Chapter 1 Advancing Patient- and Family-Centered Newborn Intensive Care

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There is a growing consensus that patient- and family-centered care (PFCC) is an essential dimension of excellence in healthcare and of healthcare quality improvement. Numerous benefits of PFCC have been reported, including decreased length of stay, enhanced parent-infant attachment and bonding, better mental health outcomes, better allocation of resources, decreased likelihood of lawsuits, greater patient and family satisfaction, and better staff satisfaction.1–12

Given these benefits, the expectation that healthcare delivery should be patient- and family-centered continues to grow at the policy level, within the healthcare provider community, and among the general public. Leading healthcare organizations, including the Institute of Medicine, the Agency for Healthcare Research and Quality, the World Health Organization, the Joint Commission, the National Quality

Patient- and Family-Centered Care

As defined by the Institute for Family-Centered Care (IFCC), patient- and family-centered care places an emphasis on collaborating with patients and families of all ages, at all levels of care, and in all health care settings. Further, it acknowledges that families, however they are defined, are essential to patients’ health and well-being and are allies for quality and safety within the health care system. The core concepts of patient- and family-centered care are:

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

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

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

Collaboration. Patients, families, health care practitioners, and hospital leaders collaborate in policy and program development, implementation and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.16
Forum, the Institute for Healthcare Improvement (IHI), and the American Academy of Pediatrics, strongly voice support for PFCC. These organizations also recognize that involving patients and families in system redesign and improvement initiatives is critical to success.

Over the last several decades, maternal and child health and newborn intensive care have taken a leadership role in the PFCC movement, laying the groundwork for a change that now informs all clinical areas. While we celebrate the gains, there is much more to do. In newborn intensive care, we are still a long way from delivering PFCC to every infant and family, 100 percent of the time, in every NICU.

Opportunities for learning and improvement are numerous. Effective plans for improvement initiatives can be developed by involving all who have experience in newborn intensive care. This includes clinicians and staff from across disciplines, but most importantly, these initiatives must include family members as partners in facility design, policy review, program development and implementation, and staff education.

Getting to PFCC: What Will It Take?

When the Centers for Medicare and Medicaid Services chose to post patient experience rankings for hospitalized adult patients, IHI and many other organizations were peppered with questions on how to achieve an exceptional patient care experience. The questions centered on what things needed to be done and how these things fit together. In order to respond to these questions, IHI led a research and development project to identify key drivers (that is, the system components) that have a positive effect on the care experience. Patients, family members, clinicians, and administrative content experts across healthcare participated in the project. They determined that the key drivers are:

- Governance and executive leaders demonstrate that everything in the culture is focused on patient- and family-centered care and is practiced everywhere in the hospital.
- The hearts and minds of staff and providers are fully engaged.
- Every care interaction is anchored in a respectful partnership anticipating and responding to patient and family needs.
- Hospital systems deliver reliable quality care 24/7.
- The care team instills confidence by providing collaborative, evidence-based care.

Conclusions drawn from this project support the concept that patient- and family-centered care is inextricably linked with quality and evidence-based care. The challenge then becomes how to hardwire the components necessary for a unit or hospital to begin or expand PFCC. A natural place to start is by assessing the current status of integration of PFCC.
Publicly Verifiable PFCC

When health professionals are asked if their practice is patient- and family-centered, the typical response is “Yes.” It is something they value but when questioned what the elements are, answers come up short. A number of organizations have developed self-assessment tools including Family Voices, the Institute for Family-Centered Care, Planetree, IHI, the National Initiative for Children’s Healthcare Quality (NICHQ), and the American Hospital Association. These tools explore a range of publicly verifiable elements of patient- and family-centered care, asking whether patients and families:

- Participate as key members of the care team (and are not viewed as visitors by staff and clinicians)?
- Have access to the paper and electronic record?
- Have access to the most accurate clinical information by participating in rounds and change of shift report?
- Receive education and ongoing communications at appropriate literacy levels and in the language spoken at home?
- Serve on governing board and hospital strategic, operating, quality, or facility design committees?
- Participate on patient and family advisory councils?
- Assist in personnel selection and orientation processes?
- Serve as educators for students, trainees, clinicians, and staff?

