Many regulatory and professional agencies champion the idea of patient- and family-centered care, yet lack a supportive infrastructure or health care professionals with the necessary education, experience, or skills. This is the only comprehensive guide to family-centered care for healthy, ill, or preterm newborns. It guides health care professionals in creating, supporting, and advancing a culture that values partnerships with families. The book is replete with practical suggestions, strategies for effectively communicating with families, and best practices for health professionals who wish to develop partnerships with families before and after childbirth.

At the core of family-centered care is the belief that such care and the ability to convey its particular language is as important to newborn and family well-being as clinical care. The book offers helpful strategies for communicating with and about families before and after delivery, as well as substantial coverage of requisite clinical skills and technical expertise. It offers strategies to promote implementation of a family-centered environment in the delivery room or NICU, how to design a birthing plan, and tips on policy review to facilitate a culture of family-centered care. The book also discusses how to welcome families during interdisciplinary rounds and nurse hand-offs, and ways to bolster families during procedures and resuscitation. Additionally, the book addresses supporting parents in their decision-making role, palliative care, withdrawal of support, and bereavement.

KEY FEATURES:
• Provides a comprehensive guide to implementing family-centered care for healthy, ill, and preterm newborns
• Guides health care professionals in creating, supporting, and advancing a culture that values partnerships with families
• Offers strategies for effectively communicating with families to foster family-centered care
• Reflects on the power of language used with and about families
• Includes tips on policy review to foster and support a culture of family-centered care
Family-Centered Care

for the Newborn

The Delivery Room and Beyond
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Family-Centered Care
for the Newborn
The Delivery Room and Beyond

Terry Griffin, MS, APN, NNP-BC
Joanna Celenza, MA, MBA
This is a sample from FAMILY-CENTERED CARE FOR THE NEWBORN: THE DELIVERY ROOM AND BEYOND

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This book is dedicated to the countless babies and families who have welcomed me in their lives over the past 4 decades. Whether I knew them for minutes, days, weeks, or months, they have all had a profound influence on my professional practice. The babies may be the smallest, the youngest, or the sickest patients in a hospital, but they are brave, beautiful, and represent the hope of our future. These families may be the most joyful, the most frightened, or the most devastated, but we are grateful every day that we were trusted to help care for their babies. Together we have witnessed the miracles and tragedies that befell us. They taught us to be better human beings and more compassionate in our work. For that we thank them. This book is a testimony to all that we have learned to support and partner with families to improve care of all newborns.

Personally, this book is dedicated to my husband and three children who have loved and supported me in all my professional endeavors. Although my career is devoted to patient- and family-centered care, my family is the center of my life.

—Terry Griffin

I would like to dedicate this book to the babies and families that I have met over the years who have taught me so much and continue to inspire me. I am honored to have been part of their journeys and hope that in some way I can pass along the wisdom they have so graciously given me. I would also like to recognize my colleagues and the organizations who have supported my learning in the field of patient- and family-centered care. On a more personal level, I would like to acknowledge my own family and especially my husband and two beautiful children who continue to humble me and to teach me life’s most important lessons. Additionally, I would like to acknowledge the wonderful health care professionals who cared not only for my premature babies, but who nurtured, supported, and collaborated with my husband and me. This partnership many years ago was a transformational life experience for me and is the basis of my passion for the importance of nurturing, supporting, and advancing patient- and family-centered care practices.

—Joanna Celenza
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Foreword

*Family-Centered Care for the Newborn: The Delivery Room and Beyond* is a timely publication about partnerships in critically important aspects of health care.

Family-centered care in birthing and newborn intensive care settings that is genuinely respectful, supportive, and collaborative creates lasting memories that can shape the views and attitudes of women and their families toward health care professionals and the health care system for a lifetime. These experiences can be ones where women and families develop trusting, collaborative relationships with health care professionals and the competence and confidence to be active participants in care and decision making.

From the beginning, *Family-Centered Care for the Newborn* models professional and family partnership with the co-authors representing the perspectives, experience, and expertise of a clinician who is also a nurse educator and of a mother with experience in newborn intensive care who is now a family leader. Throughout the book, the authors weave insights and practical suggestions about the language of partnership and how to communicate with women and their families during care processes from the birth experience, in newborn intensive care settings, through the transition to home, and for end-of-life care.

*Family-Centered Care for the Newborn* provides a powerful guide for changing organizational culture in health care settings providing care to newborns, women, and families and, in the curriculum and educational settings, preparing the next generation of clinicians and staff.

The core concepts of patient- and family-centered care—respect and dignity, information sharing, participation, and collaboration—are foundational and serve as the framework for how nurses, nurse practitioners,
and other health care professionals can communicate with families. Each chapter includes tips and vignettes illustrating how to communicate effectively in a collaborative manner. By describing every-day, “real-world” situations, the tips and vignettes encourage reflection on current practice and approaches to communication. Occasionally, the authors provide illustrations representing how not to communicate. A rationale is always given for why this approach might undermine the confidence and competence of families, or serve as a barrier for developing mutually beneficial partnerships. The communication tips show the subtle and not-so-subtle differences between language that fosters partnerships and language that does not.

