a method of communication with patients and families might demonstrate a way for staff to build confidence in communicating with patients' families.

Huffines, M., Johnson, K.L., Smitz Naranjo, L.L., Lissauer, M.E., Fishel, M.A., D'Angelo Howes, S.M., Pannullo, D., Ralls, M., & Smith, R. (2013). Improving family satisfaction and participation in decision making in an intensive care unit. *Critical Care Nurse*, 33(5), 56-68.

Huffines et al. (2013) researched the effectiveness of a communication algorithm to increase effectiveness in three realms identified as areas for improvement in their family satisfaction survey: shared decision making (decisions made with families and the multidisciplinary team); doctor and nurse team work; and family support and encouragement. The research was completed in a single site – a surgical ICU at the University of Maryland with 72 patient families receiving communication via the

algorithm. A pre-post-test design was used for this quasi-experimental study with interventions provided within 24 hours, 72 hours, and 96 hours of the patients' admission to a surgical ICU. A rating of II for the strength of this study, and B for quality, was allocated upon my review.

The 24-hour intervention goal was focused on the need to inform families of roles of health care providers, as well as the role of families in shared decision-making. An on demand video and various written resources were available at this time. The 72-hour intervention goal was to offer support and re-assure family members of the information provided at the 24-hour mark. Family members were encouraged to get involved in decision making at the level they wished to and were encouraged to participate in interdisciplinary rounds at this stage. The 96-hour intervention mark included the implementation, or planning, of a family meeting alongside the interdisciplinary team to ensure goals, treatments, communication, and expectations were clear. Huffines et al. (2103) also identified certain factors that escalated the algorithm response so that clinical staff could expedite the information and support provided to be received at any time and did not restrict families from receiving certain information just at the allocated 24, 48, and 96 hour time marks.

41 pre and 48 post-test satisfaction surveys were analyzed with a noted improvement in participation in decision-making raising from 45% prior to the intervention to 68% after the algorithm was in place. Staff teamwork was also improved from 64% pre to 83% post algorithm use. Some improvement in support provided to family members was noted, however, statistical significance for this finding was not attained.

The authors noted the small convenience sample size, which could affect generalizability to other settings, as a limitation for this study, however, they were able to reach a high percentage of families and attain statistically significant results.

Interestingly, Huffines et al. (2013) are completing a secondary analysis of the research in order to replicate the study and prove effectiveness on a broader scale.

It was also noted by Huffines et al, that other interventions to improve communication and family centred care were occurring while this study was taking place that may have influenced the positive study results. This limitation was not deemed sufficient enough to disqualify the study from my analysis as there will often be multiple research interventions occurring, especially in a teaching hospital, and the authors were still able to provide consistent and relevant findings. It should also be noted that these findings are consistent with other research on the same topic (Scheunemann, McDevitt, Carson et al., 2011). Based on these findings, I see the value for early, repeated, structured and multidisciplinary communication within a model of shared decision-making – an intervention that nurses are capable of leading and facilitating in the ICU.

Jacobowski, N.L., Girard T.D., Mulder, J.A., & Ely, E.W. (2010).

Communications in critical care: Family rounds in the intensive care unit. *American Journal of Critical Care*, 19(5), 421-430.

Jacobowski et al. (2010) conducted a quasi-experimental study on communication in ICU interdisciplinary rounds. Particularly, the authors wished to test the hypothesis that by including families on interdisciplinary rounds in the ICU, family satisfaction, as well as provider/family communication, would increase. The study took place in a 26

bed ICU where families were asked to fill out the Family Satisfaction ICU (FS ICU) tool pre and post intervention as a measure of their satisfaction. The control group consisted of families, with available contact information, who had been admitted prior to the initiation of the study intervention. Ethics approval from the local institution was received for this study and consent was implied in participation. A rating of I for the strength of this study, and B for quality, was allocated upon my review.

Families were invited to participate in daily rounds by nursing staff and interdisciplinary rounds were conducted as per usual (presentation of the last 24 hour events by nurses, residents and fellows, summary of assessments/interventions, attending physician's comments on 24 hour events, along with appropriate teaching). The intervention for the study was the addition of a session where the attending physician would provide an explanation to the family in 'lay' language (1-2 minutes) and ask if the family member had any questions for the team. Prior to rounds, the families received a written and verbal explanation of the process and their role in rounds.

As a result of the intervention, a statistically significant increase in satisfaction with communication, as well as an increase in support felt during decision-making was noted by the study authors. As much as satisfaction with communication and decision-making increased for this intervention, the *time* for decision-making was still found to be lacking. The *overall* measure of satisfaction in analysis of the pre and post intervention was not significant.

Limitations of this study included the single site nature of the study where conditions might not be replicable to other ICU's, as well as the fact that families who were non-English speaking were excluded from the study. It should also be considered

that, due to the nature of interdisciplinary rounds occurring in the middle of the working day, families who were not able to attend in order to continue employment were excluded from this study. Given the authors concentrated efforts to statistically ‘level the playing field’ in terms of participant involvement, as well as the pre and post test nature of the study design, these limitations were not enough to exclude this study from my inclusion in this integrative review.

This study was of particular interest to me in this integrative review, as I believe nurses can play an integral role in the implementation of interdisciplinary rounds. As much as the attending physicians’ 1-2 minute summary, and invitation to families to ask any questions, is key to the authors’ intervention in this study, nurses still have a tremendous role in the set up of this intervention. My experience as a bedside critical care nurse is that families can feel intimidated by the attending physicians and are reluctant to ask questions directly of the intensivist. As a result, families are often found to be relaying their questions to the nursing staff, versus asking questions directly of the attending physician, and nursing staff find themselves the conduit between two worlds. By forging better relationships and expectations of both physicians and families, such as interdisciplinary rounds has the potential to do, I think additional benefits other than just satisfaction with communication and overall support could potentially be seen. Creating an expectation of families and staff that it is acceptable to ask questions is one of the biggest predecessors to good communication, and ultimately one route to achieving patient and family centred care in the ICU.

Lautrette, A., Darmon, M., Megarbane, B., Joly, L.M., Chevret, S., Adrie, C.,...Azoulay, E. (2007). A communication strategy and brochure for relatives of patients dying in the ICU. *The New England Journal of Medicine*, 365(5), 469-478.

Lautrette and colleagues conducted a randomized control study on end of life communication in the ICU and the benefit of a brochure on death and bereavement. The study took place in 22 different ICU's in France with 66 families in both the control and intervention groups. The intervention group's family conference was framed around the mnemonic VALUE (value what the family members are saying, acknowledge the emotions of families, listen, understand who the patient was outside of their illness by asking questions of the family, and finally to elicit any questions that the family members may have). 90 days following the family conference intervention, a family member was contacted via phone and asked questions about his/her level of anxiety, depression, and post-traumatic-stress disorder related symptoms. A rating of I for the strength of this study, and A for quality, was allocated upon my review.

The study authors found that families were more likely to agree with the interventions made by the team, and withdrawal of vasopressor and mechanical ventilation support was more common, in the intervention group rather than the control group. There was no significant increase or decrease found in the length of stay in the ICU. Interestingly, the post survey of families in the intervention group revealed that 95% of families were able to express their emotions versus 75% in the control group. Families in the intervention group also noted a decrease in stress, anxiety, and depression compared to families in the control group.

Although the study took place in France, and different conditions in Canadian and French ICU's may limit generalizability of the authors' findings, the sample size, as well as the diverse sampling of families could negate this limitation and the study was, therefore, included in my analysis. A limitation of the study is that it was not blinded and therefore there might be some sampling bias as a result of the exclusion of families who had poor relationships with the interdisciplinary team. Perhaps the largest limitation of this study was that it did not provide pre-data regarding the family's level of anxiety, stress, and depression and, without this pre-level data, it is difficult to ascertain actual improvement. Instead, the comparison between the stress, depression, and anxiety level of the family member in the control versus intervention group is the only method for measurement of success.

