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Family Centered Care Across the Lifespan in an Intensive Care Unit Setting

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Background and Significance

Intensive Care Unit (ICU)

More than 5 million patients are admitted each year to Intensive Care Units (ICUs) in the US, and approximately 55,000 critically ill patients are cared for each day. ICU patients are a diverse population that has a need for an increased level of care. These patients often require ventilatory or cardiovascular support, invasive monitoring, and intense nursing and physician observation (Society of Critical Care Medicine, 2015). There are five primary admitting diagnoses for adults, which include respiratory failure, postoperative management, ischemic heart disorders, and sepsis. The mean age of patients is rising, particularly due to the baby boom generation, and the number of patients 65 years and older is projected to increase by 50% between 2000 and 2020 (Angus et al., 2000).

In 2000, children and adolescents accounted for 18%, or 6.3 million of the hospital stays. As of 2007, the US had 337 pediatric ICUs with 4,044 beds, and 1,500 neonatal ICUs with 20,000 beds (Halpern and Pastores, 2010). Some of the most common admitting diagnoses for neonates include respiratory problems or infections, screening for infections or immunizations, other conditions that occur around the time of birth such as jaundice, premature birth, low birth weight, medical evaluation, fluid and electrolyte disorders (most commonly dehydration), asthma, and other birth defects (Odetola et al., 2005)

What is Family Centered Care?

The days of staff enforced visitor restrictions are over. Consumers demand access to hospitalized loved ones, the media is encouraging family vigilance, and the literature proclaims the benefits of a family centered approach to care (Hanley and Piazza, 2012). With the sizeable

number of patients in the ICU setting, the amount of family visiting and participation in care is vast. In order to incorporate the needs of the patients and families, patient and family-centered care has been introduced. The Institute of Patient- and Family-Centered Care (PFCC) describes family centered care as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families” (Finlayson et al., 2014, p. 119). PFCC revolves around the patient, not the physician, nurses, or hospital organization. Patient and family-centered care is a priority and is identified as an important component of safe and quality care by the American Association of Critical Care Nurses (AACN) and The Joint Commission (AACN Practice Alert, 2011; The Joint Commission, 2010). The Institute for Patient- and Family-Centered Care is seen as the driving force in the movement toward implementing family centered care in the hospital setting. The key elements of PFCC include: “respect for family preferences, flexibility and customization of care, honest information sharing to promote participatory decision making, collaboration across all levels of the healthcare delivery system, and a strength based approach to working with patients and families” (Institute for Patient and Family-Centered Care, 2010, p. 1). In order for healthcare to progress, providers must overcome preconceived notions of knowledge superiority and empower families. Family empowerment is essential in advancing family roles in the patient-centered care environment, and providing the best care to patients (Riley et al., 2014).

Despite national and worldwide healthcare priorities and approaches that incorporate families into the decision making process and care of patients in the intensive care unit (ICU), as many as 90% of ICU’s in the nations hospitals have restrictive visitation policies (Liu et al., 2013). Restricted ICU visitation policies traditionally foster beliefs that visitors can obstruct nursing and medical care, exhaust patients, and can interfere with healing. It was also previously

believed that there could be negative psychological effects for patients and visitors, increased infection risk, unsafe work environments, and jeopardizing patient privacy (Riley et al., 2014). As will be discussed, these reasons for restricted visitation are no longer valid, and the benefits of family-centered care far outweigh the costs. This paper will uncover research regarding family role in PFCC, nurse and physician perceptions, and PFCC during Cardiopulmonary Resuscitation (CPR). Comparisons between neonatal, pediatric, and adult ICU's will be made, benefits and drawbacks of patient and family-centered care will be concluded, as well as recommendations and nursing implications discussed.

Literature Review

Family Role

As a healthcare provider, it is fairly easy to have the mentality of knowing what is best for the patient. As medicine has evolved, providers have begun to lose this superior mentality and consider the family as a source of knowledge. Patient's family members believe they know their family member better than anyone else, and are in the best position to provide emotional support and a voice for their loved one. As surrogates in decision making, family members believe they should always be involved and should have the opportunity to ask as many questions as necessary to satisfy decision making needs (Riley et al., 2014). Family testimonials regarding family centered care are powerful. Many family members believe they provide a calming effect to their loved one, while others provide motivation. One family member in the study completed by Riley et al. explained that providing reassurance lets the patient know "...they have loving family care, just to let them know that we're here, and that we didn't just leave you here and let these people take care of you. We're still out here, and we still love you" (2014, p. 318).

