

Evaluation and Development of Potentially Better Practices for Improving Family-Centered Care in Neonatal Intensive Care Units

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ABSTRACT. *Objective.* Technological and scientific advances have progressively decreased neonatal morbidity and mortality. Less attention has been given to meeting the psychosocial needs of the infant and family than on meeting the infant's physical needs. Parents' participation in making decisions and caring for their child has often been limited. Environments designed for efficient technological care may not be optimal for nurturing the growth and development of sick neonates or their families. Eleven centers collaborating on quality improvement tried to make the care of families better by focusing on understanding and improving family-centered care.

Methods. Through internal process analysis, review of the evidence, collaborative learning, and benchmarking site visits to centers of excellence in family-centered care, a list of potentially better practices was developed. Choice of which practices to implement and methods of implementation were center specific. Improvement goals were in 3 areas: parent-reported outcomes, staff beliefs and practices, and clinical outcomes in length of stay and feeding practices. Measurement tools for the first 2 areas were developed and pilots were conducted.

Results. Length of stay and feeding outcomes were not different before the collaboration (1998) and at the formal end of the collaboration (2000).

Conclusions. Prospective parent-reported outcomes are being collected, and the staff beliefs and practices questionnaire will be repeated in all centers to determine the impact of the project in those areas. *Pediatrics* 2003;111:e437–e449. URL: <http://www.pediatrics.org/cgi/content/full/111/4/e437>; family-centered care, parental involvement, collaborative quality improvement, multidisciplinary, benchmarking, neonatal intensive care, NICU 2000.

ABBREVIATIONS. NICU, neonatal intensive care unit; NIC/Q 2000, Neonatal Intensive Care Unit Quality Improvement Collaborative Year 2000; VLBW, very low birth weight; PBP, potentially better practice; IFCC, Institute for Family-Centered Care; PO, oral.

KEY POINTS OF ARTICLE

- Family-centered care best practices are not limited to specific guidelines for family's presence but

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include beliefs about family-centered care by leaders and the organization.

- Making improvements in family-centered care may require changing the beliefs and culture of the unit.
- Measurement tools for parent-reported outcomes and staff beliefs and practices were developed and piloted in this project.
- Clinical outcomes of length of stay and feeding were not different before the project began and in the second year of the project (2000).

APPLYING LESSONS LEARNED TO PRACTICE

- Family-centered care is a concept that must be integrated into the culture and functioning of a neonatal intensive care unit (NICU).
- An environment that supports the presence and involvement of families may enhance family-centered care.
- A high level of collaboration with families is more dependent on the attitudes of the care providers and the relationships that they establish with the families than on the physical facilities.
- The absence of useful measurement tools at the outset of the project was a barrier but presented an opportunity to use the strength of the collaboration to develop them.

The field of neonatal intensive care has changed dramatically in the past 40 years. Technological and scientific advances have progressively decreased neonatal morbidity and mortality. However, the NICU environment is one of high stress, crises, and turbulent emotions for the families of premature and ill neonates.^{1–8} Less attention has been focused on finding the best ways to meet the psychosocial needs of the infant and family than on meeting the infant's physical needs.^{9,10} Parents play the central role in providing for most children's emotional, physical, social, and developmental needs, yet historically they have been limited in participating in their child's care in the NICU.^{11–13} There is growing recognition that environments designed to make delivery of technological care efficient for staff may not be optimal for nurturing the growth and development of sick neonates or for their families.^{14–16}

Family-centered care places the needs of the individual infant in the context of the family and redefines the relationship between parents and caregivers. Information sharing and collaboration are cornerstones of family-centered care, and they shape

a unit's culture, policies, programs, and facility design as well as the day-to-day interactions between caregivers and families.¹⁷ The potential benefits of family-centered care include improved satisfaction with care, decreased parental stress, increased parental comfort and competence with postdischarge care, improved success with breastfeeding, shortened hospital lengths of stay, decreased readmissions postdischarge, and increased staff satisfaction.^{18–21}

The overall aim of this project was to use Vermont Oxford Network Neonatal Intensive Care Unit Quality Improvement Collaborative Year 2000 (NIC/Q 2000) quality improvement methods to foster early and ongoing family involvement in care, education, and administrative processes in the NICU. There were 3 areas that we believed would be improved: parent-reported outcomes, nursery staff beliefs and practices about family-centered care, and clinical outcomes. At the beginning of this project, there were no available tools for standardized outcome measurements in the first 2 areas. Part of this project involved developing these tools. Comparative data before and after the project are therefore unavailable. In the third area of clinical outcomes, we used the population of 401- to 1500-g birth weight infants to reflect improvements. Two reasons for selecting this population of infants were that they have long and complex hospital stays, and historical and current data would be available in the Vermont Oxford Network database on very low birth weight (VLBW) infants. Setting clinical improvement goals was difficult because of the indirect and complex relationships between improved family-centered care and clinical outcomes. Length of stay and feeding outcomes were chosen because of previously reported effects or hypothesized relations, as in support of feeding choices.^{18,19} The incidence of chronic lung disease has been reported to be reduced with individualized developmental care.^{22–24} Because there is some overlap in family-centered care and developmental care, the incidence of chronic lung disease at 36 weeks' corrected age was analyzed, although no specific improvement goals were set. Clinical improvements were based on comparing data from 1998 to outcomes in 2000, except for the support of feeding plans, which was measured only for 2000.