Despite these limitations, Lautrette et al. provide a solid intervention with excellent research techniques which contributes to a common theme in the literature concerning ICU patient and family centred care – communication.

Lily, C.M., Sonna, L.A., Haley, K.J., & Massaro, A.F. (2003). Intensive communication: Four-year follow-up from a clinical practice study. *Critical Care Medicine*, 31(5), S394-399.

Lily et al. conducted a non-blinded, quantitative research study to examine the effectiveness of an intensive family communication strategy that would take place within 72 hours of admission to the ICU. The authors defined the intensive communication intervention as a: “coordinated, proactive process of communication in which an initial formal family meeting was preceded by communication among providers with regard to

the plan of care and the outcome goals” (Lily et al., 2003, p. S395). The initial session with care providers and patient/family created the cornerstone for the communication strategy. This initial session included four integral points: “1) to review the medical facts and options for treatment; 2) to discuss the patients perspectives on death and dying...3) to agree on a care plan; and, most important, 4) to agree on criteria by which the success or failure of this care plan would be judged” (2003, p. S396). A rating of II for the strength of this study, and A for its quality, was allocated upon my review.

The authors completed the study over the period of four years with 2,891 ICU patients enrolled consecutively. The three independent variables that were used as measures for the outcomes of the study were length of stay, mortality, and agreement between patient/family and health care team. Results of the intensive communication strategy revealed a reduction in the length of stay (from a median of 4 days to a median of 3 day length of stay) as well as a reduction in mortality (from 31.3% in the pre-intervention stage to 22.7% in the intervention stage). Satisfaction of communication with physicians and nurses, as measured by patients and families, increased from 93% to 100%. Although mentioned as one of their measurable variables, no results on agreement between health care team and patient/family were reported in the study.

One limitation of this study, as described by the authors, is the generalizability of the findings to other ICU populations. However, given the large sample size and randomization of participants in this study, I believe the findings could be useful for practitioners in adult ICU settings to consider. The lack of a control group in this study is noted and the findings could have been strengthened if they were compared to a control group. The authors noted that the intervention was labor intensive but had significant

positive outcomes and a larger, randomized, multisite reproduction of the study would be helpful.

McDonagh, J.R., Elliott, T.B., Engelberg, R.A., Treece, P.D., Shannon, S.E., Rubenfeld, G.D., Patrick, D.L., & Curtis, J.R. (2004). Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with satisfaction. *Critical Care Medicine*, 32(7), 1484-1488.

McDonagh et al. conducted a multi site quasi-experimental study that examined duration of family speech and duration of practitioner speech during interdisciplinary family meetings in the ICU. The study was conducted in four Seattle area hospitals and involved the audiotaping of 51 conferences with 214 family members and 36 different physicians. In addition to the audiotaped timing data collected, the authors also provided a post family meeting survey to all participants that focused on satisfaction with communication. A rating of II for the strength of this study, and B for its quality, was allocated upon my review.

The authors' hypothesis was that increased time of family speech in family meetings would be correlated with increased satisfaction of care – a hypothesis that was supported by the authors' findings. In addition to proving their original hypothesis, the authors were also able to demonstrate an increase in family satisfaction with physician communication and a decrease in family conflict with physicians. The authors listed major limitations for this study; the researchers were only able to audiotape 50% of the possible conferences identified, and the evaluation did not include any communication

outside the formal family meeting setting such as nurse to family conversations at the bedside.

Despite these limitations, McDonagh et al. conclude that paternalistic methods of providing information to patients and families needed a transition to information sharing *with* patients and families in order to respect the body of knowledge that the patient and family hold as well as to share medical and nursing knowledge. This concept of information sharing is a core tenet of patient and family centred care and can be recognized as a major theme for McDonagh et al.'s research.

The researchers provide important information for modeling behavior of staff employed in an ICU. Increasing the family's percentage of speech time, in order to increase time for shared decision-making and real collaboration in decision-making, is key. Increased time of family speech in family conferences should be used as one mechanism in which to improve satisfaction rather than the only method of choice.

Mitchell, M.L., & Chaboyer, W. (2010). Family centred care - A way to connect patients, families and nurses in critical care: A qualitative study using telephone interviews. *Intensive and Critical Care Nursing* 26, 154-160.

Mitchell et al. conducted a qualitative, phenomenological study where telephone interviews were completed with family members who performed care for their family members who were admitted to the ICU. Purposeful sampling techniques were used to collect 10 family members (9 female, 1 male). For the purposes of this study, Mitchell et al. defined family as "an individual who visited and had a sustained and direct relationship with the patient" (p.155). After agreement for participation in the study, a

research nurse, who was not involved in the care of the patient/family member, called the family member, and the research nurse posed 9 questions. The telephone interviews took between 6 to 15 minutes to conduct. Recurrent themes and trends were then taken from the research nurses' notes that were written during the interview. A rating of III for the strength of this study, and A for quality, was allocated upon my review.

Three themes emerged from the data: “1) ‘enacting care’; 2) ‘connecting with sick relatives’ and 3) ‘partnering with nurses’” (p. 157). In all three themes, family members identified the important need of being present with their loved one. This family presence offered an opportunity for communication to occur and improve outcomes and satisfaction. Although this intervention can be deemed as a small-scale change, Mitchell et al. noted that the involvement of family members could contribute to a much greater level of satisfaction and communication for staff and families.

Although the sample size was small, the authors of the study noted that saturation of data occurred after the tenth interview was conducted and, therefore, the sample size was deemed adequate. Limitations noted by the authors included the gender of the participants – notably that only one male participated in the study, and patient and nurse perspectives were not included in the study. On replication of this study, it would be interesting to examine families who did not receive an intervention and assess if satisfaction was higher with family members who believed they could participate in care with nursing support.

The researchers emphasized the everyday benefits that family inclusion in the ICU can have on satisfaction. While many investigators examined more complicated

interventions, Mitchell et al. focused on an intervention that is both small and feasible with nursing encouragement and support.

Olausson, S., Ekebergh, M., & Lindahl, B. (2012). The ICU patient room: Views and meanings as experienced by the next of kin: A phenomenological hermeneutical study. *Intensive and Critical Care Nursing*, 28, 176-184.

Olausson, Ekebergh, and Lindahl completed a qualitative, hermeneutic phenomenological study with purposeful sampling techniques to evaluate the ICU patient room as experienced by the patient's family member. The study was completed in two Swedish ICU's with the authors collecting data from 14 family members. Family members used a photo voice technique, a qualitative technique where study participants take photos of their surroundings and then provide meaning to these photos in an interview. Once the photos are taken, participants were then involved in an in person interview session with a researcher to extract meaning from the photography. The interviews were approximately one hour in length and were open ended in design. The family member's response was tape-recorded, then themes were developed and assigned to consistent categories. A rating of III for the strength of this study, and B for quality, was allocated upon my review.

The authors reveal that families experience the ICU in 'visible' and 'invisible' dimensions. These invisible and invisible dimensions played a role in factors ranging from the welcome that the family received, to the power that the health care provider or family was perceived to hold. As Olausson et al. (2012) stated, "[t]he design and the interiors of the ICU room affect the next of kin's mode of being, either amplifying

feelings of homelessness or evoking an emerging at-home-ness...[this experience depends] on how the next of kin is received and welcomed” (p. 182).

The nature of photo voice as a mechanism of research is that it very much reflects the opinions, thoughts, and feelings of those studied and it is impossible to extrapolate these findings to a broader population. These limitations being understood, Olausson et al. still produced an interesting study for supporting a patient and family centred ICU.

The authors examined the concept of spatial qualities of the ICU where most other researchers focused on the skills and abilities of ICU staff. While examining physical space alone may not be the only answer to supporting a patient and family centred care model, these findings, used in combination with other mechanisms, such as increasing the amount of speech in family conferences, or including families on interdisciplinary rounds might be helpful in optimizing patient and family centred care in the ICU.

