“CHALLENGING FAMILIES”: THE ROLES OF DESIGN AND CULTURE IN NURSE-FAMILY INTERACTIONS IN A HIGH ACUITY INTENSIVE CARE UNIT

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“CHALLENGING FAMILIES”: THE ROLES OF DESIGN AND CULTURE IN NURSE-FAMILY INTERACTIONS IN A HIGH ACUITY INTENSIVE CARE ICU

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SUMMARY

The trend towards patient-and family-centered care (PFCC) invites families of critically ill patients to participate more fully in the care and recovery of their loved ones through partnerships with the critical care team and personalized care that respects the values, beliefs and experiences of the individual. This level of family engagement is unprecedented in a high acuity intensive care unit (ICU), which typically places restriction on family access and involvement. Healthcare stands at an important moment of transition in which attitudes, behaviors and expectations are changing. In response to the growing needs of families, institutions such as Emory University Hospital are re-designing the way patient and family care is delivered in terms of policy, culture and the physical environment.

Despite the many benefits that come with closer collaboration, nurses report that “challenging” families are a key source of workplace stress. This exploratory case study documents some of these challenges as perceived by staff nurses at Emory’s Neuro ICU while examining the role the built environment plays in shaping such perceptions. Through a series of ethnographic interviews and observational methodologies, the study sheds light on some of the challenges and benefits that come with balancing patient and family needs. Nurse strategies to reassert spatial and temporal control over workspaces are also identified. The second half of the paper compares communication patterns generated from two different ICUs to explore the link between unit design and the frequency and quality of nurse-family interactions. Findings suggest that space plays a role in moderating the degree of exposure to the often unstructured and
unpredictable aspects of family interactions. These encounters, set within a highly charged

critical care setting, may contribute to perceived challenges. Together these results reinforce the

need for adequate tools, training and education to further support nurses in the transition to this

new care culture.
1. INTRODUCTION

In today’s changing healthcare landscape, family members of critically ill patients are taking a more active, hands-on role in the care and recovery of their loved ones. Families not only provide patients with vital emotional and social support during critical illness; they themselves benefit from enhanced connectivity (Hammond, 1995). The growing trend towards patient-and family-centered care (PFCC) in the intensive care unit (ICU) invites families to participate more fully in the care of their loved ones, while helping to bring wholeness to the patient through partnerships with the critical care team and personalized care that respects the values, beliefs and experiences of the individual. A particular focus on departmental changes—such as the elimination of restricted visiting hours—is helping transform the perception of family members from visitors to full participants. In relation to the built environment, PFCC is often expressed through the expansion and differentiation of facilities for family members, including sleeping accommodations in patient rooms and amenities on nursing units—all measures that serve to break down barriers between clinician and family.

However, despite the many benefits that come with closer collaboration, many nurses report that “challenging” families are a key source of workplace stress. This study uses interviews and observations to explore nurses’ perceptions of challenging families and to better understand the nature of interactions between nurses and families that inform these perceptions. Through structured observations, the study further explores the design of the physical
environment as it interacts with nurse’s expectations and workplace demands. These insights are framed by the current evolution in healthcare where knowledge, attitudes and behaviors of both staff and families are changing and where institutional resources must align to support this change in culture.

It is important to contextualize nurse perceptions within the current changes in care culture. Indeed, critical care stands at the precipice of an important moment of transition. Patient- and family-centered care is a new concept that requires substantial changes in expectations and behaviors by all involved. While PFCC was initially developed in non-acute care settings, units caring for the sickest patients have been slower to make the change (Landro, 2007). The Neurosciences ICU at Emory University Hospital in Atlanta, Georgia, was one of the first ICUs in the country to respond to the growing needs of families through changes in both policy and design. In 2007, the newly renovated unit opened its doors to encourage greater family presence and participation in the day-to-day care process. The unit won accolades for its addition of private family “studios” adjacent to patient rooms and the provision of amenities such as shower and laundry facilities for those traveling far from home. Visitation hours were revised to allow around the clock access to loved ones and greater visibility of care team activity. These initiatives were designed to provide families with greater control and comfort during their stay in the ICU.

These policy and design changes fundamentally alter the experiences and expectations of both nurses and family members. This new level of family engagement is unprecedented in the
high acuity ICU, which traditionally places greater restrictions on family access and involvement. No longer expected to simply comply with protocol, this new paradigm encourages their full participation as empowered partners. Such changes do not come without stresses, however, especially in an emotionally charged unit where patients are acutely ill and very often require immediate, life sustaining attention. By redrawing temporal and spatial boundaries, PFCC enacts a new form of reciprocity in which families gain unprecedented access to the critical care environment while nurses are subject to greater exposure to families under duress—the implications of which are the focus of this study.

While families are not new to the ICU, the degree to which staff moderate family presence and participation has changed. In a more traditional, clinician-centered model, restricted visitation hours and inhospitable waiting areas discourage family presence at the bedside while allowing nurses greater control over time, workspace and patient. In PFCC, the reorganization of care around the family has expanding the nurse’s role as technical and social conduit between patient, family and staff. Frontline caregivers are often in the best position to attend to family needs yet are most likely to absorb the aftershocks of a family in crisis.

The impetus for this research comes from the results of an in-house survey on workplace stress conducted two years after the Emory ICU reopened its doors. Over 100 registered nurses (RN) were asked to rate perceived sources of emotional distress. Surprisingly, nearly half of the respondents sited “dealing with challenging families” as the primary stressor, above withdrawal
of care, peer conflict, patient mortality and personal disagreements with plan of care.¹ This current investigation builds upon these findings, using the Emory’s two Neuro ICUs as a case study to further explore the nature of nurse-family interactions and the role design plays in the delivery of family-centered care.

The paper is divided into two parts—the first is a report of findings from staff interviews and field observations, the second presents the data from empirical observations exploring the relationship between communication and space.

• Chapter 1 begins with an introduction to the core principles and values of PFCC and how these concepts have been integrated into the design of Emory’s 2D Neuro ICU. Staff members also work in an older 2G Neuro ICU located in the same building. A programmatic comparison sets the foundation of the study while shedding light on the physical and symbolic changes in attitude towards families.

• Chapter 2 presents the body of literature addressing the potential conflicts and constraints of caring for patients and their families as well as the potential link between spatial layout and communication.

• Chapter 3 offers a general overview of unit life and some of the conditions nurses and families face in the wake of a patient’s medical crisis.

• Chapter 4, 5 and 6 present qualitative findings from ethnographic interviews with RNs that identify some of the perceived challenges of balancing patient and family needs. The

¹ This unpublished, in-house survey was the initiative of Emilie McGrath, RN-BSN, CCRN.
paradoxes of PFCC, the variability of family presence and ways in which caregivers attempt to regain control over their environment are explored.

- Chapters 7 and 8 compare communication patterns between 2D and 2G using two methodologies—behavior mapping and nurse tracking—, which measure the frequency, location and quality of interactions.
- Chapters 9 and 10 present the results of the behavior mapping and comparative analysis of communication patterns.
- Chapters 11 and 12 present the nurse tracking findings and a theory of exposure that may account for the perceived challenges of family interactions.
- Chapter 13 concludes with an overview of findings and suggestions for future research and development.

It should be noted that the findings presented here are in no way intended to diminish the vital role families play in their loved ones care or the great strides healthcare organizations such as Emory University Hospital are making to better understand and support the important needs of patients and families. The nursing staff at the Neuro ICU display great empathy and compassion for and commitment to their patients and patients’ families on a daily basis. It is important to recognize their voice, and to gain new insights through a deeper understanding of challenges of PFCC as they see it. This study does not endeavor to address the nature of family care from a holistic perspective, but rather to focus on specific issues emerging from the rich, diverse and complex set of relationships between caregivers and families. PFCC is a complex and continually evolving model both in concept and practice. So, too, are the relationships between
nurse and family. The hope is that through knowledge gained, all participants may receive the support needed to ensure the future sustainability of this new care culture.

1.1 Background

To build a more complete understanding of the nursing experience in a PFCC environment, it is important to first establish the conceptual framework underpinning the changes in care delivery and facility design. The Institute for Patient-and Family-Centered Care (IPFCC) defines PFCC 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.” The results are “better health outcomes and wiser allocation of resources, and greater patient and family satisfaction” (IFCC, 2010). The concept first took root in the consumer and family movements of the 70s and 80s, when parents in neonatal ICUs began to seek more active participation in their children’s healthcare. While these early initiatives focused on caring for children with special needs, the movement has since expanded to adult patients and families across a variety of clinical settings (Johnson, 2000).

PFCC encompasses four core principles based on the belief that family play a vital role in influencing an individual’s health and wellbeing, and, thus, should be supported as caregivers. According to the IPFCC, these principles include:
• **Respect and dignity.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

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

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

• **Collaboration.** Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

For the successful implementation of these principles, patients and families must first be seen as individuals and members of a family and community. Second, families are recognized as diverse and defined by the family themselves. Third, family-centered principles must be comprehensive and permeate the entire system of care, from mission statement to facility design.
Finally, patients and families must have meaningful participation in the development of programs and policies (Conway, Johnson, & Edgman-Levitan, 2006).

These principles, when set into practice, align caregiver and family under one common goal: patient care. The nurse’s primary objective is to monitor and maintain life-sustaining measures. Family members, in turn, want to ensure the best care is being given to their loved one. These goals are often mutually beneficial: the nurse working in close proximity to the patient possesses rich information that can help reassure the family and assist in decision-making. Likewise, family brings personal knowledge that can help guide the plan of care and further humanize the patient. At other times, however, these agendas can create the potential for conflict. For instance, a nurse may need to prioritize one patient over another, or delay family needs to respond to a more urgent medical situation. In a traditional ICU, nurses have exerted greater control over patient care and family involvement. As families gain freedom to observe and participate in daily activity, the boundaries between nurse and family domains begin to blur and encounters may become harder to predict.

PFCC engages families at multiple levels--experiential, clinical, organizational, and national--and invites collaboration in not just the daily care of the patient but the design of processes, policies and facilities. Facility design, in particular, has become an increasingly important and recognized vehicle for supporting the principles of PFCC. A review of award-winning ICU designs from the past decade indicates that the industry is beginning to acknowledge family as an integral part of the healing process (Cadenhead, 2010). Healthcare administrators and architects are carving out more family space inside the ICU and within the
patient room itself, while continuing to build safer, more efficient environments for patients and staff. Emory University Hospital’s 2D Neurosciences ICU is one such example of this intersection of PFCC principles and design (Figure 1). The 20-bed unit was renovated in 2007 with input from a multidisciplinary team of architects, academic faculty, clinicians and former family members and patients. Based on the latest evidence linking the built environment with improved outcomes, the re-design aimed to improve family access to loved ones, foster social support and encourage information sharing with the care team.