The process for improving family-centered care was similar to that used by all of the NIC/Q 2000 focus groups. This included a detailed internal process analysis by each center, an ongoing review of the evidence base for proposed improvements, collaborative learning by conference calls, focus group activities at joint meetings, and planning and conducting benchmarking site visits to centers of excellence in family-centered care. One goal of these activities was to develop a list of potentially better practices (PBPs) for improving family-centered care. These evolving concepts were translated into quality improvement cycles that were individualized at each center. This article describes the steps taken to define a list of potentially better family-centered care practices, the development of measurement tools for par-

ent-reported outcomes and staff beliefs and practices, and the comparative clinical outcomes.

METHODS

Forming the Focus Group

Eleven centers in collaboration with the Institute for Family-Centered Care (IFCC) formed the focus group (Appendix A). A neonatologist led the group, which was also facilitated and supported by Vermont Oxford Network NIC/Q 2000 project faculty. Initial work included the definition of goals for the project, a review of the literature on family-centered care practices, and the development of a process for selecting benchmark sites of excellence in family-centered care for visits. Biweekly teleconferences and communication via electronic mail listserv facilitated collaboration and project management.

Participating centers completed the "Family-Centered Care in Newborn Intensive Care Units: A Self-Assessment Inventory" developed by the IFCC.²⁵ This survey helps a center assess policies, programs, practices, and the environment of the NICU. We believed that 2 additional areas that were covered less thoroughly by the inventory but also keys to the success of family-centered care were administrative support and continuity of care in the community. The group therefore expanded the survey to include assessment of strengths and opportunities for improvement in these areas as well. Completion of the expanded inventory tool created a common ground for dialogue among centers, as well as helped centers identify individual improvement goals. (After benchmark site visits were completed, the survey was edited to the shorter version in Appendix B.)

Benchmark Site Visits

Identifying benchmark sites of excellence in family-centered care was challenging. There are no standard rating scales for success in delivering family-centered care. Twelve potential centers were identified using published reports of programs, recommendations from the IFCC, the *NIC/Q 2000 Collaborative Learning Directory*, which identifies areas of clinical and organizational excellence, and suggestions by members of the focus group.^{18,26} Representatives of each of the 12 potential benchmark centers were interviewed by telephone using a standard set of questions (Table 1). Each of the 8 content areas was scored using a scale of 0 to 5. Four centers with a composite score of 37 or higher out of a maximum possible score of 40 were then contacted to arrange benchmark site visits. The 4 sites selected were the University of Massachusetts Memorial Medical Center (Worcester, MA), Rainbow Babies and Children Hospital (Cleveland, OH), Utah Valley Regional Medical Center (Provo, UT), and Evergreen Hospital Medical Center (Kirkland, WA).

TABLE 1. Interview Questions for Potential Benchmark Sites

1. Your NICU has been identified as a potential benchmark site for the provision of family-centered care. Do you believe that your unit is, in fact, a benchmark site in this area? If so, why?
2. What strategies does your unit use to incorporate parents into the decision making and care planning for their infant?
3. When and how do you facilitate a parent's participation in the hands-on care of their baby in the NICU?
4. What components in your NICU environment and/or design support the families' and staff's ability to embrace family-centered care?
5. What practice characteristics do your clinical team members (MD, NNP, RN, RT, etc) have that allow for this level of support for families in the NICU?
6. Does your hospital have a parent feedback mechanism in the formal NICU committee structure? How does it facilitate feedback?
7. Do you have mechanisms in place that effectively position the NICU hospitalization in the context of a child's life? For example, do you provide pre- and posthospital care, and how do you accomplish this?
8. How do you recognize and build on the unique strengths and characteristics of a specific family both during the hospitalization and in the discharge planning process?