This is a time of dramatic change in health care. It is a time of redesign of systems of care, payment models, and even change in the way clinicians and staff are prepared for practice. It is a time with new expectations about how patients and families will participate in their health and health care and in the improvement of health care organizations. In 2012, the Institute of Medicine (IOM) released the publication, Best Care at Lower Cost: The Path to Continuously Learning Health Care in America. In its recommendations and in the statements shown below, the IOM underscored the importance of authentic partnerships with patients and families and linked these partnerships to improving health outcomes, the experience of care, and cost efficiencies.

*Involve patients and families in decisions regarding health and health care, tailored to fit their preferences.* S-23

*In a learning health care system, patient needs and perspectives are factored into the design of health care processes, the creation and use of technologies, and the training of clinicians.* 5-5

*When patients, their families, other caregivers, and the public are full, active participants in care, health, the experience of care, and economic outcomes can be substantially improved.* 7-1 and 7-2

*Family-Centered Care for the Newborn* can be used by quality improvement teams and as a resource for educational programming for staff on basic communication or for change in care processes like bedside rounds and change of shift report. The book can be a resource for the orientation and support of family advisors and leaders who wish to partner with NICU
staff and clinicians to bring about change and improvement in newborn intensive care or in the care of women experiencing high-risk pregnancies. It can also serve as a guide for the development of a curriculum that can be co-taught by family leaders, staff, and clinicians to students and trainees and for staff continuing education programs.

The “Family Support” chapter discusses the importance of and varied ways to connect families with others who have experienced similar situations while at the same time respecting individual preferences and priorities regarding receiving support. It notes that family advisors can be effective partners in building and strengthening NICU family support programs. The partnership language in this book and the recommendations for proactive planning and offering options brings meaning for how to support families when providing palliative care, when withdrawing care, and through bereavement.

A particularly helpful chapter, “Challenging Situations,” deals with many of the negative, difficult situations often raised by staff as barriers to family-centered practice, and offers wise counsel: “If we change our language, eliminate rigid rules, and cement our desire to partner with all patients and families to ensure best outcomes, we can eliminate many challenging situations.”

*Family-Centered Care for the Newborn* heightens the awareness and understanding of the words we choose to use and the power of language. While practical, it is also inspirational for a new, more collaborative, joyful way to work.

*Beverley H. Johnson*

*President/CEO*

*Institute for Patient- and Family-Centered Care*
Preface

There are multiple textbooks that teach staff and physicians to provide physical care to newborns who may or may not require hospitalization in a neonatal intensive care unit (NICU). These books may offer approaches to examination, diagnosis, and treatment of newborns and their medical problems. Although there may be chapters or sections devoted to care of the family, this book is intended to focus solely on developing meaningful partnerships with families of newborns. This book acknowledges that families are not “visitors” in the hospital, but rather the constant in a baby’s life. As organizations strive to provide family-centered care, this book can serve as a guide, offering actual situations and examples of conversations that hopefully will help staff and physicians change their approach to families, to acknowledge and respect the integral role families play in the care of the newborn. The individual chapters and practical examples can serve as a framework for learning and changing the way families are included in the care of their newborn.

Terry Griffin
Joanna Celenza
Introduction

The purpose of this book is to offer nurses, physicians, and other staff a primer on family-centered care of the newborn. We hope the vignettes and practical advice provide guidance to inspire health care professionals to see the value in mutually beneficial partnerships with families. This book will specifically address the theme of family-centered care of the newborn and how to establish partnerships with the family prenatally and postnatally, as well as delineate best practices to improve both the quality of newborn care and family support.
Family-Centered Care for the Newborn: The Delivery Room and Beyond
Basic Concepts of Patient- and Family-Centered Care
Defining Family-Centered Care

QUESTIONS TO BE ANSWERED IN THIS CHAPTER:
What does family-centered care of the baby mean? We do a lot for families already; aren’t we practicing family-centered care for the newborn?
How can our unit or organization continue on our journey to become truly family-centered?

This book offers a primer on changing our language, thinking, and practices so that care of a baby is truly family-centered. Although we interchangeably speak of the mother, father, and family, we acknowledge and respect that families are diverse and in fact can include two mothers, two fathers, grandparents, or other relatives who are the primary “parents” of the newborns. Nurses, physicians, and other staff have the opportunity to offer families countless moments of exceptional care or support in the process of this care. Just as we examine an approach to the diagnosis and treatment of a medical condition, this book offers ideas for creating and maintaining partnerships with families to improve the baby’s care, the family’s satisfaction, and the joy providers feel knowing they have made a difference in others’ lives.

Although the term family-centered care has become increasingly popular and organizations tout this philosophy of care on websites, in commercials, and in written materials, many organizations do not truly practice family-centered care of the newborn. How can this be true when we consider that every baby is born into a family and during the infant’s time in the hospital, physicians, nurses, and other staff provide exceptional care to the baby, in addition to caring about and doing much for families every day? It can be challenging for staff to accept that our long-held practices and policies are not necessarily family-centered and may need to be restructured or rewritten to reflect mutually beneficial partnerships.
Partnering in Family-Centered Newborn Care

In true family-centered care, whenever possible, we do things with the family, not for the family. Some staff argue that parents cannot be our partners in care because they lack knowledge and expertise. Yet the best partnerships share the same goals, even though different parties bring unique perspectives, expertise, and experience to the table. In health care, we are partners with families because staff and families share the same goals: safe, high-quality, and satisfying care with the best possible outcomes.