Potentially the most stressful role the family faces when a loved one is hospitalized in the ICU, is the role of a surrogate. They become in charge of crucial decisions, and need to know all information to make informed decisions. Experiencing her husband's admittance to the intensive care unit, one wife explains "I feel safe and secure that they're treating him, but I need to know sometimes, my husband's in a paralytic state so he can't speak for himself, so I'm the one they need to be telling things to and keeping me informed of what's going on with him" (Riley et al., 2014, p. 318). This provides a glimpse to the stress the surrogate role can place on family members. If families were able to have continuous visitation, they would be better able to make informed decisions regarding the care of their loved one. Nurses generally believe that if family members were allowed open visiting hours and to be present during procedures, they would not be naïve regarding the patient's health status and be completely informed, compared to when there is scheduled visiting hours and family members are allowed "snap shots" of information. Families are also understanding of the physician and nurses who need time to perform medical routines and procedures, which helps with nursing and physician concerns regarding open visitation.

Nurse Perceptions of Family Centered Care

Nurses are generally divided in opinions regarding the roles of families in the ICU setting. Beliefs include that open visitation would detract from patient care and present issues with difficult family members. Concerns that nurses presented included open visitation impeding patient care and demanding family members. One nurse explained that spending an hour talking to a patient's family is an hour of care she is not providing to a patient that needs aggressive care. Also, nurses have found through experience that families can become demanding. An ICU nurse explained that the longer the patient is admitted to the intensive care unit, the pickier the

patient's family gets, and it is harder for nurses to please the family. She describes that the family believes it is the nurse's fault for the patient's lack of progression related to inadequate care (Riley et al., 2014). There was also an issue regarding nurse safety with open visitation. Nurses felt "frightened by situations that patients bring with them to the hospital, such as fights between family members and visitors threatening to finish the job" (Riley et al., 2014, p. 322).

Although there are nurses that have negative perceptions about family centered care and open visitation, there are also positive nurse perspectives as well. One nurse in a study regarding family centered care commented, "these patients, belong to family who care about them and who should not be denied the opportunity to have interaction" (Riley et al., 2014, p 318). Nurses also believe if family members are exposed to medical procedures and daily care, they will better understand the complexities and demands of the intensive care unit setting, and may be able to assist with activities of daily living. Finally, nurses agreed that taking care of a patients family during a time of need, could be the only gift that the nurse can give to a dying patient (Riley et al., 2014).

Physician Perceptions of Family Centered Care

Although there were some nursing concerns regarding PFCC, positive feedback from nursing was found. Physicians did not have the same beliefs regarding patient and family-centered care. Many physicians believed it would be too stressful on family members to see medical procedures or be present during medical emergencies. One physician had the drastic statement that "twenty four hour visitation is not preferred. It is not possible" (Riley et al., 2014, p. 320). Some physicians felt there was not enough time to adequately answer questions and visit with patient families. They stated that making rounds was for acute interventions and teaching residents, and that there was no time to spare for communicating with patient family members.

Communicating with patient's families could be delegated to other members of the health care team, such as residents and nurses (Riley et al., 2014).

Physicians did agree that the family had a role in the care of the patient, but did not agree with the stationary presence of families in the intensive care unit. They shared the belief that families were the primary caregivers outside of the ICU, and should receive detailed information about the patient in preparation of care. A physician stated, "it is an integral part of what we've done for the patient. Allow their family to visit, because the family is going to take care of this patient when they make it out of the ICU" (Riley et al., 2014, p. 318). There were also some physicians within the study who were not opposed to flexibility in visiting, understanding that when patient's family members arrive from out of town, or any time after a surgery or procedure, they may need additional visitation time. Some facilities are educating physicians to be more mindful, informative, and empathetic when considering patient and family-centered care. This education helps transform their role from authority to a role that has goals of partnership, solidarity, empathy, and collaboration (Epstein and Street, 2011).

Cardio Pulmonary Resuscitation (CPR)

CPR is a delicate topic, especially when it is regarding a loved one. There is much debate on family presence during a critical situation such as CPR. In 2000, the American Heart Association became the first national organization to recommend the option of family presence during CPR and other invasive procedures (American Heart Association, 2000). There are varying opinions on the presence of families when a loved on is receiving CPR. Health professionals supporting family presence believe that witnessing CPR increases the families understanding, allows the family to see that everything was done, and increases rapport with the medical staff. The professionals supporting family presence also believe that family presence

facilitates grieving, especially when the patient passes away. In general, nurses are the most supportive of family presence during CPR. Nurses are more supportive than physicians, attending physicians more than physicians in training (residents), and pediatricians more than physicians who care for adults (Meert et al., 2013).

Health professionals who oppose family presence during CPR, caution that family presence may lead to increased anxiety and fear among family members, misunderstanding of events, and interference with procedures or decisions to stop CPR. Additional concerns include violations of patient privacy, staff performance anxiety and distractions, increased malpractice lawsuits, and the potential need for more resources such as staff, space, and time (Meert et al. 2013).