Shaw, D.J., Davidson, J.E., Smilde, R.I., Sondoozi, T., & Agan, D. (2014). Multidisciplinary team training to enhance family communication in the ICU. *Critical Care Medicine*, 42(2), 265-271.

Shaw, Davidson, Smilde, Sondoozi, and Agan conducted a quasi-experimental design study where they examined the effect of a clinical training program on clinician communication and family satisfaction. The authors hypothesized that the implementation of a communication training program would improve staff collaboration. The study was completed in three adult ICU's with 46 caregivers completing both the pre and post-test. Although 98 staff members completed the education sessions, only 46 pre

and post-tests could be matched. The authors noted that the data collected on the remaining 52 staff who participated in the study had to be discarded as some staff did not complete both the pre and post-test and some participants did not use the same identifier code (the last four letters of their mothers maiden name) on the pre and post-test.

Intensivists, residents, nurses, social workers, chaplains, case managers, pharmacists, and respiratory therapists were included in the training. Mailed surveys, using the FS-ICU 24 (Family Satisfaction – Intensive Care Unit 24) validated questionnaire, were used to evaluate improvement in communication from a family perspective. A rating of II for the strength of this study, and B for quality, was allocated upon my review.

The intervention consisted of a pre-reading session followed by a presentation, role-play simulation, a self-assessment and a debriefing session. The pre-reading included information about the SPIKES model (setup, perception, invitation, knowledge, emotions, and strategy) that was discussed in the presentation, as well as comments from patients and families about the positive and negative experiences of communication in the ICU. Ninety-eight staff members were trained in 14 separate sessions.

Results of the training session showed significant increase in confidence in family presence, increased confidence in assessing how much the patient wanted to know, as well as an increased confidence in handling patient's or family's emotional reaction. There was little improvement, despite the intervention, in health care providers' abilities to detect family anger and confidence in managing their own responses to patient distress.

Limitations for this study included the low number of survey responses from family members, and no link or question that would confirm that the family member had

received communication from one of the staff who had or had not received the intervention. The small sample size in a single site is also a major limitation.

Despite these limitations, the authors identified a method through which to provide communication techniques to health care providers that has shown small-scale benefit. This study would benefit from duplication in a larger multisite centre with refinement in the pre and post-test coding to ensure no evaluation was wasted. On replication of this study, a family assessment of those who have and have not received communication from a care provider who has been trained in this method would also be beneficial to examine the true impact of this intervention.

Slatore, C.G. Hansen, L., Ganzini, L., Press, N., Osborne, M.L., Chestnutt, M.S., & Mularski, R.A. (2012). Communication by nurses in the intensive care unit: Qualitative analysis of domains of patient-centered care. *American Journal of Critical Care* 21(6), 410-418.

Slatore et al (2012) conducted a qualitative review of ICU nurses' communication behaviors with 6 patients in two ICU's. The study was conducted using an ethnographic method and ethics approval was granted with informed consent collected by study authors prior to the implementation of the research. A rating of III for the strength of this study, and A for quality, was allocated upon my review.

The authors were able to collect qualitative data from 98% of the potential nurse candidates and established five domains of communication; bio-psychosocial, patient as person, sharing power and responsibility, therapeutic alliances, and clinician as person. The authors found that the majority of nurses communicated in the bio-psychosocial

(vital signs and basic physical status), patient as person (attempts to understand the patient as they were prior to hospitalization), and clinician as person (reacting to prognosis or informing others about their concern) domains and had difficulty communicating in the other two domains. Slatore et al. substantiated that all realms of communication are appreciated and valued by family members but nurses have difficulty communicating in the last two domains.

Slatore et al. revealed an interesting pattern in nursing communication in that nurses have difficulty with the domains of sharing power and responsibility and creating therapeutic alliances - two domains of communication that have been expressed as integral to the provision of patient and family centred care. These findings are key to my integrative review as the researchers identified two domains of communication that can be applied to nursing practice to integrate patient and family centred care into the ICU.

A noted limitation to the study was that other staff or family members did not complete an evaluation of nurses' communication. This meant that data was not collected to measure the satisfaction with the communication that did occur as judged by the family/staff. Therefore, no direct correlation can be found between the use of these domains and an increase in satisfaction. While the authors do not evaluate this correlation, they do provide extensive literature on the link between communication and satisfaction and underscore that the purpose of the study was to better understand the patterns of communication between nurses, staff and families. Knowing that the link between satisfaction and communication has already been well established in prior literature, and noting the authors' excellent research methods, this study was included in my integrative review.

Steel, A., Underwood, C., Notley, C., & Blunt, M. (2007). The impact of offering a relatives' clinic on the satisfaction of next-of-kin of critical care patients – A prospective time-interrupted trial. *Intensive and Critical Care Nursing* 24, 122-129.

Steel, Underwood, Notley and Blunt conducted a time interrupted quasi-experimental study by implementing a relative's clinic that was available by appointment. The clinic was staffed by the physician and the nurse caring for the patient and was available on weekdays from 2-3 PM. The authors' hypothesis was that by offering a regular clinic operated by ICU staff, family satisfaction, satisfaction with staff/relative interaction, and ultimately, patient care, would improve. The Critical Care Satisfaction Survey was used to measure satisfaction of family members who were able to access the clinic and those who were not able to access the clinic. A rating of II for the strength of this study, and B for quality, was allocated upon my review.

Of the 321 eligible next of kin, 151 were included in the intervention group and 170 were in the control group. Seventy of the 151 possible participants in the intervention group responded to the survey, and 79 of the possible 170 in the control group responded. It is unclear how many of the 70 survey respondents actually used the clinic and how many did not. The researchers demonstrated that there were high levels of satisfaction in both groups with no statistically significant increases in the intervention group versus the control group. The authors noted that while no statistical difference was found in this intervention, the survey feedback revealed worthwhile points for improvement in the unit such as open door visitation for the ICU and the provision of direct telephone numbers of physicians for families to use if they had any questions.

Limitations of this study included the small sample size, therefore, the generalizability of findings to other geographical areas was not possible. No statistical significance was found with the intervention and while the hypothesis and intervention are interesting, it is discouraging to see that no merit of the intervention was found in the analysis.

Wall, R.J., Engelberg, R.A., Gries, C.J., Glavan, B., & Curtis, J.R. (2007). Spiritual care of families in the intensive care unit, *Critical Care Medicine* 35(4), 1084-1090.

Wall et al. (2007) conducted a large, multisite, cluster randomized control trial to examine the effectiveness of provision of spiritual care on overall satisfaction of ICU families. The authors formulated this study after they examined preliminary results of their ICU satisfaction surveys that saw only two-thirds of respondents reply to questions of spirituality. Of those respondents, less than half gave the spiritual aspects of care a rating of 'excellent'. The authors were discouraged by these ratings and devised two goals to better examine this finding in a second analysis. In this second analysis, Wall et al. had two goals, first, the authors wanted to assess the difference between families who did and did not rate their spiritual care, and second, Wall et al. desired to see if certain factors were associated with a higher level of satisfaction.

In order to assess these links, Wall et al. (2007) mailed the FS-ICU survey and family members were asked specifically about their spiritual preferences. Three hundred and fifty six family members responded to this mailed survey. In addition to the mailed survey, a chart abstraction was done by research assistants who collected information on

clinical situation, family conferences, patient demographics, and estimated length of stay. The authors compared this data to observe differences between those who were satisfied with their spiritual care needs while in ICU and those who were not. A rating of II for the strength of this study, and B for quality, was allocated upon my review.

Findings from the survey reveal that family members who had a high satisfaction rating with their spiritual care also had high satisfaction in their *overall* experience of care. No particular patient or family characteristics (such as age, sex, level of education, or race) were associated with a higher level of satisfaction with spiritual care. The authors maintain that any comprehensive approach to PFCC should include an aspect of spirituality within the family unit.