Health care professionals and families bring their individual expertise to the table. Each contributes his or her own unique perspective and expertise to ensure a thorough and complete team, one that is committed to achieving the best possible outcomes for both infants and their families. The parents may be first-time parents, but they are the best historians. They can provide a history of the infant that predates the birth experience, and they get to know their baby through the birthing process and beyond. In health care, staff and physicians may be the experts at delivering care, but families are the experts at the experience of care. Partnerships with families teach us how to improve not only bedside care but care within the larger system of care that is experienced on a very intimate level.

Patient- and family-centered care (PFCC) is an approach to health care that engages the patient and family as partners on many levels. All parents desire a gratifying birth of a healthy baby whom they love, care for, and protect. In the hospital, health care professionals can partner with parents antenatally, during and after the birthing process, and in the newborn intensive care unit (NICU) to achieve this goal. When it is known that the baby will not be born healthy or will not survive, it is just as important to partner with parents to honor and support their role as nurturers and decision makers in times of uncertainty and grief.

For the sake of the newborn, the goal of family-centered care is developing an essential and meaningful partnership with the baby’s parents to ensure safe, high-quality, and satisfying care with the best outcomes possible. This vital collaboration can occur in every interaction with the parents before birth and at the baby’s bedside throughout the hospitalization. On a broader level, policies, guidelines, and programs should reflect and support this commitment to family-centered care.

Just as partnerships are essential at the bedside, collaboration with patients and families at the organizational level is another layer of PFCC. Patients and their families have valuable insights, perspectives, and expertise, and they
can serve as partners in health care redesign and improvement. This role for families, often referred to as a family advisor, family partner, family leader, and so on, is discussed briefly in this chapter and in greater detail in Chapter 2.

The core concepts of PFCC go beyond being nice to patients and their families. Although it is important to be helpful, kind, and caring, PFCC is more than good customer service. Customer service provides a foundation for partnering with patients and families, but it is not equivalent to PFCC. The goals of PFCC are to improve our health care system and to improve the safety and quality of care by partnering with families from the bedside to the boardroom. It is about establishing mutually beneficial partnerships at the bedside with the patient and family, as well as using the unique perspectives of patients and families to enhance, enrich, and improve systems of care.

The Institute for Patient- and Family-Centered Care (IPFCC) (www.ipfcco.org) is a valuable resource for those working to plan, design, and enhance systems of care that provide the best care experience for patients and their families.

PFCC has four underlying concepts (Johnson et al., 2008):

- Respect and dignity
- Information sharing
- Participation
- Collaboration

The following sections explore how each of these concepts relates to family-centered care of the newborn.

**Respect and Dignity**

**Core Concept**

People are treated with 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 (www.ipfcco.org/pdf/getting_started.pdf).

Although this concept of being respectful and treating others with dignity is taught to all health care providers, situations continue to occur in which we fail to demonstrate adequate respect for the family or fully acknowledge
family members’ dignity. For example, health care staff may not identify themselves or their role. Parents have a right to know who each staff member is and to receive an explanation of his or her role; this is critical for establishing a partnership based on mutual respect and understanding.

**Communication Tip**

When addressing the mother of a newborn, health care professionals show respect by introducing themselves and explaining what they do.

“Mrs. Smith, my name is Dr. Brown. I am the neonatologist in charge of your baby’s care. If this term is new to you, it simply means I am a pediatrician who specializes in the care of newborns.”

“Mrs. Smith, my name is Jane. I am the nurse who will be helping care for your baby until seven this evening.”

Health care staff sometimes enter the mother’s hospital room without knocking or identifying themselves. Instead, take this approach:

“Mrs. Smith, this is Jane, your baby’s nurse. May I come into your room?”

A health care professional may begin examining the baby without explaining the examination’s purpose to the mother. For example, you might enter a mother’s room, needing to check the baby’s blood sugar, yet the mother is holding her baby. One approach might be the following:

“I am putting the baby back in his bed. I need to check his blood sugar.”

Although this approach explains to the mother what you’re doing and why, it does not treat the mother with respect. She may feel you’re coming between her and her son. A more collaborative approach that is respectful of the mother’s role would be this:

“Mrs. Smith, I see you are holding your baby, but I need to recheck his blood sugar. You can continue to hold him if you’d like, or if you prefer, we can put him back in his bed. Either way, I can show you how to comfort him while I poke his heel.”

This approach explains what you need to do, allows the mother to decide how to proceed, and makes her a participant in her baby’s care.
Holidays and seasonal celebrations also offer an opportunity to practice respect and dignity. We may celebrate holidays we consider important, but we may fail to ask the family about holidays they would like to celebrate. For example, it is not unusual to find a baby’s room decorated by staff for traditional Christian holidays, yet not all families are Christian. Instead of assuming they know which traditions and celebrations are important to the family, the staff should identify the family’s religious or cultural traditions and facilitate these celebrations in the hospital.