Each center was asked to complete the expanded self-assessment of family-centered care (Appendix B) and return the responses before the site visit. Benchmark centers were also asked to provide key information about family-centered care, including vision and philosophy statements, visitation policies, and job descriptions. Centers were asked whether they would be willing to share specific Vermont Oxford Network VLBW outcomes data for comparison with the family-centered care focus group centers. For each visit, an individual from our focus group collaborated with a contact person at the benchmark site to clarify goals and objectives and to outline the agenda and details for the visit. Each center in the focus group decided which benchmark visits they would make. The composition and size of the visit team was also individual choice, although the most effective visiting teams were multidisciplinary, consisting at a minimum of physicians, nurses, and parents. Many centers also brought respiratory care technicians or other NICU staff. All 11 centers made at least 1 site visit, and most visited all 4. A typical site visit began with an informational presentation including a description of the NIC/Q 2000 project and the specific goals of the family-centered care focus group. Comparative outcome data on clinical outcomes were presented without identification of centers. The subsequent agenda for the day varied among sites but included tours of the unit(s) and support services departments (eg, physical/occupational therapy, family resource center, child care). Breakout sessions with families, administrators, and staff were excellent opportunities for group learning. It was particularly important for site visitors to have an opportunity to spend unstructured time on the unit talking with staff and families. At the end of the day, representatives from the benchmark site were asked to list the top 10 practices in their NICU that they believed supported and promoted family-centered care. The visiting centers then spent an hour discussing what had been learned during the visit. Assignments were made to compile all of the information and write a summary report of each visit.

Parent-Reported Outcomes

Outcomes of care as reported by parents were important for assessing the impact of improvements in family-centered care. Although patient satisfaction surveys are now commonly used by hospitals to identify areas for improvement, few have been designed specifically for families of NICU patients.^{27–29} Available instruments were not particularly oriented toward family-centered care, were prohibitively expensive, or were insufficiently developed to use in the time frame of this project. The lack of acceptable tools for this project led us to design one. This tool for parents of NICU patients was based on a well-established and validated group of health status surveys developed by the Dartmouth COOP project.^{30,31} The tool is web-based and uses templates and formats of questions used for older age patients (<http://www.howsyourbaby.com>).

An initial draft of the survey questions was reviewed for content validity with multidisciplinary input from all centers, from representatives from the IFCC, and through focus groups with families of previous NICU patients. A pilot trial of the survey was conducted at 6 of the 11 focus group centers. One site with poor computer access conducted the pilot on paper. A coordinator at each site asked families to complete the computer-based survey. The goals of the pilot were to validate content and determine clarity, ease of use, and general impressions about format. The time to complete each survey was recorded by the site coordinator. After revisions, the survey was extended into a more prolonged trial in which 10 of the 11 centers are participating.

Questions that were designed specifically to address goals of improving family-centered care were as follows:

- How well do you know your infant (personality; likes and dislikes; ways my infant uses to calm himself/herself)?
- During your infant's hospital stay, how often did you feel like a parent?
- How ready do you feel you are to care for your infant after discharge from the hospital?
- How do you feel about feeding your infant?
- How have you felt about breastfeeding? (for mothers planning to breastfeed)

NICU Care Provider Questionnaire

One area expected to reflect improvements in family-centered care was NICU staff beliefs and practices related to family-centered care.^{32,33} A multidisciplinary subgroup from all 11 hospitals and a representative from the IFCC reviewed the available literature and measurement tools.^{34–36} Desirable characteristics were that the tool be comprehensive, appropriate for all staff who interact directly with infants and families, and able to measure change over time. Because no currently available tool completely met these criteria, a new tool was developed.

The process for developing a new staff beliefs and practices questionnaire began with generating a list of beliefs and practices that the subgroup believed reflected family-centered care. This list served as the basis for a draft questionnaire. The draft underwent several revisions after review by families of NICU graduates, NICU staff, and experts in survey development and family-centered care. A pilot trial of the questionnaire was then administered to 72 care providers in February 2000. Analysis of the data from the pilot and feedback from the 72 respondents was used to develop a final version of the questionnaire.

Clinical Outcomes

Quantitative clinical improvement goals for this population were 1) a 10% decrease in hospital length of stay, 2) a 10% decrease in the gestational age at which full oral feedings were achieved, and 3) support of family feeding plans resulting in 85% of infants at discharge being fed according to the feeding plan the family declared as their choice within 48 hours of admission. The incidence of chronic lung disease was also compared, but no specific improvement goal was set. We used data from the Vermont Oxford Network VLBW database for the clinical outcomes of length of stay and chronic lung disease. Length of stay was defined as the number of days to initial discharge home. Infants who were transferred to another hospital rather than discharged from the hospital were excluded. Chronic lung disease was defined as need for oxygen supplementation at 36 weeks' corrected age. The incidence was imputed for infants who were no longer in the member hospital using a published algorithm in the Vermont Oxford Network Annual NICU Quality Management Report.³⁷