The Neuro ICU staff at Emory currently divides their time between the new 2D unit and 2G, an older 7-bed ICU located in the same hospital (Figure 2). Both units practice the same family-centered policies and initiatives but within vastly different architectural settings. This study represents a remarkable opportunity to observe two spatially distinct units sharing the same staff, patient population and care culture. A comparison of unit program (below) best illustrates this conceptual and spatial shift from a clinician-centered model to one of family inclusiveness.
Figure 1. Diagram of Family and Staff Support Spaces in the 2G Neurosciences ICU

Figure 2. Diagram of Family and Staff Support Spaces in the 2D Neurosciences ICU
Table 1. Programmatic Comparison for 2D ICU and 2G ICU*

<table>
<thead>
<tr>
<th></th>
<th>ICU Beds</th>
<th>Unit Size</th>
<th>Patient Room</th>
<th>Waiting Room</th>
<th>Nursing Station</th>
<th>Shower Facility</th>
<th>Laundry Facility</th>
<th>Bathroom</th>
</tr>
</thead>
<tbody>
<tr>
<td>2G-ICU</td>
<td>7</td>
<td>4,000 sf</td>
<td>180 sf</td>
<td>540 sf**</td>
<td>340 sf</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>2D-ICU</td>
<td>20</td>
<td>24,700 sf</td>
<td>350 sf****</td>
<td>675 sf</td>
<td>640 sf***</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

* Dimensions are approximate  
** 2G-ICU waiting rooms (2) combined  
*** 2D-ICU nursing stations (2) combined  
**** Patient room and family studio combined

Circulation

The changing attitudes towards families are reflected in evolution of three key design features from 2G to 2D: circulation, nursing stations and family support spaces. We begin with the organization of circulation. In 2G, staff and family enter the unit through separate doors, one leading to a centralized nursing station, the other to an outer family corridor encircling the unit. Family members are restricted from entering the clinical core and must access waiting areas and patient rooms via the semi-private family hallway. This segregation reinforces boundaries between nurse and family zones, thus allowing staff to exercise greater control over their workspace and potential interactions. The circulation in 2D ICU is unusual in its adoption of a single interior corridor shared by staff and family. While each group enters the unit from different access points, this central artery facilitates encounter through movement and co-visibility—in other words, the ability for two people to see one another without obstruction. This route is also the only way to access patient rooms and family studios, further bridging clinical and social spaces.
Nursing stations

Staff members in 2G work in a centralized nursing station within the clinician corridor. This communal workstation serves multiple functions, including charting, monitoring and peer socializing. Patient rooms form a buffer between the clinical core and family zones, further reinforcing boundaries between the two groups. In 2D, two nursing stations anchor either end of the unit while nurse alcoves are distributed along the corridor and nested between pairs of patient rooms. While designed to promote patient safety through proximity and visibility, the location of alcoves in the public flow may enhance the potential for interaction.

Family zones

The location of family space in the ICU indicates the degree to which an organization has accepted and integrated family (Rashid, 2006). In the comparison between 2G and 2D we find substantial differences in how families are provided for. In 2G, visitors are pushed to the corners and edges without direct visual access to patients and staff located inside. Visitors are provided two waiting areas connected to the outer corridor, a niche with a reclining chair just outside patient room or a single, upright chair inside the patient room. Small rooms make gathering at the bedside difficult while uncomfortable furnishings makes overnight stays inhospitable. Curtains can be drawn over the semi-private niche and doors between patient room and hallway can be closed to preserve patient and family privacy, however this may further inhibit co-
visibility. Visitors wishing to use bathrooms and service facilities must walk down the hall to 2D.

In contrast, 2D offers a constellation of family spaces that offer comfort and flexibility. These areas form a gradient of support, allowing families to choose their level of engagement—a key imperative of PFCC. Inside the unit, large patient rooms encourage family presence at the bedside to provide comfort and care to loved ones or converse with caregivers at work. The private “studio” inside the patient room further enables proximity and patient monitoring while creating a place for respite and retreat. Here, family members are invited to come and go during the day and stay overnight on comfortable reclining chairs. These spaces also flex to accommodate family meetings and consultations with the care team (Figure 1.1). Just outside the unit, a family coordinator provides visitors with additional education and assistance. The availability of a spacious waiting area with shower, laundry and kitchen facilities, consultation room and children’s play zone further support the family’s need for self-care and socialization (Figure 1.2). For those wishing to step away from the unit entirely, the hospital cafeteria and general waiting area offer additional refuge.
Figure 2.1. Diagram of 2D Patient Room/Family Studio

Figure 2.2. Diagram of 2D Family Waiting Room
The provision of these support spaces and amenities in 2D fulfills the family’s need to be near the patient, receive timely information and ensure their loved one receives the best care possible (Lam, 2004). Woven into the daily fabric of the unit, families are no longer bound to the spatial and temporal restrictions of the traditional ICU. The ICU is designed as a high visibility environment to, in part, improve patient monitoring and safety. Family presence on a more regular basis encourages opportunities to monitor patient progress and caregiver activity. In this new setting, families gain more control while caregivers are placed under greater surveillance. In his essay on privacy, Archea writes, “the regulation of interpersonal behavior is influenced by the possibilities for monitoring the behavior of others (access) and by the possibilities that others can monitor one’s own behavior (exposure)” (Archea, 1977) (p. 121). Without adequate support resources, this reciprocity can result in a loss of control over the timing and location of interactions and workspace privacy, which may contribute to nurse stress. The result is exposure to the unpredictable nature of family presence in an already variable ICU environment. This study suggests that some of the perceived challenges of PFCC may reside in these opportunities for exposure and control.

1. Purpose

Few studies have explored the relationship between nurse and family from the nurse’s perspective as it relates to changes in PFCC policy and design. This shift in the ICU’s spatial and temporal boundaries has meant greater family involvement in the care process while increasing nurse exposure to families in times of crisis. While this potential for interaction can often prove mutually beneficial, exposure may have unintended consequences for the nurse. This exploratory
study begins with several broad questions: how are staff nurses experiencing this new care culture as it is manifest in both practice and design? What constitutes a stressful or challenging family interaction, and when is family interaction beneficial for the nurse? What role does the built environment play in determining how and where nurses and families interface and communicate?

The study is divided into two sections. In Part I, ethnographic interviews and observations paint a richer understanding of the challenges nurses face in this new care paradigm while identifying some of the tactics used to regain control over time, workspace and family. Part II takes a deeper dive into the composition of nurse-family interactions through the use of two empirical methods—behavior mapping and nurse tracking. A comparative analysis of communication patterns between 2D and 2G explores the link between unit layout and the frequency and quality of encounter.

Together the results suggest that exposure to families working in the 2D and 2G units, specifically within this current transition to the PFCC care model, introduces a new level of uncertainty and loss of control in an already unpredictable and variable critical care setting. This research does not intend to diminish the many therapeutic relationships between caregiver and family. Rather, the purpose is to better understand the day-to-day perceptions of nurses working in this new care landscape and some of the challenges faced when caring for patients and their families. At the same time the hope is to broaden our conception of the built environment as an important moderator which influences how and when these exchanges take place.
2. LITERATURE REVIEW

The impact of PFCC is perhaps most visible in the daily interactions between family and care team. The staff, or bedside nurse, works in close and constant proximity to family members to provide invaluable information and support. At its best, these encounters can build trust and respect. However, critical care is inherently stressful and “the actual relationships [between nurse and family] are often tense, complicated and multifaceted” (Yetman, 2008). Families are stressed, confused and facing unfamiliar situations; nurses have complex and difficult medical tasks that require close attention.

Family presence in the ICU is not a new phenomenon, nor is the perception that families pose a significant source of distress for the nurse. Early research exploring nurse experience in the ICU identified disruptive family as “one of the most distressing problems the nurse contends with (Cassem & Hackett, 1972). Two decades later, a another study revealed that dealing with “aggressive” families constituted a major stressful event in the neurosurgical ICU (Snape & Cavanagh, 1993). ICU nurses are particularly vulnerable to manipulative and passive aggressive family behaviors (Maunder, 1997). While numerous reports expound the benefits of PFCC, including improved information sharing and greater family satisfaction, experts also acknowledge the challenges nurses faces in calibrating to this new care culture (Griffin, 2003) (Garrouste-Orgeas & Philippart, 2008) (Lee & Friedenberg, 2007).
Staff members most often consider family as an important part of their job and recognize the numerous benefits for the patient and family. Indeed, the integration of family through caring nurse behaviors has been shown to ease family stress in times of crisis (Pryzby, 2005). Thus, while families are not always viewed as “difficult”, nurses often express the difficulty of caring for families. The *Nursing Stress Scale* was one of the early quantitative measures demonstrating that ICU nurses may feel unprepared to meet the emotional needs of patients and family (Gray-Toft & Anderson, 1981). For example, nurses may experience increased stress when ill equipped to answer family questions. This was particularly cogent for new or inexperienced nurses who felt overwhelmed by the prospect of meeting a family’s informational and psychosocial needs (Benner & Tanner, 1996).

Communication is the glue that binds nurse and family yet these delicate conversations can pose significant challenges in an emotionally charged ICU. A recent literature review by a team of critical care experts acknowledged the stress of family interactions are often a bi-product of breakdowns in communication (Davidson, 2007). Research by Jee & Reason (1988) showed that determining “what to say and how to say it” to a family in distress is one factor that can increase cognitive load and lead to a stress response (Corr, 2000).

Studies also shed light on nurse concerns that family presence can compromise care delivery while having deleterious effects on a family’s physical and emotional health. In one study, caregivers perceived family presence as creating additional stress for the patient and cause interference with patient care while also exhausting the family (Benwick & Kotagal, 2004).
response, family members struggling with patient diagnosis or critical situation were encouraged to take time away from the unit to rest. In other cases, nurses spent time protecting the patient and themselves by preventing family from interfering with their work (Hupcey, 1999). Family presence during invasive procedures or resuscitations was also viewed as a source of distraction and performance anxiety for the nurse with the potential to adversely affect the family emotionally (Duran, Oman, Abel, Koziel, & Smymanski, 2007).

Jee and Reason (1988) showed that conflicting or contradictory job demands are also a common sources of nurse tension (Corr, 2000). An early article by Vreeland and Ellis (1969) discusses the paradoxical position of the ICU nurse when caring for a critical patient. “On the one hand, she is expected to be objective and firm; on the other she is expected to emanate warmth and feeling. Maintenance of an appropriate balance in these opposing attitudes is itself a stress” (p.133) (Vreeland & Ellis, 1969). This dilemma extends to family care as well. In one study, nurses felt torn between attending to their patients and taking time to comfort family members (Cassem & Hackett, 1972). In a more recent study by Hupcey (1999), nurses reported conflicts caring for an unstable patient while having to answer questions from a stable patient’s family. Nurses felt frustration that “families did not see that they…were in control of the situation” (p. 257). According to Stayt, some nurses experience role conflict in balancing patients, family and technology (Stayt, 2009). Yetman, too, underscores the “double bind” that nurses face, particularly without adequate support, tools or training to meet organizational expectations (Yetman, 2008). While resources have been developed to assist nurses in the
transition, PFCC continues to be met with varying levels of resistance and success (Browne & Langlois, 2004) (Conway, et al., 2006) (Davidson, 2007).

The trend towards patient-and family-centered care is reformulating how critical care units are designed. Surprisingly, references to the built environment are noticeably absent from the nursing literature. Studies addressing caregiver-family dynamics have tended to focus on their relationship as part of the physiology of the unit without addressing the anatomy, or physical context, itself (O. Samuels, personal communication, July 20, 2010). In recent years, architects and researchers have explored the impact of facility design on patient outcomes, family satisfaction and nurse performance. However, there are few, if any, studies exploring how layout influences communication between nurse and family in the ICU. A small body of research linking office design and communication suggests that spatial attributes such as visibility, accessibility and openness can impact the frequency of face-to-face interactions (Rashid, Kampschroer, Wineman, & Zimring, 2004). For example, Hall (1966) demonstrated that two employees facing one another increase the likelihood of a conversation. Similarly, Parsons (1976) showed that an employee is more likely to approach a colleague if visible from his/her position (Rashid, et al., 2004). Spontaneous interactions are often desired in the workplace to strengthen social cohesion, organizational culture and the dissemination of knowledge. In a critical care situation, however, these encounters have the potential for both collaboration and disruption.
PART I: INTERVIEWS + OBSERVATIONS
3. BACKGROUND

The ICU is an inherently stressful workplace (Donchin & Seagull, 2002). Rising turnover, staff shortages and burnout are major concerns (Commission, 2002). In fact, ICU nurses are more likely to suffer from post-traumatic stress disorder (PTSD) than general nurses (Mealer & Shelton, 2007). Caring for one, often two, critically ill patients can place great physical, emotional and cognitive demands on frontline caregivers. Shifts are long, breaks are few and patients are often heavy to lift. The work requires a deft choreography of technical precision and the ability to multitask and communicate information effectively. The death of a patient, moral and ethical conflicts, disagreements over plans of care and dealing with difficult family members are just a few of the factors that contribute to workplace stress and fatigue (Snape & Cavanagh, 1993).

