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How do the Attitudes and Beliefs of Critical Care Nurses  
Influence the Process for Family Presence Resuscitation?

A DISSERTATION

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By

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How do the Attitudes and Beliefs of Critical Care Nurses  
Influence the Process for Family Presence Resuscitation?

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Understanding critical care nurses' attitudes and beliefs regarding FPR can help identify what interventions can be used to promote and support the family presence during resuscitation in the ICU setting. The purpose of this research study was to describe the attitudes and beliefs of the critical care nurse and develop a beginning theory describing the process and practice critical care nurses use regarding family presence during resuscitation. Grounded theory methodology (Glaser, 1992) based on symbolic interactionism was used. The conceptual orientation influencing this project is the Patient Family Centered Care model. Results: Nurses' use constructs of attitude and beliefs as their basis to support their understanding that FPR is "the right thing to do" and "putting the patient first". The first priority at the initiation of the resuscitation is for the patient; that the resuscitation begins in a timely manner, and that all members of the team are present. During this crucial time, the nurses ask family members to leave the room for the resuscitation. When the resuscitation outcomes are expected to end with the demise of the patient, the staff then begins to address the needs of the family and the need for a FPR event. In this study participants identified that family facilitator availability is crucial in making a decision to allow a FPR event to occur. This study also identified a new phenomenon of allowing or involving family members input in regard to the decision to

end resuscitation. Participants expressed this practice as common in critical care settings. It is unclear as to the benefit to the family or the efficacy of this practice based on evidence. Data from the conceptual model themes were used to develop the beginning theoretical model for FPR in critical care the “Justice Model”. Central to this model that critical care nurses are guided by the ethical principles of “Justice” their right to be there, and beneficence to first do no harm to the patient first (resuscitation attempt) and family second for closure.

This dissertation by Jesus Cepero fulfills the dissertation requirement for the doctoral degree in Nursing approved by Janice AgazioT, Ph.D, as Director, and by Janice Hinkle, Ph.D, and Cathie E. Guzzetta, Ph.D, as Readers.

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Dedication:

I dedicate this dissertation to my parents. Their personal sacrifice, support, and unconditional love have given me my desire to succeed. My wife and son, who have supported my efforts to achieve my degree through many missed meals, my son's weekend sporting events, and husband and fatherly duties.

To my professors and CUA, I cannot imagine a better program. The support I received from the entire faculty has led me to this moment. To my committee, for their support and endless hours preparing me. Dr. Guzzetta for inspiring me to study Family Presence Resuscitation, and Dr. Agazio who truly has gone out of her way to facilitate my success.

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## CHAPTER I

### INTRODUCTION

Today, an increased family expectation includes remaining at the bedside during invasive procedures and resuscitation. Despite this desire, the attitudes of health professionals remain mixed (Miller & Stiles, 2009). Fears persist that family members may interfere with resuscitation efforts or that they will be psychologically traumatized by their experience (McMahon-Parks, Moule, Bengner, et al., 2009).

Family presence during resuscitation (FPR) has been discussed in the literature since the mid-1980s. Most documented experiences in family presence resuscitation events in the literature have been in emergency department settings. There have been few articles (Bassler, 1999; Duran, Able, Oman, Kozial & Szymanski, 2007; Fallis, McClenathan, & Pereira, 2008; Knott & Kee, 2005; MacLean, Guzzetta, White, Fountain, et al., 2003, Twibell, Siela, Riwits, et al. 2008) describing the experience of family presence in critical care units. This author conducted a meta-synthesis of FPR literature and identified that only 29% of the participant nurses were critical care nurses. Furthermore 692 of the 2180 nurses or 32% in literature had experienced an actual family presence event.

With more than two-thirds of the sample of nurses in the literature having never experienced an actual family presence event and being primarily from the emergency care experience, findings from these studies do not translate to a critical care environment and cannot be generalized to the critical care nurse population. A gap existed in studying

American critical care nurses on their attitudes, beliefs, and process for FPR.

Several national healthcare organizations such as the Emergency Nurses Association, (ENA, 2005, 2010), American Association of Critical Care Nurses (AACN, 2010) have published position papers endorsing FPR practice. Currently, there is no information recorded on how often FPR events occur or how many departments have policies and procedures. MacLean, et al. (2003) estimated that less than 5% of critical care departments in this country have actually developed policies and procedures and carry out this practice.

#### Problem Statement

There was a paucity of published research that describes critical care nurse's attitudes, beliefs, and practices regarding family presence resuscitation (FPR). Understanding critical care nurse's attitudes, beliefs, and process for FPR will fill the gap in the literature and help identify what interventions are needed to support and promote the practice of FPR in the critical care nursing environment. In this author's experience, nurses are usually the gatekeepers, as well as the advocates for family presence in most environments. If potential barriers can be identified in regard to attitudes, beliefs and process for FPR in critical care nurses, then this research will support practice change and support safe, efficient FPR events utilized by critical care nurses.

### Statement of Purpose

The purpose of this research study was to describe the attitudes, beliefs and process that critical care nurses' use in deciding whether to support FPR in critical care. This information led to a theory utilizing a Grounded theory method, describing the attitudes, beliefs, and process critical care nurses have regarding FPR. The primary research question was "How do the Attitudes and Beliefs of Critical Care Nurses Influence the Decision Making Regarding Family Presence Resuscitation"?

### Research Aims

- 1) Describe how the attitudes and beliefs of critical care nurses' impact decision making regarding FPR.
  - a. What are the attitudes and beliefs of critical care nurses regarding FPR?
- 2) Describe the process critical care nurses use in making the decision to permit or restrict the presence of families during resuscitation.
  - a. What are the process facilitators in the decision making process?
  - b. What are the decision points or processes used that restrict FPR?
- 3) Describe how the multidisciplinary critical care team influences critical care nurse's attitude, belief, or process about FPR.
  - a. How do the attitudes, beliefs, and processes of other healthcare team members impact critical care nurses' attitudes, beliefs, and process for FPR?

- 4) Describe what critical care nurses believe about the impact of FPR on family members who are present during resuscitation.
  - a. What do critical care nurses believe is the impact of FPR on family members?

### Conceptual Orientation

This study utilized Glaser (1992), grounded theory methodological approach to understand critical care nurses' attitudes, beliefs, and process for FPR. The theoretical underpinning for this ground theory study, utilizes pragmatic reflection, as described by Sandelowski, (1986) as experiencing an interactive process involving individuals and their social and natural environment and symbolic interactionism as: (1) people act toward things and people on the basis of meaning they have for them, (2) meaning stems from interactions with others, and (3) people's meanings are modified through an interpretive process used to make sense of and manage their social world.

### Operational Definition

Family Presence for Resuscitation: is defined as the attendance of family in a location that affords visual or physical contact with the patient during resuscitation events (ENA, 2005 & 2010).

Attitude: is defined as an accumulation of information about an object, person, situation, or experience. A predisposition to act in a positive or negative way toward some object (Littlejohn, 1983)

Belief: is defined as a representation of information someone has about an object of attention and although not necessarily factual, the person holding the belief thinks it is (Kahle, 1983).

Critical Care Nurse: is defined as a nurse practicing in the following environments: Intensive Care Units, Cardiac Intensive Care Units, Cardiovascular Intensive Care Units, and Surgical or Trauma Intensive Care Units caring for adult patients greater than 21 years of age.

Pediatric Critical Care Nurse: is defined as a nurse practicing in a Pediatric Intensive Care Unit and caring for patients less than 21 years of age.

Neonatal Intensive Care Nurse: is defined as a nurse working in a Neonatal Intensive Care Unit and caring for patients 0-12 months of age.

General Nurse: is defined as a nurse practicing in non-critical care areas as defined above.

Emergency Nurse: is defined as a nurse working in an Emergency Department.

Actual FPR Experience: is defined as an actual personal experience having brought a family member into a resuscitation area.

### Assumptions

The major premise of this study was that critical care nurses believe in providing holistic care and that having a family member involved in patient care is essential for the

patient's support. Nurses consider FPR events as the "right thing to do" and in the best interest for family member and patients. Although there are many published articles in the literature identifying nurses' support for FPR in emergency care, there are too few studies in critical care to assume that the practice of FPR is supported by critical care nurses.

The multidisciplinary team has an influence over critical care nurses' attitude, belief, and process for FPR. Published research identifies that nurses are more favorable in their responses to FPR than physicians. Physicians are primarily responsible for authorizing FPR events after an assessment is made by a nurse that a family member is a suitable candidate for a FPR event. Even with an endorsement and formal position statement from the Society of Critical Care Medicine for FPR, there is still much resistance to FPR by critical care physician providers (Bauchner, Waring & Vinci, 1991, Doyle, Post, Bureney, et al., 1987, Gold, Gorenflo, Schweink & Bratton, 2006, Grice, Picton & Deakin, 2003). This resistance to FPR events may have a strong influence on critical care nurses for FPR.

### Limitations

Several limitations were inherent to this study. The study location was an adult tertiary care hospital in an urban metropolitan city. With this understanding, the data and theory developed from this sample do not reflect the attitudes, beliefs, and process for FPR of critical care nurses in non-urban, teaching, or suburban hospitals.

This study examined the attitudes, beliefs, and process of critical care nurses as defined previously. Excluded from this study were nurses from Post Anesthesia Care Units (PACU), the Operating Room, the Emergency department, and Non-Intensive Care areas.

### Significance to Nursing

This study begins to fill a significant gap of knowledge by studying American Critical Care Nurses' attitudes, beliefs, and process for FPR. The background review of the literature and research suggested the need for a Grounded theory approach to develop a beginning theory on the practice of FPR in the critical care setting. The findings and theory developed by this study may identify facilitators, barriers and other variables to be examined in future studies to advance the practice of FPR in critical care environments. Information learned will assist in the development of guidelines, policies, and procedures that are applicable to the intensive care nursing environment. It was therefore crucial to first identify how the attitudes and beliefs of the critical care nurse impact the process for FPR.

### Summary Chapter 1

This introductory chapter included the background of the problem, the conceptual orientation, and the purpose of the study. The research question, "How do the attitudes and beliefs of critical care nurses influence FPR?" was identified as well as the definition of terms, and significance of the study to critical care nursing and its assumptions. This

study begins to fill the gap that exists in literature of FPR in critical care by describing critical care nurses' attitudes, beliefs, and the process for FPR. A beginning theory was presented to facilitate the identification of facilitators, barriers, and other variables to be examined in future studies to advance the practice of FPR in critical care environments.

CHAPTER II  
REVIEW OF THE LITERATURE  
Introduction

Today, an increased family expectation includes remaining at the bedside during invasive procedures and resuscitation. Despite this desire, the attitudes of health professionals remain mixed (Miller & Stiles, 2009). Fears persist that family members may interfere with resuscitation efforts or that they will be psychologically traumatized by their experience (MacLean, et al., 2003).

There are few studies that have been completed on the practice of family presence resuscitation in adult or pediatric critical care units. Some nurses express strong support, while others are reluctant to allow a family member into the room to witness their loved one's resuscitation. Two surveys of nurses strongly criticize the practice of FPR because of a lack of rigorous scientific research and do not support the current Emergency Cardiovascular Care recommendations on FPR (Helmer, Smith, Dort, Shaprio & Katan, 2000; McClenathan, Torrington & Leyehan, 2002).

Several national healthcare organizations such as the Emergency Nurses Association, (ENA, 2005) and the American Association of Critical Care Nurses (AACN, 2010) have published position papers endorsing FPR practice. Currently, there is no information recorded on how often FPR events occur or how many departments have policies and procedures. MacLean, et al (2003) estimated that less than 5% of critical care departments in this country have actually developed policies and procedures and

carry out this practice.

Supporters of FPR tend to emphasize the basic human right of patients and patient's families for the families to be present during resuscitation. Some authors have argued that paternalistically protecting families by barring the families from the resuscitation room is no longer warranted because bystanders witness critical events in the field (Halm, 2005). Television shows such as *ER* and *House* have allowed many individuals to have an idea of what they might see if they are present during resuscitation. However, FPR opponents are cautious about possible interruptions of resuscitation attempts as well as risk of litigation and traumatic memories experienced by patient's families (Halm, 2005).

Family presence during resuscitation (FPR) has been discussed in literature since the mid-1980s. Most documented experiences in family presence resuscitation events in the literature have been in emergency department settings. There have been few articles (Bassler, 1999; Duran, et al, 2007; Fallis, McLement & Pereira, 2008; Knott & Kee, 2005; MacLean, et al, 2003; Twibell, Siela, Riwits, et al., 2008) describing the experience of FPR in critical care units. This author conducted a meta-synthesis on FPR literature and identified that only 29% of the participant nurses were critical care nurses and 692 of the 2180 or 32% of the nurses surveyed had experienced an actual family presence event.

With more than two-thirds of the sample of nurses in the literature having never experienced an actual family presence event and being primarily from the emergency care experience, findings from these studies cannot be generalized to the critical care.

### Seminal Research

The first documented experience with FPR occurred in 1982. The staff of the Foote Hospital emergency department began to question the standard practice of excluding close family members from the treatment room during resuscitation of cardiac arrest victims. On several occasions, family members asked to be present with a dying relative who was undergoing resuscitation. One person, after riding in the ambulance with resuscitation in progress, refused to leave the room and another begged to be with her police officer husband who had been shot. Individual decisions to permit these relatives to enter the resuscitation room briefly, with chaplain support, were allowed (Doyle, et al, 1987).

In this study, a survey evaluating chaplain services, including those provided during resuscitation was sent to a number of families. One of the questions was “Do you wish you had been present during resuscitation?” Result posted that, 18 surveys were returned with 72% said yes and 28% said no. This led to the first structured FPR program created to permit selected family members to be present in the resuscitation room (Doyle, et al, 1987).

This work by Doyle, et al, 1987, was followed 3 years later by a retrospective survey involving the distribution of a questionnaire to 21 emergency department staff.

The findings revealed that 81% had experienced FPR in the resuscitation room and 71% endorsed the practice. The author acknowledged that some resuscitation seemed “more human” in the presence of family members and that some staff expressed increase in their stress levels as the patients was being resuscitated (Walker, 2008). In a follow-up paper, Hanson and Strawser (1992) asserted that in their nine years of facilitation acceptance of death and grieving by this FPR method, staff members continue to find it a humanizing and a workable experience.

The first British survey to examine ED staff views on FPR was a pilot study conducted by Back and Rooke (1994). Almost two-thirds (65%) of the respondents had experienced FPR and of these, (54%) reported positive feelings. However, reservations about the practice included concerns that FPR would inhibit staff performance (Engel, 2005).

Compton, Madgy, Goldstien, et al., (2006) concluded that FPR was a “norm” in the pre-hospital setting. In a survey of emergency medical services (EMS) providers, it was reported that (93%) had substantial experience of performing resuscitation in the presence of family members and most (77%) had performed more than 20 adult cardiopulmonary resuscitation attempts. Urban EMS providers more often reported having been threatened or concerned about their own wellbeing because of FPR, (66.7%,  $p = 0.003$ ), and a similar number reported that FPR had a negative impact on their ability to perform CPR (53.7%,  $p = 0.006$ ).

### The Multidisciplinary Team's Influence on FPR

There is evidence that family presence (FP) during invasive procedures and Family Presence Resuscitation (FPR) are supported by multidisciplinary teams, patients and families (Bauchner, Waring & Vinci, 1991; Doyle, et al, 1987; Meyers, Eichhorn, Guzzetta, et al., 2004; Sacchetti, Lichanstein, Carraccio, et al., 1996). Most of the studies are descriptive in nature. Evidence from these studies suggests that families want to be given the option to attend resuscitation events (Davidson, Powers, Hedayest, et al., 2007; Doyle, et al, 1987). These studies were conducted in emergency department settings. It is unknown what the impact of the multidisciplinary team has in the critical care environment on nursing decision for FPR.

### Psychological Effects on Resuscitation Teams

Redly and Hood (1996) surveyed 38 Emergency Department workers in their study to identify major factors of concern about FPR. In that survey, more nurses were supportive of FPR practice than physicians, (nurses – 75%, doctors – 50%). The concern that ranked highest by the respondents was that the emotional stress on the staff would increase (61%).

Timmermans (1997) conducted in-depth interviews with 28 multi-professional staff in an emergency department setting. The study identified that no professional staff reported episodes where FPR had an adverse effect on the resuscitation process due to staff stress. However, Engel (2005) reported that FPR would not interfere with patient

care, although 68% of the professional staff surveyed felt anxiety and stress having the family member in the resuscitation room.

### The Effect of FPR Education on Staff Attitudes and Beliefs

Some articles examine the preparation of staff for FPR. These articles are interventional in nature and do not explore the attitudes and beliefs of providers prior to implementation. The studies identified that staff experience with FPR is improved through education (Bassler, 1999; Meyers, et al, 2004; Parkman, Henderson & Knapp, 2006). Performance anxiety, i.e., running resuscitation, announcing medications or performing procedures with FPR, is primarily felt by resident physicians (Bauchner, et al, 1991; Doyle, et al, 1987; Gold, Gorenflo, Schwenk & Bratton 2006; Grice, Picton & Deakin, 2003). In the Emergency Department settings, attending physician and nursing staff are in support of FPR practices with set FPR guidelines that have inclusion and exclusion criteria.

Bassler (1999) used a quasi-experimental pre-test, post-test design to determine if an educational program could change nurse's beliefs about FPR. In this study, the intervention involved a class in which nurses from the emergency department and critical care learned about the hospital's FPR policy, risk management perspectives, obstacles to letting patients' families be present during resuscitation and protocol for offering FPR. The program significantly increased the proportion of nurses who thought that patients' families should be given the option for FPR from (56% to 89%) and who planned to offer the FPR options to families from (11% to 79%). In addition, the study reported that

emergency nurses were 2 times more likely than critical care nurses to allow FPR. The reasons for this disparity have not been explored. To date, no study has examined the attitudes and beliefs of critical care nurses on FPR.