Limitations of the study, listed by the authors, included non-responder bias, and generalizability of findings, as the study focused only on dying patients and their families. The authors noted that families of patients who did survive might have different ratings of their satisfaction of care. As there is a noted difference in the literature in satisfaction with care of families with patients who die while in the ICU, and those whom survive, no matter the type of intervention, generalizability of findings to other ICU families is a limitation for this study (Wall, Curtis, Cooke, Engelberg, 2007). From my own clinical experience, this is often due to the clinicians' need to document family conversations and bring families together when it is clear that a patient will not survive despite medical and nursing interventions. In this case, the need to satisfy perceived or actual legal actions is the motivator for practitioners versus the satisfaction or comfort of the family members. Despite these limitations, Wall et al.'s research is worthwhile as it

emphasizes an intervention not commonly discussed in the literature in terms of pastoral care support to integrate patient and family centred care in the adult ICU.

The authors' findings underscore the variety of interventions available to involve families with the aim of creating a more patient and family centred ICU experience. Nurses can play a role in facilitating or enacting these recommendations and are clearly positioned to create environments that are patient and family centred. While the concept of patient and family centred care has been evolving for over thirty years, the actual research methods available to measure this aspect of care are a relatively new force of work. This research is as much driven by the consumers of the research (nurses, physicians, policy makers, etc.) as it is by the population that practitioners serve in our daily health care interactions.

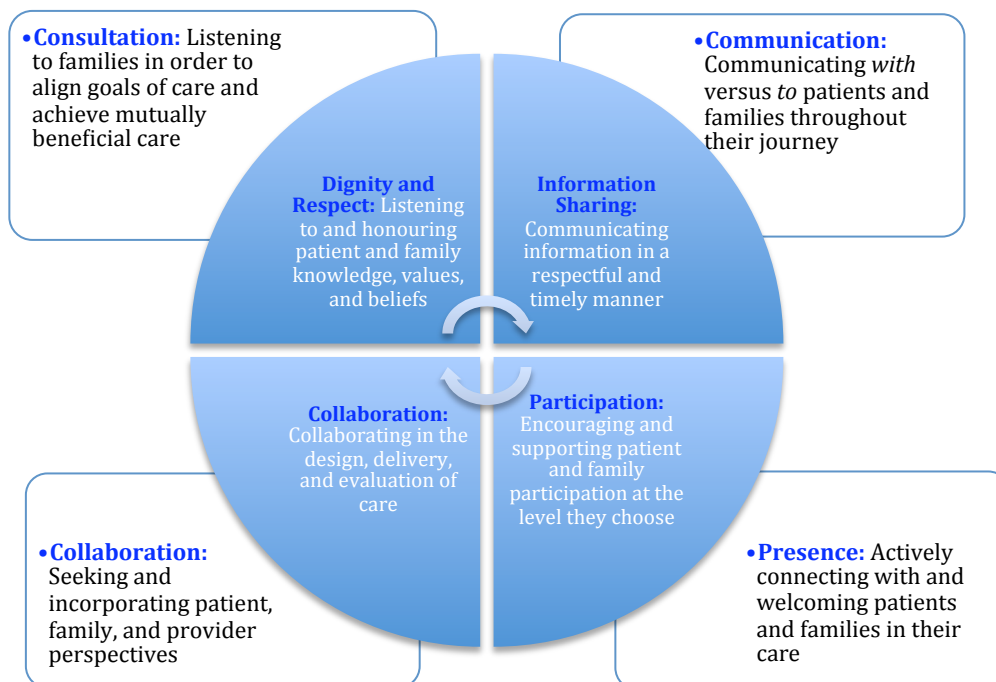
In the next section, the accumulation of the data derived from the integrative literature review is presented. A particular focus to the research has been given to the role nurses play in implementing patient and family centred care in the adult ICU.

#### **Stage 4.4: Conclusion Drawing and Verification**

My analysis of findings from the integrative literature review revealed four major themes. The four themes; consultation, collaboration, presence, and communication were determined after the selected references were reviewed and the findings were coded for trends. A mind map (Appendix C) was used to gather and streamline themes as they arose, a process that has been previously outlined in the section entitled methodological approach. Relational inquiry was used to inform the creation of these four themes, as guided by the works of Hartrick Doane and Varcoe (2005), and the theoretical underpinnings outlined at the start of this project.

Each theme cannot be seen as a singular entity but rather exist in relation to each other. For example, the term communication was chosen as a theme as it cannot be done in isolation – by its very definition communication must be shared or in tangent with those that are involved. Collaboration is much the same, since we cannot collaborate singularly, rather it must be done in partnership with another. The four themes are also in alignment with the four core components of patient and family centred care as outlined earlier in my project (Figure 2.0). All four themes that were developed through this integrative review contribute to evidence informed methods of integrating patient and family centred care in the adult ICU.

*Figure 2.0:* Aligning the four core principles of patient and family centred care with the four themes found in the integrative review.



**Consultation**

I recognized consultation as important among diverse health care providers as a way to optimize patient and family centred care and this is also frequently cited in the literature (Davidson et al 2007; Rose 2011). Nurses often call upon the expertise of other nurses or individuals with knowledge in other health disciplines in order to provide best care to patients and families. It is no wonder that consultation is a theme in my integrative review, as the very core of patient and family centred care, when recalling the IPFCC's definition of the term, involves the expertise of each person, family member, patient, or health care provider, being shared in a timely and respectful manner in order to provide the best outcomes and care possible.

For instance, Wall et al. (2007) provided an interesting analysis of the benefit of consultation with spiritual care providers and revealed that overall satisfaction of care increased when families perceived spiritual needs were met. While the authors identified that perceived level of satisfaction with spiritual care needs was higher with the consultation of spiritual care practitioners, they did not provide consistent correlation between the provision of these services and the care of the spiritual care staff exclusively. Nurses are in a good position to identify patient/family needs for consultation. Working together in order to realize the best experience becomes the larger message – something that critical care nurses currently do and are well poised to facilitate.

**Collaboration**

Much like consultation, critical care nurses are expected to collaborate regularly with other specialties as well as work in partnership within the field of nursing in order to provide the best patient care. Rather than assimilating consultation and collaboration into

a singular theme, I chose to differentiate between the two, as two very different themes arose, which called for a separate analysis.

Ultimately, collaboration was identified as a separate theme in my literature analysis stage as collaboration was seen as an *elevated* form of consultation. While many health professionals might ask for opinions and consultation, on various disease processes for example, in order to gain more knowledge outside of their own fields of expertise, collaboration offers an elevated plateau in which to truly engage with a partner/family member in care. In other words, my analysis of the selected references revealed consultation to be the seeking of other's opinions, and collaboration as the true blending of those differing opinions to create an environment that was patient and family centred.

Returning to the definition of patient and family centred care provided by the Institute for Patient and Family Centered Care reviewed at the beginning of my paper, the '*mutually beneficial*' core of the definition is brought forward when differentiating between consultation and collaboration. In order to find mutually beneficial partnerships – that is, true patient and family centred care, practitioners, patients, and families need to step past the state of consultation and push to a state of meaningful collaboration.

The literature I reviewed provided me with many examples of collaboration to promote PFCC in the adult ICU. For example, Mitchell and Chaboyer (2010) identified how collaboration permeated into three different themes; 'enacting care', 'connecting with sick relatives', and 'partnering with nurses.' The authors demonstrated that true partnerships provided the most fulsome definition of that mutually beneficial, patient and family centred care, and families needed to be supported in their presence and partnership in care so they could find value in this contribution and thus minimize stress and anxiety.

Family members were invited to connect with their sick family members in a safe and comforting way by partnering with the bedside nurse.

Chien, Chiu, Lam and Ip (2005) also identified in their needs based study that collaborating with families to identify their needs was worthwhile and beneficial to all involved. Chien et al customized the provision of spoken and written information around a family needs assessment at the level of involvement preferred by the family. This study is an example of collaboration that is time and resource intensive, but not all methods of collaboration located in the literature search required significant additional amounts of staff time in order to be successful.