The Neuro ICU holds a unique position in critical care. Patients arrive in varying degrees of cognitive impairment as a result of an accident, existing medical condition or illness. Nurses at Emory have described the ICU as a “feast or famine” environment where patient condition can change at any moment—small changes can mean the difference between life and death. On any given day, beds are filled with a range of diagnoses, from mild aphasia to traumatic brain injury, often the result of a stroke or aneurysm. The contrast can be dramatic: in one room a patient and caregiver prepare for home discharge, while in the next family gather with the care team to make difficult end-of-life decisions. While doctors focus on overall trends, the bedside nurse remains
in close proximity monitoring and assessing conditions on a minute-by-minute, hour-by-hour basis. As Cassem and Hackett (1972) stated, the nurse “bears the awesome responsibility of performing chores that are at one instant perfunctory and at the next, heroic” (p. 1430). Duties stretch far beyond bedpans and IVs—in effect, they must prevent minor changes from devolving into life-threatening issues. Neurologically impaired patients are particularly sensitive to sensory stimulation. Thus, nurses take great care to create a protective, stabilized environment to promote healing. While the role of the nurse is often undervalued or invisible to the public eye, he/she functions as a critical component in the patient’s life support system.

In the wake of a patient’s medical crisis, the family arrives at the ICU exhausted, confused and scared. Their loved one has likely suffered a traumatic event that is unexpected and sudden, and they are eager for information, reassurance and hope. Uncertainty runs high in a Neuro ICU, where the very essence of the patient—one’s personality and sense of self—may be compromised. Anger, shock, grief, guilt and feeling a loss of control are common emotions experienced by a family thrown into personal turmoil. PFCC endeavors to assuage some of these fears and concerns through partnerships that foster information sharing and informed decision-making. While families contextualize the patient and often serve as surrogate decision makers, nurses provide invaluable information about patient condition to help families make the best decisions possible (Shannon, 2001). In this highly charged environment, where patient mortality runs high, the importance of family presence is at its greatest. So, too, is the need to deliver focused and efficient patient care. When nurse and family meet inside the unit, these needs can create opportunities for collaboration, and in some cases, contention.
3.1 Purpose

Building upon the existing literature, this first phase of research was designed to gain a more detailed understanding of the daily challenges the staff nurse faces in this new family-centered environment—from the perspective of nurses themselves. The study employs a series of ethnographic interviews to capture the thoughts, feelings and opinions of frontline caregivers working in Emory’s 2D and 2G Neuro ICUs. This qualitative inquiry was guided by the following questions: What is the day-to-day life of the staff nurse working in this new care environment? Why are families perceived as challenging? How have changes in policy and design impacted the quality of interactions with family members? In the process, what tactics or coping skills have nurses developed to maintain balance between patients, families and self?
4. METHODOLOGY

4.1 Ethnographic Interviews

Research was conducted in the 2D and 2G ICUs over the course of three months in the summer of 2010. Twelve registered nurses were interviewed, along with seven other members of the critical care team, including charge nurses, nurse practitioners, doctors, family coordinators and chaplain services. Participants worked primarily weekday or weeknight shifts and were selected based upon prior recommendations from colleagues or general availability at the time of data collection. Most interviews took place in 2D as opposed to 2G due to a larger pool of potential subjects. Conversations took place in nurse alcoves or nursing stations and lasted approximately twenty minutes to one hour, depending on workload. This allowed for concurrent observation of daily activities while prompting respondents to recall pertinent scenarios. Nurses were free to interrupt the interview at any time to attend to patient and family needs.

Interviews began with an explanation of research intent and exploratory questions. In most cases, conversations unfolded organically, as nurses were eager to share their experiences and impressions. Structured questions were added with each interview to confirm and clarify information from previous discussions. An initial attempt was made to audiotape interviews, however, most preferred to remain “off the record.” As a result, notes were taken by hand, with key words, phrases, scenarios and short quotes recorded. Data collection was similarly
generative, allowing patterns to emerge directly from the subjects and context in question. After each interview, field notes were coded and grouped into one of eight themes: Pros and Cons of PFCC; Family Behaviors; Communication; Paradoxes of Care; Coping Strategies; Organizational Expectations; Resources; and Use of Space. While various members of the care team were interviewed, analysis was formulated using mainly insights gleaned from the RNs. And finally, a researcher diary was kept to capture personal thoughts and observations during the process.

The interviews in this section are primarily intended to document the participant’s perceptions of problematic families and of the potential support that they need.
5. RESULTS – INTERVIEWS AND DIRECT OBSERVATIONS

This section identifies some of the key factors that nurses perceive constitute a stressful family interaction, the ways in which nurses have reasserted control over time, workspace and patient and some examples of challenging behaviors and situations as documented by the researcher. Findings are presented in four parts: Impressions of PFCC; Defining the Challenging Family; The Paradox of Caring for Patient and Family; and Opportunities for Control. It should be noted that while some differences between 2D and 2G were articulated, interviews were largely the gestalt, or cumulative experience, of nurses working in both units. A more in-depth unit comparison will be discussed in Section II.

5.1 Nurses’ Impressions of PFCC

“Family-centered care is good...but to what extent?”

Respondents expressed a range of opinions about PFCC but most agreed that family presence and participation in the care process is “good in theory” but complicated in practice. Positive interactions were largely seen as dependent on a combination of ingredients: patient condition, family personality, caregiver workload and work style and, at a higher level, the support of the organization. When asked, “when does PFCC work best?” many believed family were most beneficial when the patient was “intact” (e.g. normal cognitive function.) They cited
the valuable role family play as a resource, helping to calm an agitated or disoriented patient, assist with daily tasks, provide emotional encouragement and serve as a “second pair of eyes” to alert staff of any changes in condition. For patients unable to speak for themselves, family became vital decision makers and advocates for quality care. Families, too, helped staff “get to know” their patients. In the more acute cases, however, some nurses questioned the degree of appropriateness of 24/7 family presence.

When comparing experiences between the two units, 2D was generally considered a better environment for the delivery of family-centered care than 2G. Improved access and visibility meant family were able to witness daily activity and feel reassured that everything was being done for their loved one. Consequently, this helped the care team gain consent and consensus in decision-making and plan of care. However, this newfound co-visibility had tradeoffs, including loss of patient privacy and misperceptions of nurse activity (e.g. a nurse sitting at her computer could be reassuring to one family and misconstrued as “on the internet…not working” by another.) While some RNs felt that the smaller 2G ICU was more conducive to teamwork, layout configuration made visibility—thus information sharing and consent—more difficult. Nurses reported that this restrictive layout made it easier for “doctors to dodge [the] mere presence” of family.

Interestingly, some staff perceived family difficulties as less about the design of space and more about the design of systems, beginning with organizational expectations. As one nurse lamented, “they aren’t in the room with us, so they don’t get that it’s hard to take care of patients
and appease family.” Many respondents felt they had not been given adequate tools, training or resources to navigate communications and interactions with families. A lack of clarity about the definition of PFCC and questions about the extent of their role and responsibilities also contributed to a sense of frustration. The creation of more regimented protocols, team-based strategies to better support family needs, “family contracts,” education for nurses (e.g. communication skills, understanding family psychology and needs) and education for families (e.g. clearer behavioral codes and guidelines) were some suggested improvements.

5.2. Defining the Challenging Family

Nurses offered several broad descriptions of family behaviors perceived as difficult. Families were loosely categorized as either “compliant” or “challenging.” A compliant family was considered to be respectful, supportive and “willing to pitch in.” They often exhibited higher “situational awareness”—in other words, they were realistic about patient prognosis, supportive of the nurse and knew when to step back to let the nurse do his/her job. These families had the potential to bring high personal and professional satisfaction. On the other hand, a challenging, or “complex”, family was one “whom the medical team perceive consume more time than they feel they have available; they impede the work of the medical staff with demands, complaints, lack of cooperation and/or prevent medical staff from carrying out therapies designed for their loved one’s benefit (Wolf & Robinson-Smith, 2007). “Hovering”2; “needy”; “in the way”;

2 A study by Jameson and colleagues (1996) presents four stages of family integration into the ICU after a loved one has been admitted. “Hovering” is the first stage, “where families experience uncertainty, emotional turmoil and stress.” This is followed by ‘seek information’, ‘tracking’ and ‘garnering of resources.’
“demanding”; “excessive questioning”; “passive aggressive”; and “dictating care” were common terms used to describe particularly challenging behaviors.  

Interviews and observations revealed that the compliant and challenging family represented opposite ends of a highly variable, and often conditional, spectrum of experience. Quality of interaction was, in fact, often predicated on a variety of individual and situational factors. As one subject described, “every family situation is different.” Thus, personality, ability to cope with stress, socio-cultural and religious backgrounds as well as inter-family relationships and expectations of care were identified as potential influencers of family behavior. Likewise, some nurses explained that personality, experience level, coping skills, cultural background, etc., also often shaped their own attitudes and behaviors towards families. One nurse expressed difficulty anticipating family behavior. A particularly disconcerting scenario involved a nurse being “blindsided” by a family who was unhappy with care yet unable to express their concerns. While the nurse believed the relationship was positive, she was unexpectedly taken off the case at the request of the family. In contrast, observations revealed numerous instances of families offering direct praise and support to the nurse for his/her efforts.

In addition to interpersonal factors, respondents identified windows of time where family stress was likely to flare. These included the first few days after patient admission and several weeks (even months) later, when family may experience difficulty leaving the patient beside. Critical tasks and shift changes were other times when nurses felt the pressure of family

\[3\] An article by Maunder offers interesting insight into the theoretical underpinnings of “difficult” family behaviors and the proclivity for nurse exposure to aggressive families (Maunder, 1997).
presence…but not always. While family behaviors and responses were often conditional, they were not always predictable. Many nurses felt that the quality of relationships with family hinged upon these interpersonal and situational factors, while others argued that more systemic issues were at play. For some, the issue was “not a matter of personalities” but reflected the need for more regimented and consistent systems, protocols, tools and guidelines. Recognizing that personalities under stress are difficult to control, some felt that the implementation of more organizational “structure” would help nurses in the transition.

5.3 The Paradox of Caring for Patient and Family

As interviews unfolded, initial impressions gave way to some of the deeper complexities and contradictions of PFCC. Key situations and scenarios have been organized into one of seven themes: “The patient is the priority”; “Family impacts my ability to care for the patient”; “The family becomes the patient”; “Nurses walk a fine line”; “Everybody sees”; “Family is complex”; and “It depends on the family.” Through these insights we discover that nurse distress resides not simply in the challenges posed by family behavior, but in the challenge of balancing the needs of patients, families and self.

“The patient is the priority”

In the ICU, nurse and family are united by one common goal: patient care. By placing patient and family at the “center” of care, PFCC creates an unanticipated dilemma for the nurse:
in caring for two critical patients, each patient becomes the priority for his or her family. The bedside nurse sits at a critical juncture of having to prioritize patient needs while running the risk of alienating or upsetting a family member. In one scenario as told by the nurse, a daughter approached a busy nurse with concerns about her father’s comfort level. The nurse was unable to immediately attend to this concern due to the changing condition of her critical, unstable patient in the next room. Frustrations arose when “families don’t always see what you are trying to do” and may not understand the hierarchy of tasks or patient acuity. As one nurse explained, “We feel like we’re getting pulled between…taking care of [our] patient, being a nurse, taking care of [our] other patient…It’s hard to sit there and explain to somebody ‘I have another patient. It’s not all about you.’ You can’t tell them that. It’s rude.”