### Psychological Distress on Family Members

Weslien and Nilstun (2003) interviewed emergency department staff. In this study, (73%) of physicians reported they would “never” advise family members to be present during resuscitation. The reason cited was the concern for sensory disturbances that would be experienced and, in particular, considered that the witness would suffer posttraumatic stress in the form of flashbacks. Several studies, (Booth, Woolrich & Kinsella, 2004; Macy, Lampe, O’Niel, et al., 2006; Ong, Chan, Srither, et al., 2004; Redley & Hood, 1996) reported that witnessing emergency procedures involved in patient care would offend family members. This concern could partially explain why so many staff members cite potential litigation as a major disadvantage for FPR. However, no evidence indicates any litigation arising from FPR (Halm, 2005).

The majority of the FPR literature indicates that there are little psychological or untoward events that have occurred due to family presence (Powers & Rubenstein, 1999; Robinson, Mackenzie-Ross, Campbell-Hewson, et al., 1998; Tinsley, Hill, Shah, et al., 2008). In these studies, the data from interviews indicate that families believed their presence helped comfort their family member. Tinsley et al, (2008) studied the experience of families during cardiopulmonary resuscitation in a pediatric ICU. In this

study, it was identified that over 50% (N=10 out of 20) of the participants believed that it helped them accept their child's death. In addition, 67% (N=14 out of 21) believed touching their child brought comfort to the patient.

Robinson and colleagues (1998) investigated the psychological effect of FPR on patients' families by randomizing patients to standard care or FPR. In a survey used to examine anxiety, depression, grief, intrusive imagery, and avoidance behavior at 1, 3, and 9 months post events. Psychological disturbance did not differ in the two groups at 3 different time periods. All family members who participated in FPR were also satisfied with their decision to remain with their loved one. There have been no published articles on FPR experience in an adult critical care setting.

#### Relevant Themes Identified In the Literature

In two studies, nurses reported that FPR was a right of patient's families to be present (Grice, Picton & Deakin, 2003, Mangurten, Scott, Guzzetta, et al., 2006). These two studies identified that nurses' comfort with FPR increased with the presence of a Family Presence Facilitator (FPF). The facilitator is a specially trained staff member who stays with the family member to comfort, assess, and educate the individual to assist in coping with the experience (Grice, Picton & Deakin, 2003; Jarvis, 1998).

Five studies (Bassler, 1999; Mangurten, Scott, Guzzetta, et al., 2006; Powers & Rubenstein, 1999; Sacchetti, et al., 2000; Twibell, 2008) identified that there was no statistically significant increase in support for FPR related to the age of the nurse, years of experience, or educational levels. However, Twibell (2008) identified that nurses

working in an emergency department setting, having attained national certification, and those who were members of a professional organization statistically had more support for FPR than those in other settings and those nurses without certifications or professional organization membership.

In all studies identified to date, there was only one negative experience recorded on the part of a family member. Powers and Rubenstein (1999) identified that one nurse documented the FPR event as harmful to the family member. The article did not elaborate on the experience or why the nurse perceived the experience to be negative.

#### Environment of the Resuscitation Area

An area of concern, by staff during FPR has been the amount of space available during the resuscitation. During resuscitation, code carts, ventilators, and other equipment are brought into the room. This reduced considerably the resuscitation space and area available to families to witness the resuscitation. This concern was expressed in two studies (Macy, et al., 2006; Timmermans, 1997) who reported space in emergency departments as a reason to not accommodate relatives request to be present.

Environmental impacts on FPR in critical care areas has not been studied or identified in the literature.

#### Attitudes and Beliefs for FPR of Healthcare Staff

Mitchell and Lynch (1997) found that (63%) of nurses and physicians in emergency departments were not in favor of FPR. Similarly, Ong and colleagues (2004) identified that (75%) of Asian nurses and physicians were not in favor of FPR. The

impact of cultural and religious beliefs on the part of healthcare providers in regard to FPR has not been studied.

Large surveys of professional organizations have also found disparate results among nurses and physicians. Helmer and colleagues, (2000) studied members of the American Association for the Surgery of Trauma (AAST) comparing them to members of the Emergency Nurses Association. More members of AAST felt that FPR was inappropriate during all phases of resuscitation because it would interfere with patients' care and increase the stress of the trauma team. Furthermore, more AAST members did not think that FPR was the right of the patient. Only (18%) of AAST members considered FPR beneficial.

McClenathan and colleagues (2002) found that fewer physicians (20%) than nurses and allied health professionals (39%) would allow FPR in adults. Nurses were more likely than residents to support FPR and more attending physicians than residents supported FPR. In a study by Ong, et al., (2004) of Asian healthcare staff, found that more nurses than physicians thought that the decision whether to offer FPR always should be a team decision, whereas, physicians thought that the senior medical officer should have the decision-making authority.

Mitchell and Lynch (1997) found that FPR was more likely to be adopted by healthcare providers with higher seniority, which coincides with increased experience, confidence, and competence in dealing with resuscitation procedures and distressed

members of patients' families. Other correlating factors were having an Emergency Nurse certification and practicing in the Midwestern states.

Doyle and colleagues (1987) identified that despite some disadvantages to FPR perceived by staff members, staff do endorse FPR. Seventy one percent of staff endorsed FPR because it makes patients "more human". Similar findings were reported by Meyers, Eichorn, Guzzetta, et al., (2000) who identified that (76%) supported FPR and (88%) felt that a FPR should continue.

Grice and colleagues (2003) found that more than half of physicians and nurses favored giving patients' relatives the option of being present during resuscitation. In two studies (Back & Rooke, 1994; Chalk, 1995) it was found that the majority of nurses thought that patients' family members should be able to be present and would allow the families presence if the family member were informed and were supported by dedicated personnel.

(See Table 1 – Literature supports FPR)

<u>Author</u>	<u>Support FPR</u>	<u>Actual FPR</u>
Bassler	89%	0
Duran	90%	84
Fallis, et al.	92%	0
Fein, et al.	88%	0
Grice, et al.	66%	0
Jarvis	100%	37
Knott & Lee	NR	10
Mangurten, et al.	90%	38
MacLean, et al.	NR	345
Mian, et al.	71%	86
Miller & Stiles	NR	17

Twibell, et al.	NR	75
Range:	66-100%	
Median	89%	
Mean	86%	

However, most of the literature relates to emergency providers' care in nature. One cannot make the assumption that because generally there is support for FPR by emergency nurses, that the experience, attitudes, and beliefs of critical care nurses are similar.

#### Actual FPR Experience

This author's meta-synthesis identified that (n= 692) of the 2180 or 32% nurses surveyed had identified an actual FPR event experience. Actual FPR experience was defined as: A nurse having had an actual personal experience having brought a family member into a resuscitation area. With more than 2/3 of the sample never having experienced an actual FPR event, findings from these studies cannot be generalized to the critical care nursing population. A gap exists in studying American Critical Care Nurses in the adult and pediatric setting on their attitude, beliefs, and process for FPR.

#### Advantages / Disadvantages of FPR

There are many advantages identified in the literature regarding FPR. This include helping meet the emotional and spiritual needs of patients' families and assisting families to understand the patient's condition to appreciate that the code team did its best to help the patient (Booth, et al., 2004; Meyers, et al., 2000; Redley, & Hook, 1996).

Meyers and colleagues, also identifies that (15%) of nurses perceived resuscitation attempts to be more aggressive than efforts when family members were not present.

There are several disadvantages identified by staff members in the literature. Disadvantages have been expressed more often than advantages. The disadvantages have been a perception that FPR could interfere and disrupt the resuscitation process by impairing the function of the code team. Additionally, staff members worry about performance anxiety and not having enough personnel available to fully support patients' families and discussed previously on p. 16 because of the focus on resuscitation care (Bassler, 1999, Ong, et al., 2004).

Boyd and White (2000) identified that almost (25%) of staff reported two or more symptoms of acute stress after a non-traumatic adult resuscitation. However, these symptoms did not differ between events with FPR and those without family presence.

Staff members are generally concerned that family members are ill equipped to be present during codes and might interfere with resuscitation. Booth, et al, (2004) surveyed 172 emergency departments in the United Kingdom and found few reported problems with or interference by patient's family members.

The following table presents an aggregate compilation of advantages and disadvantages found from the literature: (See TABLE 2)

Table 2 Advantages and Disadvantages

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## Advantages:

- Family members presence calms staff behavior during resuscitation / procedure
- Assures family that everything is being done
- Provides patients support during event or resuscitation
- Family member has the right to be there
- Facilitates information from family members during procedures
- Educates families as to what is going on during resuscitation
- Overall has no impact on care

## Disadvantages:

- Stress on team
- Hinders communication within resuscitation team
- Medical legal concerns
- Negative feelings of being watched
- Afraid families will see a mistake
- Stress on family member witnessing resuscitation
- Afraid of family member being traumatized
- Inadequate space to accommodate family members
- Interference or disruption of resuscitation process

### Ending Resuscitation Attempts

In a descriptive survey method study, Helmer and colleagues (2000), identified that neither Emergency Nurses Association members nor American Association of Surgical Trauma members believed that FPR would lead to more prolonged or heroic resuscitative efforts. However, Mitchell and Lynch (1997) and Yanturali, Ersoy, Yuruktumen, et al., (2005), found that (68%) of emergency department staff believed that abandoning the resuscitation attempt would become difficult in the presence of family members. Additionally, (79%) cited this as the third highest reason for rejecting FPR. Compton and colleagues, (2006) identified that (65%) of EMS providers had experienced situations where the family members had wanted resuscitation to continue even when this was deemed futile.

### Facilitating the Death Experience

From the seminal work done by Doyle, et al. (1987), FPR has been seen as supportive to families. The opportunity to touch or talk to the patient has been regarded as very helpful to the relatives. The holistic resuscitation perspective is usually championed by a nurse, chaplain or physician. Evidence that FPR allows the opportunity for the family to see that everything has been done facilitates mourning and the acceptance of death was documented in several studies (Ong, et al., 2004; Weslien & Nilstun, 2003). Yanturali and colleagues, (2005) identified that the biggest benefit to FPR was the ability to facilitate communication with family members (80%) and having family members present allowed them to witness the resuscitation efforts and sometimes

facilitating the termination of resuscitation efforts thereby making the notification of death easier (58%).

### Ethical – Theoretical Viewpoints on FPR

Ethical or theoretical perspectives are sometimes not clearly discernable or described in the articles reviewed. Most studies on FPR appear to be teleological, or consequence based theories (Halm, 2005). Ethical theory is concerned with actions that bring about the most benefit to all, identifying the foreseeable good and harm that can result in a given situation. (Beauchamp & Bowie, 2001). Studies in this review identified the universal ethical principles of autonomy (respect for a person’s values and decisions), beneficence (to do no harm) in support of FPR.

McClenathan, et al. (2002) and Redley and Hood (1996) both identified a deontological perspective, a duty-based theory that emphasizes moral duties and principles rather than consequences of action (Beauchamp & Bowie, 2001). They agreed that the “duty” for FPR is the emphasis on caring for patients’ families to meet their needs, and duty to prevent psychological harm. Autonomy and justice (treating like cases alike by distributing benefits and burdens fairly) were the two ethical principles raised in support of FPR as authors advocated either that the patients’ families have the right to be present (autonomy) or questioned the fairness of excluding patients’ family members (justice).

Helmer, et al. (2000) presented an opposing viewpoint. He and colleagues argue that the families do not have the “right” to be there. The first imperative is to advocate

for the patient. The two issues that they identified opposing FPR were that it (1) violates confidentiality and thus a patient's right to privacy, indicating a concern for the ethical principles of nonmaleficence and (2) that FPR could lead to post-traumatic stress disorder because of witnessing resuscitation "is not an appropriate sight for distraught family members to witness". This view represents a paternalistic, consequentialist view focused again on nonmaleficence.

However, the majority of the family literature indicates that there are little psychological or untoward events that have occurred due to family presence. (Powers & Rubenstein, 1999; Robinson, et al., 1998; Tinsley, et al., 2008).

#### Patient Family Centered Care Model

As a Grounded theory study, the conceptual orientation influencing this research proposal is the Patient Family-Centered Care model (PFCC) The PFCC model is an approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients, families and healthcare practitioners (Frampton, Gilpin, & Charmel, 2003). Central to this model is the belief that healthcare providers and family are partners, working together to best meet the needs of the patient.

PFCC is significant to this study because it is the family member who provides the patient's primary strength and support. Families are central to the care of the patient in all settings and degree of illness. In PFCC, the healthcare team enters into a collaborative relationship focused on the care of the individual patient in order to provide

quality, comprehensive care. There are eight core concepts in the PFCC model as describe by Frampton, and colleagues (2003) and are detailed in the next section.

**Family Strengths:** Family is recognized as a constant in the patient's life. This concept obligates the healthcare provider to support and empower the family member as partners and decision-makers in the patient's care. This concept is significant to FPR because the family is responsible for making decisions and in order for families to feel comfortable in their decisions and in the care being provided, support is needed to include families in all levels of care including resuscitation events.

**Respect:** PFCC requires "trust and respect" for families' values, beliefs, religion, and background. Respect helps foster a partnership and decreases false judgments of families on the part of providers based on assumptions or misconceptions. The literature review has demonstrated that many families choose and sometimes demand to remain at the bedside. Nursing staff should make decisions to support families' wishes and beliefs.

**Choice:** Families can feel helpless and powerless at times when faced with grave or serious conditions. Therefore, information and knowledge is important to empower families to make choices regarding their family member's care. Being present during the resuscitation event allows family members the knowledge that all care is being done and facilitates the beginning of the grieving process.

**Information sharing:** The two-way sharing of information helps build a trusting relationship and partnership. Knowledge about the patient's customs and beliefs during a time of crisis may be helpful for both the patient and providers during resuscitation events.

Support: Family strength involves respecting the decisions that families make, offering comfort as families cope with their loved ones illness, meeting the social, developmental, and emotional needs of the patient. This support allows families to have increased self-sufficiency and confidence managing their loved ones care.

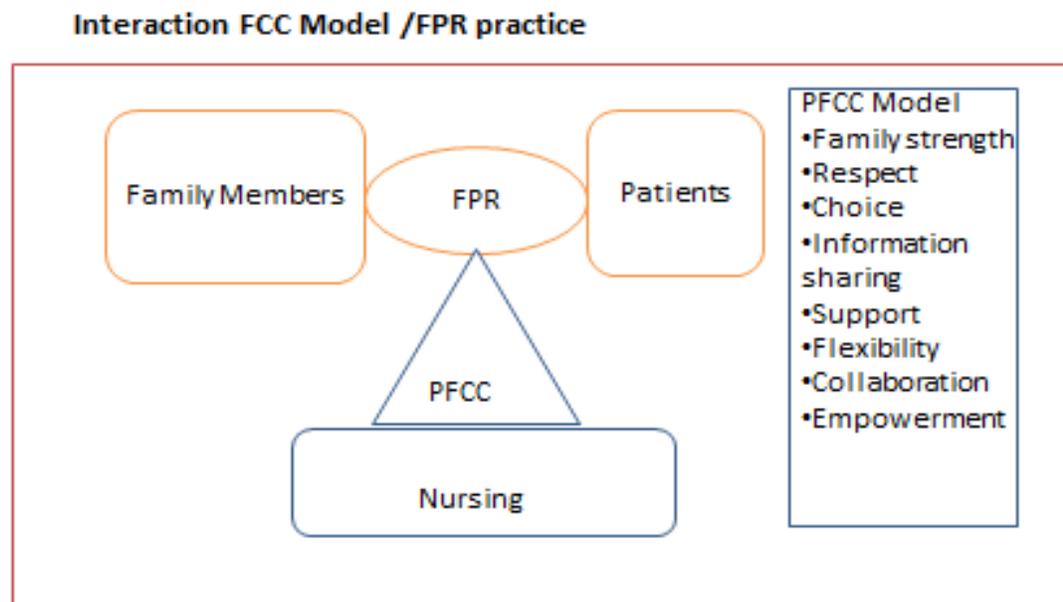
Flexibility: Families have different personalities, life experiences, values, beliefs, religion and cultures. Healthcare providers need to understand that preferences to remain at the bedside are different and providers must be able to adapt to meet the individual families wishes without judgment.

Collaboration: Families and healthcare providers working together in the best interest of the patient define collaboration. In an atmosphere of mutual respect for the understanding that each brings to the situation knowledge, i.e., information as to the patient's wishes for resuscitation and providers knowledge on the medical aspects and ethics of those wishes, help in delivering and in the receipt of quality care.

Empowerment: This concept establishes the family as having constant role in the patient's life. Removing a family member during a resuscitation event could be perceived as diminishing the family member's rights of empowerment to make decisions on behalf of the patient.

To illustrate the relationships between nursing, the FPR process and PFCC model, the FPR interaction model is being proposed (See figure I). To influence a positive FPR experience, it is assumed that the critical care nurse may use some or all of the eight key concepts of the PFCC model to make their decision regarding the FPR process and to protect both the patient and family members.

Figure 1- Interaction Model



#### Research Methods Identified in the FPR Literature

In the search of the literature there were 105 articles identified using the FPR search criteria. Of these, thirty-four articles were screened as not relevant to the topic or meeting inclusion criteria. Fifty-seven articles had FPR information that was relevant to the topic. After careful analysis of these articles, eighteen met the initial screening criteria and had relevant information regarding critical care nurses' attitudes and perceptions on FPR.