Jacobowski et al (2010) worked within an existing structure to collaborate with families to provide additional time with staff and families. The authors introduced ICU families to interdisciplinary rounds with the hopes of improving satisfaction and support decision-making. While the authors found overall satisfaction was not impacted as a result of the pilot project, they did identify interdisciplinary rounds as a beneficial resource for some patients and families.

My literature review provides a sample of how practitioners and families using collaboration can encourage PFCC in adult ICU's. Given the proximity and continued presence of nurses at the ICU patient's bedside, nurses are well positioned to collaborate with families to optimize patient and family care.

### **Presence**

Presence for families can have multiple meanings in the intensive care unit. Presence can mean comfort for the family member as he/she seeks to find meaning in a loved one's illness (Lam & Beaulieu, 2004) and it can also mean a loss or gaining of

power for families looking to ‘belong’ in a complex environment (Ciufu, Hader & Holly, 2011). Physical presence of family, as Mitchell and Chaboyer (2010) state, can:

“...transcend physical boundaries incorporating an existential domain, by promoting reciprocity between patients and family members and by promoting collaboration with nursing staff. ...it provides [families] with a vehicle to connect with the patient on an emotional or existential level” (p. 159).

Interestingly, Olausson et al. (2011) suggest that presence took on an additional meaning that has not commonly been reported in the literature. They posit that presence can mean welcoming families into a space where they can feel distanced from the world around them: “you are homeless in the ICU in two ways; firstly, you do not have a place of your own and secondly because of the chaotic situation you are facing” (p. 181). By welcoming families into this distanced environment, nurses are well positioned to bridge this gap between family presence that is welcomed or discouraged.

While more and more intensive care units in Canada discuss and adopt policies around open visitation in ICU’s, the theme of presence (AACN Practice Alert, 2012; Ciufu, Hader & Holly, 2011) can take on a larger meaning as Olausson et al suggest. “The room is lived as an unbound space...this means that the lived ICU patient room is not merely the place generally defined by staff. This extension means that the room emerges as a consequence of the time spent there, movement and interaction with people” (Olausson et al., pp.181-182).

### **Communication**

Communication was by far the largest and most consistent theme I identified in my integrative literature review. Many authors of ICU needs’ assessments, or

satisfaction surveys, identified that some sort of communication was a key tenet in the provision of patient and family centred care. For example, Obringer, Hilgenberg & Booker (2012) looked at the needs of ICU family members and identified communication, and specifically assurance, as one type of communication, as the most desired need of families with loved ones being cared for in the ICU.

Downar, Barua, & Sinuff (2014) also identified communication as a major theme in their study which focused explicitly on supporting families in the ICU during the stage of death and dying. The authors found families had a desire to receive communication specific to bereavement, while ICU clinicians voiced that they had difficulty expressing themselves during this period or simply 'not knowing what to say' to an affected family member. Also, in the palliative spectrum of ICU care, Nelson et al. (2010) identified the family's need for consistent, timely, and empathetic communication between health care provider and family member, as well as effective communication from one member of the health care team to another. At all levels of care in the ICU, communication can be seen as a necessary stepping stone in the provision of patient and family centred care.

Chien Chiu, Lam, & Ip (2006) identified one method in which to attain effective communication in the ICU. They customized communication, based on a needs assessment at the start of the ICU patient/family journey, and provided communication based on this assessment. Azoulay et al (2002) looked at the provision of an information leaflet to family members as one method to improve patient and family centred care in the ICU. While the authors acknowledged that the leaflet was not provided in isolation of other interventions, they still provided evidence that the provision of an information

leaflet might be an effective way for staff to communicate and provide patient and family centred care in the ICU.

Daly et al (2010), in their study on intensive communication structures, provided additional evidence as to why communication was so important in PFCC, as well as a method in which to provide effective PFCC communication. While their hypothesis that communication would reduce length of stay was not established in the study, and the actual intervention was labor and time intensive, the authors said that communication should nonetheless be an important part of the PFCC ICU. Nurses need to encourage and participate in effective, collaborative communication in order to foster the mutually beneficial partnership that nurtures the very foundation of PFCC.

### **Discussion**

Incorporating patient and family centred care in an ICU is, simply put, the right thing to do. Engaging patients and families from the perspective of relational inquiry as a theoretical underpinning can ensure patient and family centred care is provided at all levels of health care. Relational inquiry can function much more than a theory that guides practice and can be seen as the major tenet of the provision of patient and family centred care. Staff interacting with patients and families, with the understanding that meaning is brought from so much more than just *what* they discuss to refocus on *how* they discuss, brings a reflective nature to situations that inspire the provision of patient and family centred care in the adult ICU.

Upon reflection of relational practice in her own nursing experience in a pediatric ICU, Rashotte (2006) states:

I wish us to consider taking the viewpoint that the relationship itself is the philosophical and practical foundation of health care ethics...it is in our relationships with the patients and/or families that we have the opportunity to consider, not only the medical facts of the patients' illness, but also the other components of their lived reality, a reality that embodies the mind-body-spirit wholeness of the individual as a unique, autonomous person, while recognizing that each individual is a part of a whole family and whole community" (p. 4)

Rashotte later emphasizes these points stating, "I believe it is *how* we enter into conversation and *how* we create the relational space that is vital for ethical decision making" (2006, p. 4). In this fashion, relational inquiry becomes less of a theory, that by definition must remain rigid to a core set of values, and much more of a fluid sense of knowing and being, very much applicable to the patient and family centred adult ICU.

Nurse philosopher, Sally Gadow, speaks to the need for nurses to construct interactions on a much more relational basis (1999). Gadow (1999) argues that an ethical cornerstone is needed if nursing is to have a philosophy, as standard Cartesian views provide us with less and less certainty in a constantly changing world. Gadow goes on to say that relational knowing becomes an ethical cornerstone as "[i]n composing a narrative between nurse and patient, it does not matter who is the author, because each is poet; it matters only that there are enough words between them to make a story" (1999, p. 65). Gadow explains that relational inquiry, or ethics, has become the narrative that can encompass personal engagement without attributing any one character to be on a moral high ground over another. By responding with respect and dignity, nurses looking to achieve patient and family centred care in the ICU can use this relational outlook to

situate themselves as coexisting among patients and families versus dominating over patients, and, thus, better integrate the outcomes both hope to achieve.

Kapossy and Khraishi (2012) provide an example of how this relational perspective can be used within a critical care triage protocol within a pandemic setting and help to bring to life many of the points that Gadow (1999) discusses in regard to relational ethics. Kapossy and Khraishi combine eight North American critical care triage protocols and discuss the potential flaws of enacting a triage protocol based on standardization of care to maximize resources for maximum patient impact. While standardization of triage can provide the basis of a process, the authors argue that what is more important is not the characteristics of each person but *how* each person socially identifies. From this relational perspective, while triaging patients, staff would include the assessment of the physical, emotional, and psychological components that they have always considered, and also take into account the larger impact of the whole person and persons with whom they are interacting. Although this is a large-scale interpretation of relational inquiry, the point remains the same, incorporating rich, context based interactions to come to collective mutually beneficial understandings can produce much more meaningful patient and family centred care.

In alignment with my integrative review, encouraging the support of families through consultation, collaboration, presence, and communication, the Canadian Association of Critical Care Nurses (2005) have produced a position statement on family presence during resuscitation. Within this statement, the Association encourages the presence of families during resuscitation and acknowledges the vast capacity that families have in their ability to support, nurture, and restore health in critically ill patients. The

Association also supports the need for more research and expanded policies to support care of patients and families in critical care environments. Not only do these existing guidelines support my findings from this integrative review, they also support the theoretical framework from which these findings are formulated, and the four core components of patient and family centred care outlined by the IPFCC.

As the body of literature that supports PFCC in ICU's continually develops, the role of nurses in transporting this research to the bedside, and supporting patients and families in their daily care, will become increasingly important. Efforts, such as this project, can help bring informed practice to the bedside so nurses can satisfy their professional and regulatory body responsibilities as well as build *mutually beneficial* partnerships that construct the very foundation of patient and family centred care in adult ICU's.