Feeding data were obtained by retrospective chart review for infants who had a birth weight of 401 to 1500 g and were discharged from the hospital in 1998. Feeding data for infants who had the same birth weight and were discharged from the hospital in 2000 were collected prospectively and entered by each center into an Internet-based data entry program designed for this project. Definitions for data elements were the same for both periods. Gestational age is the Vermont Oxford Network database definition in completed weeks and days; date of full oral (PO) feeds is the date of the last gavage feeding + 1; gestation at full PO feeds is calculated by adding the weeks and days from birth to the date of full PO feeds to the gestational age at birth. Admission feeding plan was defined as the type of feeding the parent(s) intended to use after discharge from the hospital. The declaration of parent preference for feeding must be obtained within 48 hours of admission. The admission feeding plan was categorized as breast milk (the parents plan to feed breast milk exclusively, either by nursing or feeding expressed breast milk by bottle), combined (the parents plan to feed breast milk but plan to use formula when unable to breast feed), formula (the parents plan formula feeding only), and unknown (clear declaration of parent preference for postdischarge feeding was unavailable within 48 hours of admission, or parents have not decided). Discharge feeding plan was defined as breast milk (feeding at discharge is exclusively breast milk by nursing taking expressed breast milk from a bottle, nursing aid, or other artificial source or any combination), combined (feeding at discharge includes any combination of breast milk and formula supplement), or formula (feeding at discharge is by formula exclusively). Concordance between admission and discharge feedings plans for breastfeeding was defined as the percentage of mothers who had an admission feeding plan of either breast milk or combined and whose discharge feeding plan was breast milk or combined. Concordance for formula feeding was the percentage of mothers who had an admission plan of formula feeding and whose discharge feeding plan was formula feeding.

TABLE 2. Family-Centered Care PBPs Center Plans for Implementation of Each Practice

	No Plan	Plan Only	Active Change	In Place Monitor
Vision and philosophy: the unit's vision and philosophy address principles of family-centered care				
Vision and philosophy of care statements articulate the unit's commitment to family-centered care.	0	4	1	6
Family-centered vision and philosophy is consistently applied to unit policies, practices, and programs	0	6	3	2
Leadership: hospital and unit leadership promotes family-centered care principles				
Leadership promotes and models a family-centered vision and philosophy.	0	4	5	2
Leadership creates opportunities to collaborate with families in policy and program development activities.	0	4	5	2
Families participate in the hiring of key nursing and physician leadership personnel.	7	4	0	0
Unit culture: unit culture reflects a philosophy of inclusive ownership, teamwork, and a spirit of cooperation.				
Vision and philosophy of care statements are developed collaboratively by representatives of all disciplines working on the unit, and family representatives.	0	5	1	5
Committees that develop programs and practices have members who represent all disciplines working on the unit, and family representatives.	1	4	4	2
Accountability for patient and family outcomes is shared by all unit staff.	0	5	4	2
Multidisciplinary team approach: the foundation of the unit's work is multidisciplinary collaboration				
An atmosphere of trust and respect between all health care disciplines and families is fostered.	0	4	5	2
All staff and families are viewed as partners on the care team.	0	5	5	1
Representatives from all disciplines, and families, have the opportunity to contribute to the plan of care.	0	4	5	2
Representatives from all disciplines and family members have the opportunity to participate in rounds and other meetings concerning an infant's care.	0	6	3	2
Experience of care: care processes are designed and followed with attention to the experience of the infant and the family				
Staff seek to understand the experience of care from the perspective of the infant and family.	1	4	5	1
Individualized developmentally supportive care is provided to each infant.	0	3	3	5
Care is coordinated and delivered in a holistic manner in which an infant's physical, psychosocial, and developmental needs are addressed, and the infant is viewed within the context of its family and the community.	0	2	6	3
There is a system in place to ensure consistency in care providers assigned to the infant and in the manner in which care is provided.	2	3	1	5
Families are specifically asked to provide feedback on their experiences and their perceptions of their infants' experience at intervals throughout their stay, and at the end of their stay in the NICU.	0	2	7	2
Family participation in care: families are supported to participate in the care of their infant/s to the level they desire.				
Families are viewed as integral members of the care team and as primary caregivers to their infants (not as visitors).	0	4	5	2
Families are seen as the primary decision makers for their infants.	2	5	2	2
Families are asked how they would like to participate in their infants' care and are given the education, resources, and support to participate to the level they desire.	0	4	6	1
Families have the opportunity to discuss and record observations of their infant.	1	4	3	3
The unit welcomes families 24 hours a day, including during rounds and change of shift.	0	2	2	7
Environment: the physical environment reflects and supports a family centered approach to care.				
The unit entrance creates a positive first impression and promotes a welcoming atmosphere.	2	4	1	4
Signage is worded positively and respectfully and is helpful in assisting families to find their way around the unit and hospital.	2	2	1	6
Families have space designated in the clinical areas that offers privacy and the ability to participate in care.	1	5	1	4
There are a variety of supportive spaces for families outside the clinical area that offer resources and educational opportunities, support activities, respite, privacy, nourishment, and space for breastfeeding or pumping.	0	5	1	5
Planning committees or task forces for renovation or new construction projects include representatives from all disciplines working on the unit, and families.	2	4	1	4

TABLE 2. Continued.