Of these 18, 6 studies identified and assessed nurses' attitudes and perceptions of FPR but had not differentiated those nurses' findings from the general sample population (Bauchner, et al., 1991; Gold, et al., 2006; McClenathan, et al., 2002; Powers & Rubenstein, 1999; Sacchetti, et al., 2003). These articles identified that nurses were included in the survey but lead to no insight on nurses' attitudes or perceptions regarding FPR events. These articles were then excluded from the findings portion of the review and analysis.

In the final sample of 12 articles, there were 2180 nurses surveyed on FPR

TABLE 3

<u>Work Environment</u>		<u>Nurses</u>
Emergency Care Nurses		725
Critical Care Nurses	Canada	450
	US	640
Other (not specified)		262
Neonatal		66
Pediatric Critical Care		37

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N = 2180

Of the 12 studies, five utilized mixed methods, two utilized a descriptive survey design, two utilized a descriptive Quantitative design, one used a quasi-experimental design, one used a descriptive Qualitative design and one utilized a Phenomenological design.

Eight studies were conducted in the United States. The international studies on FPR included three from the United Kingdom and one from Canada. Sample sizes from these studies identified in this review ranged from as few as 10 RNs to as many as 450 critical care nurses as seen in the Fallis, McClement & Pereira, (2008) article surveying the Canadian Association of Critical Care Nurses.

#### Instrumentation

Of the 12 studies that identified Critical Care Nurses' attitudes and beliefs, only 2 used a modified version of the Parkland FPR 1997 version instrument (Duran, et al., 2007; Mangurten, et al., 2006). In these two studies, the authors identified the need to modify the tool for appropriateness in their studies. Duran, et al., (2007) and Mangurten, et al., (2006) reported estimated utilized Cronbach's alpha. Knott and Kee, (2005) utilized the Parkland FPR instrument to develop semi-structured interview questions utilized in her descriptive qualitative method study.

Of the remaining 10 articles, the authors describe creating their own survey tools. (Bassler, 1999; Fein, et al., 2004; Grice, et al., 2008; Jarvis, 1998; MacLean, et al., 2003; Mangurten, 2006, Mian, Warch, Whitney, et al., 2007; Miller & Stiles, 2009; Twibell, 2008). These surveys ranged from 10 to as many as 85 questions. In three studies, Fallis, Maclean and Mian utilized different statistical methods to assess reliability of their instruments. Where Jarvis utilized face validity and Mian utilized experts to review study questions. Grice and colleagues did not elaborate how the reliability of the survey instrument was measured.

Overall, use of the survey method was the predominant design. So far, studies in the literature on FPR are hampered by the use of convenience samples, small sample size, low response rates, and the lack of description of sample characteristics. These validity issues creates difficulties creating conclusions, comparing samples, generalizability, and an inability to replicate studies. The knowledge on the attitude and beliefs about FPR from nurses is predominately from the emergency care practice setting derived from descriptive retrospective survey methods.

### The Critical Care Nursing Environment

#### Critical Care Nurses Support Family Presence Resuscitation

When a patient is admitted to a critical care unit, the nurse assigned is primarily accountable and responsible for the care the patient receives and managing the family's needs for support, care, and education. In this setting, a close relationship occurs between the patient, family member, and nurse. The critical care nurses identify with the universal principle autonomy and being a patient advocate for their patients and family members. This advocacy leads their decision making to support the needs for a family member to "be there" during resuscitation and sometimes the final moments of their loved one's life. Critical Care nurses believe that it is the "right thing to do" for family members when conditions permit to allow families to be present during resuscitation in the ICU.

Critical care nurses use a holistic family centered approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial

partnership among patients, families, and healthcare practitioners (Institute for Family Centered Care, 2008). Central to this model is the belief that healthcare providers and family are partners, working together to best meet the needs of the patient.

The evidence is compelling in the literature that the benefits of FPR far exceed the risks. Therefore, in reviewing the advantages and disadvantages as they relate to literature, critical care should support FPR. Unfortunately, there are very few studies that can support the claim, “critical care nurses support FPR”.

This study begins to fill the significant gap of knowledge studying American critical care nurses’ attitudes, beliefs, and process for FPR. The review of the literature and research methods used thus far suggested the need for a Grounded theory approach to develop a beginning range theory on the practice of FPR in the critical care setting. The findings and theory developed by this study will facilitate the identification of facilitators, barriers, and other variables to be examined in future studies to advance the practice of FPR in critical care environments. Information learned from the data will assist in the development of guidelines, policies, and procedures that are applicable to the intensive care nursing environment.

## Conclusion

To date, findings from current studies support that FPR is a practice that can be utilized in the environment of intensive care units. This study identifies the process, attitudes, and beliefs of critical care nurses to bridge this knowledge gap. Developing a

beginning theory facilitates future studies by identifying the phenomena of decision making in critical care as it relates to the FPR practice.

There were no research studies that utilized a qualitative approach studying nurse's attitudes and beliefs of FPR in a critical care setting. The review of the literature and the research methods used thus far suggested the need for a Grounded theory method approach to develop a beginning theory on the practice of FPR in the critical care setting. The findings from this study identified variables to be later studied using mixed methods approaches to advance the study and practice of FPR in critical care.

#### Summary

The meta-synthesis identified that 692 of the 2180 or 32% nurses surveyed had identified an actual FPR event experience. With more than 2/3 of the sample never having experienced an actual FPR event, findings from these studies cannot be generalized to the critical care nursing population. A gap existed in studying American critical care nurses in the adult and pediatric setting on their attitude, beliefs, and process for FPR.

There was no consistent use of any particular measurement instrument. Most studies identified study tools that were created by the researcher for that study. The use of the Parkland FPR tool was found reliable in two studies but not consistently used in the literature on FPR. The lack of consistent measurements makes the evidence on the efficacy of FPR in critical care areas questionable. There were no documented findings of the variables or constructs that preclude or support FPR practice in the critical care setting.

In this chapter, the literature on FPR was reviewed from the seminal research conducted by Doyle and colleagues, (1987), through the current knowledge. This chapter explored the psychological effect of FPR on the resuscitation teams, psychological distress literature of family members witnessing resuscitation, relevant themes identified, environmental factors of the resuscitation area, the attitudes and beliefs of FPR by healthcare staff, the effect education has on FPR beliefs, the effects actual experience with FPR has, the perceived advantages and disadvantages of FPR, how FPR facilitates the death experience, ethical and theoretical viewpoints, the patient family center care model's impact on FPR, a model of a conceptual map derived from current literature, methods, and instruments used to study FPR, a conclusion and summary.

The review of the literature and the research methods used thus far suggested the need for a Grounded theory method approach to develop a beginning range theory on the practice of FPR in the critical care setting. The findings from this study identified variables, to be later studied, to advance the study and practice of FPR in critical care. To date, the studies in critical care does not support that FPR is a practice that can be supported in the environment of intensive care units.

## CHAPTER III

### METHODOLOGY

#### Introduction

The purpose of this study was to describe how the attitudes and beliefs of critical care nurses' impact the process for FPR. One aim was to develop a theory utilizing a Grounded theory method, describing the attitudes, beliefs, and process critical care nurse have regarding FPR. The primary research question was "How do the Attitudes and Beliefs of Critical Care Nurses influence the Process for Family Presence Resuscitation?"

#### Study Design

The design for this study was based on an inductive qualitative descriptive method of inquiry. Qualitative designs are useful in the generation of categories for understanding human phenomena and the investigation of the interpretation and meaning that people give of the events they experience (Polkinghorne, 1991). This study utilized a Grounded theory (Glaser, 1992) methodological approach to understand critical care nurses attitudes, beliefs, and decision-making process for FPR. Grounded theory is primarily based on symbolic interactionism as described by Sandelowski (1986) as based on the tenets that: (1) people act toward things and people on the basis of meaning they have for them, (2) meaning stems from interactions with others, and (3) people's meanings are modified through an interpretive process used to make sense of and manage

their social world.

According to Burns and Grove (2005), grounded theory has been used most frequently to study areas in which previously little research has been conducted and to gain a new viewpoint in a familiar area of research. While there has been significant research on FPR in emergency care settings, little was known on the attitudes, beliefs, and decision-making process for FPR in critical care nursing settings.

### Grounded Theory

Using Grounded theory led to an initial theory on attitudes, beliefs, and process used by critical care nurses on FPR. A Grounded theory is one that is induced from the data rather than deduced from the data (Lincoln and Guba, 1985). The definition of Grounded theory states the theory will: "... Fit the situation research and work when put into use. By fit we mean that categories must be readily (not forcibly) applicable to and indicated by the data under study; by work we mean that they must be meaningfully relevant and able to explain the behavior under study...." Glaser and Strauss (1967, p 635)

In 1964, George Herbert Meade developed symbolic interaction theory. Symbolic interaction theory explores and emphasizes that people construct their realities from symbols around them through interactions; therefore, individuals are active participants in creating meaning in a situation. According to Strauss & Corbin, (2008),

grounded theory both describes and explains the system or behavior under study and consequently is a methodology for developing theory that is grounded in data systematically gathered and analyzed. Grounded theorists aim to discover patterns and processes and understand how a group of people defines their reality via their social interactions and grounded theorist search for social process present in human interactions.

According to Polit and Beck (2010) in Grounded theory, both the research problem and process used to resolve it are discovered during the study. A procedure referred to as constant comparison is used to develop and refine theoretically relevant categories. Categories elicited from the data are constantly compared with data obtained earlier in the data collection process so that commonalities and variations can be determined. As data collection proceeds, the inquiry becomes increasingly more focused on emerging theoretical concerns. A central feature of Grounded theory is purposive theoretical sampling, which involves purposive selection of sample members and the method of constant comparative analysis whereby the researcher observes, collects, organizes, and simultaneously analyses data.

#### Research Question

The research question for this study was "How do the Attitudes and Beliefs of Critical Care Nurses Influence the Process for Family Presence Resuscitation"?

### Participants and Recruitment

A non-probability, purposive sample of critical care nurses was used to recruit participants who had at least 1 year of critical care nursing experience and had experienced an actual family presence during resuscitation event. Non-critical care nurses from units such as ED, PACU, NICU, and OR were excluded from the study. Morse (1992) contends that people who have lived with certain experiences are often best sources of knowledge about those experiences. Participants were contacted by internal hospital communications through staff meetings, emails, and flyers posted on selected units.

### Setting

The study was conducted in a 320 bed tertiary non-teaching hospital in an urban area of Baltimore, Maryland. The critical care unit participants were recruited from critical care units that include a 28 bed Medical Intensive Care Unit, and a 10 bed Cardio-Thoracic Intensive Care Unit, primarily of adult patients.

### Protection of Human Subjects

Protection of study participants was assured throughout the study. A preliminary expedited study approval for this study was obtained from the Investigational Research Board from the organization's Health Science Institutional Review Board of St. Joseph's Medical Center. The study received IRB approval through the Committee

for Protection of Human Subjects and the Vice-Provost of Graduate Studies at The Catholic University prior to the initiation of the study. (See Appendix A)

To protect participants, after verbal and written information was given to participants as to study purpose and procedure, the participant were asked to sign a written informed consent prior to the start of each interview. The Principal Investigator (PI) conducted all interviews, and protected both written, taped information, and specific identifiers of participants.

Interviews were downloaded electronically for transcription preparation. When downloading was complete, the digital interview was erased. All transcripts, logbooks, memo, demographic sheets, and consents with participant identifiers were stored in a locked cabinet. The PI's laptop was password protected to assure confidentiality and the protection of participant information and data.

Participants were informed that taking part in the study was on a voluntary basis and they had the right to terminate the interview at any time or request a withdrawal from the study without reprisal. There was minimal risk or discomfort to the participant. However, tape recording and observations were the method of data collection and could have made participants uncomfortable. In addition, the participants were informed that if they should become uncomfortable during the interview, they could request a recess or termination of the interview. Additionally, the investigator could have discontinued the interview to avoid perceived intense anxiety or discomfort on the part of the participant from unpleasant memories at any time.

## Procedure

To protect and guarantee confidentiality, after written consent was obtained, all study materials, transcripts and consents were secured. Transcripts of interviews did not have any participant's names or identifiers. The only information recorded on the heading of each transcript was given a number of the interview, date and time the interview occurred. The demographic sheet did not have the participant's names and was kept separate from the consent form when completed. (See Appendix B)

The consent form after completion was stored in the PI's home office in a locked cabinet. Additionally, stored electronic interviews and transcripts were held in the PI's password protected laptop and backed up to a 100 MB storage device, which was also password protected. When transcripts were shared with the committee chairperson, after review, the transcripts were shredded. Additionally, when transcripts were shared with the committee chairperson, the information was made available through a data storage device not through email communication. After the interview is reviewed, the data was erased from the storage device by the committee chairperson and PI.

## Interviews

Prior to beginning the interview, the PI engaged the participant in informal conversation to develop rapport, and alleviate any perceived anxiety. Semi-structured focused taped individual interviews lasting 60-90 minutes were recorded on two digital recording devices. The second device was used as a backup in case there was a recording

error or a battery failure. The interviews were conducted in private locations convenient for the participant and PI.

The study preliminarily began with the following questions: (Appendix C)

PI: Tell me about your experience having family members present during resuscitation?

Possible probe: How do you make the decision of whether to include the family?

Under what circumstances do you not allow FPR?

PI: When considering allowing FPR, what do you think about?

Possible probe: Clinical situation, psychological assessments?

The space in room, use of a facilitator?

PI: How does the multidisciplinary team influence your decisions on FPR?

Possible probe: Doctors, respiratory therapists, other nurses?

PI: In your experience, how does the family member cope with witnessing FPR?

Possible probe: Outward appearances, comments, impede resuscitation?

PI: If you were to guide other nurses on, what advice would you give?

Possible probe: Do and Don't

PI: Please share an experience of FPR from a decision to end resuscitation?

Using constant comparative analysis, preliminary questions changed to focus on emerging theoretical concern data from interviews. Sampling continued until data saturation was achieved, in other words, sampling to the point that no new information is obtained and redundancy is achieved (Morse, 1992). Additionally, to assure saturation and confirm or disconfirm cases to test refine and strengthen the theory proposed, five more interviews were conducted and coded. After reviewing the last three coded interviews, verification of data saturation and to validate the theory proposed, the committee chair authorized the end of data collection.

At the completion of the interviews, participants were thanked for their time, and information on how to access the PI was provided if there was a need for follow-up questions. Immediately after each interview, the PI recorded interview session comments on themes, insights, new codes, concepts, and impressions in the form of memos that were recorded in the PI logbook for interviews. The PI maintained memos to bracket and record thoughts and insights of the observations and experiences during the interviews sessions. According to Strauss & Corbin, (2008), memos and journals facilitate credibility by creating an audit trail.

#### Instrument

In a Grounded theory qualitative method design, there is no specific instrument used. A demographic sheet was used to gather pertinent information from each

participant excluding any identifiable information (S Appendix B). The demographic information that was collected included: (1) unit, (2) age, (3) gender, (4) years as a critical care nurse, (5) certification, (6) number of FPR events in the last year, (7) number of FPR events in their career, (8) level of education, (9) training on FPR, and (10) their response to whether they thought a policy or procedure on FPR would be helpful?

### Method of Analysis

All interviews were transcribed word for word. Transcripts were then loaded into Ethnograph 6 analytical software to facilitate coding. Beginning with the first interview, the PI coded data using the constant comparison method of Grounded theory. Initial coding of the data was accomplished by reviewing each transcript several times to identify and label data with substantive codes that described participants' perceptions and experiences.

After the initial three interviews had been transcribed and coded, the PI reviewed the interview process, techniques and coding process with the committee chairperson. After confirming the interview process and coding technique, a codebook was generated to assure uniformity of codes. Additional codes were added based on new data collected through subsequent interviews. Once an agreement was reached on codes and process, additional participants were interviewed until data saturation was reached.

Data analysis was performed using steps outlined by Glaser (1992) method of generating theory. The steps were: (a) Level I coding-open coding, (b) Level II coding-axial coding, and (c) Level III coding-selective coding.

Level I substantive coding was accomplished by reviewing the data line by line looking for data from the participant's interview. The two substantive codes in level one coding included: (1) from the participant themselves and (2) from implicit codes constructed by the researcher based on concepts obtained from the data.

Level II categorization coding occurred through the constant comparative method in the treatment of data. The PI read and re-read interviews to compare data and then assign the data to clusters or categories according to best fit. Categories are simply coded data that seem to cluster and may result from the condensing of Level I codes.

### Level III

The PI then grouped conceptually- related codes into categories and elaborated the properties and dimensions of each category. Throughout the analysis and coding process, frequent consultation with the committee chairperson who is an expert in Grounded theory provided validation of technique and accuracy of coding.

Following data analysis, an initial FPR theory and schematic process map for FPR events in critical care was developed. To validate the initial theory and schematic process map for FPR, a group of three participants who volunteered after the initial

interview reviewed the themes, concepts, proposed theory, and schematic process map for accuracy. The information obtained from the feedback facilitated clarification of major concepts, theory, and schematic process map.

### Rigor

Lincoln & Guba (1985) identified four criteria for establishing trustworthiness (confidence in the data) of qualitative data: credibility, confirm ability, dependability, and transferability.

#### Credibility and Confirm Ability

Credibility is the believability of the findings that the researcher has produced (Leininger & McFarland, 2002). In order to establish credibility in this study, the PI maintained a journal that reflected decisions, impressions, bracketing occurrences, and analysis procedures. Additionally, the PI recorded participant's non-verbal responses, such as emotional responses during an interview question and any interruptions during the interview process and during data collection.