5.3.2 “Family impacts my ability to care for the patient”

Family participation in the care process was regarded as both help and hindrance. While nurses recognized the value of family presence, respondents were unanimous in their concern that families could also impede patient care, particularly when caring for very sick patients. Especially in 2G where rooms are small, nurses described family members as more likely to be “in the way” of staff working at the bedside. Nurses also cited difficulties fielding questions

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4 The evolution and rationale of the term PFCC is beyond this paper but worthy of mention. Several different iterations exist in academic and organizational literature, which may add to the confusion about the true definition of PFCC. Subtle shifts in semantics can signal subtle but varying degrees of family involvement and expectations of care. For example, Emory uses “patient-family-centered care, which conveys unity and equality (versus family-centered care or patient-and family-centered care.) For departments struggling with the transition to PFCC it is perhaps worth re-visiting this terminology and better clarifying organizational goals and intent first.

5 During observations, family were “in the way” at the bedside in both units, even though 2G rooms are substantially smaller (120-200 versus 345-440 sq ft.) This meant having to work around family (who did not move when nurses approached the bed) or asking family to step away from the bedside to reach equipment.
while performing tasks and having to spend additional energy and resources troubleshooting family queries as obstacles to patient care. Falling behind on work, delays in treatments and missed tests were cited as some of the consequences of working with (and around) family. Family presence is especially complex for a neurologically impaired patient—sound, even touch, can increase intracranial pressure (ICP) and exhaust the patient. Thus, nurses acknowledged spending time protecting the patient from a family’s good intentions. This included prohibiting or supervising feeding, restricting visitation and terminating conversations viewed as tiring or stressful for the patient.

5.3.3 “The family becomes the patient”

RNs considered themselves more than simply a conduit for information, but rather as a therapist, educator, financial advisor, spiritual supporter, even housekeeper. Most accepted, even welcomed, family as part of their job (“we are their support”) while others were cautious, particularly if they felt disrespected by the family (“they treat me like I’m the maid.”) Nurses frequently took time to ensure a family’s well being by fetching coffee and blankets or offering advice and encouragement. Attending to the needs of family, however, sometimes meant a distraction from patient care. In one instance, a nurse reported being cornered by a family member and was unable to see or attend to her unstable patient next door. As one nurse described

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6 Hourly neurological assessments (rousing the patient to assess degree of cognitive function and state of consciousness) are an essential part of the nurse’s job. Families may learn by watching the nurse then “do their own checks” later. While this can give family a sense of purpose and hope, it can potentially over-stimulate and exhaust the patient, leading to false alarms and unnecessary and costly MRIs. However, what can harm can also humanize. There were many other cases where touch, music, and stimulation were thought to provide comfort and encouragement for the patient. The degree of family interaction with the patient depends on nurse judgment and patient acuity.
this dilemma, “the patient is the focus…[families] take away your focus from what you have to do, but you don’t want to dismiss them.” Nurses also worried that continuous family presence may adversely affect a family’s emotional and physical wellbeing. Those sensitive to the unfamiliar sights and sounds of the ICU or who had difficulty leaving the patient bedside were prone to suffer from fatigue, anxiety, even anger. Chaplain services, social workers, and palliative care specialists were called upon for additional assistance when nurses recognized they were unable to fully attend to the family’s emotional and informational needs.

“Nurses walk a fine line”

Communication is the heart of the nurse-family dynamic yet is often the most precarious to navigate in a high stress environment. Many nurses—particular those with less experience—described the difficulty in knowing “what to say and how to say it”—in other words, how to provide information without provoking anxiety. This was particularly true for family members having difficulty accepting patient diagnosis. Nurses shared examples of the tenuous nature in which information is received: they are “looking for hope” and “hear what they want to hear.” Good news one day can change to poor the next, yet a family may hold on to the previous day’s hopeful message. As a result, they may request everything be done for their loved one when there is no quality of life for the patient. This may lead to a moral dilemma for the nurse that can build resentment and erode communication. Nurses, too, are not immune to the stress of the ICU. Some admitted that “niceties” were not always possible, especially when having to balance an
urgent patient situation with less immediate family needs. In rare cases, nurses may avoid the patient room altogether to escape contentious conversations.7

“Everybody sees”

In a PFCC environment, families are now privy to the continuum of patient care. The ability to “see everything” keeps family updated and involved--particularly helpful when the care team needs to gain consent. However, nurses stated that a lack of experience in a critical care setting means families may not understand the intricacies of protocols, treatments and conditions. For example, a nurse may need to be physically rough with an unresponsive patient--family may interpret this as “hurting their loved one.” Similarly, a family member may be alarmed by a high blood pressure reading, which has, in fact, been purposefully set by the care team. These misperceptions can lead to anxiety and mistrust of the staff. For the nurse, the family’s inability to understand (or “see”) the reality of a situation constitutes a major source of distress.

While families may feel reassured seeing the care team at work in nursing stations and in the hallway, some nurses expressed feeling under scrutiny, particularly with an “aggressive family watching and questioning every move.” As a result, some felt they were “always on” and “[couldn’t] have a bad day…or make a mistake…with everybody watching.”

“Families are complex”

7 While not the emphasis of this study, it is worth further exploration of the impact of nurse personalities and attitudes on family relations. Interviews revealed that there are some nurses who “complain no matter which family” and others who may be technically skilled but may lack the “customer service” personality that PFCC requires.
In PFCC, the definition of “family” has expanded to include friends, neighbors, partners, mistresses, pastors and other interpretations. In an open access ICU, more visitors are likely to be present, often coming and going at different times throughout the day. According to respondents, identification of a family spokesperson and clear communication among group members can pose a significant challenge, particularly when caring for a large family. PFCC assumes families arrive as a cohesive unit. In reality, they are often neither intact nor fully functional. Each member differs in personality, coping skills and quality of relationship with the patient and each other. As one nurse described, “family bring baggage into the room with them,” which means nurses are subject to—and sometimes pulled into—“family drama.” Thus, the nurse must serve as a gatekeeper for family presence and the flow of information while remaining sensitive to individual needs and family politics.

“It depends on the family”

Many nurse statements contained an important caveat: “It depends on the family.” A respectful and supportive family can bring high personal and professional satisfaction while a demanding or ungrateful one can “make it not worth it.” For example, a busy nurse may not mind being approached in the alcove by a member that has been supportive, whereas an “overbearing” family member may generate feelings of frustration. The variability of

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8 This definition is based on comments and observations made by staff. The IFCC website offers a similar yet incomplete definition of “family.” While it is acknowledged that family define themselves, little emphasis is given to the complexity and variability of family personality, their potential dynamics dysfunctions and how these might impact the quality of interactions.
personalities and dynamics brings a certain day-to-day unpredictability to interactions. These encounters may be harder to anticipate and prepare for. According to some, this creates a layer of nurse subjectivity that can lead to inconsistent rule enforcement. One nurse may adhere to visitation rules while another may be more lenient. Some may attend to the personal needs of a “nice” family while others, feeling scrutinized, may be less inclined to make the effort.

5.4 Opportunities for Control

“Family impact my ability to care for the patient” was the most commonly cited challenge facing nurses in the ICU. In response, some have developed coping strategies to control family movement, behavior and participation while reasserting workspace boundaries. Interviews and observations suggest that nurses used two types of behavioral tactics to regulate their interactions with family members: integration and separation. Integration strategies brought families into direct involvement and communication with the nurse while separation created physical and temporal distance. Interestingly, both tactics shared a dual purpose: by informing and reassuring anxious family members, nurses were better able to quell concerns, questions and interruptions. Nurses conceded that, while beneficial for the family, these tactics also created more “breathing room” to do their job and focus on the patient.

“You do yourself a huge favor by getting family to help”
As an example of integration, families were frequently invited to participate in daily tasks, from turning the patient to feeding and bathing. By “putting family to work”, nurses not only empowered the family with a sense of purpose but helped alleviate their workload.

Transparency of communication was another form of integration that reaped dual benefits. By keeping family “involved and updated” while remaining “open, honest and upfront” in their exchanges, nurses were better able to build trust and respect. Similarly, nurses also recognized the value of letting family members talk as a way to alleviate stress. Both techniques were viewed as a way to support families while staving off concerns and questions that may arise later.

“You have to put families in their place”

Some nurses were able to create “space” between themselves and family by establishing control early in the relationship. Initiating conversations, explaining tasks, setting expectations of care and projecting confidence were a few of the preemptive ways to offer reassurance while demarcating personal and professional boundaries.

Managing information was another tactic used to structure time and space around patient care. For example, changing a machine’s parameters to reduce the frequency of alarms and bells could limit family “hyper-vigilance” at the bedside. Conversely, overwhelming a family with information was another strategy that encouraged families to take retreat from patient room. Physically relocating to achieve visual and aural distance was a third tactic employed. This
involved “diverting” to another workstation to avoid family interference or to discuss patient information in private. This was most evident at shift change. While PFCC initiatives invite family members to take part in this information exchange, many nurses preferred to exchange sensitive or technical information out of family range first and then return to ask family if they have questions. While observations revealed some degree of inclusiveness, pairs of nurses frequently relocated to primary workspaces (alcoves in 2D, nursing station in 2G.) This intention was multifold: to protect patient confidentiality; to get off their feet; to speed up the process so that the outgoing shift could leave on time; and, after a day fielding questions, to limit lengthy conversations and questions.

In addition to these interpersonal strategies discussed above, nurses recounted ways in which they modified the physical environment to protect both workspace and patient. Several examples from 2D are highlighted below:

“*Family should never be in our flow*”

The shared circulation in 2D physically and symbolically integrates families into the unit. However, many nurses expressed deep concern that this hallway encourages “gawking”—an invasion of patient privacy. As a result, nurses practiced “staring down” visitors looking into patient rooms. Nurses were also encouraged by administrators to shepherd visitors found lingering in the hallway.
“[Curtains are] our only protection [in 2D]”

Based on observations and interviews, alcoves located in the shared hallway were sites of frequent interaction. While conversations were sometimes friendly and social in nature, others appeared to be an interruption, particularly if the nurse was performing a task. In one case, a nurse delayed interaction by continuing to work without looking up, then asked the family member to return to the room until finished. Another nurse who felt hampered by a “hovering” family member “diverted”, or re-located, to another computer down the hall. Both instances displayed avoidance behaviors through body language and repositioning.

Full sensory monitoring of the patient room is essential for safety—a nurse must rely on sight, smell and sound to assess a patient’s condition. Thus, curtains and doors largely stayed open. When the patient was intact or undergoing a procedure, these devices (in both units) were used to modulate privacy levels between the patient room and hallway. This served a dual purpose in protecting the nurse from family sightlines.

“The family studio is a godsend”

Creating space around the bedside to perform procedures sometimes meant “pushing families out” of the patient room. Nurses in 2D felt the private studio allowed breathing room without causing families to feel isolated or cut off from loved ones. Dimming lights and closing

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9 The nurse later verified this interpretation of behavior.
studio/patient room doors also were used to signal to the family that it was time to let the patient rest.
6. DISCUSSION

Throughout the study respondents maintained that “challenging” families constituted a minority of cases. Based on the data, however, these encounters have clearly left a deep impression on the collective consciousness. The general consensus among staff was that PFCC is neither good nor bad, but complicated. Indeed, interviews suggest that much tension is derived, in part, from the inherent paradox of caring for families in an environment where the patient is the priority. The benefits and burdens of family participation appear to be conditional and slippery in nature. Quality of interaction hinges upon a host of interpersonal and situational factors such as personality, coping skills, patient condition and, to some extent, the time and locus of interaction. The complexity of family—an issue often overlooked in the literature—was frequently sited as a factor contributing to nurse tension. More specifically, family presence, personality and interpersonal dynamics introduce a level of unpredictability that can prove difficult to anticipate. Within these shifting tectonics, nurses must maintain a delicate balance between caring for (and at times protecting) patients while remaining sensitive to family needs—in other words, keeping focus on the patient without dismissing the family. Coupled with the daily demands of the ICU and the instability of patient condition, increased exposure may push nurses to a breaking point. Indeed, while some respondents felt one incident could “ruin the day”, most believed a steady drip of stressors over several days could “break a good nurse down over time.”
Results further suggest that the paradox of family care is also manifest in the temporal and spatial attributes generated by PFCC policy and design. While experiences between 2D and 2G were not fully differentiated in this phase of research, one can infer that, even without controlling for design features, visitation policy alone has changed the baseline of nurse-family relationships. The provision/location of family spaces and their activation through flexible visiting hours have improved access, visibility and integration. As respondents attest, these attributes at once foster collaboration, consensus and reassurance while creating opportunities for misperception, interruption and a lack of “breathing room.” Together these dualities begin to build a picture of a highly variable PFCC environment makes structuring the location and timing of family encounters more difficult.