**Communication Tip**

Asking about these traditions requires only a few words:

“Mrs. Smith, as you know, your baby is likely to be here for a couple of months. Are there any special holidays or traditions that are important to you and your family that will happen during this time? Let us know, and we can help you honor them.”

Staff often offer special celebrations for hospitalized babies out of kindness; however, these celebrations may be upsetting to some families, who deem them inappropriate. For example, a mother arrives in a NICU and finds her preterm baby dressed in a Halloween costume. She was unaware that her baby could be clothed and is upset that the primary nurse chose the baby’s first Halloween costume. On the other hand, when staff members partner with families ahead of time and plan for holidays and special occasions together, such disappointments can be avoided and staff demonstrate respect for the family’s role in the baby’s care.

“Mrs. Smith, as you know, Monday will be Halloween. Is this a day your family celebrates? If you would like, you can bring an outfit for your baby and we’ll help you take pictures of her and her siblings.”

When staff members honor important family traditions such as holidays or special events, they have an opportunity to connect with the family in a way that otherwise would have been missed. Holidays and celebrations present an opportunity for staff to learn about diverse beliefs, cultures, and traditions.
**Information Sharing**

**Core Concept**

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 (www.ipfcc.org/pdf/getting_started.pdf).

Information is power. Staff must acknowledge that a baby is born into a family, not a hospital or NICU. When we fully partner with families, sharing information is vital. Information must be shared freely, in a way that is meaningful and understandable to families. Even if we do not have answers to questions, we should share what we know and admit that we might not be able to predict the future.

**Communication Tip**

There may be times when you cannot answer a parent's question, so make sure to explain why you do not know and how you will obtain an answer if possible.

“Mr. Smith, I know you want to know the next steps for your baby. We are waiting for the specialist to call back. If we do not hear from her by 10 a.m., I will call her and get back to you.”

Another vital way to share information is by welcoming parents during nurse hand-offs and medical rounds, a topic that will be addressed in Chapter 8. Nurturing a culture that embraces families during these important exchanges of information is the cornerstone to providing a true patient- and family-centered environment where parents feel empowered to share information and help make informed decisions about the care of their newborns.

Hospitalization of a newborn often puts the family under considerable stress, so providing both written and verbal information that is easily understood is a key consideration for establishing meaningful sharing. Written information can be helpful for families to process and reread as they are able to comprehend that information more fully. Written information can also be shared with other family and friends who may be confused about the situation.
Communication Tip

When a parent asks you a question, make sure you are sensitive to the family’s interpretation of the situation, which might be vastly different from the staff’s.

The mother of a critically ill preterm infant asks when he can be circumcised. The nurse inquires why she asked this question. She replies, “My grandmother told me to ask.”

There can be a disconnect between reality and how other family members or friends understand the baby. Parents with written or electronic information to share may be able to garner appropriate support from family and friends.

When a baby is born prematurely or is sick, parents may need guidance about sharing information with family and friends. Staff can offer suggestions that have worked for other families.

For example, Mrs. Smith, the mother of a 3-day-old infant born at 25 weeks, says, “My in-laws want to know if they can start telling people about Sara’s birth.” The nurse suggests that some parents send birth announcements immediately. Such an announcement might state: Announcing the arrival of Sara Smith. Due September 18; born June 11. Weight: 1 pound, 2 ounces. The nurse also shares that some parents wait until the baby is home and send a combined birth and coming-home announcement: We’re proud to announce the birth and homecoming of …

Vignette

The parents are told, “We are doing an echocardiogram to evaluate for heart failure.” Heart failure is an example of a term that can have a devastating meaning to parents. To many parents, failure is equivalent to stopped beating. Usually, however, this is not true.

Instead, the health care professional delivering this news to the parents could state it like this:

As you know, Billy has been breathing faster and needing more oxygen. One reason for this could be that the hole in his heart is sending too much blood to his lungs. We are going to get an ultrasound of his heart, like the ultrasounds you had during pregnancy. We are going to see how well his heart is working or whether he needs medicine to help.
Acronyms and complex or vague medical terms can undermine a parent’s confidence in being a competent member of the care team, so use language that parents can understand.

**Participation**

**Core Concept**

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose (www.ipfcc.org/pdf/getting_started.pdf).

Events and procedures that are routine to medical staff may be completely unfamiliar to families. If the baby must endure one of these invasive procedures, it can be emotionally taxing on the parents. Health care professionals should consider the comfort level of families participating in seemingly commonplace procedures and events. Instead of assuming that parents do not wish to be present during procedures, staff must explain a procedure’s purpose and the process involved, and then determine whether the family wishes to stay. Often, parents decide to stay to offer comfort and support to their baby. Sometimes, however, they may opt to step away to take a break. In all cases, giving parents the option to decide what’s best for them and their baby is crucial.