Credibility and confirmability was assured with assistance of the committee chairperson, reviewing initial interviews, codes, and interpretations. When agreement was reached after the initial three interviews, data collection continued until data saturation was reached. When data saturation was reached, an additional five interviews were conducted, transcribed, and coded. The committee chairperson and PI met to review themes and categories with citations from various interviews. When no new

relevant information was obtained, data collection was completed with the consent of the committee chairperson.

The final step taken to assure credibility and confirmability involved member checking. Polit and Beck (2010) identifies member checking as when a researcher returns to participants with an interpretation of the data thus seeking to obtain their reaction. At the completion of analysis, three participants were presented with themes, categories, theory, and process map for FPR. The information learned was then incorporated into the analysis.

According to Polit and Beck (2010) confirmability reflects the objectivity and neutrality of the data. In order to assure confirmability, reflexive journaling was practiced by the PI. Reflexive journaling allows the researcher to keep personal interpretations of the data in check and not allow his or her own feelings and experience to supersede the experience of the participant (Lincoln & Guba, 1985).

The PI is an intensive care nurse who has experienced multiple FPR events. Reflexive journaling citations were reviewed with the committee chairperson along with manuscripts and coding to assure proper bracketing preventing bias in interpretation or reporting of findings. Additionally, confirmability was assured through consistent communication and feedback from the research committee chairperson.

Initial bracketing was completed by the PI. The presuppositions identified by the investigator in this study include the following:

- Most critical care nurses support FPR, therefore, they should support FPR practices in critical care settings
- It is the right for family members to be present during resuscitation, therefore, critical care nurses should advocate for FPR events in their practice
- FPR should be the standard of practice for critical care environments and critical care nursing practice

### Dependability

According to Sandelowski (1986), dependability in a study is consistent when another researcher can clearly follow the “decision trail” used by the researcher as well as including rich descriptions provided by participants for the reader. The PI maintained a log and audit trail of all decisions related to data analysis as well as methodological decisions. The committee chairperson reviewed the methodological decisions to actual coded transcripts to assure proper application of codes, emerging themes, and concepts.

### Transferability

Transferability is the extent to which research findings can be transferred to other settings (Lincoln & Guba, 1985). Transferability was established by providing detailed findings with participant’s own word examples into the insight and context of this study, the attitudes, beliefs, and process for FPR. According to Polit and Beck (2010), this detailed description promotes an understanding and ease of transferring this study’s findings to other participant groups, settings, and other studies.

### Limitations

The findings in this study are derived from the participants in the setting described. Transferability to other settings such as NICU, PACU, OR, and emergency care settings may not be fitting.

As a critical care nurse and a supporter of FPR practice, potential bias could influence data collection and interpretation. The PI bracketed personal views and assure confirm ability and credibility by maintaining a logbook, reflexive journaling and having assumptions, theories, and concepts derived through data collection verified by the committee chairperson.

### Summary

The purpose of this study was to examine how do the attitudes and beliefs of critical care nurse's impact the process for FPR. This chapter describes the methodology, process, and procedure used in this qualitative study. A Grounded theory method was utilized to identify the attitudes, beliefs, and process critical care nurses have for FPR.

CHAPTER IV  
PRESENTATION OF FINDINGS

Introduction

The purpose of this study was to describe the attitudes, beliefs, and process that critical care nurses use in deciding whether to support Family Presence Resuscitation (FPR) in critical care. This information led to the development of a theory utilizing a Grounded theory methodology, which describes the attitudes, beliefs, and process critical care nurses have regarding FPR. The primary research question was: How do the Attitudes and Beliefs of Critical Care Nurses Influence the Process for Family Presence Resuscitation? The conceptual orientation was the Patient- and Family-Centered Care Model described in Chapter II. This study utilized Glaser, (1992) Grounded theory methodological approach to understand critical care nurses attitudes, beliefs, and process for FPR.

The research aims were to:

- 1) Describe how the attitudes and beliefs of critical care nurse's impact decision making regarding FPR.
  - b. What are the attitudes and beliefs of critical care nurses regarding FPR?
- 2) Describe the process critical care nurses use in making the decision to permit or restrict the presence of families during resuscitation.
  - a. What are the process facilitators in the decision making process?
  - b. What are the decision points or processes used that restrict FPR?

- 3) Describe how the multidisciplinary critical care team influences critical care nurses' attitudes, beliefs, or process about FPR.
  - a. How do the attitudes, beliefs, and processes of other healthcare team member's impact critical care nurses attitudes, beliefs, and process for FPR?
- 4) Describe what critical care nurses believe about the impact of FPR on family members who are present during resuscitation.
  - a. What do critical care nurses believe is the impact of FPR on family members?

To facilitate a discussion of the findings, this chapter is organized as follows: (a) data collection and transcription, (b) description of the participants, (c) findings, (d) the process by which patterns, themes and conceptual categories emerged, and (e) a description of the beginning theory as a consequence of the participant's data from this research study.

#### Data Collection

A total of 26 individuals participated in this study; nine were from the 10 bed Cardiac Intensive Care Unit and seventeen were from the 26 bed Medical Intensive Care Unit. A focused interview guide ( See Appendix C) was used initially as a beginning point for this research study to delineate major concepts. Questions selected were reviewed by the committee chairperson, who is an expert in Grounded theory as well as by Dr. Guzzetta, an expert on Family Presence Resuscitation in Emergency Care.

As interviews progressed and major concepts and themes emerged, the researcher incorporated additional questions. These questions were not originally part of the focus interview questions, but elaborated on participant data incorporating and clarifying themes and concepts that arose during the study.

All interviews were open-ended lasting 60 – 90 minutes. Each participant was encouraged to elaborate on his or her responses as much as possible and within his or her comfort level. Each participant was assured there were no right or wrong answers. The researcher maintained openness to the participants' description of attitudes and beliefs about Family Presence Resuscitation and attempted not to influence the participants' descriptions of their experiences.

The researcher verified accuracy of transcriptions by listening to the taped interviews and reading transcripts. Once the transcript was deemed accurate, the taped interview was erased to maintain confidentiality. All written transcripts were maintained secure by the researcher in a locked cabinet. The electronic transcripts and coded interviews were maintained in the researcher's password protected laptop.

Prior to and during the interview process, the researcher attempted to establish trustworthiness in several ways. First, the researcher bracketed any bias and preconceived notions concerning the subject under study. Memos were also used to reflect researcher's thoughts, feelings, and ideas regarding participants' responses and the research process. Secondly, before each interview and analysis activities, the researcher re-read all the bracketed biases and preconceived notions to enhance and maximize

qualitative rigor. The researcher also spent extended periods of time engaged with the data. Additionally, to further establish credibility of the findings, the researcher consulted with the committee chairperson and expert on Grounded theory.

### Interview Setting

The interview locations were determined by the participants. All interviews occurred on the Intensive Care Unit of the prospective participant. Interviews were conducted in staff lounges, and nursing unit main desk areas, at the convenience of the participant, as well as, assuring some degree of confidentiality. In 100% of the interviews, the participants preferred that the interviews were conducted on their shift of duty. Colleagues covered the participant's nursing duties during the interview process. On several occasions, the interview was interrupted when patient care questions needed the attention of the nurse being interviewed. Although several interruptions occurred, the researcher only experienced one occasion where the participant seemed distracted, but it was unclear if that the distraction was related to the patient care assignment.

Prior to beginning the taped interview process, each participant was given a thorough explanation of the researcher's interest in conducting the study, as well as the purpose of the study. Once potential participants felt informed regarding the study and its purpose written, informed consent was obtained and each participant was asked to sign the consent form (See Appendix A). Each participant was then asked to complete a demographic

form (Appendix B). Codes were assigned to each participant to ensure and maintain confidentiality.

### Development and Use of Memos

Immediately after the interview session and coding of the individual interviews, the researcher would document in memos, personal thoughts, and impressions denoting analytic and synthesis processes. In each memo, the researcher included personal thoughts, feelings, and reflections that emerged during the interviews or coding process. Themes, concepts, and codes emerging from the interviews or analysis were also documented in memos to ensure auditability of the data. Additionally, memos guided the researcher as a means to generate new questions for subsequent interviews as well as confirming that certain themes did appear to be emerging from the data.

### Data Analysis

The management of transcribed focused interviews was conducted by the use of Ethnograph 6.0. Analysis of the data began with repeated reading of the transcripts and listening to tapes several times prior to erasure. The data were examined to discover patterns, themes, and categories of the phenomena under study. The categories were coded and analyzed through further collection of the data. Data comparisons were made between the research demographic data and the information that was obtained from the interviews, memos, and participant's personal background information. Data analysis from the second interview occurred simultaneously and through comparative analysis

using Glaser's (1992) steps, which are open coding, axial coding, selective coding, and description of the basic social process. Data collection continued until the categories were saturated and no new data information was forthcoming. Data saturation occurred with interview twenty-one. However, the researcher interviewed an additional five participants to assure credibility and to confirm that saturation had been attained.

### Demographic Characteristics

Demographic data were collected prior to the interview process to provide a description of the study participants and to determine if participants met inclusion criteria. In order to maintain confidentiality and anonymity, participant names on the demographic sheet were deleted, and each participant was assigned a participant number for identification.

The total number of participants (n=26) was 35% (n=75) of the total sample of intensive care nurses in both units. The characteristics of participants are summarized in Table 4. The participants ranged in age from 31 to 64 years old, with a mean age of 45 years. Twenty-two (85%) were women and four (15%) were men. Seventeen (65%) were Medical Intensive Care Unit (MICU) nurses and nine (35%) were from the Cardiac Intensive Care Unit (CICU). (See Table 4)

**TABLE 4**  
**DEMOGRAPHIC DATA**

Description	MICU	CICU
<b>Total Registered Nurses</b>	60	15
<b>Total Sample 26 (35%)</b>	17 (65%)	9 (35%)
<b>Mean Age of Participants</b>	45 (Range 32-64)	44.6 (Range 31-55)
<b>Gender Female / Male</b>	15/2	7/2
<b>Mean Years of Experience</b>	19.8 (Range 8-39)	21.6 (Range 4-34)
<b>Levels of Education</b>		
<b>Dipl</b>	1	0
<b>AD</b>	7	1
<b>BSN</b>	9	6
<b>MSN</b>	0	2
<b>National Certification</b>		
<b>Yes</b>	10 (58%)	2 (22%)
<b>No</b>	7 (42%)	7 (78%)
<b>Training on FPR Policy would help?</b>		
<b>Yes</b>	10 (58%)	7 (78%)
<b>No</b>	7 (42%)	2 (22%)

The mean number of years of experience was similar in both units; MICU was 19.8 and the CICU was 21.6 with a range of 4 to 39 years of experience for both units. Although similar means, the MICU participant's lowest years of experience was eight years compared to four years of experience in the CICU. In both groups, there were fifteen BSN prepared nurses (56%); eight AD (30%), two MSN (8%) and one Diploma nurse (4%). National certification varied widely between units. The MICU staff had 58% certified nurses (n=10), compared to only 22% in the CICU (n=7).

The most striking characteristic of the participant was that 100% (n=26) had never had any formal education on Family Presence Resuscitation (FPR). Additionally, 65% (n=17) identified that having a formal policy and procedure on FPR would be beneficial to their practice. However, descriptive data from the participants identified some felt formal policies or guidelines would not be appropriate due to the fact that FPR was very individualistic. For example, one participant stated: “No cookie cutter approach to FPR would be appropriate; it’s too specific to the situation and family member”. (# 22)

## Findings

Research Aim 1, 1(a) and 2:

This section of Chapter IV will focus on the researcher’s findings specifically related to: (a) FPR (b) Attitudes (c) Beliefs (d) and (e) Process for FPR.

## Family Presence Resuscitation

All participants in this study had a FPR event experience as a requirement for inclusion. Although all (n=26) supported FPR, there were differences expressed regarding their support for this practice in critical care. One nurse (# 7) expressed her personal concern about FPR, but would still support families’ wish to be present during resuscitation:

I personally would not want my family seeing my resuscitation, but if the family is present at the time of the code, I don't ask them to leave or if they ask to stay, I believe it is their right to be present....

Participant # 13 also reflected:

I think 99% of the staff is in favor of FPR, but that is based on individual case-by-case basis. If we don't feel it is right for the family to be there or if a pastoral care person or nursing supervisor is not available, they cannot be here during the code. Our primary duty is to the patient first

The presence of the patient care facilitator to support the family during the witnessed resuscitation event was integral to nursing support of FPR events. Twenty-five of the participants expressed that not having a facilitator available was a contraindication in their support to allow family members to witness a resuscitation attempt.

We are blessed to have such strong pastoral care staff; it is their job to sit with the families and explain what is going on. Also, if the family is over the top or not dealing well, they are the ones responsible to take them out of here....

On the night shift (7p to 7a) several participants expressed their support was contingent on having someone available to be with the family. The participants expressed a different level of support for the facilitator role being the charge nurse or

nursing supervisor; although, none expressed that this different level of support had a major impact on resuscitation attempts.

### Nurses' Attitudes Regarding FPR

Attitudes on FPR varied among participants. The four conceptual categories that emerged from this concept were: (1) nurse as champion, (2) families as an afterthought, (3) personal experience with FPR events, and (4) nurses' experience.

#### (1) Nurses as champions

Participants expressed that the ICU nurse was most often the initiator and champion for FPR in their unit. Although there were several participants who expressed that hospital administration, physicians and other team members were in support of FPR in both ICUs.

... (# 17) it's sometimes difficult when families are not there.... we do mini-codes to allow families to get there because we feel it is important for them to be there....when they arrive they see that everything was being done and sometimes it helps them make the decision to stop or withdraw care. We do this to give them closure....

....(# 19) I think it [FPR] should always be offered to any families, there are some that will not want to be at the bedside, but I think ummm it should be offered to all families...

At times when there are barriers to FPR in the units, nurses overcome resistance by their advocacy for FPR events:

(# 2) ... It seems like some physicians who have been in practice a number of years tend to be more close-minded to FPR .... It is difficult because you have the stress of dealing with the patient as well as dealing with the physician who doesn't want families there.... I try to talk to the physician in advance of the code and work on improving my day-to-day working relationship with them so that a discussion on FPR events can occur before the code happens. I have found that this has been helpful and successful to consider when you are deciding to allow a family member in or not...

## 2) Family as an afterthought

It was evident from the participants that resuscitation patient care demands take precedence over allowing or engaging family members during FPR events. As stated by participant # 2:

...sometimes we don't even remember if the family is there during a resuscitation because we are so focused in on the patient umm and then after the event some of us will certainly circle back and speak to the families and again just because there are so many competing demands some of us don't, it's so hard...

... (#19) A lot of times we may start a code without family members and when we realize that the situation is not going to improve it's actually requested by one

of the code team members to get the family.... It's helpful to families and also the code teams when they come in see.... There is a mutual respect and understanding that I think helps families come to terms and some of them visually see the lengths and measures that we go through to help save a family member...

...(# 23) [Family presence] is not our first thought, the first thought is always the patient, if the family member is there that's one thing, but, the team goes into action and then it's has anyone gone to get the family?

### 3) Personal experiences with FPR

Of the 26 participants eleven, ( $n=11$ ) had personal event experiences with their family members and FPR. These personal experiences, nine ( $n=9$ ) positively influenced their desire and practice to allow family presence resuscitations. However, two participants had divergent views: Participant # 25 stated:

... I think as long as somebody kept my family updated that would be enough for them. I'd wouldn't want the last picture in their minds' eyes is standing there or laying in the bed three-quarters naked with 10 people standing around me.... barely covered because they need to access every part of you and being bounced up and down on your chest, having CPR, no, no, that would be the last thing I want my family to see...

However, the same participant expressed:

...I think it is good to have family members present, I believe it can give them some closure. I believe when a family member is dying and we are doing everything we can that you could possibly do and that can lead to the decision to stop when things become futile instead of letting things go on because of ethical issues...

Participant # 26 expressed that her personal FPR event was detrimental to her and her daughter and she would never allow or encourage FPR. She had experienced a loss of her husband 4 years ago and she and her daughter were allowed to stay and witness the resuscitation.

...Watching did nothing for us but leave a bad memory and those will never go away.... watching was too much for us. My daughter cannot speak of that night.....After 4 years later, it is still in my head - I am not sure why he died...

The majority of the participants who did have personal experiences with FPR would do it again and shared their personal experiences with reluctant colleagues to encourage FPR events in the intensive care units. Participant # 15 stated:

... if staff would place themselves in the family member's shoes, they would have to allow FPR; if they asked if this was my mother, father, they would want to be there also. It's a good thing if the person can handle it, handle being present, then it's a good thing for them to be present.... It makes us treat the body

as a human being...it's like we lose focus, it's a human being, and somebody's mother, son, brother, or sister...

#### 4) Nurses' Experience

A counter intuitive finding was identified as it relates to nurses' clinical experience. Overwhelmingly, fifteen plus years of experienced nurses identified that less experienced nurses, were more likely to allow FPR events, and are more supportive of FPR. Participant 1 stated:

There are lots of generational differences in nursing, but, let me tell you some nurses my age [52] are mostly against FPR, so the younger generation are more open but....Some very experienced nurses are much more dead set in our ways....FPR philosophy is sometimes a little more difficult for some of the older staff to change, whereas, novice nurses are more open minded to different things

However, although more positive to the approach for FPR, the less experienced staff expressed (1) performance stress, (2) being watched, and (3) worries about making a mistake that would be witnessed by family members. Several participants expressed that in the beginning of their careers, they were more focused on managing the code, performing, and concerns about being sued. After they achieved comfort managing a code experience, these concerns, fears, and barriers to FPR dissipated.