	No Plan	Plan Only	Active Change	In Place Monitor
Quality improvement: continuous quality improvement is supported and expected; quality plans include indicators relating to the promotion of family-centered care.				
Unit leaders promote and support a culture that strives for excellence and embraces and adapts to change.	0	3	4	4
All staff are encouraged to generate ideas and develop plans for changes that improve the experience and outcomes for infants and families.	0	2	4	5
Specific goals and outcome measurements relating to family-centered care are identified for each quality improvement project.	1	4	4	2
There is a process for continuous evaluation and feedback to staff on efforts to improve the quality of care of infants and their work with families.	0	5	4	2
Families are asked to give feedback about their experiences using a variety of formal and informal methods.	0	1	7	3
Families serve on committees and other quality improvement projects and help to define key quality indicators.	0	5	3	3
Families as advisors: there are a variety of opportunities for families to serve as advisors.				
Families serve on family advisory boards.	0	5	0	6
Families are included as members of family-centered steering committees.	1	6	1	3
Families provide family-to-family support within the unit.	0	7	1	3
Opportunities exist for families to serve on other hospital committees and task forces.	6	1	1	3
Paid positions are established for former family member/s to serve as family consultants or family liaisons.	4	4	1	2
Families serve as faculty and trainers in orientation and other education and training activities.	3	6	1	1
Staff support: expectations for family-centered practice are clear, and all staff are offered education, resources, and support to actualize family-centered change.				
Job descriptions and performance appraisals detail specific expectations for all staff to demonstrate behaviors and attitudes consistent with family-centered care.	3	3	1	4
Ongoing training for family-centered care initiatives is offered.	1	2	6	2
All staff have opportunities to reflect on their practice and openly discuss problems and challenges with supportive mentors.	1	4	4	2
Efforts to deliver care within a family-centered approach are recognized and rewarded by unit and hospital leadership.	0	7	3	1

RESULTS

PBPs and Implementation

The PBPs developed through this collaborative quality improvement process are listed in Table 2. Ten content areas were identified. Within each content area is a list of more specific practices. Decisions about which practices to implement as well as how to prioritize them and which strategies to use to make improvements was at the discretion of each participating center. Table 2 also contains a summary of the implementation status among the centers for each of the practices at the conclusion of the formal NIC/Q 2000 project (September 2000). For each practice, the following possible statuses are tabulated: no plan (there are no plans to institute this practice), plan only (this practice will be instituted in the future, but no active changes in process), active change (improvement cycles addressing this practice are in progress but not completed), and complete (the practice is fully in place and only being monitored).

Parent-Reported Outcomes

For the pilot trial, 76 surveys were completed at 6 sites. Of parents who completed the pilot surveys, 90.8% believed that all (48.7%) or most (42.1%) of the questions addressed important issues. Seventy-five of the 76 parents surveyed believed that the ques-

tions were clear (57.9%) or mostly clear (40.8%). Of the 69 parents who used the computer form of the survey, 95.7% believed the survey was very easy (66.7%) or easy (29.0%) to use. When asked whether they would be interested in reading more about the areas identified by the survey as concerns, 53.9% would like more information on the computer, 86.8% would like the information as printed handouts, and 75% would like information as a book. The average time for completion of the survey by computer varied from 10 to 15 minutes, with the variation mostly related to differences in computer hardware and connection speeds. The longest recorded time to complete was 25 minutes. Pilot center contacts reported few problems with administering the on-line survey.

NICU Care Provider Questionnaire

A pilot trial of the NICU Care Provider Questionnaire was conducted at 10 of the 11 centers. A contact at each center selected individuals to complete the 81-item questionnaire and an accompanying feedback form. For determining whether the questionnaire was relevant across disciplines, the pilot included nurses, neonatologists, unit secretaries, respiratory therapists, pharmacists, physical and occupational therapists, social workers, paid parents, and parent volunteers. Pilot participants represented

a range of ages as well as years of experience in neonatal intensive care.

Data from 72 pilot questionnaires and feedback forms were analyzed and used to guide a final revision. Respondents evaluated the questionnaire on a scale of 1 to 4, where 1 = strongly agree and 4 = strongly disagree. Results for 3 attributes of the questionnaire were 1) directions were clear and easy to follow (mean: 2.0), 2) questions were easily understood (mean: 2.0), and 3) items were relevant to family-centered care (mean: 1.8). The questionnaire was completed on average in 26 minutes. Ten percent of the pilot participants believed that the questionnaire took too long to complete. The development subgroup also believed that reducing the time for completion would increase acceptance and return rate for the questionnaire. A detailed review led to deleting redundant questions and removing those that were unclear. The final questionnaire uses a 7-point Likert scale to elicit responses across 5 global areas: nursery environment, preparedness for traditional care and family-centered care, beliefs in family-centered care, family-centered practices, and level of organizational support. In addition, 3 open-ended questions ask respondents to identify barriers and challenges in practicing family-centered care, changes that they wish to make in their individual practice, and necessary resources to improve their work with families.