Neonatal Intensive Care Unit (NICU)

As a pioneer in Family Centered Care (FCC), neonatology has progressed to offer an extensive range of services and activities incorporating environmental, educational, psychosocial, and behavioral characteristics into their approach in offering FCC services. These services seek to place families at the heart of care planning (Finlayson et al., 2014). Because NICU staff collaborates with parents, families become more involved in decision-making and feel empowered to influence the process of their infants recovery. They may alternate or share leadership of the care plan with the physician and nursing staff (Gooding et al., 2011). The collaboration between parents and nurses is essential for implementing family centered care in neonatal intensive care units.

Even though some units offer unrestricted access to parents, this did not necessarily coordinate with a positive experience, such as mothers developing a bond with their child, or establishing parental sense of ownership or involvement. This was especially apparent when

infants were first admitted or placed in the incubator. Even several weeks later when mothers were preparing to leave the NICU with their child, some were still struggling to come to terms with the maternal role (Finlayson et al., 2014). Facilities that allowed “rooming in”, or the family to stay with the infant 24 hours a day, have more satisfactory bonding rates and decreased total length of stay for premature infants in the NICU. In Örténstrand et al. (2010), it was concluded that the total length of stay for premature infants (<37 weeks on admission) whose parents “roomed in” had a length of stay 5.3 days shorter than infants whose parents had restricted stay in the NICU.

As a nurse in the NICU, it is vital to form a caring and therapeutic relationship with the mother, this has been shown to greatly facilitate bonding between mother and infant. It has been discovered that a positive and trustful relationship between the staff and mother enables the mother to connect with her infant, whereas a negative relationship may lead to an unfortunate disconnection (Finlayson et al., 2014). Physical and emotional closeness are crucial in the physical, emotional, and social wellbeing of the mother and infant, and are fundamental in the development of a secure bond (Flacking et al., 2012).

Even though mother-infant bonding is vital, father and family bonding is just as important. Special efforts should be made to help fathers create care-giving and bonding moments, since fathers may encounter more barriers to establishing a relationship with their infant than mothers do and often are not able to spend as much time in the NICU (Gooding et al., 2011). Family bonding that takes place in the NICU needs to focus on not only on the newborn, but on the existing children as well. Because the family’s newborn has become the source of attention, a family support approach should address the needs of siblings who are often sidelined. Gooding et al. (2011) found that when children are informed of what to expect in the NICU, are

prescreened for psychological readiness, and are provided with activities appropriate for their developmental age, visiting the infant can be healing and not stressful. There are multiple ways to educate children when visiting a new sibling, such as reading and coloring books to help understand the experience and express their thoughts. There are multiple positive outcomes of children visiting new siblings in the NICU, which include fewer behavioral problems, decreased aggressive and regressive behavior among siblings, and an increased sense of family unity for the parents (Gooding et al., 2011).

In preparation for discharge, education classes and workshops for parents can be facilitated, which provides the opportunity to learn skills, such as infant CPR. This is also an opportune time for staff to educate parents on issues such as SIDS, safe sleeping practices, smoke free homes, respiratory syncytial virus, car seat use, preventative measure for subsequent pregnancies, such as reducing preterm birth. Spending the night with the infant in a transition room before discharge was vital in properly preparing the parents for discharge (Gooding et al., 2011).

Pediatric Intensive Care Unit (PICU)

Despite widespread acceptance of patient-family centered care, implementation into PICUs has remained a challenge. Families report wide disparities in experience in quality and family centeredness of the care they receive (Baird et al., 2015). During this crucial time in a child's illness, much of the caregiving role is transferred to the healthcare professional from the parent. This alteration in parental role has been identified as a source of stress for parents whose children are admitted to the PICU (Meert et al., 2013). In order to decrease stress, health care professionals should allow the parent to interact and participate in daily care when appropriate.

Many parents wish to be present during invasive procedures. Most parents believe that their presence during these difficult times helped them, as well as helped their child. The parents anxiety about the procedure was reduced if the parent was present, but the anxiety toward the child's condition was unchanged (Meert et al., 2013). Although healthcare professionals may feel that parents witnessing CPR would have a great negative impact, parents who witness CPR have a tendency for lower degrees of intrusive thoughts, posttraumatic avoidance behavior, and symptoms of grief three months later. Witnessing CPR is also beneficial in allowing the parent to understand that all life saving measures had been taken to revive the child (Meert et al., 2013).

Adult Intensive Care Units

Many of the same principles for patient-family centered care are present in the adult intensive care units as in the pediatric and neonatal intensive care units. There is a major aspect of PFCC that is present in adult ICU's related to child visitation. As a child visiting an ICU, the many machines, sounds, and smells can be difficult to handle at a young age. Concerns regarding child visitation include: potential line and tube dislodgement, emotional upset, causing patient physiological changes such as vital sign instability and intercranial pressure (ICP) changes in neurological patients, and the potential for infection from children. There are also concerns about risks to the child such as infection, emotional trauma, and worry about how things should be handled if the visit does not go as anticipated (Hanley & Piazza, 2012).