Experience has taught us that these self-assessment tools are most effective when they are completed by a team that includes patients and family members and staff from various organizational levels and disciplines. The question “how do things work here” gets answered very differently based on where you work. Healthcare historically has focused much more on working within silos as opposed to in teams. Often direct-care staff have differing perspectives of processes from those of managers. Patients and families, in sharing their care experiences with the assessment team, highlight the difference between organizational values and actual practice. It’s particularly important that the team include management as well as direct-care staff. When the team completes self-assessments together, there is often striking use of expressions such as “I thought we started…” “Don’t we…?” “When did we stop…?” Leadership, in particular, has made statements like the following: “If you asked me before the self-assessment process, I would have said absolutely—we are patient- and family-centered. After this process, I see we have barely begun.” Or “I thought of this as a value and not a lot of things.”

We learn through this type of evaluation that the statements highlighting commitment to PFCC in organizational core values and marketing materials do not automatically lead to hard-wiring specific policies and practices across the organization. Once a thorough self-assessment has been completed, strategic priorities for change can easily be determined.
Establishing an Effective Team to Improve PFCC

The experience of organizations such as the Vermont Oxford Network (VON), IHI, NICHQ, and other organizations dedicated to healthcare quality and safety tell us that the most effective improvement teams are made up of representatives who have knowledge about the area of focus. Typically, teams strive for inclusiveness and yet often exclude a key constituency – patients and families. However, if the aim is to advance PFCC or improve any aspect of the care experience, patients and families must be active participants in improvement initiatives. Their perspective of the experience of care is vital.

In observing organizations where there is a struggle with this approach, the model is typically just the action of a few clinical leaders who are committed to patient- and family-centered care who are allowed to implement models as long as no one voices an objection. Administrators and clinicians often struggle with issues of privacy, boundaries, liability, cost, and losing control. At times of enormous demands and constraints, staff worry that there will be a further burden imposed if families are at the table. Each of these concerns is real and underscores that you just don’t “throw” parents and staff into partnerships. It won’t work for the staff or the parents. Families and staff require preparation and training to build the knowledge, skills, and trust that are essential to effective partnerships.

Despite the concerns of staff, we have seen NICUs where parent collaboration is effectively executed. At the root is the clear expectation from unit and organizational clinical and administrative leadership that this is not an “if” discussion but a “when and how.” Ongoing collaboration is not being put to a vote or left to a few clinicians to implement in isolation. Instead the focus is on how it can be implemented in a way that is respectful of families, respectful of staff, and informs processes to most effectively achieve goals. Integration of families in quality and redesign initiatives is conducted in a thoughtful, sensitive, and strategic manner that matches the strengths of parent advisors with the needs of the team. Considerable resources and examples exist to guide organizations in this effort.24–28

Improving PFCC in the NICU

Families are often unprepared for the NICU journey, and struggle to understand this intimidating world of equipment, monitors, and staff caring for their baby. Many, if not most, of the approximately half million premature and critically ill infants born each year (and their families) have experienced care and caring anchored in patient- and family-centered tenets. Yet parents often express concern that they are treated as outsiders in the care of their own infant. Examples include not being a part of critical clinical decision making, not being communicated to in a language or at a level they understand, and not feeling competent and confident to effectively care for their child when they go home.
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However, by engaging families to participate in care and decision making—for example, by including them on multidisciplinary rounds and nurse change of shift reports—NICU staff can help parents begin to feel more like parents and like active members of the care team. Instead of being passive observers watching the physicians and staff care for their infant, parents can be included at their specific comfort level and encouraged to participate in the plan of care and any decisions related to their infant. This active engagement and participation provides a sense of purpose for the family in their baby's recovery. Additionally, if parents’ informational needs, observations of their infant, and their concerns are acknowledged and addressed by the care team, this too can build their confidence and competence in caring for their baby, especially as they prepare to transition home.