In May 2000, the revised 72-item questionnaire was distributed to all staff at the 11 family-centered care focus group centers, and 1143 surveys were completed. The questionnaire will be repeated at the same centers by the end of 2002.

Clinical Outcomes

Clinical outcomes are shown in Table 3. There was no difference in the gestational age or birth weight for VLBW infants who were admitted to focus group hospitals in 1998 compared with 2000. The length of stay to initial discharge home was the same for both years. The incidence of chronic lung disease was 31.4% in 2000, compared with 27.3% in 1998. For both the outcomes of length of stay and chronic lung disease, great variability existed among centers. The mean length of stay decreased in 7 of the 11 centers and increased in 4. The incidence of chronic lung disease increased in 7 centers and decreased in 4. Statistical analysis was not performed. There was no

difference in the mean corrected gestational age at which full oral feedings was reached between 1998 and 2000 (36.2 weeks for both periods). The median corrected age for reaching full oral feedings varied among centers from 34.7 to 36.6 weeks. The second feeding outcome was the concordance between admission and discharge feeding plans. This outcome was calculated from prospectively collected data. The concordance for mothers who planned to breast-feed for all centers was 67%, with a range among centers from 51% to 91%. Concordance for formula feeding was 94% with little variation among centers. For breastfeeding and formula feeding combined, the concordance was 74%, with a range among centers from 68% to 87%.

DISCUSSION

Using quality improvement strategies to improve the practice of family-centered care proved challenging. Family-centered care is a concept that must be integrated into the culture and functioning of an intensive care unit.³⁸ At the beginning of this collaborative project, individual centers were at different stages of belief in the values of family-centered care and in practicing according to them. This diversity was apparent from the internal reviews and as the participating centers learned about each other's strengths and challenges through collaboration. The time frame for this project was relatively short to document changes objectively in behavior and culture. The benchmarking site visits were conducted in June and November of 1999, with the draft of the PBPs completed in December. Few of the practice concepts had been implemented completely by the time of the formal end of the project (Table 2). Vision and philosophy of care statements that articulate the unit's commitment to family-centered care were in place in 6 of the 11 centers, with 1 actively in the process of creating them and 4 centers in the planning stages. Seven centers had policies that welcomed families 24 hours a day, including during rounds and change of shift, and the other 4 centers were either actively changing or planning such a policy. However, only 2 centers believed that families were truly viewed as integral members of the care team and as primary caregivers to their infants rather than as visitors. Another practice that was initiated or planned in all centers was the practice of families serving on family advisory boards for the

TABLE 3. Family-Centered Care Clinical Outcomes

	1998		2000	
	N	Mean SD	N	Mean SD
Gestational age (wk)	1450	28.0 ± 2.9	1572	27.9 ± 3.0
Birth weight (g)	1450	1028 ± 301	1572	1026 ± 299
Length of stay	1225	64.0 ± 36.6	1103	63.6 ± 33.5
Chronic lung disease	1187	27.3%	1322	31.4%
Feeding Outcome Data*				
Gestational age (wk) at full PO feed	279†	36.20 ± 2.19	723	36.19 ± 2.32

SD indicates standard deviation.

* Excluding discharges who never reached full feeds (2.8% in 1998; 3.2% in 2000).

† Discharges in 1998 up to last 30 per center.

unit. For many centers starting such advisory boards, there was inadequate time to measure actual changes that those boards might have stimulated. No other PBPs were completely implemented in even a majority of participating centers, although active change projects were in progress or planned for most. Many of the centers have identified major deficits in the physical environment of the NICU and have initiated planning processes for renovation or new construction to address those deficits. It became clear particularly through site visits that an environment that supports the presence and involvement of families could enhance family-centered care. It was equally clear that a high level of collaboration with families was more dependent on the attitudes of the care providers and the relationships that they established with the families of infants in their units than on the physical facilities. Several centers discovered that including families as full participants in their infant's care depends on effective functioning of the multidisciplinary care team. Those centers have initiated projects to improve teamwork, projects that in many ways are as difficult as planning and building new physical facilities.

Literature supports family-centered care as a compelling philosophy for improving communication and relationships with families.¹ Firm evidence to support an impact on physical outcomes is sparse. Families tell us that they want to have a voice in how they will participate in their children's care, but there are few tools to measure how successful we are in giving them that voice.^{39,40} Preliminary evidence from the web-based parent survey developed for this project suggests that there will be great variation among centers in how successfully we practice family-centered care (data not shown). Comparative data should lead to better insights into areas for improvements. Success at supporting breastfeeding for mothers of VLBW infants is extremely limited. The proportion of women who provided breast milk for their VLBW infant varied from 46% to 91% among centers. Most of these mothers were providing expressed breast milk. Success at breastfeeding VLBW infants by suckling at the breast at discharge was rare.