### **Limitations**

As I discussed the limitations pertaining to each individual study in the summary of chosen references, here I discuss larger themes in order to identify the limitation trends in the selected references. The most notable limitation was the small sample size in many studies such as Chien et al., (2006); Huffines et al., (2013); Mitchell et al., (2010); Olausson et al., (2012); and Shaw et al. (2014). Of note, all of these studies were qualitative in nature, where sample size is frequently smaller, with the exception of Shaw et al.'s (2014) study which was quasi experimental in design. Shaw et al.'s study was included in my analysis as the authors were able to include more than half of the staff in the ICU in their analysis but the overall population was small.

Although the sample size was noted to be small in some of the selected quantitative studies, the authors, such as Chien et al. (2006), were still able to demonstrate the statistical power of their findings. Huffines et al. (2013) also mention small sample size as a limitation, however given the intensity of the intervention and the author's ability to generate statistically significant findings, the study was included in my review.

Another limitation noted in my analysis was the number of single site research studies (Chien et al., 2006; Huffines et al., 2013; Jacobowski et al., 2010; Lily et al., 2003; Steel et al., 2007). Single site research studies, meaning research conducted in one ICU versus multiple ICU's with comparable patient/staff populations, can still provide research findings that are reproducible to other similar units. Lily et al.'s research findings provide an excellent example of rigorous research despite the single bed medical ICU in which the research took place. In their study, length of stay, number of counseling sessions, and mortality was measured in 2,361 patients admitted into the ICU. 530 additional patients were then assessed using these same measures in a pre-post test design four years after the original research was done in order evaluate the continued change.

An interesting limitation that was apparent in four of the research studies was the exclusion of participants that did not speak the language of majority for the research site (Azoulay et al., 2002; Jacobowski et al., 2010; Lily et al., 2003; Wall et al., 2007). As research on patient and family centred care in adult ICU's expand, it will be interesting to see how more representation of patients and families who do not speak the language of

the majority is included in research considering that no restriction of culture or language is placed on the admission of patients to an ICU.

Non-responder bias (Wall et al., 2007) and selection bias (Shaw et al., 2014) were two additional limitations listed in the included studies. In the case of Wall et al.'s research, where they identified non-responder bias as a limitation, the study was still included in my analysis as the authors were able to attain statistical significance through diverse sampling across ten different ICU's in the Seattle area.

It should be noted that a limitation of this integrative review is that it was completed and designed by one person – myself. Prior, and during the completion of this project, I was employed as a practice consultant charged with introducing patient and family centred care across an organization and, as such, was regularly exposed to various research, projects, and policies regarding patient and family centred care. I was also the author of the family presence policy, which is referred to in the definition of family at the start of this paper. Examining my beliefs and prior exposure to the field of PFCC, I conclude that I am very keen to have patients and families involved in all aspects of care, and therefore, might have introduced personal bias to this project.

I attempted to eliminate these possible limitations in the process of completing this integrative review by following the guidelines set out by Whittemore and Knafel (2005). I also attempted to add rigor to the process by tracking themes as they arose in a grid (see Appendix B), and then again collectively during the theming process (see Appendix C), so as little bias as possible would be introduced.

Although I attempted to review every article available within the search limitations on the selected search engines, it is very possible that I may have excluded

articles based on too narrow search criteria or simply because articles were not available on the online databases. In this age of technology, an Internet database search can be completed, but there is never a guarantee that every piece of research associated with families in adult ICU's will be located despite the best of efforts.

Despite these limitations, I believe the contribution of each authors' study, and the strength of the design of this integrative review, provide insight into evidence informed practice in the adult ICU. Each study was reviewed in light of the limitations identified by the study authors, or upon my review, and chosen for its merit according to the Johns Hopkins Research Evidence Appraisal Tool. While I may have introduced personal bias, as listed above, I do not believe that this would diminish the validity of my work overall as all attempts to maintain rigor of my integrative review process were made. Given the opportunity to repeat the integrative review, I would have maintained the methodological process, and research question, but I would have expanded the list of key words to include adult ICU and family involvement.

### **Implications for Practice, Education, and Research**

Upon completion of the integrative review, I have formulated recommendations for integrating patient and family centred care in the adult ICU setting. I grouped the recommendations for four populations; recommendations for providers, recommendations for patients and families, recommendations for leaders and policy makers, and finally, recommendations for providers, leaders/policy makers, and patients and families

*Recommendations for Providers:*

- Establish next of kin, or family member, based on patient preference disregarding traditional views of ‘family’ to incorporate the patient’s definition of family. When the patient is unable to discern and define family for themselves, health care providers should do due diligence to define, locate, and provide information to the next of kin and share these findings with other staff by way of the medical record or other written tool.
- Offer opportunities for involvement of patient/family in daily routines and decision-making, adopting the principles of ‘nothing for me, without me’.
- Incorporate patient and family members in all aspects of information sharing at the level in which the patient/family members wish to be involved. For example, incorporating patients and families in interdisciplinary rounds or by providing a nurse navigator for the patient/family.

*Recommendations for Patients and Families:*

- Become involved in the monthly ICU Quality and Safety Committee in order to provide feedback on possible changes in the unit, and provide an active voice that will be heard alongside clinical staff when discussing errors, opportunities for improvement, or unit success.

*Recommendations for Leaders and Policy Makers:*

- Identify and designate nurse and physician champions for patient and family centred care in the ICU.

- Develop competencies for health care providers to comfortably and regularly communicate with patients, families, and each other in the care of ICU patients.
- Revise or create new policies, which uphold the four core principles of patient centred care.
- Review current organizational practices or policies that conflict or are in opposition to a model of patient and family centred care.
- Develop a protocol and order set for the standardization of palliative care in the ICU that encourages harmony in staff relations, reduces anxiety and stress for patients and families, eliminates pain for patients, and reduces possibilities of post traumatic stress for staff. Staff and families who experienced the death of a patient/loved one in the ICU could develop this protocol.

*Recommendations for Providers, Leaders/Policy Makers, and Patients and*

*Families:*

- Create and sustain a culture of patient and family centeredness by supporting all members of the health care team to be sensitive to the needs of others and promote respect and dignity of staff, patients, and families in the ICU.

### **Dissemination of Findings**

My research project will be presented to a review committee in partial fulfillment of a Master's in Nursing degree with a specialty in education. In addition to the required presentation, I hope to prepare and publish an abbreviated version of these findings for an

academic journal and/or conference. The results from this integrative literature review have and will continue to inform my clinical practice and duties as a practice consultant for my employer. I am currently completing work to take these clinical findings and implement interdisciplinary rounds with patients and families in the ICU environment as well as introduce patients and families to the currently running Quality and Safety Councils that operates across all acute and residential sites. I hope to implement these findings on a broader scale to create a larger organizational wide influence that would see the involvement of patients and families in all aspects of their care alongside their health care providers.

### **Conclusion**

My goal in this integrative review was to complete an assessment of current research in order to identify evidence informed practices for patient and family centred care in adult ICU's. Incorporating relational inquiry as a way to inform this work has provided a strong theoretical underpinning in which to fully identify and apply the findings. Relational inquiry, and patient and family centred care are linked, as both require the full participation and open awareness of who and how we are in this world. Patients react to circumstances based on the knowledge and understanding of a much larger world than a hospital visit. This 'larger' world is relational to a patient's being and understanding, and health care providers can begin to encounter this world with a much deeper understanding by incorporating the primary players – the patient's family.

Nurses are in an ideal position to assist and understand patients in this relational context as nurses are at the front line of patient and family care. By leveraging nurse's proximity to patients and families on a daily basis, and harnessing patient and family

centred care in a relational light, nurses have a tremendous opportunity to improve the foundation of health care delivery. This project has underscored for me the full and meaningful capabilities nurses have to incorporate patient and family centred care in a tangible and powerful way. My hope is that by presenting and analyzing the multiple ways that nurses can affect change in the realm of patient and family centered care, they can use this information to bring about powerful change for patients and families. Nurses are well positioned to consult, collaborate, participate, and share information with patients and their families in a way that leaves lasting and positive impact on the patients and families receiving care in the ICU environment.