**Vignette**

A baby requires a surgical consult for abdominal distension and has been transferred from the mother–baby unit to the NICU. The parents wait anxiously in their child’s room for the surgeon’s evaluation and plan. The surgeon arrives in the NICU and receives an overview from the staff. When she is about to enter the baby’s room, the surgeon stops and asks, “Are those the baby’s parents? I would prefer to see the baby without them in the room. I have never seen this baby before.”

The neonatal nurse practitioner (NNP) suggests,

“It’s okay. I will introduce you. Mr. and Mrs. Smith, this is Dr. Jones, the surgeon, who is here to examine your baby. She looked at the x-ray and is seeing your baby for the first time. Let’s have her examine the baby and then hear what she has to say.”
A 24-week preterm baby is admitted to the NICU. The physician obtains consent for line placement and blood transfusions, knowing that this baby will likely need a future transfusion. Several days pass. The baby becomes anemic and needs a transfusion. The parents have already given consent, so the staff order blood and administer the transfusion. Later, the mother is extremely upset that she was not notified before the baby was transfused. She wanted to be present during the transfusion and missed that opportunity. The health care team did not anticipate that she would want to be present.

As health care providers, our interpretation of a situation or its significance might differ from the parents’. We can avoid such problems by sharing anticipatory guidance and options for the mother’s participation in a procedure:

Offer parents the opportunity to participate in decision-making whenever possible. Absolutely, some decisions must be made solely by health care providers, such as when to order laboratory tests, which antibiotics to begin, or when to intubate a patient. Families trust health care professionals to make decisions that are in the best interest of their babies. Still, there are times when families can and should be involved in decision-making at the level they choose. For example, blood transfusions are not uncommon in the NICU. To a parent, however, a necessary transfusion can be a frightening prospect.

After this introduction, the parents wait quietly, offering the baby a pacifier, while the surgeon examines her.

Being a champion for parents with colleagues in a way that is respectful, thoughtful, and in alignment with PFCC principles can demonstrate the importance of including the parents. It can set the tone for future interactions with families and other colleagues.

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Vignette (continued)

“Mrs. Smith, even though you signed a consent form for blood, we will let you know if your baby needs a transfusion. If it is not an emergency, and you want to be here when he is transfused, we can work together to make that a possibility.”

Although the mother cannot determine when the baby needs a transfusion, she can decide to be present if circumstances allow. If the transfusion is a true medical emergency, staff should at the very least make a phone call to the mother, explaining the need for an immediate transfusion.

“Mrs. Smith, I know you want to be here when Billy needs blood, but I am calling you to explain that we need to give him blood right now. I wish we could wait for you, but this is an emergency because his blood level has fallen very low. It would not be safe to wait any longer. I know you also want to make sure he’s okay, so we are going to start the blood transfusion. If you want to come now, it will likely still be infusing when you get here.”

Collaboration

Core Concept

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 (www.ipfcc.org/pdf/getting_started.pdf).

Patients and families are also partners to be included in decision-making and processes on an institution-wide basis.

Families who have the personal experience of being in the hospital or having a hospitalized family member can be a successful part of the improvement process. As improvements to the system of care are considered, involvement of a patient or family member provides a more robust vision of this system of care. Patients and family members can provide insight into the health care experience, and this insight can help to reshape and improve practices, policies, programs, and information for families.
These family members are referred to as family advisors, family partners, family leaders, or family liaisons, among other terms. They can serve as part of a multidisciplinary approach to quality and systems improvement. If your organization does not have a formal advisory council or other formal group of family advisors, there are informal ways to engage their perspective.

Consider, for example, what frequently happens during the winter months. During this time, it is common to see hospitals post signs that attempt to restrict visitation in direct and noncollaborative ways. Posted signs may state:

“STOP! Due to the cold and flu season NO children under the age of 18 will be allowed in the maternity units.”

“Due to the cold and flu season, visitors are prohibited from coming to see our patients if they have a fever, cough, or congestion.”

“NO visitors under the age of 18 due to the flu outbreak.”

“STOP! No admittance due to flu activity in the community.”

Are the public health concerns valid? Absolutely. However, signs with such language do not reflect collaboration; they provide no information to help a family understand the importance of hand hygiene and health screens to reduce the risk of infection. This is not the language of partnership; this is the language of power. In partnership with families, staff can work to create information that stresses the need for vigilance in the winter season yet reflects the importance of the family’s presence and role in preventing infection through educational efforts. This information can then be shared with other families.

A more collaborative approach, such as the one described previously, helps maintain a safe environment for patients while ensuring a PFCC approach to messaging.

Families can provide unique insight and perspective, creating a lens through which we can explore and improve the health care system. Families who have reflected on their health care journeys and transcended that experience to provide insight into how care was provided can help hospitals move forward with PFCC practices. Serving as an advisor can be a rewarding experience for patients and families, offering staff an opportunity to partner with families in a distinct and collaborative way.
Vignette

Staff in a NICU want to post a sign reminding parents to be vigilant during the cold and flu season. Although the unit does not have a formal advisory council, willing parents present in the NICU help staff create a sign that symbolizes partnerships between staff and families to prevent contagion.