The outcomes chosen at the beginning of this project were somewhat arbitrary and were based more on hypothesis than on existing evidence. It is not particularly surprising that this project was not associated with demonstrable improvements in length of stay, feeding, or chronic lung disease. Changes in parent-reported outcomes and in staff beliefs are perhaps more likely, but tools to measure those outcomes before and after the project did not exist. We plan to repeat the NICU Care Provider Questionnaire at all of these centers at a time more likely to reflect changes that have been initiated, as well as to measure the parent-reported outcomes over time. We believe that 1 of the successes of this project will be to make these tools available to other centers that are interested in improving their care and in establishing some baseline data from centers participating in this focus group that can be used for comparison.

The PBPs that this focus group discovered are a combination of generic principles of leadership and teamwork as well as specific guidelines for creating structures to foster collaboration with families across all areas of functioning of the NICU. Applying their practices will lead to a more fulfilling work environment for care providers and an environment where families are respected as essential partners in the care of their children.

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Appendix A

Vermont Oxford NIC/Q 2000 Family-Centered Care Focus Group Participating Centers

Children's Hospital at Dartmouth
Children's Hospital at Providence Alaska Medical Center
Children's Hospitals and Clinics, Minneapolis, MN
DeVos Children's/Spectrum Health
Fairview University Medical Center
Legacy Emanuel Children's Hospital
Miami Valley Hospital
Presbyterian St. Luke's Medical Center
Woman's Hospital, Baton Rouge, LA
Women's Hospital of Greensboro
Yakima Valley Memorial Hospital

The Institute for Family-Centered Care

FAMILY-CENTERED CARE

QUESTIONS RECOMMENDED FOR BENCHMARK VISITS

I. Baby Questions

1. What is your hospital's philosophy about developmental care? How is it actualized? What impact has developmental care had on your unit?
2. Are the staff knowledgeable about the concepts of developmentally supportive care? How were they educated?
3. How are parents educated on developmental care? How are parents educated and involved in developmental care?
4. How is developmental care led in your unit? If you have a developmental care team, please describe the member's roles and functions.
5. How do you encourage staff to relinquish "control" of some activities to parents? Do clinical pathways reflect that parents are caregivers, nurturers, and decision-makers for their infants?
6. What can hold/touch the baby? Do you have guidelines or protocols for holding/touching or skin-to-skin care? Are parents encouraged to provide skin-to-skin care?
7. How do you encourage breastfeeding on your unit?
8. What tools are used for pain assessment? How are parents involved in the processes and plans? Do parents stay for procedures?
9. Are ventilated infants routinely sedated? If so, do you have guidelines for initiation, maintenance, and weaning?

II. Family Questions

1. How does your facility share information with families? Does your hospital provide Internet support to link home and hospital? Does this include bedside video viewing?
 - handbooks
 - videos
 - telephone calls
 - Internet
 - 1:1 conferences
 - educational materials - are they available in different languages?
2. Are there community and/or hospital living arrangements for the families to be close to the hospitalized patient (including mothers hospitalized prenatally)?
3. Does your unit welcome parents 24 hours/day, including during rounds and shift change? Please describe your visitation policy? How do you control traffic, security, and confidentiality?
4. Please describe your sibling visitation policy? Do you have any seasonal changes that affect this policy? If so, what are they? What is the sibling's involvement with the infant while he/she is visiting?

5. How are families encouraged and supported to participate in routine care of the infant? How? Give examples.
6. What barriers to family involvement have you identified and what methods/interventions were used to overcome them?
7. Do parents document in the chart? What, how and where? Are parents encouraged to read the chart?
8. Do staff support parents in their appreciation and pride in their baby's individuality and development? Are there ways for families to mark and celebrate developmental milestones or important events in their infant's life? (e.g., Baby Book).
9. Is there a family-centered care steering committee for your unit? Are families who have experienced newborn intensive care members of this committee? How are these activities funded? What format or guidelines do you use for your parent work group/advisory board? Is any formal education and ongoing education provided? How many active parents are involved? In what capacity do they serve?
10. Do you have an early discharge program? What is parent involvement in planning and evaluating early discharge? Do you have a facilitator or paid coordinator? How often does the group meet?
11. Is the advisory group involved in parent meetings with families whose infants are currently in the hospital?
12. Are families involved in advisory roles in other ways?
 - hospital family advisory committees
 - formal committees and task forces
 - informal workgroups and discussions
 - written surveys
 - in-service or continuing education programs
13. What sort of support systems are in place for family-to-family support?
14. What supports are in place in your unit to address cultural/ethnic diversity?
15. Are family satisfaction surveys used? If so, what is done with the information from the survey? What areas are surveyed? Were parents involved in developing the survey?
16. Do clinical pathways reflect that parents are caregivers, nurturers and decision-makers for their infant? How does it work practically?
17. Please describe your parent resource center. How was it established, maintained and staffed?
18. Have you had to change your staffing needs to support family-centered care?
19. Please describe the role volunteers play in your unit.
20. What nutrition is provided at no cost for families? How is this funded?