Participant 8 stated:

...initially my response in having families present was “oh no way” because I don’t want them to be criticized or critiqued; however, I see a necessity to have people at the bedside like when we know the patient is going to die...

#### Nurses’ Beliefs about FPR

Four substantive codes regarding nurses’ beliefs on FPR events were derived from the data. They were (a) faith based, (b) facilitates grieving stage, (c) positive for families, (sub-codes for positive were (1) see everything done, and (2) support ending resuscitation efforts), and (d) intuitive assessment for appropriateness of family member to witness resuscitation event (sub-codes for assessment were (1) communication, and (2) rapport with families).

Additionally, this section will cover nurses’ beliefs, Aim # 3, regarding the multidisciplinary team’s role and impact on decision-making.

#### Faith Based Practice

Eight participants (30%) commented that personal faith-based beliefs influenced their FPR practices. The study site was a Catholic Hospital and the Catholic culture influences practice, policies, and guidelines. However, the organization has no policy or guideline on FPR in the ICU. The best example of how faith-based [spirituality] beliefs influence FPR is from participant 16:

I think sometimes the patients are hanging on maybe because there isn't a family member there and maybe there is someone that is miles away and they are like holding off for that because I've seen that, and I truly believe in that I have seen that happen too many times, where you know Uncle Bob or my son is away out in California, and this patient is like pretty much been dead for three days but then when person flies in, and they come and then they gone in like five minutes, it's like they are holding on waiting for that person. I think allowing [FPR] helps the actual dying patients to be free to pass on to wherever they are going...

Faith-based practice was also identified by a participant who had personal experience with loss and witnessed family members being resuscitated. Participant # 9 stated:

... oh yea, I think that if I hadn't had that experience [loss of her grandmother] and being able to be there, even though I don't know if I helped, and that I had the ICU background and sort of knew behind the scenes.... or if it was more important for me to have that connection to be with my grandmother when she actually entered the next life. That was more important. I didn't want my grandmother going to Jesus without me being present so it had to happen like that....I was there and I was holding her hand....So I mean I don't know if it helps, but I am more of an advocate for families being in the room because of that situation...

...(# 9) I think not only that, but to let the family know that is a loving decision to let someone pass, and not I'm giving up or I'm throwing in the towel sort of phase, but it's a loving decision to let someone go to heaven, that how I always felt about it. That is what I always tell the families to help my families, you know, cope...

### Intuitive Assessment of Family Members for FPR Events

Most participants expressed that it was appropriate for families to be present during resuscitation. However, they also appreciated the need to evaluate and assess when it was appropriate, and that it was not right for all who requested to stay. Several expressed that this part of the assessment was intuitive; there was no right and no wrong criteria. Overwhelmingly the criteria most often mentioned were primarily not to “interfere with the resuscitation”. As participant 23 stated: [Family presence] is not our first thought, the first thought is always the patient.”

### Rapport

Building a close rapport with family members was seen as one of the initial steps in the assessment process for allowing FPR events by nurses. It was the experiences of critical care nurses who generally take care of the patient for a period of time prior to the code event occurring. In two instances, nurses asked potential participants if they wanted to be there prior to the patient coding.

(# 2) one decision point if the person is not doing well is to ask the family member at the point of admission or first assessment if they want to be there if something happens. Understanding their point of view will help in the course in the hospital if that is something that they would want to be involved in because you don't want to push someone to view this if they are uncomfortable.

This exposure to patient and family members builds rapport as well as sometimes impacts intensive care nurses psychologically as well.

(# 17) I don't think they [families] realize you know that it's very hard for us when we've had people here for a while that I have taken care of and get a rapport with them it's not easy to let them go, we have feelings too ... you are involved in the grieving as well...both sides are...

(# 23) you have to have good rapport and even if it's not a good rapport , let's face it we all have different personalities, you know, I might label him as a difficult family...you might say oh it's the nicest family in the world ... having professionalism and having that rapport allows you to take control and you know I am the nurse providing care and you set limits... and when you have to ask someone to step out of the room as I give care for whatever reason that rapport leads to a good communication with families... that is what I have learned over the years...

## Communication

Open and honest communication with family members was a recurrent theme. Communication was especially important when nurses were making decisions as to whom to allow in witnessing the event and preparing family members for what they would see:

(# 17) I don't know... I'm just more open... I'm up front... I'm very honest... I'm very frank and I really don't sugar-coat anything... that is why I don't have any problems with people even when things don't you know not gone so well."

(# 23) the best thing any nurse can do is to communicate in open communication is most important thing and it doesn't matter if it's the nicest patient or family member or the most difficult, introducing yourself, giving them your name gives them a sense of confidence that you respect their loved one and I'm your loved one's nurse today...

## The Multidisciplinary Team Influence in FPR

Overall, the participants expressed that all team members have a role to play during the resuscitation. There were no concerns or perceived resistance to the nurses' assessment of family members for a FPR event and the nurses and their approval to allow families in. In these participants, the nurses expressed that

physicians, respiratory therapists, social workers, and chaplains were very supportive of the FPR process.

Aim number 4: Impact of FPR on families:

FPR facilitates the grieving process for family members.

Participants identified that one of the purposes to allow FPR was to facilitate the grieving process for family members. Participants felt that having a family member present witnessing the resuscitation efforts allowed them to see that everything that could have been done was completed by the resuscitation team. Also, having families see the termination of the resuscitation efforts was clinically justified and allowed them to begin the grieving process without remorse or guilt that everything wasn't done. This belief was best articulated by participant # 20:

I think you have the stages of grieving, the first it's denial which is normal, and then you go into the anger, and then you start toward acceptance, and I think (FPR) it gets you to that acceptance stage quicker because you saw it, you were there, and you know that everything was done and it allows you to get to that closure quicker because you were there and then you know it... just, I think makes them stronger in dealing with it. Having a pastoral person with them also helps them get through the grieving stages. I am a Christian and I see how that helps them also... it makes a huge difference so when you incorporate all that they see and hear from the pastor, they don't feel like angry because they know...

### Positive Experience for Families

In all but two interviews of participants, critical care nurses expressed that FPR was a positive experience for family members. The conceptual categories that emerged from the data were (1) seeing that everything was done and (2) support or assent that the code must end.

(# 18) I believe that 99% of patients, if asked, would want their family members there.... for the families, I think it kinda opens their eyes to see, you know, how fragile life is and you have to live each day, because you could be here today and gone tomorrow.... It helps them accept that we are working on and seeing, you know, what's been done for their loved one...

(# 24) we bring them in they see everything is taking place, when they see us shock someone and the body jumps a little bit you know, I've had families scream, you know they are scared, they don't, you know, understand. Their emotions are high and sometimes, you know, want them to say that is it.... But, sometimes we need to say that, because we tried everything we could and we realize we aren't going to win this battle. We have exhausted every measure we can to help your family member.... and they need to see that...

(# 24) the only negative experience was when a family got angry that all of them couldn't be in there but there was no room and you cannot monitor what is going on with five family members.... you can't...

## Process for Family Presence Resuscitation

Aim 2(a), 2(b) - Process Map: - (See addendum D)

Five conceptual categories were derived from the data in regard to process. They were (a) family involved in the discussion to end resuscitation, (b) facilitator presence is crucial to the process of FPR, (c) staff expressed concerns influencing the process of FPR, (d) environment (environment had three sub codes: (1) differences between units culture, (2) maintaining privacy, and (3) visitation practices). (e) staff education on FPR and (f) policy and procedure on FPR.

### Family Involved in the Decision to End Resuscitation

Ten (38%) of the participants identified that during the resuscitation process medical staff would provide medical information such as “we have done everything we could” for the expressed purpose of allowing families to either participate in the decision to end resuscitative efforts or have them express the wish that the team end resuscitation.

(# 10) I know from reviewing codes [code sheets] family being there has stopped a few resuscitations to say the least that umm.... they like you know.... Ok, you've had enough and I've seen families who have been told up front.... this doesn't look good and they will say I want everything done. Mostly, they understand when enough is enough and stop. I've seen that in writing a lot.... family present asking to stop resuscitation...

(# 9) In my experience.... I have had it happen three or four times and they [family] have actually said ok that's enough.... so knowing that the efforts were made in attempt to try to resuscitate them, but once they see how long it takes and the horrible things we have to do to prolong life.... helps them make the decision to stop...

However, participant # 26 had a personal experience in the loss of her husband where the emergency department physician came to her to facilitate making the call to end the resuscitation.

They coded him for 25 minutes; the nurse kept coming out and giving us updates that he was not doing well and not responding. I knew that because I was able to see what they were doing. The ED doctor came out and told me he was not responding. He asked me to make a decision if we should stop. I was in a panic, how could he ask me that to stop my husband's resuscitation. I didn't want him to go on but I wasn't ready to let him go. I asked they do everything they can do to bring him back. After about another 10 minutes he came out and told me he would stop the code, there wasn't anything else he could do ... That was unfair and I felt it was cruel for the doctor to ask us to stop the code. It would have caused me great guilt having told them to stop the code. I would not have been able to live with myself.... I am not sure if the doctor asked me because I was an ICU nurse but that still in my mind is inappropriate...

... There should never be an occasion to have the family member asked if they want to stop resuscitation...

### Facilitator Role

In all twenty-six interviews, the Family Presence Facilitator role of having someone with the family during a resuscitation event was seen as crucial. Staff expressed that it was easier for FPR events during the day shift (7a – 7p) due to the fact that there was the availability of pastoral care support in-house. As participant # 26 expressed, “we are blessed to have them here.” On the night shift, the role was performed by either the ICU charge nurse or the nursing supervisor.

Participants overwhelmingly identified that there were few contraindications to having families present other than those resuscitations that required open surgical interventions and age restrictions [under 15]. The participants expressed comfort in the ability to remove any family members that would possibly interfere with the code at any time.

(# 3) I think the family needs someone there with them... I couldn't imagine being stuck in a corner of the room kinda just watching by myself not having anyone to ask questions.... to or you know.... help me understand what is going on. Additionally, they are there if they become disruptive to the code... or too emotional that they get them out of here...

(# 2) I don't think it's a good practice not to have someone with them to talk with them or being available to them to answer questions. Not having someone available would be an absolute no.... to FPR...

#### Staff Concerns about FPR

There were several participants who felt pressure and distractions from having family members witness their resuscitation attempts. The participants were newer to the practice of intensive care nursing, and self-identified that, as their experience managing codes increased, they were more comfortable with the practice of FPR. Concerns expressed were: (1) "what if I make a mistake and they see it – will they sue me?" and (2) being watched was identified as increasing staff stress during stressful events of resuscitation.

(# 20) the biggest fear that people have .... if they are not comfortable with their role and they bring in someone who is watching them you basically cause more anxiety...

(# 1) one thing that worries me is that sometimes conversations and things that go on among team members can be misconstrued, umm, and, you know, when everybody is excited, humor comes out, but it may not be humor that they see as humor especially if the code is very disorganized...

## Environment

There are significant differences in the culture of both the CICU and the MICU such as visitation policy. The CICU see their unit as a “sterile” environment and keep the visitation of family members to a minimum (10 minutes on the hour). Whereas, the MICU has a more open visitation practice than the CICU. Family members are welcome to stay at the bedside during normal visiting hours and especially when the patient is very ill and likely to code.

(# 10) a lot of our patients are surgical.... we may have to open chest during resuscitation and that is not appropriate for family members to watch.... Our codes sometimes last for hours and involve chest tubes, incisions and other open invasive procedures.... Families are never here, we have to go out to the waiting room to find them during a code... we cannot leave that is why it's important to have a family member with someone from pastoral care.... We aren't comfortable with families in our unit...

The physical environment was also identified as a facilitator in the MICU and a barrier in the CICU. The MICU was renovated several years ago into large private rooms with a waiting area inside the unit. The CICU is decades old and an open bay type unit. Several of the CICU nurses expressed FPR event concerns as it relates to the privacy of the patient in that open environment.

## Education

In these participants, all identified that they had never received any formal information or instruction on FPR in the intensive care environment. Additionally, only one participant was aware of the American Association of Critical Care Nurses position statement on FPR (2010), but was unaware of the content of the position paper. However, 16 participants (61%) expressed that formal education on FPR would be beneficial. As participant # 25 identified:

...teaching on this subject is trying to teach the impossible, something that is unteachable, maybe some sort of guideline would be better because this is very individual, and every event and family is different, nobody fits into one particular mold....

## Formal Policy or Guideline to FPR

The demographic survey results identified that seventeen ( $n = 17$ ) participants (65%) favored a formal policy or guideline on FPR. However, during the interview process, the majority did not believe that a formal policy or procedure would help and that a “cookie cutter approach” to FPR was not possible, participant # 25 stated:

Yeah, there is no cookie cutter approach for this; I mean you know it’s one of those things that have to be moldable, bendable, and flexible to meet the family’s needs. I wouldn’t want to try to sit down and figure out even a broad base set of

guidelines for this. Yea, not something I think a policy can actually be drawn up... a policy would not help, I wouldn't encourage FPR, I will only do it based on if the family asks...

In order to facilitate a discussion of the overall research findings, analysis and initial theory, the following portion of this chapter will focus on the emergence of patterns, themes, conceptual categories, and initial theories.

#### Emergence of Patterns, Themes, and Conceptual Categories

The Grounded theory method first described by Glaser and Strauss (1967) was utilized in this study. The method seemed appropriate as it is designed to generate explanatory theory in order to further understand psychology and complex social phenomena. In order to generate theory exploring attitudes and beliefs of critical care nurses and how those attitudes and beliefs impact the process for FPR, this researcher engaged in the following activities:

1. Open coding
2. Axial coding
3. Selective coding
4. Identification of Basic Social Process / Theory Development

### Open Coding

Level 1 coding or open coding refers to codes that are developed by analyzing the participants' statements word by word. Open coding facilitates the identification of major categories and subcategories. Each substantive code is a description of an incident, idea, or event reflective of the substance of the interview (Stern, Allen & Moxley, 1984). In this study, open coding was performed in two ways; the researcher read each transcript to get an overall understanding and feel of the content of the interview. After this initial reading, the researcher read line by line and identified substantive codes that seemed to represent important concepts needed to ascertain the attitudes, beliefs, and process of critical care nurses regarding FPR. Each code was entered into a qualitative software program (Ethnograph 6.0) to track and manage all codes. Additionally, concepts and quotes relating to those codes, if significant, would also be entered into memo to facilitate tracking and reporting.

### Axial Coding

Level II coding or axial codes as per Glaser and Strauss (1967) is a complex process where the data are reconstructed or put back together by connecting categories and subcategories. During the initial phase of the research, several conceptual labels emerged from the data. As data collection and data analysis continued, conceptual labels were condensed to form categories that reflected common properties of the conceptual label. As subsequent interviews were performed, there was a constant comparative analysis of the transcripts and codes, as well as conceptual labels were assigned to those

interviews, so that conceptual labels reflected the themes and tones of the attitudes, beliefs, and process for FPR used by critical care nurses. (See Table # 5)

TABLE 5

## Emergence of Initial Conceptual Categories

<b>Concept</b>	<b>Selected Substantive Code</b>	<b>Conceptual / Theoretical Categories</b>
<b>Family Presence Resuscitation</b>	Support	Attitude / Belief
<b>Attitude</b>	Nurse as Champion Family as an Afterthought Personal Experience Nurses' Experience	Support FPR & Ethical decision making
<b>Belief</b>	Faith Based Grieving Process Positive Aspects Intuitive Assessment Rapport Communication Team's Perspective Benefits to Family	Family Centered Care
<b>Process</b>	Family stops resuscitation Facilitator Role Staff Concerns Environment Nurse Education	Patient resuscitation is the nurses' first priority

Once no new conceptual or theoretical categories, emerged the investigator concluded that data saturation was achieved. In this study, an additional five interviews were completed and analyzed to confirm that there were no new codes emerging from the data.

### Selective Coding

Level III or selective coding process is utilized in selecting the core category. Polit and Hungler's (1999) definition of core category is, "the core category is the central phenomenon that is used to integrate all categories" (p. 584). Conceptual labels from the data were compared to see how they clustered or integrated with one another. This process helped in the identification of linkages and consolidation of categories. The result of selective coding is a description of the basic social process or theoretical model, which is in the central social process resulting from the data.

### Identification of Basic Social Process

The researcher identified two dimensional concepts that influence the attitudes, beliefs, and process of FPR used by critical care nurses. Nurses use constructs of attitude and beliefs as their basis to support their understanding that FPR is "the right thing to do" and "putting the patient first".

As identified previously, the first thought at the initiation of the resuscitation is to the patient, that the resuscitation begins in a timely manner, and that all members of the team are present. During this crucial time, if the family is present, in most cases the nurses have asked them to leave the room to allow for the resuscitation. During the initial moments of the resuscitation, family members were an afterthought, or sometimes not acknowledged at all.

After the initial crucial moments of resuscitation have passed, the experience of the staff allows them to begin to form decisions whether the resuscitation will end positively or will not be successful. At this time, if the resuscitation is expected to have a positive outcome, the staff continues to focus on the resuscitation efforts. Families at this time are not the concern of the staff. When the patient has been stabilized, the family is then engaged, informed of the events, and allowed to participate and stay with the patient.

When the resuscitation outcomes are expected to end with the demise of the patient, the staff then begins to address the needs of the family and the need for a FPR event. At this time, the staff will assess the need for a facilitator. If there isn't one available then steps are taken to find one. In this study, participants identified that family facilitator availability is crucial in making a decision to allow a FPR event to occur.