HELP US KEEP YOUR BABY SAFE DURING THE COLD AND FLU SEASON

RSV is a common virus. It causes mild, cold-like symptoms in healthy adults and children.

However, this virus can be very serious in babies, especially those who are premature or have other health conditions.

What can you do to help?

- Coming to the NICU is unsafe for the babies if you, other family, or friends are sick with cold symptoms.
- Persons who are sick can easily spread germs by touching and kissing your baby!
- Washing and cleaning your hands before touching your baby is the most important way you can help stop the spread of germs.
- For added protection: Limit the number of family and friends who touch your baby.

Hospitals, as well as specific units within hospitals, have unique needs related to patient safety, design, market share, and other fiscal issues. Families and health care professionals can work together to implement a strategy that incorporates the family perspective to address these metrics. Partnering with patients and families in this way is patient- and family-centered care. As family perspectives have become more important to health care organizations, families can assist in different ways. The goal is to ensure that this partnership is mutually beneficial and thoughtfully implemented to meet the needs of the advisors, the hospital (or unit within the hospital), and the patients and

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An advisory council for the NICU works closely with the medical staff to review and edit infection-control guidelines, providing specific feedback to ensure the policy’s language is family-centered. A no-ring policy is initiated for staff, and the council advises initiation of the same recommendation for families and their guests. A parent member of the council designs a jewelry pouch to be given to each family upon admission. Included with the pouch is an information card, highlighting research findings that cite why families should consider removing wrist and hand jewelry.

families themselves. Some hospitals hire families who have received care to provide a sustainable voice as advisors or leaders. Some hospitals use a cadre of volunteers who serve as patient and family advisors, and many tap into the wisdom of a Patient and Family Advisory Board for guidance. The IPFCC website offers several resources to develop and implement the role of family advisor into hospital committees, projects, and task forces (www.ipfcc.org/advance/tipsforgroupleaders.pdf). Chapter 2 discusses the role of family advisor in more detail.

These four core concepts—respect and dignity, information sharing, participation, and collaboration—embrace the philosophy that patients and families can and must be effective partners in care. Partnering with them can lead to the ultimate result of optimal clinical outcomes for patients and their families, as well as enhanced satisfaction for patients, families, physicians, and staff.

System- and Provider-Centered Approaches to Health Care

To fully understand the family-centered approach to health care, it is helpful to review alternative approaches. In system- or provider-centered care, policies and processes benefit the staff or are focused on the system’s efficiency. Many hospitals’ policies and practices are system- or provider-centered. Historically, we have created policies and practices that work best for those who work in the health care system. Decisions and policies are made for and by the staff or the organization, with staff efficiency and protection first and foremost. An example of a system-centered approach to care is the
traditional visitation policy. In many organizations, families are excluded from a unit during rounds or report or at other times. Although this rule may seemingly benefit the staff and ensure an efficiently run system, it does not incorporate the family’s perspective; rather, this policy limits their observations of the patient and their suggestions for care. Including families effectively strengthens collaboration as they may have questions that are discussed in real time. Excluding families from rounds may require the team spending additional time answering questions or deciding upon care plans.

**Vignette**

The following sign appeared in a unit:

**QUIET TIME**
7–8 a.m.
3–4 p.m.
11 p.m.–midnight

Although the sign implies that babies rest during these hours and parents should not be in the unit “disturbing” them, in fact, the policy benefits the nurses, who want to avoid interruptions from parents during their hand-offs.

Family-centered “visitation” policies welcome the family at any time. Encouraging families to be part of the care team—involved and supported in caregiving and decision-making at the level they choose—is a core concept of PFCC. It is suggested that any policy that refers to families being present with their infant be referred to as a “Family Presence and Participation/Decision-Making” policy. The use of the word “visitor” is discouraged in these scenarios.

Bath schedules for babies in the NICU offer another example of a system- and provider-centered approach to care. Babies are often bathed at night, when they are weighed. This organization of care is most efficient for the staff. Physicians want weights available in the morning, and babies are usually undressed for the weight, so it’s convenient to bathe them at this time. However, a mother who comes every day from 9 a.m. to 5 p.m. may never have the opportunity to bathe her baby until the baby is close to going home, when bathing is identified as an educational need.
Family-Focused Approach to Health Care

In a family-focused approach, the staff do things for the patient or family and not with them. The key to understanding the difference between family focused and family-centered lies in those simple prepositions. How do the staff define family? The answer may lead to the development of policies that reflect a family-focused environment.

Staff generally acknowledge that family is important to a patient, so they develop policies that welcome some family members at certain times. The problem is that the staff—not the patient or parents—define family. Often policies state that only immediate family is welcome in a unit, which can exclude some key supports that are unique to each family. A family-focused approach defines family for the patient. A family-centered approach, on the other hand, asks the patient or family to define who is most important to them and ensures that policies and practices support the presence of these people. In this case, the staff define family with the parents. Each family is unique in its strengths and composition, and the most family-centered approach ensures families can leverage those strengths and provides an environment that enables them to use their support systems.