Workplace control is important for the nurse on a basic level: having the “freedom to get work done” allows caregivers to focus on their patients without distraction. Thus, it comes as no surprise that nurses were unified in their concern that families represent some form of impediment to patient care, primarily for the sickest patients. This collective perception of compromised care is particularly striking, if not alarming, in a critical care setting where the patient is the primary focus. Ironically, nurses also acknowledge that it is precisely during these times of acute stress and illness when the patient may need the family the most. In protecting the patient, nurses have developed a number of behavioral tactics to “restructure” regimens and interactions. While some include family in the process, others create distance--all serving a dual purpose in reducing family anxiety while reestablishing control over workspace. It seems the unexpected consequence of PFCC policy and design is increased exposure to family, which, in
turn, impacts care delivery. For the nurse trained to take care of the patient first, this strikes a professional, and perhaps emotional, chord.

In an ICU setting such as Emory’s Neurosciences unit, changes in policy, procedure and design have redefined the boundaries between care team and family. Once restrictive environments now invite proximity to loved ones and participation in daily care and decision-making. Previously, the bedside nurse has been able to exert more control over time and workspace. With the aperture of exposure widened, frontline caregivers must now support a family’s emotional, social and informational needs on a more sustained basis. Ethnographic interviews identified key scenarios and situations that contributed to the potential stress of family interactions, and some of the ways caregivers are reasserting control over their environment. The results reiterate previous literature showing that families are perceived both sources of help and hindrance.

This study expands upon these findings by introducing the notion that spatial attributes may also contribute to the challenges of family care. The next sections takes a closer look at the degree to which these features impact opportunities for exposure and control.
PART II: STRUCTURED OBSERVATIONS
The implementation of family-centered principles and policies has reformulated the way in which caregivers and families communicate and interrelate. While the location of family support spaces indicates the degree to which an organization has integrated family into the unit, the configuration of clinical (nurse) and social (family) spaces may also tell us something about the nature of nurse-family interactions. One of the goals of PFCC is to return control to families during the uncertainty and anxiety of a loved one’s medical crisis. This means allowing families to choose their level of engagement in the care process. Practically and symbolically speaking, this is facilitated by the provision of convenient and comfortable support spaces, flexible visitation and the informational and emotional support of the care team. This phase of study further tests the proposition that by giving families greater access and control in the care process, nurses may have lost some measure of control over the timing, location and quality of interactions and are, thus, subjected to the variability and uncertainties that may come with family care.

Control is often achieved through the manipulation of environmental features (e.g. curtains, doors, partitions) or by modifying one’s behavior (e.g. eye contact, body language.) A closer comparison of 2G and 2D floor plans reveals that these opportunities for exposure and control are embedded in the organization of space itself. In the transition from a clinician- to family-centered ICU, we witness a shift in the degree in which nurses and families control their
environment. One way in which control is established is through circulation, which regulates staff-visitor movement. In 2G, families must use a separate entrance and corridor to access patient rooms and waiting areas (Figure 3). Signage clearly indicates that entry to the clinical workspace is strictly prohibited. While the unit observes a flexible visitation policy, freedom of movement inside the unit is constrained. In contrast, separate entry points are provided in 2D, however, staff and visitors share the same hallway once inside (Figure 4). This u-shaped spine forms an interstitial space that connects clinical and social domains. It also provides the only way for staff to access workstations and for family to reach the private studio. Thus, families are free to come and go throughout the day and evening (until 10pm), which may bring comfort in seeing caregivers at work.

Circulation routes in both units are designed to physically connect family with loved ones yet can create vastly different visitor experiences. In 2G, the circulation is the family zone, which means less privacy for those sitting in niches just outside the patient room door or within waiting areas connected by the narrow and darkly lit corridor. In addition, patient rooms are small and inhospitable to large families and overnight stays. Uncomfortable, upright chairs as sleeping accommodation further discourage family presence. In 2D, circulation connects the main waiting area with the family studio. Visitors have the freedom to congregate during the day and sleep overnight with direct access to the patient and staff. Large patient rooms allow multiple visitors access to the patient bedside while studio doors can be opened to maintain vigil or closed to allow family members (and patient) to rest. Interestingly, similar to the configuration of family
space in 2G, studios are located along the outer wall of the unit. However, these “havens” are stitched into the fabric of unit life due to their access via the patient room.

Figure 3. Integrated Circulation (2D ICU)
By providing families with greater control through freedom of movement and access the patient and care team members, PFCC changes the nature of visitor experience and heightens the potential for nurse-family interaction. Consequently, this new level of visibility and transparency means that once private clinical areas now become public domain. Likewise, family spaces have attained a new measure of privacy and protection. Another way to think about this inversion of privacy is in terms of “front stage” and “back stage” – in other words, space as both a stage for public “performance” and venue for private retreat (Goffman, 1959). In 2G, the separation of circulation creates more rigid boundaries between staff and family, meaning visitors are less likely to cross the threshold of the nursing station (Figure 6). Front stage performances (e.g. tasks carried out in the presence of family) are limited to the patient room while backstaging in the
nursing station affords the nurse freedom to attend to patient care as well as the benefits of
downtime with peers.

In 2D, the reformulation of clinical and social domains is perhaps most strongly
evidenced in the decentralization of nursing stations (Figure 5). This includes two distributed
stations at either end of the unit (used by the care team) and smaller alcoves dotted along the
shared hallway (used primarily by the RN). While alcoves are designed to improve patient safety
through proximity and visibility, they may also expose the nurse to the potential for interruptions
and distractions. Indeed, the unit—designed with glass doors and open workstations--achieves a
new level of transparency catalyzed by greater family presence. As one healthcare administrator
described, “it’s like designing a restaurant…[where] you have to walk through the kitchen to get
to your table.” Clinical areas typically kept behind closed doors and away from visitor eyes are
now brought front and center stage. At the same time, family members are privy to front stage
activity while gaining more control and privacy over their environment. This redistribution of
control, as suggested in interviews, is a double-edged sword. As one nurse described, “I want
[family] to see everything, but I feel like I have to always be ‘on’.”
Figure 5. Programmatic Distribution (2D ICU)

Figure 6. Programmatic Distribution (2G ICU)
The availability of backspace may help mitigate the side effects of co-presence and co-visibility. Indeed, researchers recommend the provision of a staff break room to encourage socialization and restoration. In a critical care setting, however, these refuges may be underutilized or, in the case of the Emory nurses, perceived as “too far” from critically ill patients. This is particularly true in 2D where the break room is located at the end of an administrative corridor. In fact, there appear to be few places for the bedside nurse to retreat for either personal or patient-related purposes. As interviews attest, the opportunity to work without interruption or surveillance can be difficult to achieve, particularly when families are large in number and/or hyper-vigilant. As one nurse described, “the only time I have alone is in the bathroom stall.” However, nurses working front stage without backstage retreat does not necessarily predict a difficult encounter, however it may hold the potential. The following research endeavors to evaluate these instances of actual and potential encounter.

7.1 Purpose

This study presented a rare opportunity to explore the link between the built environment and nurse-family interactions while controlling for staff, patient population and care culture. Building upon interview findings, this empirical investigation was designed to better understand the link between spatial layout and communications between caregiver and family. Two methodological approaches, behavior mapping and nurse tracking, were conducted in each unit to characterize the topology and quality of interactions at both macro and micro levels. While behavior mapping examined the overall frequency and location of interactions and the
distribution occupants, nurse tracking captured the more nuanced aspects of encounter by documenting conversation content, type and location. A comparison of these communication patterns provides new insight into the ways in which layout can influence the degree of exposure. While this generative study was designed to allow patterns to emerge from the data, a few a priori suppositions were made:

1. The 2D-ICU was designed to encourage greater family presence and communication between nurse and family. It was anticipated that 2D would yield a higher number of interactions than 2G.

2. Given the assumption that greater family access means greater exposure, more nurse-family interactions were expected across a larger area of the unit in 2D, particularly in nurse workspaces.

3. Given the assumption that nurses may have lost some control in the new ICU, it was predicted that there would be more instances of verbal nurse instructions given to family.
8. METHODOLOGY

8.1 Behavior Mapping

Behavior mapping, a research tool used to relate “various aspects of behavior to the physical spaces in which they are observed” was used in the first half of this empirical study (Proshansky, Ittleson, & Rivlin, 1970). An architectural floor plan served as the basis of the map onto which behaviors were systematically observed and recorded. The result was a “snapshot” of activity captured within a structured timeframe. Two types of data were of primary interest: 1) a census of RNs and family members and their distribution across both 2D-ICU and 2G-ICU; and 2) the location and frequency of interactions and co-presence. “Interaction” was defined as a one- or two-way verbal conversation initiated by a nurse or family member. “Co-presence” was defined as at least one member of each group occupying the patient room simultaneously without verbal exchange—the implication of which is the potential for interaction.

Both units were observed for one week, or four days each (Wednesday/Friday and Saturday/Sunday). Each 2-hour observation period consisted of eight time intervals, or approximately six total hours each day (9-11am, 1-3pm and 6-8pm.) Times fluctuated slightly due to researcher schedule. Approximately one mapping data set was recorded every 15 minutes for each 2-hour period. In 2D, the procedure consisted of the researcher walking through the unit and marking occupant presence and interactions directly onto the floor plan. Subjects were
recorded as they passed the plane of the researcher’s body. The route began at the visitor’s entrance and followed rooms sequentially until reaching the last room. Only activity visible from the hallway was recorded. In addition to the hallway, activity was recorded in the following spaces: nursing stations, alcoves, patient rooms and family studios. Activity in the nurse break room and main waiting room was excluded. Only nurse presence in the family studio was recorded, and again, only when visible from the hallway.\(^{10}\) Data collection in 2G covered the entire unit: the outer family hallway; two adjoining waiting rooms; patient rooms; interior staff hallway; central nursing station and break room. Rooms were excluded if curtains and blinds were drawn or if beds were empty.

### 8.2 Nurse Tracking

While behavior mapping captured a bird’s eye perspective of unit activity, nurse tracking explored the interactions between groups at a more cellular level. Tracking involved shadowing and recording subject behavior over a structured period of time or activity. One nurse “trip”, or visit, into the patient room was the unit of analysis. Due to time constraints, the procedure followed a pre-determined set of criteria. First, nurses were required to have at least one patient present in the two assigned rooms. Second, each patient needed to have at least one or more family members present in the patient room, family studio (2D) or family zone (2G). Nurse activity in rooms without family members present was also recorded, as long as one family

\(^{10}\) Given the frequency of mapping intervals, family presence in the studio was not recorded due to privacy concerns and the potential for intrusion.
member was present in the unit. The observation period consisted of one nurse trip, or, in the event of no activity, a 10-minute cap, whichever came first.