Once a facilitator is available, the family is informed, and asked if they would like to be present. Families that agree are then allowed to be present. At this time, the communication begins and expectations of the outcome are shared with the family. The resuscitation continues, sometimes longer than patient resuscitation care demands, so that the family can witness that everything is being done. At times, the physician then communicates with the family expressing that everything has been done and then they ask family members for input in regards to ending the resuscitation. The decision to end the resuscitation is made with the support of the families input, or against the

families wish to continue, if it is determined by the medical staff that continuing the resuscitation is futile.

### Process Map for FPR in Critical Care

Unlike the literature on FPR, in this sample when a resuscitation is called the initial step taken, in one-hundred percent of the sample, was to ask the family, if present, to leave the room. Based on the data, the focus of the staff is initially to the patient's resuscitation. Family members are escorted, in most cases, out to the waiting room.

Once the resuscitation has been initiated, after several interventions, the team determines if this resuscitation is going to be a positive or negative outcome. When the resuscitation is expected to be successful, the focus of the team remains on the patient, until the patient can be stabilized. When the patient is stable, the family is then escorted into the room for visitation and information sharing regarding expected status, long-term outcome, i.e., rehab or palliative care, or Do Not Resuscitate (DNR) status.

If the team determines during the resuscitation that the expected outcomes will be the death of the patient, the team requests for a Family Presence Facilitator (FPF). If one is not available, the family remains in the waiting room, and will remain there until the physician ends the code and then informs the family of the outcome.

When there is a facilitator available, the family is located and the communication about the expected outcome begins. The family is offered the option to witness the resuscitation. If the family elects not to enter or witness the event, the facilitator supports

the family in the waiting room and informs the team. At the end of the code, the physician with the facilitator informs the family of the death and supports the family.

If the family member elects to be present, the facilitator must be there to support the family, explain what is occurring, and facilitates the experience of “everything being done”. During the witnessed event, updates are given by the facilitator and at times from physicians as to the fact that “things are not going well, not responding to resuscitation”.

At some time, the physician will engage the family in a discussion as to how to proceed. The data identified communication occurring between the physician and family as “we have done everything we could and he or she has not responded. What would you like us to do? Would you like us to stop?” In most cases, respondents identified that most families agreed to end the resuscitation with the assent of the medical staff. For those who felt that the resuscitation should continue, the medical staff would continue for a few more minutes until the physician deemed the resuscitation efforts futile, and would then terminate the code.

### Positive Family Experiences

In all but two interviews of participants, critical care nurses expressed that FPR was a positive experience for family members. The sub codes that emerged from the data were (1) seeing that everything was done, and (2) support or assent that the code must end.

(# 18) I believe that 99% of patients, if asked, would want their family members there... for the families, I think it kinda opens their eyes to see you know how fragile life is and you have to live each day because you could be here today and gone tomorrow.... It helps them accept that we are working on and seeing, you know what's been done for their loved one....

(# 24) we bring them in, they see everything is taking place, when they see us shock someone and the body jumps a little bit you know, I've had families scream, you know they are scared, they don't, you know, understand. Their emotions are high and sometimes you know want them to say that is it.... But, sometimes we need to say that because we tried everything we could and we realize we aren't going to win this battle. We have exhausted every measure we can to help your family member.... and they need to see that...

(# 24) the only negative experience was when a family got angry that all of them couldn't be in there but there was no room and you cannot monitor what is going on with five family members. You can't...

#### Intuitive Assessment of Family Members for FPR Events

Participants expressed that although most felt that FPR was appropriate, it was not appropriate for all who requested to be there, to be allowed to be present during resuscitation. Several expressed that this part of the assessment was intuitive, no right and wrong criteria, but overwhelmingly the criteria most often mentioned was primarily

not to “interfere with the resuscitation”. As participant # 23 stated: It’s not our first thought [family presence]; the first thought is always the patient...

### Open and Honest Communication

Open and honest communication with family members was a recurrent theme. Communication was especially important when nurses were making decisions as to whom to allow in witnessing the event and preparing family members for what they would see:

(# 17) I don’t know, I’m just more open, I’m up front, I’m very honest, I’m very frank and I really don’t sugar-coat things... that is why I don’t have any problems with people even when things don’t, you know, not gone so well...

(# 23) the best thing any nurse can do is to communicate, in open communication, is most important thing, and it doesn’t matter if it’s the nicest patient or family member, or the most difficult, introducing yourself, giving them your name gives them a sense of confidence that you respect their loved one, and I’m your loved one’s nurse today...

### Summary

During the course of this research, demographic data were collected and analyzed via discussion and descriptive statistics, in order to describe the general characteristics of the participants. Transcripts generated from audiotape interviews were examined,

producing substantive codes that were developed word-by-word analysis of this immigrant population statements and no-verbal behaviors.

Memos were also written immediately after each interview and after coding each participant interview, to reflect the investigator's feelings and thoughts during each activity; any codes, which seemed to have arisen, were documented and used to guide further research interviews. These codes were used to describe the attitudes, beliefs, and processes used by critical care nurses in their practice of FPR.

## CHAPTER V

### SUMMARY AND DISCUSSION OF FINDINGS, CONCLUSION, AND RECOMMENDATIONS

#### Introduction

This chapter will cover a summary of findings and discussion with an emphasis on the implications for nursing practice, education, and theory development. The chapter ends with the study conclusion and recommendations for future research.

This study examined the attitudes, beliefs, and process for FPR used by 26 critical care nurses in urban Intensive Care Units. The study addresses the research question: How do the attitudes and beliefs of critical care nurses impact the decision making process regarding FPR? An exploratory design based on Grounded theory methodology by Glaser (1992) was used in this study.

The analysis of the data answered the four research aims of the study. They were: 1) describe how the attitudes and beliefs of critical care nurses impact decision making regarding FPR, 2) describe the process critical care nurses use to permit or restrict the presence of families during resuscitation, 3) describe how the multidisciplinary team influences critical care nurses' attitudes, beliefs, and process for FPR, and 4) describe how critical care nurses believe FPR impacts family members.

To facilitate a discussion of the findings this chapter is organized as follows: (a) demographic characteristics, (b) findings, 1) attitudes, 2) beliefs, 3) decision making

regarding process, and (c) beginning theoretic model (Justice Model) for FPR in critical care, conclusion, implication for nursing clinical practice, nursing administration, education, theory development, recommendation for theory development, and a chapter summary.

### Summary of Findings

#### Demographic characteristics

This sample was purposefully chosen because of their actual experience with FPR. The most striking finding within the participant sample was that 100% ( $n=26$ ) had never had any formal education on Family Presence Resuscitation (FPR). Additionally, 65% ( $n=17$ ) identified that having a formal policy and procedure on FPR would be beneficial to their practice. However, descriptive data from the participants identified that formal policies or guidelines might not be appropriate because FPR was very individualistic events.

There are research articles that examine the preparation of staff for FPR. These articles are interventional in nature and do not explore the attitudes and beliefs of providers prior to implementation. The studies identified that staff experience with FPR is improved through education (Bassler, 1999; Meyers et al, 2004; Parkman, et al., 2006). Performance anxiety, i.e., running a resuscitation, announcing medications or performing procedures with FPR is primarily felt by resident physicians (Bauchner, 1990; Doyle et

al, 1987; Gold, et al., 2006; Grice, et al., 2003). In the Emergency Department settings, attending physician and nursing staff are in support of FPR practices with set FPR guidelines that have inclusion and exclusion criteria.

Bassler (1999) used a quasi-experimental pre-test, post-test design to determine if an educational program could change nurses' beliefs about FPR. In this study, the intervention involved a class in which nurses from the emergency department and critical care learned about the hospital's FPR policy, risk management perspectives, obstacles to letting patients' families be present during codes and protocol for offering FPR. The program significantly increased the proportion of nurses who thought that patients' families should be given the option for FPR from (56% to 89%) and who planned to offer the FPR options to families from (11% to 79%).

Five studies (Bassler, 1999; Mangurten, et al., 2006; Powers & Rubenstein, 1999; Sacchetti, et al., 2000; Twibell, et al., 2008) identified that there was no statistically significant increase in support for FPR as it relates to the age of the nurse, years of experience, or higher educational levels. Qualitative interview data and this study's demographic findings support that national certification or educational level had no impact toward support of FPR. However, this study identified that staff experience with resuscitation has an influence on FPR decisions.

To facilitate the discussion regarding attitudes, beliefs, and the decision making process, a theoretical model for family presence resuscitation was developed from this study, (See figure 2, Justice Model - p. 111).

## Findings

Overwhelmingly, participants describe their core value of “primary duty is to the patient first”. This core value described that the initial decision-making by nurses is to care for and the resuscitation of the patient. This value supersedes the family members’ need to be there. When families were in the room, the initial action was to ask them to leave or wait outside the room. Several described “families as an afterthought” to the patient care needs. This finding is contradictory to the family presence literature that allows families access at the initiation of the resuscitation.

This study identified that critical care nurses believed that their decision making process to allow or restrict family member presence was intuitive and that “no cookie cutter approach” was possible. Individual decisions to allow or restrict FPR were based on communication and rapport with family members and patients. This finding is contradictory to positions statements from both ENA (2005, 2010) and ACCN (2010) which state that having a guideline and policy would benefit the FPR process. Although one individual was aware that there were position statements and guidelines available, they were currently not being recognized in this setting.

The ACCN (2010) position statement clearly identifies the need for evidence based guidelines and policy for FPR. The position statement identifies the need for proficiency standards for all staff involved in FPR to ensure patient, family and staff safety. Intensive care units should actively measure the compliance with family

presence events and develop and implement educational programs and communication strategies to alert staff about the FPR option. Additionally, the position statement recommends standard documentation for a FPR and contra-indications. It was clear from the findings from participants, that in this setting, the FPR was not in adherence to these guidelines. Participants did express the need for education and the majority felt that guidelines and policies would be helpful.

#### Attitude

The participants expressed that their primary duty was “patient first”. Respondents identified that their attitude toward FPR arose from “doing the right thing for the patient”. When all measures were exhausted or when the resuscitation team identified that this would not “end well”, they would then consider the family member needs to be present and allow for FPR events. The attitude of this learned behavior for the initial process of FPR is the primary theme for initiating an event experience.

Attitude themes in this sample were identified by (a) nurse as champion, (b) positive experience – closure, (c) nurses’ personal experience with FPR as positive, (d) nurses’ experience with resuscitation, and (e) family as an afterthought.

#### Nurse as Champion

Participants identified that in most cases the nurse is the initiator of the FPR event. Resistance from other providers was overcome by communication prior to the

event experience. Although there was no policy or procedure at the hospital organization used in the study, all participants expressed consensus that FPR was the “right thing to do” and supported FPR. This finding of a multidisciplinary alignment and support by all providers is contradictory to the literature. Mitchell and Lynch (1997) found that (63%) of nurses and physicians in emergency departments were not in favor of FPR. Similarly, Ong, et al, (2004) identified that (75%) of Asian nurses and physicians were not in favor of FPR. The nurses in this study identified being uncomfortable having families watch as CPR was being done and at times needing to expose the patient during resuscitation. Earlier in the history of the FPR, there were mixed support for this practice. As identified, now in 2012, the multidisciplinary team, at least in this sample, is very supportive of FPR.

#### Positive Family Experience – Closure

From the seminal work done by Doyle et al (1987), FPR has been identified as a positive experience for families. The opportunity to touch or talk to the patient has been regarded as very helpful to the relatives. The holistic resuscitation perspective is usually championed by a nurse, chaplain, or physician. Evidence that FPR allows the opportunity for the family to see that everything has been done in the resuscitation facilitates mourning and acceptance of death, and was documented in several studies (Ong et al, 2004; Weslien, & Nilstein, 2003). This study identified that all participants felt that allowing family presence was positive for families and supported closure.

Nurse personal experience having witnessed a family member's resuscitation, develops support for FPR and is a positive influence.

In this sample, eleven ( $n=11$ ) of the 26 participants had personal experience with FPR. Of the eleven, nine ( $n=9$ ) had positive experiences that influenced positively their FPR practice. However, one participant although attested that her modesty [concern for being bodily exposed during the resuscitation] would make her uncomfortable, and would prefer that her family be kept in the waiting room, expressed that "I think it's good for families to be there, I believe it can give them some closure". The other participant, based on her experience, was adamantly opposed to FPR after witnessing her husband's resuscitation, "watching did nothing for us but leave a bad memory and those will never go away". These finding of how nurses' personal experience influences attitude toward FPR has not been found in the literature and needs further scientific exploration.

#### Nurses' Resuscitation Experience

Mitchell and Lynch, (1997) found that FPR was more likely to be adopted by healthcare providers with higher seniority, which coincides with increased experience, confidence, and competence in dealing with resuscitation procedures and distressed members of patients' families.

Data from this study identified a counter intuitive finding as it relates to nurses' clinical experience. Overwhelmingly, fifteen plus years of experienced nurses identified

that newer, less experienced nurses were more likely to allow FPR events and are more supportive of FPR.

However, although more positive to the approach for FPR, the less experienced staff expressed performance stress on being watched, and worries about making a mistake that would be witnessed by family members. Several participants expressed that in the beginning of their careers, they were more focused on managing the code, performing, and had concerns about being sued by family members witnessing their mistakes.

#### Family as an Afterthought

This study is the first to identify that critical care nurses first thought was the patient. In most cases, even when the family was present, the first action was to ask them to leave the room. This finding is contradictory to the literature that implies that families that are there upon arrival as in the emergency care experience or initial resuscitation and are or should be allowed to stay. The data identified that after the resuscitation is on-going, the thinking from the participants is to allow family presence for the benefit of the family member to, “see and allow families to experience that everything was done”.

#### Nurses’ Belief Regarding FPR

FPR beliefs among respondents involved more of a decision making thought process than personal opinions or position. Overwhelmingly, nurses’ consensus opinion

was that allowing FPR was more accepting of their “right to be there” than a judgmental decision whether to allow or restrict FPR.

Patient- and Family-Centered Care (PFCC) model is an approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients, families, and healthcare practitioners (Frampton, 2003). Central to this model is the belief that healthcare providers and family are partners, working together to best meet the needs of the patient.

PFCC is significant to this study because it is the family member that provides the patient’s primary strength and support. Families are central to the care of the patient in all settings and degree of illness. In PFCC, the healthcare team enters into a collaborative relationship focused on the care of the individual patient in order to provide quality, and comprehensive care. The four core concepts that were identified from the data were (a) dignity and respect, {benefit, faith based}, (b) information sharing, (communication), (c) participation (team perspective), and (d) collaboration (rapport) were evident in the data from this study.

### Dignity and Respect

Family Strengths: Family is recognized as a constant in the patient’s life. This concept obligates the healthcare provider to support and empower the family member as partners and decision makers in the patient’s care. This concept is significant to FPR because the family is responsible for making decisions, and in order for families to feel

comfortable in their decisions and in the care being provided, support is needed to include families in all levels of care including resuscitation events. Examples used under benefits to FPR, positive experience and faith based are examples of critical care nurses acknowledgement of the dignity and respect concept.

Respect: PFCC requires “trust and respect” for families’ values, beliefs, religion, and background. Respect helps foster a partnership and decreases false judgment of families on the part of providers based on assumptions or misconceptions. The literature review has demonstrated that many families choose and sometimes demand to remain at the bedside. Nursing staff should make decisions to support families’ wishes and beliefs.

A good example of the identified concepts was from participant number # 7:

...frankly (FPR) it's not basically, it's not the most important thing going on there. You know you are saving a life and that's where you have to focus so part of it is for the family to have peace.... I don't know if it's beneficial or not but it seems like the right thing to do.... (FPR) is always positive, because if it's negative I would just remove them or ask somebody to be with them and remove them from the situation...

### Information Sharing

Information sharing: The two-way sharing of information helps build a trusting relationship and partnership. Knowledge about the patient's customs and beliefs during a time of crisis may be helpful for both the patient and providers during resuscitation events.

Support: Family strength involves respecting the decisions that families make, offering comfort as families cope with their loved ones illness, meeting the social, developmental, and emotional needs of the patient. This support allows families to have increased self-sufficiency and confidence managing their loved ones care.

Flexibility: Families have different personalities, life experiences, values, beliefs, religion, and cultures. Healthcare providers need to understand that preferences to remain at the bedside are different and providers must be able to adapt to meet the individual families wishes without judgment.

Participants in this study identified information sharing were primarily the role of the facilitator. Participant number # 2 stated:

It's difficult based on patient care demand during a code to have a dedicated resource to the family, but we do our best to make sure that there is someone there, because they obviously I would assume have questions and some current concerns and we want to make sure that we answer those questions, or they may not want to be there anymore, and so we do our best to have somebody there, but it is challenging depending upon the nature what's needed from the patient, as well as, what's the needed from the family.... I don't think that's a good practice to do... not to have someone right next to them talking with them or being available to answer questions...

Choice: Families can feel helpless and powerless at times when faced with grave or serious conditions. Therefore, information and knowledge is important to empower families to make choices regarding their family member's care. Being present during the resuscitation event allows family members the knowledge that all care is being done and facilitates the beginning of the grieving process.

Empowerment: This concept establishes the family as having a constant role in the patient's life. Removing a family member during a resuscitation event could be perceived as diminishing the family member's rights of empowerment to make decisions on behalf of the patient.

In this study, one hundred percent of the participants who had actual FPR event experience would allow FPR if the family member would request to be there. There were times based on the nurses' intuitive assessment or evidence of code interruption that family members were asked to leave or be removed from the resuscitation efforts. It was evident to the nurses when the family member made the choice to remain at the bedside and they wanted to empower them in this decision, however, the gold standard of non-interruption of resuscitation efforts was still at the forefront of the nurses' thoughts.