Communication Tip

Take a family-centered approach to bathing by including the family as early as possible:

“Mrs. Smith, we typically bathe the babies three times a week. Tell me what days would work best for you so we can plan your daughter’s bath schedule with you.”

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Communication Tip

Rather than imposing a narrow definition of family, a better message would be this:

Only you know who is most important to you at this time. We do not have rules about who can be with you in the unit. To protect you and your baby, we only ask that no guests are ill.
In fact, much health care practice is family focused, where staff do things for the family. For example, when the staff make a plan to send a baby home without the input of the family, they are practicing family-focused care. In this situation, we might say, “Mr. and Mrs. Smith, the doctors have decided your baby can go home tomorrow. We have made appointments with the specialists for you. You can come and pick up Billy in the morning.”

If the plan for going home were family-centered, the staff would gather the family and review the plans with them. They might say, “Mr. and Mrs. Smith, as you know Billy is nearly ready to go home. Tell us your thoughts. What are you most worried about? How can we help you feel more confident in bringing him home? He can likely go home on Saturday. Will this work for you? What would be the best time to take him home? Can we make any follow-up appointments with specialists for you, or would you prefer to make those yourself? If you’d like us to schedule them, what days and times work best for you?”

Changing the Organizational Culture to Support Family-Centered Care

A change in the organizational culture is necessary to create a family-centered environment, and this can be a challenge (Abraham & Moretz, 2012). Although individual practitioners can commit to partnership with patients and families in caregiving and decision-making, administration must show organizational commitment to family-centered care by addressing hiring practices, orientation, and performance evaluations, ensuring that these adequately represent family-centered care.

All organizations are somewhere on the continuum of the family-centered journey. Like families, all organizations have strengths, and the goal is to capitalize on those strengths to support and create a family-centered environment.

Convene a Focus Group

What steps can organizations take to move forward? A good starting point is to clarify the core concepts of PFCC and discuss them with stakeholders.

- Attend an IPFCC-intensive training seminar. These seminars can facilitate the shifting of personal health care paradigms. Many participants attend believing they fully understand the concept of
family-centered care, only to leave awakened and energized to help change health care in ways that benefit everyone.

- Convene a group of administrators, clinical staff, physicians, patients, and families to analyze where the organization falls on the family-centered spectrum. Consider completing a formal assessment of family-centered practices individually and then comparing responses as a multidisciplinary team. The differences in perspectives and ratings can be enlightening. Patients and families who can help elucidate opportunities for the organization are ideal candidates for this type of assessment. The IPFCC offers tools to evaluate an organization’s understanding and commitment to family-centered care. Simple steps and strategies are available to facilitate the family-centered journey. Visit www.ipfcc.org/pdf/getting_started.pdf for more information.

Convene this same group and by sharing personal and professional stories, analyze how well your organization follows the four core concepts of PFCC. Reflect upon these stories by asking the group to identify ways in which the principles are supported and where improvements might be made. This type of self-assessment of the organization, paired with professional stories, may be enlightening and may tease out some themes for improvement based on what the team has personally and professionally experienced at their own health care organization. Sharing those insights can be empowering to identify, upon reflection as a team, how these experiences reflect the family-centered culture of the organization. These insights can be explored more deeply by listening to those families with a vast range of experiences. These stories can identify specific and sometimes very key points in the health care experience that can be improved. In some organizations, a patient and family panel is convened where they are asked to share stories about their experiences in your organization. This panel can be facilitated by asking each patient or family member to do the following:

1. Briefly introduce yourself and provide highlights of your experience at our organization.
2. Share an experience that went well.
3. Teach us something we could do better.
Vignette

My name is Jane, and I was hospitalized on 8 West with early labor. I was in the hospital for 6 weeks with a broken bag of water. Many of my experiences went well. Mostly, the doctors and nurses shared information with me and my husband each day. We were terrified and felt better when they explained the results of my lab tests and how well the baby was doing. They let me listen to the heartbeat and encouraged me to stay strong.

I was hospitalized at 22 weeks and begged to talk to a neonatologist. I knew the baby was not viable at 22 weeks, but I wanted to hear this from the expert. He was very kind, took his time, sat with me, and explained why my baby could not survive at 22 weeks. But he told me when I got to 24 weeks, we would have a different conversation. I was so excited when I turned 24 weeks! I asked to have the doctor come back and explain what to expect if I delivered now. The doctor who came this time seemed unhappy that she was there. She stood at my door and curtly answered my questions. I was so excited that I was still pregnant, yet she seemed so unkind and uncaring.

Using this vignette as an example, answer the following questions:

1. Thinking of what went well for Jane, which PFCC core concepts were honored?
2. Thinking of what she could teach us to do better, which PFCC core concepts were not honored?
3. What else can we learn from Jane’s story?

Convene a Journal Club

Read and discuss articles related to family-centered care. What did you learn? Is there something you might do better?

Begin Every Meeting With a Family Story

Ideally, the family involved should tell their story themselves. How does the story support the philosophy of family-centered care? What does the story remind us that we do well? What does the story teach us about what we could do better?
Think of an example from your own experience—a conversation you had or something you did that honored the core concepts of PFCC. How might your experience serve as a model for others?