Empowering families to be part of the care team and truly partnering with them throughout their NICU journey can lead to continued partnerships after their infant goes home. Families often express a profound sense of gratitude for the care received and wish to somehow give back to those who provided care for their babies and themselves during a very vulnerable period in their lives. Some NICUs and organizations have responded by establishing parent/family advisory committees. Parents of former patients have been invited to sit on committees dealing with facility design, not just to react to completed designs, but to be full members of the design team from the start. There are now a growing number of neonatal units and organizations where no clinical space can be designed without having family members as part of the design team. Changes suggested by parents include recommendations for noise control, lighting, privacy, sleeping chairs, and room design.

In other organizations, former family members are invited to be part of quality improvement initiatives, sitting on teams, providing immediate reaction to staff around tests of change. At the leading edge are those organizations where parents are full partners in all aspects of improvement and system redesign. In these organizations, parents collaborate with providers to develop policies and strategies. These include how to prepare and support parents to participate in rounds and nursing shift report; how to adapt informed consent documentation and processes so that families have full and understandable information, and how to communicate difficult information or disclose a medical error. These recommended changes often include nuances that only the unique perspective of a family member brings.

One parent whose perspective has been making a significant difference in healthcare improvement is Sorrell King. In 2001, her 18-month old daughter, Josie, died due to medical errors. The King family established a foundation and Sorrell has been working with hospitals and healthcare organizations across the nation to build safer systems and processes. In addition to the presentations she gives to healthcare professionals throughout the U.S., Sorrell has been involved in helping hospitals establish a formal process for families to call a rapid response team if they believe their loved one’s
condition is deteriorating. She has also been assisting researchers in developing a toolkit to train physicians in how to disclose medical errors.\textsuperscript{30}

**The Vermont Oxford Network Experience**

The Vermont Oxford Network began involving families on quality improvement teams in 1998. In the NICQ 2000 collaborative, twelve teams (self-named the We Are Family topic group) focused on PFCC. They involved families in on-site visits to exemplary hospitals, at the face-to-face collaborative meetings, in ongoing improvement work within their individual units, and in the work of identifying potentially better practices and developing tools to measure PFCC. After experiencing the benefits of involving families in this work, many of these teams increased opportunities for families to partner with them in providing PFCC within their individual units. Many units established family advisory councils, created parent-lead peer support programs, included families as faculty for staff and trainees, and involved families in revising parent educational and support resources.\textsuperscript{28, 31}

In the NICQ 2002 collaborative, three teams chose to build on the work of the We Are Family topic group. They enlisted families in creating and testing a Family-Centered Care Map (http://www.fccmap.org/index.htm), an interactive web-based tool designed to promote the delivery of family-centered newborn intensive care. This tool pinpoints specific strategies and programs that clinicians and staff, family advisors, and peer support personnel can test out to improve the delivery of patient- and family-centered newborn intensive care. During this collaborative, VON leadership hired a family member to serve as a consultant to the collaborative.\textsuperscript{25, 32}

In the NICQ 2007 collaborative, one of the major focus areas was engaging families as members of the quality improvement teams. In alignment with its goals for partnering with families and to model this approach, VON leadership appointed a family member to the Advisory Board for this collaborative. Participating teams were encouraged to collaborate with families in their improvement work during the face-to-face meetings as well as the work between meetings. Teams used a tool developed by the Institute for Family-Centered Care and a family advisor to measure their success in engaging families in quality improvement (see Table 1.1).\textsuperscript{33}
Table 1.1  IFCC Tool: Framework for Family Involvement in Quality Improvement