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## Appendix A: Johns Hopkins Nursing Evidence Based Practice: Research Evidence

## Appraisal Tool

<b>Article Title:</b> Spiritual care of families in the intensive care unit	<b>Number:</b> 1
<b>Author:</b> Wall, R.J., Engelberg, R.A., Gries, C.J., Glavan, B., & Curtis, J.R.	<b>Date:</b> 2007
<b>Journal:</b> Critical Care Medicine	
<b>Setting:</b> 10 Intensive Care Units in Seattle with patients of varying acuity	<b>Sample (composition/size):</b> 356 out of a 1038 families surveyed
<b>Study Type:</b> Quasi Experimental	<b>Does this study apply to my patient population:</b> Yes
<b><i>Strength of Study Design</i></b>	
<b>Was this sample size adequate and appropriate?</b>	Yes
<b>Were Study participants randomized</b>	No
<b>Was there an intervention?</b>	No
<b>Was there a control group?</b>	No
<b>If there was more than one group, were groups equally treated, except for the intervention?</b>	n/a
<b>Was there adequate description of the data collection methods</b>	Yes
<b><i>Study Results</i></b>	
<b>Were results clearly presented?</b>	Yes
<b>Was an interpretation/analysis provided?</b>	Yes
<b><i>Study Conclusions</i></b>	
<b>Were conclusions based on clearly presented results?</b>	Yes
<b>Were study limitations identified and discussed?</b>	Yes
<b>Pertinent study findings and recommendations?</b>	The authors concluded that ICU staff should assess the families' need for spiritual advisors for every patient dying in the ICU and consult with a spiritual advisor if desired by the family. The authors also recommend a comprehensive approach to assisting families with death and dying in the ICU but made no recommendations for practice.
<b>Will the results help me in caring for my patients?</b>	Yes, limitations of study must be weighed.
<b><i>Evidence Rating</i></b>	
<b>Strength of Evidence Rating</b>	Level 2

<b>Quality Rating</b>	Good (B)
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Appendix B: Individual Evidence Summary

Individual Evidence Summary

#	Citation	Author	Date	Evidence Type	Sample & Sample Size	Results/Recommendations	Limitations	Rating (Strength/Quality)	Theme	Search Database used	Where was the research generated?
1	Azoulay, E., Pochard, F., Chevret, S., Jourdain, M., Bornstain, C.,...Lemaire, F. (2002). Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients. <i>American Journal of Respiratory and Critical Care Medicine</i> , 165, 438-442.	Azoulay, E., Pochard, F., Chevret, S., Jourdain, M., Bornstain, C.,...Lemaire, F.	2002	Quantitative, Randomized, Control Trial	87 who received, and 88 who did not receive Family Information Leaflet (FIL) from 34 French ICU's. Total n =175	Provision of a family information leaflet significantly improved comprehension in medical/surgical ICU's in France. No statistically significance was found that showed an increase in satisfaction with care when FIL was provided. However comprehension and family members understanding of diagnosis and treatment	Only one family member was provided the FIL. Language and comprehension and family meetings were controlled for each centre. Statistical significance reached	I/B	Communication	CINAHL	France
2	Chien, W. Chiu, Y.L., Lam, L., Ip, W. (2006). Effects of a needs-based education programme for family carers with a relative in an intensive care unit: A quasi-experimental study. <i>International Journal of Nursing Studies</i> , 43, 39-50.	Chien, W. Chiu, Y.L., Lam, L., Ip, W.	2006	Quasi-Experimental Study (two non randomized study groups with pre/post test design)	32 control group, 34 experimental group.	Based on a administered needs assessment families in the experimental group received two one hour sessions with a RN. A pre and post test was also administered to assess anxiety and satisfaction. Experimental group showed significant decline in anxiety and increase in satisfaction. Sufficient power demonstrated for reproducibility.	Small sample size in a single unit - however power was demonstrated. Reproducibility is feasible but not fully examined.	I/A	Communication	CINAHL	Hong Kong
3	Daly, B.J., Douglas, S.L., O'Toole, E., Gordon, N.H., Hejal, R., Peerless, J., Rowbottom, J., Garland, A., Lilly, C., Wiencek, C., Hickman R. (2010). Effectiveness trial of an intensive communication structure for families of long-stay ICU patients. <i>Critical Care Medicine</i> , 138(6), 1340-1348.	Daly, B.J., Douglas, S.L., O'Toole, E., Gordon, N.H., Hejal, R., Peerless, J., Rowbottom, J., Garland, A., Lilly, C., Wiencek, C., Hickman R.	2010	RCT, quantitative	354 patients in the experimental arm and 135 in control arm.	Intensive communication system that occurred five days after admission and at least once weekly after intervention	Aim was to demonstrate reduction in LOS with ICS. This was not proven. Authors still acknowledge that ICS may be an effective tool for meeting information/support needs.	I/A	Communication	CINAHL	Canada and the US
4	Huffines, M., Johnson, K.L., Smitz Naranjo, L.L., Lissauer, M.E., Fishel, M.A., D'Angelo Howes, S.M., Pannullo, D., Ralls, M., Smith, R. (2013). Improving family satisfaction and participation in decision making in an intensive care unit. <i>Critical Care Nurse</i> , 33(5), 56-68.	Huffines, M., Johnson, K.L., Smitz Naranjo, L.L., Lissauer, M.E., Fishel, M.A., D'Angelo Howes, S.M., Pannullo, D., Ralls, M., Smith, R.	2013	Quasi-Experimental Study	41 pre and 48 post intervention family satisfaction surveys examined	Families in the pre intervention group completed FS tool and families in post intervention also completed FS questionnaire. Well done needs assessment but poor data collection and robust example of tools and tool selection. More research on validity of the tool is needed.	low sample size, no proof of saturation of data collection, reproducibility to other sites not discussed, single site data collection.	I/B	Communication	CINAHL	Maryland, Baltimore
5	Jacobowski, N.L., Girard T.D., Mulder, J.A., Ely, E.W. (2010). Communications in critical care: Family rounds in the intensive care unit. <i>American Journal of Critical Care</i> , 19(5), 421-430.	Jacobowski, N.L., Girard T.D., Mulder, J.A., Ely, E.W.	2010	Quasi-Experimental Study	227 patients enrolled (187 of those patients were survivors and 40 were non-survivors)	Authors found that some families benefited from inclusion on interdisciplinary rounds while some families felt rushed. Overall satisfaction scores (using FS ICU) did not differ between control group and those that did attend rounds. Significant improvements in some aspects of satisfaction related to communication did result from the intervention.	Only English speaking participants used in the study. Study was done in a single centre - replicability to other centres unverified. The authors noted: "it is possible that improvements in satisfaction were confounded by unmeasured factors such as time spent in further communications during the rest of the day"(p.428).	I/B	Communication	CINAHL (found from journal hand searching)	Nashville, Tennessee