In health care, we review patient care by analyzing what we did well and what we could have done better. We ask someone to present the patient’s hospital course, diagnosis, and treatment. We identify quality issues to track and improve, such as health care–associated infections. These family stories also offer an opportunity to review and improve the care we give. The goal is to move these stories to the same level of importance as our patient care reviews, because they are also powerful ways to improve care.

Create a Newsletter

Share your successes. A newsletter can inform staff of patient and family stories that cement the commitment to family-centered care or offer opportunities for improvement. Read and discuss articles with staff, and then summarize what they learned.

Develop a Philosophy of Care

A well-thought-out philosophy of care, developed in collaboration with patients and family, can help guide policies and programs in a way that’s consistent with the culture of a hospital or unit of a hospital.

For example, at the Children’s Hospital at Dartmouth-Hitchcock, the Intensive Care Nursery (ICN) Parent Council developed a Philosophy of Care statement that helps define and guide the care provided at the ICN.

*We believe the parent and child relationship is essential.*

*We believe in providing a nurturing environment*

where:

*The child is part of the family,*

*And the family is part of the care team.*

This statement reminds staff and families alike that the family is an integral part of the care team. It also underscores the importance of the parent–child relationship. This Philosophy of Care statement hangs in a prominent location as a reminder of what guides the care provided to all families.
Evaluate Partnerships

Although the partnerships we form within and among our organizations are not a focus of this book, it is vital to consider them. It is imperative to partner with patients and families, yet we often work in environments in which we have not learned to partner well with our colleagues or with other shifts, units, and departments. Perhaps the key to clinical success is creating and maintaining essential and meaningful partnerships with everyone at our organizations (Leape et al., 2012a).

As you ponder the core concepts of PFCC, consider how they might apply to your professional relationships. How might these relationships be improved? We typically practice in cultures that focus on the technical aspects of care: technical expertise and clinical competence. We may have ignored disruptive behaviors toward one another or toward patients and families, although we know such behavior can negatively affect safe care. When we are respected for our clinical prowess, we sometimes make excuses for our inability to partner with one another and with patients and families. Despite the focus on excellent clinical care, there continue to be serious issues with medical errors and with dissatisfied patients, families, and staff (Institute of Medicine, 2001).

Efforts are being made to change expectations and improve outcomes (Leape et al., 2012b). The time has come to celebrate the non-technical aspects of care—our ability to partner with one another and with patients and families. This is not to suggest that the technical aspects of care are unimportant; in fact, at any given moment technical aspects may be the priority. For example, if a patient begins to bleed, the nurse would not abandon the patient to share this new clinical finding with the family. Rather, the goal is to create an organization where the technical and non-technical aspects of care are equally important. After the bleeding has stopped, staff must notify the family of the situation, explain the bleeding, share the patient’s care plan, and explore how the family might help with that plan of care.

Consider all of the processes that have created technically expert and clinically competent staff:

- Education
- Ongoing support
- Champions
- Resources
Apply all of these components to the nontechnical aspects of care to replicate success and to partner with patients and families.

Table 1.1 The Language of Power versus the Language of Partnership

<table>
<thead>
<tr>
<th>Words That Reflect Power and Control</th>
<th>Words That Reflect Partnerships and Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allow, let</td>
<td>Welcome, embrace, support</td>
</tr>
<tr>
<td>Visitor</td>
<td>Friend, family, guest, partner</td>
</tr>
<tr>
<td>Require, mandate</td>
<td>Suggest</td>
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<tr>
<td>Rules</td>
<td>Guidelines</td>
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<td>Permit</td>
<td>Facilitate</td>
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<td>Must</td>
<td>May</td>
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<tr>
<td>Restrict</td>
<td>Guide</td>
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<tr>
<td>Stop</td>
<td>Help us</td>
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<tr>
<td>Never</td>
<td>Sometimes, often</td>
</tr>
<tr>
<td></td>
<td>Let’s see what we can do</td>
</tr>
<tr>
<td>No</td>
<td>Let’s talk about this</td>
</tr>
</tbody>
</table>

Key Points

- Policies must reflect a true partnership with families, one that meets the individualized needs of families while balancing the ultimate goal of best outcomes for infant and family.
- Policies that meet the needs of the system (only) are referred to as system-centered policies.
- Policies that strive to do what’s best for the patient and family are called family-focused policies, but these typically do not reflect a true partnership.
- Policies that meet the needs of patients and families through meaningful partnerships with them are called family-centered policies.
- Families are integral to the well-being and health of patients and should be included as partners in caregiving and decision-making.
- Families may serve as informal or formal advisors to devise strategies for moving forward—not just with PFCC initiatives, but also with improvements to enhance patients’ and families’ experiences and to optimize outcomes.
A hospital should not limit patients’ access to their support systems but instead should work together to meet the needs of each patient and family.

Policies and philosophies of care should reflect these partnerships and use the perspective of patients and families to guide the development, implementation, and evaluation of these policies and philosophies.

Staff and physicians must find ways to partner successfully with one another.

References