<table>
<thead>
<tr>
<th>Level</th>
<th>How Families Participate</th>
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<tbody>
<tr>
<td>Level I</td>
<td>Families complete surveys or engage in other evaluative activities as respondents (for example, focus groups).</td>
</tr>
<tr>
<td>Level II</td>
<td>Family advisory councils serve as a resource to the quality improvement team (for example, review projects, documents).</td>
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<tr>
<td>Level III</td>
<td>Families participate as occasional reviewers and consultants during an improvement project.</td>
</tr>
<tr>
<td>Level IV</td>
<td>Families participate as active members of improvement teams and/or may serve on unit-based task forces and committees and faculty for staff and clinician education.</td>
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<tr>
<td>Level V</td>
<td>Families are co-leaders of improvement initiatives.</td>
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One of NICQ 2007’s aims was to increase the level of involvement of families as members of the improvement teams. Utilizing the IFCC framework, baseline measurements were taken at the beginning of the collaborative and compared to individual and benchmark results at the end of the two-year collaborative. By the end of the two year project, 71 percent of the teams showed improvement and/or achieved the highest level of partnering with families. Of the participating centers, 19 percent ended the collaborative with a self-reported level IV score in the IFCC framework.

Another aim of the collaborative was to have 100 percent of the teams bring at least one parent to one of the four face-to-face meetings. By the end of the collaborative, 80 percent of the teams had done so, and 54 percent of the teams had a parent representative attend more than one meeting, an indicator of commitment and sustainability of partnerships with families in this work.

In addition to observing the changes in level of family involvement in the improvement process, many units in the collaborative voluntarily began to measure families’ perspectives and share this data within the collaborative. One of the useful tools emerging from the NICQ 2000 We Are Family group is an online survey called How’s Your Baby (Figure 1.1).
The survey tool was developed and tested by members of the NICQ collaborative, including parents. How’s Your Baby is currently being used by over 40 centers from the Vermont Oxford Network as a way to measure parents’ perception of quality of care, as well as their assessment of their overall experience. The survey provides useful data about family-centered care practices and how well these goals are being met. The information allows centers to identify areas of improvement, such as transition planning, facilitation of skin-to-skin care, and lactation support, among others. In addition to providing NICUs with information about their performance, the survey information is used in benchmarking with other VON centers.

**Resourcing the Journey to Patient- and Family-Centered Care**

As organizations and departments begin or expand their journey in patient- and family-centered care, they report that it takes time, talent, space, money, and other resources. Staff as well as patients and families need time for training and support to position themselves for success. There is the challenge of finding the time for respectful listening and relationship building. Improvement and other collaborative meetings often require staff to stay extended hours or come in off-shift. Family advisors may need funds for parking, meals, childcare, or their time to attend these meetings. Support staff and administrative resources are needed to follow up on the new initiatives.

For too long, funding of these activities has not been a part of operating budgets. NICUs have raised all funds from grateful families, other donors, and grants. Some NICUs have
established paid positions for family leaders to coordinate PFCC initiatives, yet often long-term funding for these positions is precarious. With previously referenced evidence from newborn intensive care and other clinical areas demonstrating the positive impact of patient- and family-centered care on quality, safety, efficiency, and effectiveness, it’s time to have general fund budget allocations join in funding these allocations to ensure continuity and sustainability of these efforts.26

Summary and Next Steps
Newborn intensive care units, their staff, families, and the organizations and associations supporting them have had a significant impact on advancing PFCC in their units and across the hospital. For over 10 years, participants in VON collaboratives—VON leaders and faculty, clinical leaders, clinicians, staff, and family representatives—brought their frustration, passion, caring, honesty, and energy to complete the job. VON has stood as an exemplar for how to establish and maintain a commitment to partnering with families in the care of premature and critically ill infants, as well as how to partner with families in quality improvement and system redesign. It is time to bring patient- and family-centered care to every patient and every family in the NICU and to have the NICU stand as a model and leader to guide efforts in the overall healthcare environment. We owe it to the patients, families, and staff who we are here to serve.

References
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