One solution to the concerns is to involve a child life specialist. They typically support pediatric patients and their families, but can assist with child visitation to adult units. They can be a very valuable resource. In the Hanley and Piazza (2012) study, the child life department created resources books for children visiting ICU's. It covered key concepts and had recommended readings for staff, parents, and children. Also included were interventions that

could be done for pediatric visitors, such as providing quiet distracting toys, allowing artistic play, and facilitating closeness with patient if possible (Hanley and Piazza 2012).

One hospital created comprehensive guidance plans, which were PowerPoint slides printed into booklets for families, children, and staff to view. The comprehensive guidance plan included an overview of the hospital environment, the sights and sounds that may be experienced, some changes their family may experience due to the hospitalization, and understanding that everyone has a different comfort level. These booklets explained that they will notice differences in their loved one and what support persons were available to the family before, during, or following the visit (Hanley & Piazza, 2012). The comprehensive guidance plan reminds families that it is important for the child or adolescent to share their feelings regarding the visit. It also includes the use of “best words” to describe some of the hospital language that may be encountered. Appropriate language is needed for all developmental levels to ensure understanding and avoid miscommunication in the health care setting. Defining terms, simplifying statements, and “calling it what it is”, have been determined by several family satisfaction surveys to help the family interpret and understand the norms of the hospital environment and the care of their loved one (Hanley & Piazza, 2012).

Benefits and Drawbacks of Patient-Family Centered Care

Before an ICU decides to integrate the patient-family centered care approach into their norms, they must first weigh the potential benefits and drawbacks. Included in the potential benefits are increased opportunities for families to give and receive information and to improve their understanding of the loved ones condition and treatment plans. Other benefits include an increase in their family or parental role during hospitalization, increase capacity to advocate for

loved one and participate in clinical decisions, increased transparency and trust in health professionals, and increased feelings of respect (Meert et al., 2013).

Although the benefits of patient-family centered care outweigh the drawbacks, there are issues related to physician rounds and family involvement. Potential risks of family-centered physician rounds include increased confusion due to misinterpretation of topics discussed during rounds, breaches in confidentiality and privacy, and inhibition of difficult discussions that are medically relevant, such as poor home care, medical errors, or poor prognosis. The duration of rounds has the potential to be increased, and there may be reduced teaching related to resident discomfort when presenting and asking questions (Meert et al., 2013).

Nursing Implications

Recommendations

As previously discussed, the benefits of patient-family centered care outweigh the drawbacks, and PFCC has much to offer patients, families, and healthcare as a whole. Taking into account the impending mass swell of those 65 and older, as well as family members increased demand to access loved ones, the need to enact patient and family-centered care is great. To comply with the PFCC guidelines, a few changes would need to be made. Staff perception and superior mentality is a great barrier during the beginning stages of implementing patient and family-centered care in ICUs. One of the most important aspects when considering PFCC culture is the staff and their relationships with families and perceived expectation of involvement (Finlayson et al., 2014). If there is inadequate staff-family interaction and communication, it can further exacerbate the family sense of isolation from their loved one. A change in staff attitude and behavior from considering families as visitors to primary caregivers,

demands a shift of power and role negotiation. This change in attitude needs support and active encouragement by all healthcare professionals (Finlayson et al., 2014).

A major aspect of patient and family centered care that nurses can implement is including the family in daily care of the patient. Depending on appropriateness, the family can provide the patient with a massage, full bath, eye care, mouth care, and comb their hair. The family can also wash the patients hair or face, assist them with shaving, and provide limb exercises. In assisting the family with participation, the nurse helps increase perceived respect, support, and collaboration between families and healthcare professionals (Mitchell et al., 2009). It has also been shown that assisting family members with care promotes closeness, patient safety and security, and patient integrity (Maxwell et al., 2007).

Healthcare professionals need to use effective therapeutic communication, be empathetic and available in order to achieve patient and family satisfaction with care. In regard to the neonatal ICU, efforts should be made for parents to remain in the NICU, since the benefits regarding length of stay are profound. Parents and guardians in the pediatric setting should continue to function in the parental role, and access should be granted for procedures and CPR. Evidence has shown that parent presence decreases anxiety about the procedure and grieving three months later. Adult ICU's should facilitate child visitors and continue operating under standards set by the Institute for Patient and Family-Centered Care. By incorporating patient and family-centered care ideals into practice, there is improved communication between patients, families and nurses, increase satisfaction regarding hospital stay, and improved job satisfaction scores between nurses and nurse managers (Riley et al., 2014). Although more research is needed in the realm of patient and family-centered care, it is obvious this movement in healthcare is making a huge impact on family satisfaction and patient outcomes.

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