Given the 1:2 nurse-patient ratio, pairs of rooms were drawn at random until all rooms conforming to the criteria were observed. Pairs were then redrawn and the procedure repeated. Data collection took place in alcoves and, where appropriate, patient rooms. Each “trip” began and ended when the nurse crossed the patient room threshold. Trips already in progress at the start of the observation period were omitted. The following information was recorded for each trip: number of family present; location of interaction; occupant who initiated interaction; content of conversation; nurse task; and any verbal instructions. “Instruction” was defined as any directive or rule enforcement given the family. Family presence was determined by sight or nurse confirmation. The nurse confirmed tasks after each trip. While not technically part of the "trip," interactions were recorded in the nurse alcove (2D) or interior nurse hallway (2G) during the observation period. Nurse tracking was conducted in tandem with the behavior mapping and followed the same time frame: two weeks, or four days per unit.
9. RESULTS – BEHAVIOR MAPPING

A total of 82 data sets were collected in 2D and 65 in 2G. The patient room serves as a key workspace for the nurse and critical gathering point for the family where information about the patient’s care and condition is shared. It is no surprise, then, that most interactions occurred here in both units. However, results highlight a few disparities in family presence between the units (Table 1). In the 20-bed 2D ICU, nurses were observed in 2D patient rooms more often than family members. In the 7-bed 2G unit, family outnumbered nurses all four days. The most notable finding was that over four times as many visitors (vs. nurses) were observed in patient rooms in 2G (2.24) versus 2D (.46). This indication of greater family presence in 2G was an unexpected finding. There are a number of possible explanations to account for this difference. First, behavior mapping omitted families in the 2D studio. It is unclear what proportion of visitors was present here, but one can assume 2D statistics would likely increase. Second, sample size is dependent on the size of the family. During the observation period, for example, one 2G patient had eight members visit (often at once) while a patient in the next room had only one loved one present. This brings up a third issue – the irregular nature of visitation. Indeed, nurses confirmed that some days and weeks are busier than others. Future studies should consider taking a more longitudinal time sample to gain a more accurate snapshot of activity.
Table 2. Total Nurse and Family Presence (2D + 2G)

<table>
<thead>
<tr>
<th></th>
<th>2D Presence</th>
<th>Total</th>
<th>2G Presence</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>655</td>
<td>Nurse</td>
<td>226</td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>602</td>
<td>Family</td>
<td>479</td>
<td></td>
</tr>
<tr>
<td>% Nurses Present</td>
<td>15.95%</td>
<td>% Nurse Present</td>
<td>6.89%</td>
<td></td>
</tr>
<tr>
<td>% Family Present</td>
<td>14.61%</td>
<td>% Family Present</td>
<td>15.47%</td>
<td></td>
</tr>
<tr>
<td>Nurses per Room</td>
<td>0.78</td>
<td>Nurse per Room</td>
<td>0.99</td>
<td></td>
</tr>
<tr>
<td>Family per Room</td>
<td>0.46</td>
<td>Family per Room</td>
<td>2.24</td>
<td></td>
</tr>
</tbody>
</table>

The maps produced another unexpected finding: nurses and visitors tended to congregate within their respective domains (Table 2). In 2D, nurses spent the majority of their time in alcoves, followed by patient rooms. Visitors, on the other hand, inhabited patient rooms most often, followed by the shared hallway. In a similar pattern, 2G nurses were located most frequently in the nursing station (97), followed by the patient room (87). The overwhelming majority of visitors in 2G were clustered in waiting rooms (253), followed by the patient room (147) and family hallway (75). This division between groups was further emphasized by distribution patterns inside patient rooms. In both units, nurses tended to occupy the front of the room (closest to staff spaces) while families were located in the back (closest to family areas.) In addition to the tables provided below, distribution patterns can also be seen in the raw data maps (Figures 1-2).

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11 This study did not record data from the family studio. However, one can assume that family presence was equal to, if not greater than, presence in the patient room. The reasoning follows that while families can pull up chairs to the bedside, the studio provides more comfortable amenities and room for private family gatherings.
Table 3. Nurse and Family Distribution (2D + 2G) (Weekday + Weekend)

<table>
<thead>
<tr>
<th>2D Distribution (Total)</th>
<th>Nurse</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcove</td>
<td>356</td>
<td>18</td>
</tr>
<tr>
<td>Hallway</td>
<td>37</td>
<td>78</td>
</tr>
<tr>
<td>Nurse Station</td>
<td>31</td>
<td>1</td>
</tr>
<tr>
<td>Family Studio</td>
<td>2</td>
<td>n/a</td>
</tr>
<tr>
<td>Patient Room</td>
<td>224</td>
<td>515</td>
</tr>
<tr>
<td>Front</td>
<td>142</td>
<td>155</td>
</tr>
<tr>
<td>Back</td>
<td>82</td>
<td>360</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2G Distribution (Total)</th>
<th>Nurse</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Hallway</td>
<td>32</td>
<td>0</td>
</tr>
<tr>
<td>Nurse Station</td>
<td>97</td>
<td>0</td>
</tr>
<tr>
<td>Break room</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Family Hallway</td>
<td>0</td>
<td>75</td>
</tr>
<tr>
<td>Waiting Room</td>
<td>0</td>
<td>253</td>
</tr>
<tr>
<td>Patient Room</td>
<td>87</td>
<td>147</td>
</tr>
<tr>
<td>Front</td>
<td>40</td>
<td>24</td>
</tr>
<tr>
<td>Back</td>
<td>20</td>
<td>133</td>
</tr>
</tbody>
</table>

While both units shared similar distribution patterns, they differed in the degree of boundary permeability—in other words, the degree in which a given domain can be visually or physically accessed (the focus here is on this physical crossing of boundaries.) In 2G, there were no visitors observed in clinician-only domains (e.g. nursing station) nor were staff members observed in family-only domains (e.g. waiting room.) However, in the transition from 2G to 2D we find a greater frequency of cross-domain interaction. This means there were instances of both nurse activity in the family studio (2) and visitors encroachment in nurse alcoves (18). Interestingly, there were more instances of family crossing into nurse domains (19) as opposed to nurses entering family domains (2).
Table 4. Frequency and Distribution of Nurse-Family Interactions and Co-presence (2D + 2G)

<table>
<thead>
<tr>
<th></th>
<th>2D Interactions</th>
<th>2G Interactions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interaction</td>
<td>47</td>
<td>Interaction</td>
<td>9</td>
</tr>
<tr>
<td>Co-presence</td>
<td>19</td>
<td>Co-presence</td>
<td>12</td>
</tr>
<tr>
<td>Interactions/room</td>
<td>2.35</td>
<td>Interactions/room</td>
<td>1.13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2D Location</th>
<th>Total</th>
<th>2D Location</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcove</td>
<td>6</td>
<td>Nurse Hallway</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hallway</td>
<td>3</td>
<td>Nursing Station</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Patient Room</td>
<td>35</td>
<td>Patient Room</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Nursing Station</td>
<td>1</td>
<td>Family Hallway</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Family Studio</td>
<td>2</td>
<td>Waiting Room</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

According to distribution results (Table 3), patient rooms served as the primary loci of interaction in both units (2D: 35; 2G: 9). While 2G produced more instances of co-presence, 2D yielded an average of twice as many interactions per room (2.35 vs. 1.13). Echoing the patterns above, some instances of domain crossover were observed in 2D. While interactions were recorded in the family studio (2), most non-patient room exchanges took place in nurse alcoves (6). As before, there were no interactions observed in either family or nurse-specific zones in 2G—all were contained within the patient room (9). Overall, findings reveal a general trend towards segregated distribution and interactions in both units, with slightly more family crossover into nurse domains in 2D. However, overall interaction totals were somewhat lower than expected given high family presence, especially in 2G.
Figure 7. 2D ICU Composite Behavior Map (Weekday + Weekend)
Figure 8. 2G ICU Composite Behavior Map (Weekday + Weekend)
10. DISCUSSION

10.1 Together but Separate

Behavior maps revealed several interesting and unexpected findings. First, distribution patterns indicated a high degree of separation between visitor and caregiver in an environment designed to promote greater integration. By and large, RNs and families congregated in group-specific areas—workspaces for nurses, support spaces for families. This was particularly striking in patient rooms where both groups occupied half of the room closest to their respective domains. This territoriality is perhaps less surprising in 2G where an architecturally enforced hierarchy reinforces the distinction between clinical and social space. Nurses in 2D, on the other hand, may be more inclined to enforce spatial boundaries through changes in behavior. These findings also highlight a curious incongruity between interview and mapping results. In conversation, nurses perceived family as a frequent source of interruption and time consumption impacting their ability to care for the patient. However, the total number of observed interactions was lower than expected.

While overall group separation was higher than expected, results suggest some unit differences in the degree of domain crossover. In 2G, boundary porosity—or the tendency of one

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12 There were some attempts at domain crossover in 2G that fell outside of the observation period and are not reported in these results. On several occasions, family members flagged down their nurse while standing in the doorway between the patient room and nurse hallway. Similarly, nurses were found delivering information to family just inside the family hallway, although no nurses were observed entering the waiting areas.
group to enter another group’s domain—was lowest around exclusively clinical or social spaces, which is perhaps typical of a more traditional ICU structure. As anticipated, 2D demonstrated greater boundary porosity in nurse workspaces, thus the diffuse distribution of interactions across more clinical regions of the unit. Clearly the location of the alcoves in the public hallway has created a new level of accessibility and nurse availability. This is opportune for the family but may mean greater exposure for the nurse.

The maps yielded another curious finding: there were twice as many interactions per room in 2D than 2G despite greater family presence in 2G. In 2G, nurses described family as either “in the room or not.” There are several plausible scenarios that can account for this result, although purely speculative. For example, a family maintaining vigil over the patient may be more inclined to stay by the bedside due to poor visibility to their loved one from inside the family corridor. With increased presence, familiarity between nurse and family may grow, which opens the opportunity for more continuous information. With this need for information satisfied, the family may stay in the room to watch and monitor without interaction. In contrast, the location of the studio next to the patient room in 2D provides a measure of flexibility for the family. Members can retreat to the comforts of the studio while knowing the nurse is available when questions arise. This can mean longer and continuous stays and, thus, an increased potential for the spontaneous interaction. This flexibility is also likely to add another element of unpredictability to encounters.
10.2 “Feast or Famine”

During interviews, nurses characterized the Neuro ICU as a “feast or famine” environment marked by episodic periods of activity and inactivity. Here, patient condition can change at any given moment. Distribution patterns suggest that this variability may also extend to the nature of family presence as well. A closer look at the maps themselves shows an uneven distribution of family activity in patient rooms throughout both units (Figure 1). While some rooms are heavily populated, others are sparse. This pattern has two implications. First, family presence (and the personalities and dynamics they bring) can be unpredictable and difficult to prepare for. Second, the burden of family may not be shared evenly among nurses. In corroboration with nurse statements, this distribution pattern underscores the notion that variability of patient condition and family assignment may compound workload demands. Over time, this inability to anticipate perceived stressors may lead to anxiety and burnout.
11. RESULTS – NURSE TRACKING

While behavior mapping presented communication patterns of occupant distribution and interaction frequency, nurse tracking took a deeper dive into the composition of nurse-family encounters by measuring the frequency, location, content and quality of encounters (Figures 8-11). A total of 33 trips were recorded in 2D and 27 in 2G. Overall, family presence was high during nurse trips: 31 of 33 in 2D and 24 of 27 trips in 2G (Table 4). This is attributable, in part, to the selection criteria, which only considered room pairs with at least one member present. In 2G, interactions took place nearly every time the nurse entered a room while family were present (23 of 24). In contrast, interactions in 2D occurred approximately two thirds of the time (21 of 31). There was also a higher frequency of co-presence, which suggests the potential for verbal exchange.

Table 5. Frequency of Nurse Trips With and Without Interaction (2D + 2G)

<table>
<thead>
<tr>
<th>Trip/Interaction Frequency</th>
<th>2D</th>
<th>2G</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Trips</td>
<td>33</td>
<td>27</td>
</tr>
<tr>
<td>Trips with Family Present</td>
<td>31</td>
<td>24</td>
</tr>
<tr>
<td>Interaction</td>
<td>21</td>
<td>23</td>
</tr>
<tr>
<td>Co-presence</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Trips with No Family Present</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

As Table 5 illustrates, the patient room served as the most frequent site of interaction in both units—concurrent with behavior mapping findings. In 2D, encounters took place in the
patient room (16) and nurse alcove (15) -- a somewhat more dramatic result than previously reported. More than half of these conversations stayed within the alcove, meaning they did not necessitate an immediate trip to the patient room. In contrast, all interactions initiated in the nurse hallway in 2G prompted an immediate trip to the patient room. In keeping with the mapping results, we see more instances of nurse domain crossover in 2D while the porosity of family spaces remained low. Specifically, there were three times as many interactions in alcoves (2D) vs. the nurse hallway (2G).