III. Staffing Questions

1. What are your staffing guidelines? Do staffing patterns promote consistency and predictability?

2. Do all families have a designated primary nurse and physician? Are other staff clearly identified to provide consistency when primary nurse/physician are not available?
3. Do staff interact collaboratively and respectfully with each other? Are contributions from different disciplines coordinated and integrated into the plan of care.
4. Are the roles of the team members clear to the family? Is information about the multidisciplinary roles described and presented to the family?
5. What are supportive procedures for resolving disagreements and misunderstandings between staff and families?
6. Are there means to assess staff's knowledge/comfort level with family-centered care? If yes, please describe.
7. Are there rewards for staff who demonstrate excellence in providing family-centered, developmentally supportive care?
8. Who were your key players in obtaining staff buy-in to this process when beginning family-centered care? What processes did you use to get buy-in?
9. Have orientation/precepting programs been developed for new staff to learn about family-centered care? If so, please describe. Do families participate in this process?
10. Have orientation programs been developed for staff such as housekeeping, cafeteria, parking attendants, and security guards to learn about family-centered care? If so, please describe. Do families participate in this process? Do position statements; personnel appraisal forms clearly articulate the necessity of working in respectful and collaborative ways with families? Were families involved in developing the position statements and other personnel forms?

IV. Environment Questions

1. How does the signage, displays of information, art, reflect the philosophy?
2. Is signage worded positively and respectfully throughout the unit and hospital?
3. Are formal and informal signs and bulletin board written in language(s) and at a reading level understandable to families served by the unit?
4. What provisions for privacy around the bedside do you offer?
5. Is there private space available for families to meet with health care professionals? Is there comfortable, accessible, private space available just for families?
6. Describe the following areas, if applicable and what is offered in each or any additions you would make:

<ul style="list-style-type: none"> • conference rooms • breastfeeding rooms • family space/lounge • kitchen facilities • laundry facilities 	<ul style="list-style-type: none"> • educational space • sleep areas - other than immediately before discharge or just prior to discharge
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- showers/bathrooms for family
 - lockers
 - sibling space/staffing
7. What developmental/family-centered concepts did you focus on when building or redesigning your NICU? Were families involved in the planning process?
 8. How is noise controlled?
 9. How is light controlled?
 10. Are families encouraged to make their infant's immediate environment as homelike as possible?
 11. Are there comfortable chairs available at each bedside for parents? Is there bedside storage for families?
 12. How are infants placed throughout the unit (are critically ill and convalescing infants placed together or separately)?

V. Administration Questions

1. Is there a written philosophy of care/statement of values that articulates family-centered principles? If so, please describe.
2. How have any family-centered care initiatives been funded?
3. Do you have a family-centered care department? If so, what resources do they provide?
4. Does your hospital have a family advisory council reporting to senior administration? If so, please describe.
5. Does your hospital have a senior level position designated as the staff liaison for family-centered care? If so, please describe.
6. Do you have collective bargaining units? Which groups are organized? How have you worked with unions to make practice/philosophy changes?
7. Do you have shared governance structures? If yes, what role do they play in operationalizing family-centered care?

VI. Community Questions

1. Does your hospital provide disease specific diagnosis preadmission support groups? If so, what groups?
2. Does your hospital encourage outside providers to visit family in the hospital? If so, how?
3. Are primary care providers encouraged to become involved before discharge? If so, how?
4. How is ongoing communication provided to the primary care providers while an in-patient? Post-discharge?
5. Are individuals from community organizations identified to be liaisons with the hospital for discharge planning? If so, please describe and identify who is involved.
6. Is a list of available community resources provided to each family? If yes, please describe document.

7. Does your hospital provide teaching support for outside personnel to facilitate early discharge? Is education provided to families about community, developmental, and educational support after discharge?
8. Is there training or orientation for community providers relating to family-centered and developmentally supportive care?
9. Does your hospital provide the following? Prenatally, In-patient or post-discharge?
 - a. parenting classes
 - b. breastfeeding
 - c. follow-up home visits
 - d. post-discharge phone calls
 - e. follow-up bereavement support
 - f. post discharge information line
 - g. other?
10. Are any NICU staff cross-trained to work in the home or in the community with families?

SUMMARY QUESTIONS

1. What were the most successful aspects of the environmental design processes (if applicable)?
2. What are the most important things you would tell other NICUs approaching redesign/renovation?
3. Has family-centered care altered your outcomes, and if so, how? Have you conducted a study of your unit to track outcomes?
4. What are the other ways that the hospital's newborn intensive care unit demonstrates a commitment to family-centered care?
5. What are the biggest challenges the unit faces in implementing family-centered care?
6. What are the opportunities for family-centered change at this time (e.g. a planned renovation, a responsive continuous quality improvement team)?
7. What words of advice would you offer as we approach projects to enhance family-centered care at our organization?

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