#	Citation	Author	Date	Evidence Type	Sample & Sample Size	Results/Recommendations	Limitations	Rating (Strength/Quality)	Theme	Search Database used	Where was the research generated?
6	Lautrette, A., Darmon, M., Megarbane, B., Joly, L.M., Chevret, S., Adrie, C., Barnoud, D., Bleichner, G., Bruel, C., Choukroun, G., Curtis, R., Fioux, F., Galliot, R., Garouste-Orgeas, M., Georges, H., Golgran-Toledano, D., Jourdain, M., Loubert, G., Reignier, J., Saidi, F., Souweine, B., Vincent, F., Kentish Barnes, N., Pochard, F., Schlemmer, B., Azoulay, E. (2007). A communication strategy and brochure for relatives of patients dying in the ICU. <i>The New England Journal of Medicine</i> , 365(5), 469-478.	Lautrette, A., Darmon, M., Megarbane, B., Joly, L.M., Chevret, S., Adrie, C., Barnoud, D., Bleichner, G., Bruel, C., Choukroun, G., Curtis, R., Fioux, F., Galliot, R., Garouste-Orgeas, M., Georges, H., Golgran-Toledano, D., Jourdain, M., Loubert, G., Reignier, J., Saidi, F., Souweine, B., Vincent, F., Kentish Barnes, N., Pochard, F., Schlemmer, B., Azoulay, E	2007	Quantitative. Prospective, randomized control trial.	Family members of 126 patients in 22 French ICU's	Intervention group received a brochure on bereavement as well as a end of life conference that was guided by the five objectives [VALUE - was the mnemonic used, "value and appreciate what the family members said, to acknowledge the family members emotions, to listen, to ask questions that would allow the caregiver to understand who the patient was as a person, and to elicit questions from the family members" (pp 473)]. A family member was then called via phone 90 days after the death and scored on the IES (Impact of Event Scale). Anxiety and depression was also measured as a secondary outcome.	Limitations listed by authors: paternalistic practice of MD's high in France, HADs scores were not recorded before to see change. Not blinded. Difficult to have complete control on the control group - separate analysis noted that control group had more time/detail than usual - making the intervention stronger!	I/A	Communication	MEDLINE	France
7	Lily, C.M., Sonna, L.A., Haley, K.J., Massaro, A.F. (2003). Intensive communication: Four-year follow-up from a clinical practice study. <i>Critical Care Medicine</i> , 31(5), S394-399.	Lily, C.M., Sonna, L.A., Haley, K.J., Massaro, A.F.	2003	Quantitative	2,361 patients in an adult ICU - large sample size	Intensive communication plan was applied to an adult ICU families, with LOS, mortality used as measures for the success of the communication plan. Secondary outcome variables on agreement between family and team and between team members was also measured. Pre-intensive communication and post intensive communication used as comparisons for the intervention.	Intervention deducted from one unit (is it reproducible to other units?). Labor intensive intervention.	II/A	Communication	CINAHL	Boston, MA
8	McDonagh, J.R., Elliott, T.B., Engelberg, R.A., Treece, P.D., Shannon, S.E., Rubenfeld, G.D., Patrick, D.L., Curtis, J.R. (2004). Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with satisfaction. <i>Critical Care Medicine</i> , 32(7), 1484-1488.	McDonagh, J.R., Elliott, T.B., Engelberg, R.A., Treece, P.D., Shannon, S.E., Rubenfeld, G.D., Patrick, D.L., Curtis, J.R	2004	Quasi-Experimental Study	214 Family members in 51 different families were recorded with 45 family satisfaction surveys completed/collected post intervention by family and staff.	Measurement of families spoken time in the conference completed along with post data on family/staff satisfaction done. Four intensive care units were studied in conversations about withdrawal of life support. No correlation between the length of time of conference and satisfaction but a noted correlation between satisfaction and increased proportion of family speech was found.	communication done outside the conference may have impacted on level of satisfaction. Less than 50% of the possible conferences were audiotaped. Only family satisfaction measured but many other variables exist.	II/B	Communication	CINAHL	Seattle, Washington
10	Mitchell, M.L. Chaboyer, W. (2010). Family Centred Care - A way to connect patients, families and nurses in critical care: A qualitative study using telephone interviews. <i>Intensive and Critical Care Nursing</i> 26, 154-160.	Mitchell, M.L. Chaboyer, W.	2010	Qualitative - phenomenological	10 family members contacted via telephone. Purposeful sample.	Families supported in providing physical care by bedside nurse. Demonstrated as an effective way to include family in a meaningful way and provide purpose to presence.	No control, gender of participants (only one man!), perspectives of patients and nurses not considered.	III/A	Collaborat	MEDLINE	Australia
9	Olausson, S., Ekebergh, M., Lindahl, B. (2012). The ICU patient room: Views and meanings as experienced by the next of kin: A phenomenological hermeneutical study. <i>Intensive and Critical Care Nursing</i> , 28, 176-184.	Olausson, S., Ekebergh, M., Lindahl, B.	2012	Qualitative - phenomenological/hermeneutical method	14 family members (of 16 asked) via purposeful sampling.	family members in two general ICU's asked to take photos of the ICU and then interviewed about their thoughts on the photos (triggering via photo voice method).	Small sample size - unsure if saturation met for reproducibility for other areas.	III/B	Presence	MEDLINE	Sweden
11	Shaw, D.J., Davidson, J.E., Smilde, R.I., Sondoozi, T., Agan, D. (2014). Multidisciplinary team training to enhance family communication in the ICU. <i>Critical Care Medicine</i> , 42(2), 265-271.	Shaw, D.J., Davidson, J.E., Smilde, R.I., Sondoozi, T., Agan, D.	2014	Quasi-Experimental Study	121 families pre and post the intervention in 2 adult ICU's. 98 practitioners participated and 46 of the pre/post surveys (the max of what could be matched) were analyzed	Families completed the FSICU 24 pre and post the training period. Staff completed the training with pre and post surveys to assess improvement.	low nurse involvement. Selection bias of families surveyed. No tracking to see which families received the trained staff skills versus who did not. 46/186 staff actually trained and evaluated.	II/B	Communication	CINAHL	San Diego, California
12	Slatore, C.G. Hansen, L., Ganzini, L., Press, N., Osborne, M.L., Chestnutt, M.S., Mularski, R.A. (2012). Communication by nurses in the intensive care unit: Qualitative analysis of domains of patient-centered care. <i>American Journal of Critical Care</i> 21(6), 410-418.	Slatore, C.G. Hansen, L., Ganzini, L., Press, N., Osborne, M.L., Chestnutt, M.S., Mularski, R.A.	2012	Qualitative-ethnographic	53 interviews with 33 staff was conducted to theme data around communication of nurses in the ICU	Two domains of communication need to be better utilized by nurses in order to provide PFCC. Sharing power/responsibility and therapeutic alliance.	sample size adequate, done in two sites, the population of nurses questions is rather homogenous - reproducible findings??	III/A	Communication	CINAHL	Portland
13	Steel, A., Underwood, C., Notley, C., Blunt, M. (2007). The impact of offering a relatives' clinic on the satisfaction of next-of-kin of critical care patients - a prospective time-interrupted trial. <i>Intensive and Critical Care Nursing</i> 24, 122-129.	Steel, A., Underwood, C., Notley, C., Blunt, M.	2007	Quasi-Experimental Study	321 family members	Increasing satisfaction (in particular to communication) by implementing a set time for families to chat with the attending MD and RN by appt. Satisfaction increased in control group but not with statistical significance. Ethics reviewed well - fascinating intervention. Thoughts that the time of the appointment may not have been satisfactory (2-3pm 5 days a week - perhaps, evening appointments would have been better).	Only 46% of the surveys were returned. A single site study - is it possible to reproduce in other sites?	II/B	Communication	CINAHL	Norfolk, United Kingdom
14	Wall, R.J., Engelberg, R.A., Gries, C.J., Glavan, B., Curtis, J.R. (2007). Spiritual Care of Families in the intensive care unit. <i>Critical Care Medicine</i> 35(4), 1084-1090.	Wall, R.J., Engelberg, R.A., Gries, C.J., Glavan, B., Curtis, J.R.	2007	Quasi Experimental Study. "Cross-sectional study, using data from a randomized cluster trial" (p.1084)	356 (out of 1038 eligible families) family members of patients dying during an ICU stay or within 24hrs of ICU discharge. 10 Hospitals in the Seattle areas were the basis of the study	ICU staff should assess the families need for spiritual advisors for every patient dying in the ICU and consult with a spiritual advisor if desired.	Spiritual care of families whose loved ones survived ICU stays were not measured. Primarily Caucasian respondents - findings may be hard to generalize to other ethnic/cultural areas. Non-respondent bias. Prior religious beliefs not discussed. Results based on two quantitative questions imbedded in the FS ICU 34.	II/B	Consultation	CINAHL	Washington, Seattle