<table>
<thead>
<tr>
<th>Location (2D)</th>
<th>Total</th>
<th>Location (2G)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Room</td>
<td>16</td>
<td>Patient Room</td>
<td>17</td>
</tr>
<tr>
<td>Family Studio</td>
<td>2</td>
<td>Family Hallway</td>
<td>2</td>
</tr>
<tr>
<td>Alcove</td>
<td>15</td>
<td>Nurse Hallway</td>
<td>5</td>
</tr>
<tr>
<td>Alcove (with Trip)</td>
<td>4</td>
<td>Nurse Hallway (with Trip)</td>
<td>5</td>
</tr>
<tr>
<td>Alcove (with No Trip)</td>
<td>10</td>
<td>Nurse Hallway (with No Trip)</td>
<td>0</td>
</tr>
</tbody>
</table>

The results revealed another interesting difference between units: nurses initiated conversations in 2G most often, while family members instigated first in 2D (Table 6). Numbers were highest in 2G patient rooms (13) and 2D alcoves (11) (Figure 7). One can infer that this frequency in the alcoves is attributable to their location in the public hallway, which means nurses sit in the direct line of vision and proximity to family coming and going throughout the day and evening.
Table 7. Frequency and Distribution of Nurse and Family Initiated Interactions (2D + 2G)

<table>
<thead>
<tr>
<th>Location (2D)</th>
<th>Nurse Initiated</th>
<th>Family Initiated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcove</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Patient Room</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Hallway</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Family Studio</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>19</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location (2G)</th>
<th>Nurse Initiated</th>
<th>Family Initiated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Hallway</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Patient Room</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Family Hallway</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>8</td>
</tr>
</tbody>
</table>

Conversation content and location were documented to further understand how layout influences where and what kind of information is exchanged. Not surprisingly, patient care and condition were the most frequently discussed topics in patient rooms in both units (2D: 13 and 2G: 10) (Table 7). Overall, conversations here covered a broader range of topics than secondary areas such as nurse and family hallways. Patient advocacy was the most frequent type of exchange observed in alcoves (9). Again, there were few interactions observed in the family studio (2D) and family hallway (2G), and these involved patient updates and follow-up to family
queries. Not all conversations were directly related to patient care: there were several instances of social exchange (e.g. informal greetings, nurses inquiring about family loved ones.) These took place in 2D alcoves and in 2G patient rooms.

In addition to content, conversations tended to follow one of two patterns: “single” (one topic discussed) or “cluster” (more than one topic discussed). Results show slightly more clustered vs. single topic conversations in 2G (13 vs. 10). Interestingly, there were twice as many single vs. clustered conversations in 2D (20 vs. 11), the majority of which occurred in alcoves.

<table>
<thead>
<tr>
<th>Content (2D)</th>
<th>Alcove</th>
<th>Patient Room</th>
<th>Studio</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Advocacy (PA)</td>
<td>7</td>
<td>2</td>
<td>-</td>
<td>9</td>
</tr>
<tr>
<td>Patient Care (PC)</td>
<td>1</td>
<td>10</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Introductions (Intro)</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Nurse Support (NS)</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Plan of Care (PP)</td>
<td>2</td>
<td>4</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Family Education (EDU)</td>
<td>-</td>
<td>4</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>Social (SO)</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Family Support (FS)</td>
<td>1</td>
<td>2</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Notification (NT)</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Request for Doctor (MD)</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Content (2G)</th>
<th>Nurse Hallway</th>
<th>Patient Room</th>
<th>Family Hallway</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Advocacy (PA)</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Patient Care/Condition (PC)</td>
<td>2</td>
<td>7</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Introductions (Intro)</td>
<td>2</td>
<td>4</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Nurse Support (NS)</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Plan of Care (PP)</td>
<td>1</td>
<td>5</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Family Education (EDU)</td>
<td>-</td>
<td>9</td>
<td>-</td>
<td>9</td>
</tr>
<tr>
<td>Social (SO)</td>
<td>-</td>
<td>5</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>Family Support (FS)</td>
<td>-</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Notification (NT)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Request for Doctor (MD)</td>
<td>-</td>
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</table>
Nurses are responsible for a variety of patient-related tasks during their shift (Table 9). As one nurse described, “we go into the room with a purpose.” For trips that resulted in an interaction, results showed family presence in both units triggered additional conversations beyond the initial task at hand (24 of 31 in 2D and 15 of 23 in 2G). In one example, a nurse administering medication was asked, “What is that for?” which led to an explanation of the task and further discussion about patient prognosis. As the content distribution analysis showed, these conversations often led to opportunities for patient education, more information about the plan of care and social exchanges. While length of interaction was not recorded, this attenuation has several implications for nurse performance. One might argue that tasks executed during family presence may take longer than if the nurse worked alone. (That said, a nurse working alone may take more time with her task without feeling pressure from family.) Indeed, many nurses expressed concern that family matters took time and resources away from patient care.

The 2D unit was expected to yield a higher frequency of verbal nurse instructions. Surprisingly, overall counts were low (2D: 2 and 2G: 4). In 2G, visitors trying to enter the interior nurse corridor were asked to use the outer family hall, thus reinforcing architecturally based rules that restrict access and movement. In another instance, family members crowded around the bedside were asked to make room around the patient in order to reach equipment. In 2D, nurses created new rules and boundaries in the absence of spatial and temporal ones. For example, a family member who approached the nurse in the alcove was asked to wait in the room until she was finished. In another scenario, a nurse set expectations that she would not be visible or available at all times due to having to care for two patients, but was there to help if needed.
While this sample size was low,--and somewhat inconclusive--instructions appear to support earlier findings that indicate nurses reassert control over their workspaces.
12. DISCUSSION

A comparative analysis of communication patterns between 2D and 2G reveal both similarities and subtle differences between the two ICUs. Some characteristics of nurse-family interactions appear to be inherent in family-centered care, regardless of unit typology, while other patterns suggest that design may play a role in changing the way the two groups relate. By measuring the frequency, location and quality of interactions we discover that the potential for exposure is contingent upon three key ingredients: the degree of boundary permeability, the predictability of external conditions and the opportunity for environmental control. Together these elements begin to build a tentative theory of exposure that may, in part, account for the perceived difficulties and emotional distress experiences by frontline caregivers.

12.1 Permeability

In his assessment of best-practice ICU designs from the past decade, Rashid (2004) suggests that the location of family space indicates the degree to which an organization has integrated family into the unit. This study goes a step further to propose that integration is achieved, in part, through the configuration of social and clinical space, the results of which change the degree of domain permeability, and, thus, the degree of exposure to family. This is supported by the number of observed (in)frequencies of domain crossover (e.g. lower in family zones, higher in nurse areas.) It appears that domains can be seen as gradations of permeability
that exist both within and between units. On one end of the spectrum, both ICUs demonstrated more rigid boundaries around innermost clinical and outermost family domains (e.g. family members were never observed inside nursing stations, RNs were never seen in waiting rooms.) At the other end, patient rooms continued to serve as the physical and symbolic center of ICU life. This nexus where clinical and social converge demonstrated weak boundaries in both units--no surprise, the majority of interactions occurred here. Weak boundaries were particularly evident in 2D where we see an elevation in interaction frequency. In the transition from 2G to 2D, a fundamental shift takes place, both conceptually and architecturally, from segregated to integrated circulation. It is here--in the “in betweeness” of the hallway alcoves--where the degree of exposure subtly, but most clearly, changes. This organization of space (hallway-alcove-patient room-studio) creates a new interface where the patient room is no longer the primary locus of encounter (evidenced in the equal number of interactions in patient rooms and alcoves.) As clinical and social domains (and their occupants) are brought into greater proximity, interactions increase. Tracking results corroborate that conversations are likely during nurse-family co-presence. These shifts, precipitated by PFCC policy and design, appear to be seen by nurses as taking “time and focus away from the patient.”

The implications of these boundary shifts bring us back to the initial proposition that in giving family greater control through greater access, a measure of control has been taken away from the nurse. As clinical and social, public and private meld and co-mingle, workstations begin to express a dual functionality as both a resource for both nurse and family. For instance, alcoves are used for prepping, charting, resting, monitoring and socializing with peers. For the family,
visual and ambulatory freedom means questions can be asked and answered immediately. Likewise, nurses can also benefit from family vigilance and attentiveness, including alerting staff to oversights in medication dispensing, signaling changes in patient condition as well as sharing the patient’s wishes. This spatial redistribution not only blurs the boundary between clinical/social but it means the rules of space become less clearly defined—a concept supported by a nurse’s statement that “family don’t always understand the boundaries.” This is demonstrated by the types of conversations that take place in alcoves, from informal, non-patient related social exchange to instances of patient advocacy. Without the traditional hierarchies in place, this duality of content introduces a level of ambiguity and uncertainty for the nurse in which control over the type and timing of interactions may be compromised. The observed disparities of nurse and family domain permeability—which occurs at a somewhat greater degree in 2D, further heighten this redistribution of control: once private nurse areas become public, while private family support space remains just that – private.

12.2 Variability

Exposure moderated by spatial configuration does not always predict a collaborative or contentious nurse-family encounter. The quality of interaction also depends on the perception of what the one is exposed to and the ability to control these external conditions. Part I introduced the idea that the patient-and family-centered ICU is an unpredictable, “feast or famine” environment, further illustrated in the uneven distribution of occupants in the behavior maps and the changing constitution of interactions in the nurse tracking results. Overall conversation
patterns in both units suggest that some aspects of interactions are inherent in family presence, while others may be moderated by unit design.

**Planned vs. Unplanned**

The nurse is responsible for a variety of patient-related tasks that are either planned (e.g. hourly assessment) or emergent (e.g. making adjustments). Family interactions assume a similar pattern. While there were some planned interactions (e.g. nurse introductions during shift change or the delivery of news to the studio (2D) or exterior hallway (2G)), these trips were few. In most cases, interactions were largely *ad hoc* and conducted on the fly—a particular challenge when trying to convey the right tone or information to a family in crisis. Specifically, tracking results showed that family presence usually triggered an interaction and attenuation of the nurse trip. In other words, the intention to perform patient-specific tasks gave way to longer, and sometimes unrelated, discussions about patient care and family needs. According to staff, these unstructured encounters can prove difficult to prepare for, especially for the inexperienced nurse. We also find variability within one kind of content. For example, patient advocacy can mean the nurse receives potentially life-saving alerts but may also entail erroneous concerns about the patient’s condition. While this phase of research did not assess whether family involvement was a help or hindrance, the results nevertheless indicate that nurses work in a highly variable and unpredictable workspace.

**Actual vs. Potential**
Nurses asserted that challenging families were the minority of cases, and that most encounters were positive, even personally enriching. This perceived infrequency appears to be congruous with the low frequency of interactions observed in the behavior maps (further suggesting that nurse distress may reside in the quality rather than quantity of encounter.) This reveals an interesting duality between the exposure to actual vs. potential interactions. During interviews, nurses presented a number of scenarios of actual events that constituted a stressful interaction. Another type of interaction was the one difficult to anticipate. A theme that emerged—“everybody sees”—suggests that increased family access means increased surveillance of nurse activity. On one hand, these opportunities benefit both parties: co-visibility can help educate, inform and reassure family while making it easier for staff to share information, locate family and obtain consent if needed. As a tradeoff, nurses also reported at times feeling watched, scrutinized or wishing they had more “room to breathe.” Spatially, the alcoves in 2D exemplify this tension, in that the configuration of space can generate patterns of behavior that are at once predictable and uncertain. A closer look at the composition of encounter reveals that most exchanges are family-initiated, single topic (e.g. social exchange, patient advocacy) and do not result in an immediate trip to the patient room. This implies that the type of interaction that takes place here might be predictable, however knowing when or why these encounters will take place maybe harder for the nurse to control.