(# 3) if there was a family member who just was like overly emotional... or we were afraid that someone... was distracting or disruptive, I could see you would want to move them off the unit in the waiting room or whatever...

## Developing Good Rapport

Building a close rapport with family members was seen as one of the initial steps in the assessment process for allowing FPR events by nurses. It was the experiences of critical care nurses who generally take care of the patient for a period of time prior to the code event from occurring. In two instances, nurses asked potential participants if they wanted to be there prior to the patient coding.

(# 2) one decision point if the person is not doing well is ask the family member at the point of admission or first assessment if they want to be there if something happens. Understanding their point of view will help in the course in the hospital if that is something that they would want to be involved in because you don't want to push someone to view this if they are uncomfortable...

This exposure to patient and family members builds rapport, as well as, sometimes, impact intensive care nurses psychologically as well.

(# 17) I don't think they (families) realize you know that it's very hard for us when we've had people here for a while that I have taken care of and get a rapport with them, it's not easy to let them go, we have feelings too ... your involved in the grieving as well, both sides are...

(# 23) you have to have good rapport and even if it's not a good rapport , let's face it we all have different personalities, you know I might label him as a difficult family you might say, oh, it's the nicest family in the world ... having

professionalism and having that rapport allows you to take control and you know I am the nurse providing care and you set limits... and when you have to ask someone to step out of the room as I give care, for whatever reason, that rapport leads to a good communication with families, that is what I have learned over the years...

### Collaboration

Collaboration: Families and healthcare providers working together in the best interest of the patient define collaboration. In an atmosphere of mutual respect for the understanding that each brings to the situation knowledge, i.e., information as to the patient's wishes for resuscitation, and providers' knowledge on the medical aspects and ethics of those wishes, help in delivering, and in the receipt of quality care.

The most striking example of collaboration learned from the data was the practice of involving family members in the discussion to end resuscitation. Although most participants verbalized support for this practice as "showing families that everything was done and support them through the letting go phase and initial phases of grief", one participant was apparently traumatized by the experience and would recommend we never allow this practice. Participant number # 26 stated:

They coded him for 25 minutes; the nurse kept coming out and giving us updates that he was not doing well and not responding. I knew that because I was able to see what they were doing. The ED doctor came out and told me he was not responding. He asked me to make a decision if we should stop. I was in a panic,

how could he ask me that to stop my husband's resuscitation. I didn't want him to go on but I wasn't ready to let him go. I asked they do everything they can do to bring him back. After about another 10 minutes he came out and told me he would stop the code, there wasn't anything else he could do....

... That was unfair, and I felt it was cruel for the doctor to ask us to stop the code. It would have caused me great guilt having told them to stop the code. I would not have been able to live with myself...I am not sure if the doctor asked me because I was an ICU nurse but that still in my mind is inappropriate...

... There should never be an occasion to have the family member asked if they want to stop resuscitation...

### Literature Support for the PFCC Findings

#### Dignity and Respect

Family Strengths: Family is recognized as a constant in the patient's life. This concept obligates the healthcare provider to support and empower the family member as partners and decision-makers in the patient's care. This concept is significant to FPR because the family is responsible for making decisions and in order for families to feel comfortable in their decisions and in the care being provided, support is needed to include families in all levels of care including resuscitation events.

Patient Family-Centered Care (PFCC) requires “trust and respect” for families’ values, beliefs, religion, and background. Respect helps foster a partnership and decreases false judgment of families on the part of providers based on assumptions or misconceptions. The literature review has demonstrated that many families choose and sometimes demand to remain at the bedside.

These findings were similar to the literature support of a family member’s right to be there. Grice et al,(2003) found that more than half of physicians and nurses favored giving patients’ relatives the option of being present during resuscitation. In two studies (Back & Rooke, 1994; Chalk, 1995) found that the majority of nurses thought that patients’ family members should be able to be present and would allow the families presence if the family member were informed and were supported by dedicated personnel.

#### Benefit and Faith Based Beliefs

Data from the participants support that their belief for dignity and respect are derived from perceived benefits to witnessing the resuscitation and personal faith based beliefs. Participants identified that one of the purposes to allow FPR was to facilitate the grieving stage for family members. Participants felt that having a family member present witnessing the resuscitation efforts allowed them to see that everything that could have been done was completed by the resuscitation team. Also, having families see the termination of the resuscitation efforts was clinically justified, allowing them to begin the grieving process without remorse or guilt that everything wasn’t done on the behalf of the patient. The majority of the family presence literature indicates that there are little

psychological or untoward events that have occurred due to family presence (Powers, 1999; Robinson, et al., 1998; Tinsley, et al., 2008). In these studies, the data from interviews indicate that families believed their presence helped comfort their family member. Tinsley (2008) studied the experience of families during cardiopulmonary resuscitation in a pediatric ICU. In her study, she identified that over 50% ( $n=10$  out of 20) believed that it helped them accept their child's death and that 67% ( $n=14$  out of 21) believed touching their child brought comfort to the patient.

Robinson and colleagues, (1998) investigated the psychological effect of FPR on patients' families by randomizing patients to standard care or FPR. In a survey used to examine anxiety, depression, grief, intrusive imagery, and avoidance behavior at 1, 3 and 9 months, psychological disturbance did not differ in the two groups. All family members who participated in FPR were also satisfied with their decision to remain with their loved one.

Eight participants, thirty percent of the sample, identified that faith-based personal beliefs influence their support of FPR and influenced their practice. This data concurred with the findings from Baumhover and Hughes, (2009) study that found a significant positive relationship between spirituality and support for family presence during resuscitation efforts in adults ( $r=0.24$ ,  $P = .05$ ). A significant positive correlation ( $r=0.33$ ,  $P = .01$ ) was also found between spirituality and viewing family presence as a patient's right.

### Information Sharing

Open and honest communication with family members was a recurrent theme. Communication was especially important when nurses were making decisions as to whom to allow in witnessing the event and preparing family members for what they would see:

Yanturali and colleagues (2005) identified that the biggest benefit to FPR was the ability to facilitate communication with family members (80%) and having family members present allowed them to witness the resuscitation efforts and sometimes facilitating the termination of resuscitation efforts, thereby making the notification of death easier (58%).

### Participation – Team Perspective

In this sample, the participants expressed that all team members have a role to play during the resuscitation. There were no expressed concerns or resistance to the nurses' assessment of family members and their approval to a witnessed resuscitation event. Physicians, respiratory therapists, social workers, and chaplains were very supportive of the FPR process as identified by the participants.

Study findings support the evidence from the FPR literature that multidisciplinary teams, patients, and families are in favor of FPR (Bauchner, et al., 1991; Doyle, et al., 1987; Meyers, et al., 2004; Sacchetti, et al., 1996). Most of the studies are descriptive in nature. Evidence from these studies suggests that families want

to be given the option to attend FPR events (Davidson, et al., 2007; Doyle, et al., 1987). These studies were conducted in emergency department settings. However, prior to this study, it was unknown what the impact of the multidisciplinary team had in the critical care environment on nursing decision for FPR.

### Collaboration and Family Member's Rapport with Nurse

This study identified that building a close rapport with family members was seen as one of the initial steps in the assessment process for allowing FPR events by nurses. The critical care nurses who generally take care of the patient for a period of time develop some type of rapport with the family prior to the code event. This interaction allows for comfort or concern regarding an intuitive assessment by the nurse whether to allow or restrict the family presence.

When a patient is admitted to a critical care unit, the nurse assigned is primarily accountable and responsible for the care the patient receives and manages the family's needs for support, care, and education. In this setting, a close relationship occurs between the patient, family member, and nurse. The critical care nurses identify with the universal principle autonomy and being a patient advocate for their patients and family members. This advocacy leads their decision making to support the needs for a family member to "be there" during resuscitation and sometimes the final moments of their loved ones life. Critical care nurses believe that it is the "right thing to do" for family members when conditions permit to allow families to be present during resuscitation in the ICU.

Critical care nurses use a holistic family centered approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients, families and healthcare practitioners (Institute for Family Centered-Care, 2008). Central to this model is the belief that healthcare providers and family are partners, working together to best meet the needs of the patient.

#### Decision Making Process for FPR in Critical Care

Data from participants allowed this researcher to map out the process used and identify nurse initiated decisions as they apply to a FPR event. (See Current Process Map- Appendix D). Additionally, there were several process themes that influence the decision to support or restrict a FPR event. They were (a) staff concerns, (b) the need for a family presence facilitator, and (c) the critical care environment. Incidental findings were discovered during data collection, “involving families in discussion to end resuscitation” and the “need for a policy on FPR but believing one in critical care is not possible”, will be discussed in this section.

In the literature review, there were no comparisons of the FPR process experience in critical care. The emergency department literature on FPR does not detail a specific process recommended, other than identifying that family members are not asked to leave the area. The family members are included in the witness of the event if they so choose at the onset of the resuscitation.

Through a member checking exercise reviewing of findings, participants in this study confirmed the process detailed in this report as accurate to current practice in the ICU. Additionally, this researcher completed a transferability analysis by reviewing the process map with two critical care nurses from another facility. The participants identified that findings were applicable to their organizations and that families were often approached about ending resuscitation.

The data did identify that most of the decisions made on the initial interactions between the staff and families about FPR are made by nurses. Decision making for physicians occurred at the end of the resuscitation in regard to informing families on the outcome or involving them on the decision to end the resuscitation. The data confirm that in critical care, nurses are the evaluators, initiators and primary decision makers regarding a FPR event.

#### Facilitator and Barriers to FPR Event Decisions

##### Staff concerns regarding FPR

There were several participants who felt pressure and distractions from having family members witness their resuscitation attempts. The identified participants were newer to the practice of intensive care nursing and self-identified that as their experience managing codes increased they were more comfortable with the practice of FPR. Concerns expressed were: “what if I make a mistake and they see it – will they sue me?”

and being watched was identified as increasing staff stress during stressful events of resuscitation.

Redly and Hood, (1996) surveyed thirty-eight Emergency Department workers in her study to identify major factors of concern about FPR. In that survey, more nurses were supportive of FPR practice than physicians, (RN – 75%, MD – 50%). The concern ranked highest by the respondents was the emotional stress on the staff would increase (61%).

Timmermans (1997) conducted in-depth interviews with 28 multi-professional staff in an emergency department setting. The study identified that no professional staff reported episodes where FPR had an adverse effect on the resuscitation process due to staff stress. Boyd and White (2000) identified that almost (25%) of staff reported 2 or more symptoms of acute stress after a non-traumatic adult code. However, these symptoms experienced did not differ between codes with FPR and codes without family presence. Engel (2005) found that FPR would not interfere with patient care although 68% of the professional staff surveyed felt anxiety and stress having the family member in the resuscitation room.

The litigation concern has also been cited. Potential litigation has been cited as a major disadvantage for FPR. However, no evidence indicates any litigation arising from FPR (Halm, 2005).

### Family Presence Facilitator

In all twenty-six interviews, the FPR Facilitator role of having someone with the family during a resuscitation event was seen as crucial. Staff expressed that it was easier for FPR events during the day shift (7a – 7p) due to the fact that there was the availability of pastoral care support in-house. As participant # 26 expressed, “we are blessed to have them here”. On the off shift, the role was performed by either the ICU charge nurse or the nursing supervisor.

Participants overwhelmingly identified that there were few contraindications to having families present other than those resuscitations that required open surgical interventions and age restrictions [under 15 years of age]. The participants expressed comfort in the ability to remove any family members that would possibly interfere with the code at any time.

This sense of comfort in having a Family Presence Facilitator (FPF) was identified in the FPR literature also. In two studies, nurses reported that FPR was the right of patients’ families to be present (Grice, et al., 2003; Mangurten, et al., 2006). These two studies identified that nurses’ comfort with FPR increased with the presence of a FPF. The facilitator is a specially trained staff member who stays with the family member to comfort, assess, and educate the individual to assist in coping with the experience (Grice, et al., 2003; Jarvis, 1998).

## The Critical Care Environment

There are significant differences in the culture of both the CICU and the MICU such as visitation. The CICU see themselves as a “sterile” environment and practice differences relating to the care of patients and keep the visitation of family members to a minimum (10 minutes on the hour). Additionally, the CICU nurses’ identified that resuscitations could last for hours and progress into an open surgical procedure. Having family members present as well as a family presence facilitator was sometimes not reasonable.

The physical environment was also identified as a facilitator in the MICU and a barrier in the CICU. The MICU was renovated several years ago into large private rooms with a waiting area inside the unit. The CICU is decades old and an open bay type unit. Several of the CICU nurses expressed FPR event concerns as it relates to the privacy of the patient in that open environment.

As it relates to FPR, visitation and physical environmental differences between the emergency care setting and critical care has not been studied. This will be a recommendation for future research from this study’s findings.

## Incidental Findings

### Family Involvement in the Decision to Stop Resuscitation

Ten (38%) of the participants identified that during the resuscitation process medical staff would provide medical information such as “we have done everything we

could” for the expressed purpose of allowing families to either participate in the decision to end resuscitative efforts or have them express the wish that the team end resuscitation.

This study identified this phenomenon of allowing or involving family members input in regards to the decision to end resuscitation. Participants expressed this practice as common in critical care settings. This practice finding was unfamiliar to this researcher and a search of the literature regarding this practice was not found.

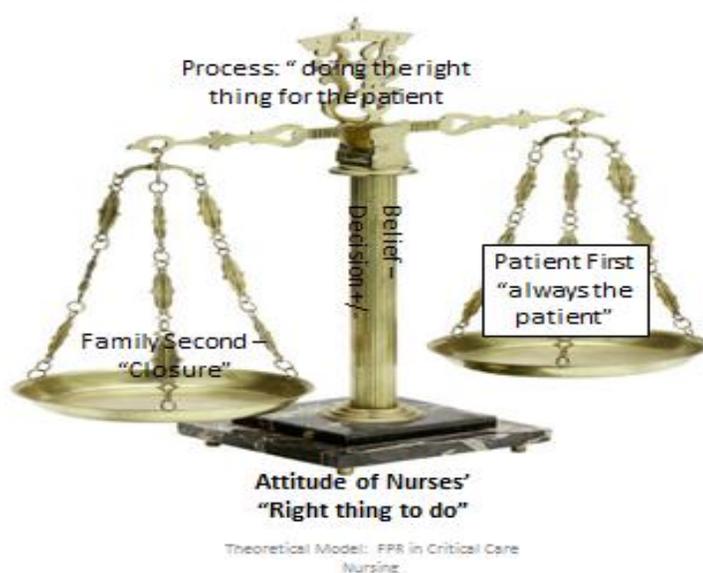
It is unclear as to the benefit to the family or the efficacy of the practice based on evidence. It was clear from the finding of one participant who had a personal experience with this practice that “is should never happen”.

#### Formal Policy or Guideline to FPR

The demographic survey results identified that 17 participants (65%) favored a formal policy or guideline on FPR. However, during the interview process, the majority did not believe that a formal policy or procedure would help and that a “cookie cutter approach” to FPR was not possible. It is clear from the literature that ENA (2005, 2010) and AACN (2010) in formal position statements have advocated for formal policies and guidelines. It is this researcher’s opinion that with the lack of scientific evidence available regarding the efficacy of FPR in critical care, at this time, a formal policy in critical care is not possible. Participants in the demographic survey acknowledged that a formal policy or guideline would be helpful.

### The Justice FPR Model for Critical Care

Data from the conceptual model themes were used to develop the beginning theoretical model for FPR in critical care, the “Justice Model”. Central to this model that critical care nurses are guided by the ethical principles of “Justice” their right to be there and beneficence to first do no harm to the patient first (resuscitation attempt) and family second – closure. (See Theoretical Model)



Attitude constructs serve as the basis for the support of FPR and the respect for family members “right to be there”. Beliefs centered in Family Centered Care Concepts serve as a guide toward intuitive decision making for the assessment and decision to support or restrict FPR events. The process used in critical care is based in to “do the right thing for the patient”. When all that has been attempted and has been unsuccessful

in the resuscitation, then allowing family presence is in the best interest of the dying patient, first in support of their families wish to be there, and bring closure to the family member.

Most studies on FPR appear to be teleological or consequence based theories (Halm, 2005). Ethical theory is concerned with actions that bring about the most benefit to all, identifying the foreseeable good and harm that can result in a given situation. (Beauchamp & Bowie, 2001). Studies in this review identified the universal ethical principles of autonomy (respect for a person's values and decisions), and beneficence (to do no harm) in support of FPR.

McClenathan and colleagues (2002) as well as Redley and Hood (1996) identified a deontological perspective, (duty-based theory that emphasizes moral duties and principles rather than consequences of action (Beauchamp & Bowie, 2001). They agreed that the "duty" for FPR is the emphasis on caring for patients' families to meet the families' needs, and duty to prevent psychological harm. Autonomy and justice (treating like cases alike by distributing benefits and burdens fairly) were the two ethical principles raised in support of FPR as authors either advocated that the patients' families have the right to be present (autonomy), or questioned the fairness of excluding patients' family members (justice).

Helmer, et al. (2000) presented an opposing viewpoint. He and his colleagues argue that the families do not have the "right" to be there. The first imperative is to

advocate for the patient. The two issues that they identified opposing FPR were that it (1) violates confidentiality and thus a patient's right to privacy, indicating a concern for the ethical principles of nonmaleficence and (2) that FPR could lead to post-traumatic stress disorder because of witnessing resuscitation "is not an appropriate sight for distraught family members to witness". This view represents a paternalistic, consequentialist view focused again on nonmaleficence.