12.3 Control
The consequences of exposure—whether physical, emotional or cognitive—hinges upon the caregiver’s ability to exert control over the surrounding environment. Nurse interviews revealed a number of strategies used to manage interactions, from initiating conversations to changing body language. This empirical study measured control by the frequency and type of verbal instruction. While numbers were lower than expected, there is some indication that unit design can reinforce boundaries yet require new ones to be created. For example, the family studio was described as a “saving grace” that enabled distance from the family without disconnecting them. The lack of instructions observed in patient rooms suggests that the studio may strengthen “weak” patient room boundaries by proxy, thus delimiting the need for verbal instruction. Similarly, the segregated circulation in 2G allowed nurses to enforce structurally based rules when family tried to access their workspace. Other areas appeared to require behavioral changes. In 2G, families were described as “in the room or not,” meaning they were located by the bedside or out of sight in waiting areas. Here we find a high concentration of nurse-initiated interactions and instances of family education, which, based on interview data, implies that integration tactics were employed to create more “space” around the bedside while also reassuring and informing family members. It should be cautioned that these observations may not always reflect the nurse’s true intention. For instance, the frequent engagement of a family does not necessarily signal the need to regain control but may indicate a close connection with the family, recognizing the reassuring power information can bring.

Reorganizing care—and space—around the family brings greater access to loved ones and integration into the care process yet widens the nurse’s exposure to the unpredictability of
family presence. While this reciprocity can be mutually beneficial, it can also produce unintended side effects. By changing the degree of access and visibility through spatial means, once private spaces become public domain. This brings frontline caregivers front stage into a more performative and public role—a concept embedded in nurse perceptions of having to “always be on” when working “in a fishbowl.” This is further supported by empirical results that showed an increase in interactions in 2D, especially those initiated by family in more “public” nurse domains. Control over workspace is perhaps reasserted through behavioral changes in the absence of clear spatial rules and boundaries. Indeed, the provision of backspace may help assuage these unintended consequences of exposure. Temporary re-location is not always possible when caring for critical patients. Thus, nurses may need more immediate privacy and “breathing room” to tend to patient care.

In sum, these elements—boundary permeability, environmental predictability and the opportunity for control—build a theory of exposure that can perhaps account for the perceived difficulties and ensuing stress experienced by nurses working in a PFCC environment. Together these qualitative and quantitative findings suggest that the challenges of patient and family care can be attributed to not only the paradoxical and variable nature of family presence but also the degree of exposure to these conditions and subsequent opportunities for control. While some characteristics of interactions are inherent in the nature of family presence, others may be moderated by the organization of space, thus influencing the ways in which nurse and family interrelate.
13. CONCLUSION

PFCC is transforming critical care culture and the ways in which caregivers and families interface and interrelate. Families are seeking a more active role in the care of their loved ones. In response, ICUs are opening their doors to once restrictive environments to invite and engage families as full participants and partners in care through the shared goal of patient health and recovery. The revision of visitation policies and the provision of support spaces and amenities mean greater access to loved ones and care team members on a more regular and sustained basis. While the benefits of families are numerous, greater family presence may have unintended consequences for the staff nurse without adequate support mechanisms in place. Interview findings indicate that nurses perceive family as both helpful and as a challenge. Indeed, these opinions and experiences may be reflecting this larger critical transition in healthcare, and the challenges faced in acclimating to a new care culture. PFCC enacts changes in attitudes behaviors and knowledge as well as boundaries, relationships and new ways to interface and integration. Through these insights we also see the important role of space in shaping these perceptions. Without temporal, procedural and physical structures or adequate tools and resources in place, the built environment may play an even greater role in moderating the degree of exposure to the unstructured and ad hoc nature of patient condition and family presence. In recalibrating the boundaries between public and private, clinical and social, PFCC has given family members greater control over their loved ones care. In response, nurses have developed strategies that at once integrate families into the care process while seeking to regain control over
workspaces. As the evidence suggests, the unpredictability of PFCC may be both part and parcel of family presence and a factor of spatial configuration.

The results of this study are perhaps unique to the nursing experience in Emory’s Neurosciences department and capture only a snapshot of activity within a vastly complex and nuanced system. However, there are several issues raised that can both inform future research and benefit from further development.

• Findings suggest that territory and boundaries play an influential role as indicators of the degree of separation and integration between nurse and family—thus impacting the potential for interaction. These patterns of boundary permeability and domain territoriality generated in the maps of Part II warrant further elaboration that is beyond the scope of this study. For now, a few cursory ideas are proposed. First, clinical and social zones could be categorized or measured by the degree of “nurse-ness” or “family-ness” of a given space. For example, a highly restricted area that serves as a primary locus of activity for one group (e.g. administrative offices) would receive a high grade (thus demonstrating low boundary permeability). Similarly, spaces that serve a multiple function for more than one group (e.g. patient room) would receive a lower grade due to the likelihood of co-presence (high permeability). The degree of boundary permeability, as an indicator of integration or separation, would be measured by the frequency in which one group crossed the threshold of the other group’s domain.
The transfer of control from nurse to family is evidenced in the reconfiguration of public and private domain, or “front stage” and “back stage.” As findings suggest, previously backstage clinical areas (e.g. alcoves) have now been brought forward, thus exposing the nurse and potentially impacting the freedom to work without interruption. By the same token, families have been provided new backstage retreats (e.g. studio) that foster privacy, social gathering and patient proximity. Greater family presence may lead to opportunities for information exchange and monitoring in which nurses may feel unprepared to answer questions or unable to control when and where interactions occur. This increase in public “performance” brings a greater need to counterbalance with physical and mental space to troubleshoot, problem-solve, synthesize and reflect. It is not surprising then that nurses expressed a need for “more structure” in their daily regimen. “Re-structuring” can take several forms: temporal, procedural or spatial. For instance, it was recommended by one nurse that the unit re-establish some window of visitation restriction during shift change to allow the incoming nurse a chance to catch up and prepare for the day/night. While this is one possible solution, structure does not always mean “keeping out” as much as keeping order. As interviews and observations revealed, the ICU is a largely ad hoc, unstructured environment. Adding more planned family meetings or establishing consistent, team-based strategies for managing certain family scenarios make reassert a new sense of order. More broadly this can also involve investing in the social architecture that generates shared expectations between staff, patients and families.
For the healthcare architect, “restructuring” may require a re-examination of the spatial configuration between clinical and social spaces. The designer may be tempted to reinstate segregated circulation to restore coveted backspace for the nurse. However, this gesture may also eliminate microclimates (e.g. alcoves) that foster patient advocacy and social cohesion. Indeed, these spontaneous moments may serve as interstitial glue to support and encourage greater family integration and collaboration. As with any design intervention, there are tradeoffs. This paper does not endeavor to make definitive recommendations, but rather to bring a renewed appreciation for the delicate ecosystems in which these interventions are inserted and their potential ripple effect they may have on the quality of nurse-family interactions.

PFCC was initially developed and implemented in low acuity care settings. Thus, departments caring for the sickest patients, such as neuro and coronary, may experience greater staff resistance to necessary culture changes. This raises several important questions: are these changes an unreasonable expectation in this type of care setting, or is it a matter of rethinking what nurses do? Are the challenges of family inevitable or can they find resolution over time? Indeed, nurse attitudes and opinions presented in Chapter 5 seem to reflect some persistence of a clinician-centered approach to family care, albeit not exclusive. Even though family members are often considered beneficial for some patients, at times they are regarded as an additional burden for the nurse. In fact, many questioned the degree to which family presence is appropriate for the neurologically
compromised patient. In other words, “what is right for one patient may not be for another.”

- Rashid (2006) proposes an alternative explanation to this reluctance to change culture. In his article linking layout with face-to-face interactions, he proposed that, “spatial layout on its own might be insufficient to generate, sustain, and increase interaction without the necessary changes in the attitudes, programs, and policies of an organization.” In other words, designing for integration does not necessarily guarantee interaction will occur. While the physical environment of 2D has been designed to encourage and invite participation, the support mechanisms that energize these spaces and the relationships that take place within them may still be in the early stages of development. This is further echoed by the “together but separate” distribution patterns presented in Chapter 9. This distinction between nurse and family occupancy suggests that families may not be fully integrated beyond the symbolic. One way to create more bridges between the two may involve making more clear delineations between when and where family involvement is appropriate—when should families be engaged and when should they be asked to step away? What is the balance between family as resource and full time caregiver? One approach might be to look at how often Neuro patients require in-home care after discharge—are there more opportunities here for nurses and families to collaborate? Are there additional, formalized opportunities to encourage information sharing and relationship building? As this study reveals, these procedural and cultural changes require organizational support and the provision of tools and resources to educate, empower and
energize caregivers. Admittedly, this study focuses primarily on one type of interaction set within an infinitely larger and more complex system of relationships and processes. For a more robust understanding of the context in question, future study should evaluate the function of the critical care team and communication patterns between family and team members in their totality.

In conclusion, the findings presented here bring a new mindfulness to the complexity of the social aspects of critical care. The design of space is just one component in an intricate matrix of factors and conditions—many of which are beyond the control of the clinician and the healthcare designer. Today, the bedside nurse is in a position of greater responsibility (and expectation) as the primary conduit between patient, family and care team. As hospitals continue to open their doors, the need to consider the challenges and concerns of the frontline caregiver has never been greater. Only through the support of the nurse can we ensure the future sustainability of the model while providing the highest quality of care for families and their loved ones.
APPENDIX A

Nurse Tracking Coding and Results

Table 9. Conversation Content Coding Categories

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PC</td>
<td>Patient care/condition/status</td>
</tr>
<tr>
<td>PP</td>
<td>Patient plan of care</td>
</tr>
<tr>
<td>PA</td>
<td>Family as patient advocate</td>
</tr>
<tr>
<td>EDU</td>
<td>Explanation of task/medical condition</td>
</tr>
<tr>
<td>MD</td>
<td>Request for doctor</td>
</tr>
<tr>
<td>Intro</td>
<td>Introduction/greeting</td>
</tr>
<tr>
<td>SO</td>
<td>Informal social exchange (patient or non-patient related)</td>
</tr>
<tr>
<td>NT</td>
<td>Family notifying nurse of whereabouts</td>
</tr>
<tr>
<td>FS</td>
<td>Nurse offering family assistance/support</td>
</tr>
<tr>
<td>NS</td>
<td>Family supporting nurse with patient care</td>
</tr>
</tbody>
</table>

Table 10. Nurse Task Coding Categories

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRO</td>
<td>Procedure</td>
</tr>
<tr>
<td>AS</td>
<td>Assessment (neuro exam, vitals, pupil check, etc.)</td>
</tr>
<tr>
<td>Rx</td>
<td>Administer medication, IV fluids, etc.</td>
</tr>
<tr>
<td>XF</td>
<td>Preparing patient for transfer/arrival</td>
</tr>
<tr>
<td>ADJ</td>
<td>Adjustment of equipment</td>
</tr>
<tr>
<td>CH</td>
<td>Charting</td>
</tr>
<tr>
<td>MT</td>
<td>Maintenance (turning patient, oral care, suctioning, bath, etc.)</td>
</tr>
<tr>
<td>FN</td>
<td>Response to family need (i.e. troubleshooting, personal requests)</td>
</tr>
</tbody>
</table>
Figure 10. 2D ICU Nurse Tracking Results (Weekday)
Figure 11. 2D ICU Nurse Tracking Results (Weekend)
Figure 11. 2D ICU Nurse Tracking Results (Weekend) continued
Figure 12. 2G ICU Nurse Tracking Results (Weekday)
Figure 13. 2G ICU Nurse Tracking Results (Weekend)
REFERENCES


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