However, the majority of the family literature indicates that there are little psychological or untoward events that have occurred due to family presence. (Powers & Rubenstein, 1999; Robinson, et al., 1998; Tinsley, et al., 2008).

### Conclusion

The purpose of this study examined how the attitudes do, and beliefs of critical care nurses, impact their decision making process regarding FPR. A beginning theoretical model was shaped during the course of the investigation. The basis of this model included thematic constructs from findings related to attitudes and beliefs and how those findings influence the process for and decision making as they relate to FPR. The themes also provided and facilitated the emergence of the basic social process of the ethical decision making of justice and beneficence principles used by critical care nurses for FPR and the family-centered approach used to make decisions as to allow or restrict FPR.

There was a scarcity of the literature regarding FPR in the critical care environment. Consequently, this author used this study's findings to compare to the

known literature in efforts to gain new knowledge into the FPR experience by nurses in critical care. The comparison allowed for an evaluation of similarities and differences between the study findings and those found in the literature on FPR. This study has added to the body of knowledge on FPR, however, further research is needed regarding the family presence practices, guidelines, and policies in critical care.

### Implications for Nursing Clinical Practice

This study identified practice variations from the known current evidence on FPR. The practice of removing families from the room at the onset of the resuscitation is typically not seen or reported in the literature. This study finding needs to be further explored through replication research to confirm or debate that this is a common FPR practice among ICU communities.

The practice of involving family members in the decision to stop or end resuscitation was also an unexpected finding. This practice needs to be further explored to identify when, who, or if this practice is safe for family members. Data from this study identified that although this standard of allowing family member's input is common in this practice setting, one participant with personal experience with this issue argued that it was wrong and detrimental to families. This study would suggest that until this practice is further examined, the practice of requesting input from family members to end resuscitation should be reconsidered.

## Nursing Administration

The participants in this study identified that although they felt a policy and guideline would be helpful, the FPR practice in critical care is unique. These findings lead this author to consider if the current practice guidelines and policies for FPR are applicable to the critical care setting. Participants defined the uniqueness of FPR situations in this setting. Practice implications of trying to “fit in” and current guidelines for FPR in critical care may be inappropriate. Allowing a “looser” inclusion or exclusion guideline or policy in this environment may be appropriate. The process map identified in this study may be used to create a process guideline for FPR events in critical care.

Nursing administrators responsible for critical care units should introduce the ENA (2005, 2010) and ACCN (2010) guidelines to staff. Education on FPR, establishing guidelines, policies, documentation tools and reviewing post FPR events with staff would continue to ease the concerns of staff regarding FPR. Establishing clear inclusion and exclusion event guidelines as well as formal family presence facilitator training is also recommended.

Nursing administration needs to assure FPR providers that they will be supported in their practice. Newer nurses need to feel that a mistake will not be managed in a disciplinary manner. When this comfort and trust exist, the anxiety of allowing a family member to “watch” the resuscitation will not be as stressful for staff. When staff are assured that their decision making process for allowing or restricting FPR events will be

supported by leadership, they will increasingly be more comfortable allowing FPR events.

### Education

Findings from this study may be used to create educational programs specifically for the critical care environment. Group discussions regarding the process map, and beginning theory may be used to facilitate discussions on FPR in critical care settings. As the participants identified, one-hundred percent of the sample had never had FPR education. This may be an area of knowledge that has not been fully explored or implemented in critical care settings.

Education on current guidelines established by both ENA and ACCN would also be beneficial. Examining recommendations and applying those recommendations and guidelines to their practice setting would be beneficial.

### Theory Development

The beginning theory of “Justice” for FPR needs to be further explored through replication studies. This study focused on participants with FPR event experience to investigate current FPR practices, attitudes, and beliefs. The study did not explore critical care nurses’ with no FPR experiences. The theory developed needs to be reviewed with non-FPR experienced staff to identify, if applicable, to that nursing population subset. Constructs identified in the theory need to be further defined and

explored. Quantitative instruments need to be developed to further identify concepts, constructs, and applicability of the Justice theory to other settings.

Additionally, this study did not examine the influence of nurses who had personal FPR experiences impacted on this theory. A replication study is recommended to explore the impact of nurses' personal experience with FPR and the impact of that experience on the Justice theory.

The findings of this study identified a strong relationship between PFCC concepts and critical care nurses' beliefs regarding FPR. Further exploration of this phenomenon is needed to identify the impact of PFCC on the beliefs of critical care nurses practicing FPR.

Spirituality and the impact on decision making may also have played a role in the findings and the development of the Justice theory. Nurses in this study identified that their personal experience with FPR as well as their patient-family members needs to be present were sometimes based upon faith-based decisions. Spirituality in the practice of FPR may have an influence on the Justice theory and needs further exploration.

#### Recommendation for Future Research

Based on the impact to nursing practice, education, theory development suggestions, and data from this study, this researcher suggests the need for further research:

1. Replication FPR studies using the same methodology to further explore concepts, findings, and the theory identified in this study.
2. Replication FPR studies in other critical care setting such as academic medical centers, Magnet hospitals, and other ICU settings, NICU, PACU, Neuro ICU's.
3. Further exploration of attitudes and beliefs of critical care nurses of FPR using other qualitative and quantitative methods.
4. Exploration of the role of the Family Presence Facilitator. To identify, if, in the critical care setting their presence is an absolute requirement for a FPR event.
5. Investigate how the personal FPR experiences of nurses (critical care, emergency, or other), plays a role in the support of FPR events.
6. Assess the impact of the physical design, environment and visitation restrictions on FPR events
7. Exploration of the incidental finding of this study: Should a family member, during a FPR event experience, be allowed to participate in ending the resuscitation event?
8. The theoretical model suggested in this study needs further exploration and testing.
9. Explore the role of spirituality as well as nurses' personal religious belief's influence on FPR decision making?

## Summary

This chapter has summarized the findings in this study and discussed the findings in relationship to existing knowledge regarding Family Presence Resuscitation in the ICU setting. The findings and discussion reviewed identified how the attitudes and beliefs of critical care nurses “do” impact the process for FPR. The study identified a beginning theory of “Justice” used by critical care nurses on the FPR phenomena in critical care. Additionally, a process flow for FPR was developed from the participant’s own words, presented, and discussed in this chapter. This chapter also presented implications for nursing practice identified in this study. Recommendations for administration, education, theory development, and future research were finalized.

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APPENDIX A

INFORMED CONSENT

<b>RESEARCH SUBJECT INFORMATION AND CONSENT FORM</b>	
<b>TITLE:</b>	How does the attitudes and beliefs of critical care nurse's impact Family Presence Resuscitation

**This consent form contains important information to help you decide whether to participate in a research study.**

The study staff will explain this study to you. Ask questions about anything that is not clear at any time. You may take home an unsigned copy of this consent form to think about and discuss with family or friends.

- **Being in a study is voluntary – your choice.**
- **If you join this study, you can still stop at any time.**
- **No one can promise that a study will help you.**
- **Do not join this study unless all of your questions are answered.**

**After reading and discussing the information in this consent form you should know:**

- Why this research study is being done;
- What will happen during the study;
- Any possible benefits to you;
- The possible risks to you;
- Other options you could choose instead of being in this study;
  
- How your personal health information will be treated during the study and after the study is over;
- Whether being in this study could involve any cost to you; and
- What to do if you have problems or questions about this study.

**Please read this consent form carefully.**

**RESEARCH SUBJECT INFORMATION AND CONSENT FORM**

***TITLE: How does the attitudes and beliefs of critical care nurse's impact Family Presence Resuscitation***

***PROTOCOL NO.:***

***SPONSOR: The Catholic University of America***  
Department of Nursing

***INVESTIGATOR: Jesus Cepero, RN, MSN, MPA, NEA-BC***

***SITE(S): St. Joseph Medical Center***  
7601 Osler Drive  
Towson, MD 21204

***STUDY-RELATED***

***PHONE NUMBER(S): Investigator (301) 908-5917***

This consent form may contain words that you do not understand. Please ask the study doctor or the study staff to explain any words or information that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

## ***SUMMARY***

You are being asked to be in a research study. The purpose of this consent form is to help you decide if you want to be in the research study. Please read this form carefully. To be in a research study you must give your informed consent. "Informed consent" includes:

Reading this consent form,

- Having the study investigator explain the research study to you,
- Asking questions about anything that is not clear, and
- Taking home an unsigned copy of this consent form. This gives you time to think about it and to talk to family or friends before you make your decision.

You should not join this research study until all of your questions are answered.

Things to know before deciding to take part in a research study:

- The main goal of a research study is to learn things to help patients in the future.

If you take part in this research study, you will be given a copy of this signed and dated consent form.

## ***PURPOSE OF THE STUDY***

The purpose of this research study is to describe the attitudes and beliefs and process critical care nurses use in deciding whether to support Family Presence Resuscitation (FPR) in critical care. The information that we learn will describe how do the Attitudes and Beliefs of Critical Care Nurses impact the decision making regarding Family Presence Resuscitation?

## ***PROCEDURES***

You will be asked to take part in a one-time interview that will be tape recorded. The interview should last no longer than 60-90 minutes of your time. The interviews will take place in a private location convenient for the participant and PI.

There is minimal risk or discomfort to you as a participant, however, tape recording and observations are the method of data collection and might make participants uncomfortable. If you experience discomfort with any questions, you are free to choose not to answer the question or stop the interview. Additionally, if the researcher notices that you are uncomfortable, he may stop the interview.

### ***BENEFITS***

Through participating in the interview process, new information and insight on critical care nurse's attitudes, beliefs and process for FPR in the critical care environment will be better understood.

### ***COSTS***

There is no cost for participating in this study other than the time needed for the interview.

### **PAYMENT FOR PARTICIPATION**

There is no payment for participation in this study

### **AUTHORIZATION TO USE AND DISCLOSE INFORMATION FOR RESEARCH PURPOSES**

### ***Your transcript interview information may be given to:***

- The chairperson of the PI's research committee to review transcripts, coding and analysis

### ***Why will this information be used and/or given to others?***

- To do the research,
- To study the results, and
- To see if the research was done right.

If the results of this study are made public, information that identifies you will not be used.

### ***May I review or copy my information?***

Yes, but only after the research is over.

## ***May I withdraw or revoke (cancel) my permission?***

Yes

- **Confidentiality**

To protect and guarantee confidentiality, after written consent is obtained, all data will be coded eliminating participant identifiers. Codes for interviews will be:

1. # interview, date and time
2. Demographic data sheet will contain no identifiers that can be traced back to the individual
3. Transcripts will contain only the # interviewee, date and time
4. Transcripts will be stored only on researcher's laptop – password protected
5. Transcripts shared with major professor or transcriber will be forwarded by data storage device not through email communication
6. All paper transcripts used will be shredded after use by PI, major professor or transcriber
7. Digital recordings will be downloaded into PI laptop – password protected
8. Immediately after downloading recording, data will be erased from recorders.

Total confidentiality cannot be guaranteed because of the need to give information to these parties. The results of this research study may be presented at meetings or in publications. Your identity will not be given out during those presentations.

## ***VOLUNTARY PARTICIPATION AND WITHDRAWAL***

Your participation in this study is voluntary. You may decide not to participate or you may leave the study at any time. Your decision will not result in any penalty.

Your participation in this study may be stopped at any time by the study PI without your consent for any of the following reasons:

- If it is in your best interest;
- Or for any other reason.

## ***SOURCE OF FUNDING FOR THE STUDY***

***None***

## ***QUESTIONS***

Contact Jesus Cepero at 301-908-5917 for any of the following reasons:

- if you have any questions about this study or your part in it,
- if you feel you have had a research-related injury or a bad reaction to the study drug, or
- if you have questions, concerns or complaints about the research

If you have questions about your rights as a research subject or if you have questions, concerns or complaints about the research, you may contact:

The Catholic University of America

IRB is a group of people who independently review research.

IRB will not be able to answer some study-specific questions, such as questions about appointment times. However, you may contact IRB if the research staff cannot be reached or if you wish to talk to someone other than the research staff.

Do not sign this consent form unless you have had a chance to ask questions and have gotten satisfactory answers.

If you agree to be in this study, you will receive a signed and dated copy of this consent form for your records.

### ***CONSENT***

I have read this consent form . All my questions about the study and my part in it have been answered. I freely consent to be in this research study.

By signing this consent form, I have not given up any of my legal rights.

---

Subject Name (printed)

**CONSENT SIGNATURE:**

---

Signature of Subject

---

Date

---

Signature of Person Conducting Informed  
Consent Discussion

---

Date

APPENDIX B

DEMOGRAPHIC FORM

DEMOGRAPHIC QUESTIONNAIRE

“Do the attitudes and beliefs of critical care nurses impact  
Family Presence Resuscitation?”

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Unit	
Age	
Gender	
Years of experience	
Level of Education (AD, BSN, MSN, Other)	
Certification	
Training on FRR (Yes / No)	
Would having a policy and procedure on FPR in the ICU be helpful (Yes / No)	

APPENDIX C

INTERVIEW QUESTIONS

## FPR Interview Questions

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A: Tell me about your experience having family members witness resuscitation?

Possible probe: Why do you allow FPR? When don't you allow FPR?

B: When you are considering allowing a family member in the room to witness resuscitation, what do you think about?

Possible probe: Criteria - clinical, psychological, space, facilitator?

C: How does the multidisciplinary team influence your decision on FPR?

Possible probe: Doctors, Respiratory therapist, other nurses?

D: In your experience with FPR, how does the family member coping with the being a witness to the resuscitation?

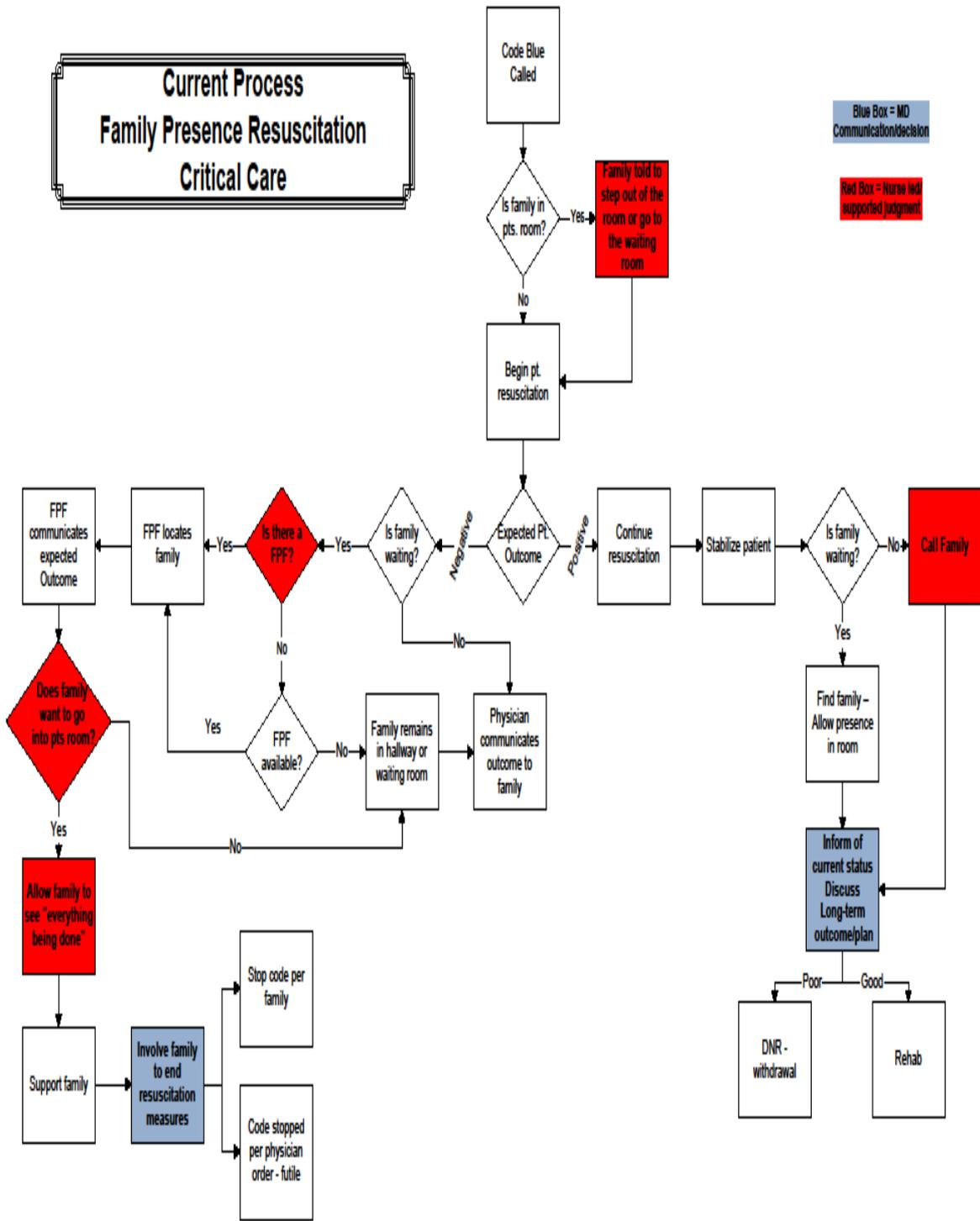
Possible probe: Outward appearance, psychological, comments made by families?

E: If you were to guide other nurses on a FPR experience, what advice would you give them?

APPENDIX D

PROCESS MAP

# Current Process Family Presence Resuscitation Critical Care



Blue Box = MD Communication/decision

Red Box = Nurse led supported judgment

