Supplement Article

Implementation and Case-Study Results of Potentially Better Practices for Family-Centered Care: The Family-Centered Care Map

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ABSTRACT

OBJECTIVE. The objective of this study was to enhance the ability to coordinate and deliver care in a holistic manner, through a family-centered care map, so that the developmental, physical, and psychosocial needs of the infant and family are met.

METHODS. A Web-based map was based on 7 distinct clinical phases with 3 variations of an infant’s course through a NICU. Sixty-three potentially better practices were identified and 7 potentially better practices were implemented through case studies.

RESULTS. Measures of family satisfaction revealed improvements in delivery of family-centered care. Increases in discharge growth parameters for extremely low birth weight infants were demonstrated. Length of stay for very low birth weight infants decreased from 73 to 60 days in Vermont.

CONCLUSIONS. The collaborative process enhances identification of potentially better practices and results in both qualitative and quantitative improvements in family-centered care.

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Key Words
family-centered care, care map, very low birth weight infants, quality improvement

Abbreviations
FCC—family-centered care
LOS—length of stay
VON—Vermont Oxford Network
PBP—potentially better practice
NIC/Q 2002—Neonatal Intensive Care Quality Improvement Collaborative 2002
SWC—Sunnybrook and Women’s Health Sciences Centre
JDCH—Joe DiMaggio Children’s Hospital
VCH—Vermont Children’s Hospital at Fletcher Allen Health Care
ELBW—extremely low birth weight

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FAMILY-CENTERED CARE (FCC) is essential to the delivery of high-quality care in the NICU. The involvement of families in the care of their infants is increasingly important to providers.1–4 Potential benefits include shorter length of stay (LOS), decreased readmissions, reduced parental stress, increased parental confidence after discharge, and increased staff satisfaction.5–7 Adherence to the principles of FCC should result in improved attachment between the infant and the family.8,9 The Institute for Family-Centered Care has identified 8 core concepts of FCC: respect, choice, information, collaboration, strengths, support, empowerment, and flexibility.10

In a previous Vermont Oxford Network (VON) collaborative, an exploratory group identified and studied 10 potentially better practices (PBPs) that merged core concepts of FCC with quality improvement techniques and developed a set of evaluation tools.11 The “Family Matters” exploratory group came together in the Neonatal Intensive Care Quality Improvement Collaborative 2002 (NIC/Q 2002) with the goal of creating an FCC map to serve as a guide for coordinating and implementing practices that enhance the delivery of FCC. The map is Web based and designed for use by NICU care providers, family advisors, and others who provide care and support to infants and families within the NICU. The infant’s course is divided into 7 phases with 3 potential variations; within each phase, PBPs were identified.12 This report describes implementation of 7 PBPs and highlights effective strategies.

METHODS
The “Family Matters” exploratory group of NIC/Q 2002 developed the FCC map phases and identified 63 PBPs. Seven of these PBPs are described through case studies (Table 1) in this report using the following domains as rationale:

- Building a trusting relationship between the family and the health care team
- Achieving optimal family involvement in care and decision-making
- Enhancing transfer of information between the family and the health care team
- Providing emotional support to the family
- Providing quality care within an environment that allows the family to feel that their infant is safe
- Preparing the family for life outside the hospital
- Facilitating infant–family attachment

PBP: Familiarize the Family With the NICU Environment, Unit Care Philosophies, and Team (Map Phase: Preadmission—Inborn)
Focus groups and family satisfaction surveys have indicated that families are better prepared to begin the NICU experience when provided with detailed information regarding what to expect. Written resources, posters, Web pages, videos, and physical tours of the NICU help with this preparation.13

Case Study: Virtual Tour (Sunnybrook and Women’s College Health Sciences Centre)
Families identified that being offered the opportunity of a NICU tour before the birth of their infant was very comforting. It also helped them mentally prepare for the possibility that their infant may require NICU care. However, not all families are able to tour the unit. Pregnant and postpartum women who are on bed rest, ill family members, and families of outborn infants may be unable to tour the NICU for several days.

In partnership with families, an interactive virtual tour was created by a multidisciplinary team that was led by a NICU nurse (Fig 1). Using a multimedia approach, the virtual tour illustrated the NICU physical environment and provided information on health care team members, medical conditions, interventions, and hospital resources that are available to families. A technical expert created the tour in electronic format for distribution to community hospitals, the NICU Web site at Sun-

| TABLE 1 | Selected Case Studies |
| --- | --- | --- | --- |
| PBP | Map Phase | Case Study | Hospital |
| Familiarize the family with the NICU environment, unit care philosophies, and team. | Preadmission | Virtual Tour | SWC |
| Provide access to a variety of resource materials regarding conditions discussed | Preadmission | Storybook With Pictures | SWC |
| Support the family’s initiative to envision and record their infant’s story. | Preadmission | Transport Card and Story | VCH |
| Establish contact between the family and members of the NICU team and/or other support individuals before the birth of the infant. | Golden Hours | Family Visit by NICU Admission Nurse | SWC |
| Create opportunities to dialogue about the infant’s condition and the family’s concerns and observations. | Acute | Family Participation in Rounds | JDCH and VCH |
| Promote and support lactation. | Acute, Growing Stronger | Got Milk | JDCH |
nybrook and Women’s College Health Sciences Centre (SWC), and the family lounge. Mothers who are on bed rest may access the tour through laptop computers.

Twenty-five staff members and 17 family members completed a questionnaire after viewing the virtual tour, and all respondents indicated that it was helpful. Staff members perceived that the medical terminology was too complex for the lay public. In contrast, families reported high levels of satisfaction with all aspects of the tour.

**PBP: Support the Family’s Initiative to Envision and Record Their Infant’s Story (Map Phase: Preadmission—Outborn)**

Emergency transport of premature and ill newborns results in significant distress for families. Anxiety interferes with the ability to absorb and retain information regarding the infant’s condition and transport. Time constraints and stress of anticipated separation interfere with the ability to remember the basics of the transport experience. Giving the family a tangible memento as part of the final interaction with the transport team provides reassurance.

**Case Study: Transport Card and Story (Vermont Children’s Hospital at Fletcher Allen Health Care)**

Families were interviewed regarding the transport experience: (1) recollection of transport team members, (2) receipt of infant photograph, and (3) receipt of diary to record infant’s story. Families expressed interest in receiving tangible mementos and information. Cards were created with the infant’s name, measurements, photographs, transport team members’ names, and the unit’s philosophy statement of FCC (Fig 2). A “My Transport Story” diary was created for the family to record information on their infant’s transport to the NICU.

In collaboration with transport team members, cards and diaries were placed with the transport equipment. The team leader was responsible for completing the card and introducing the family to the diary. Several systems issues, including poor photograph quality, lack of back-up camera, and limited card supply, hindered a smooth implementation of the project. Subsequently, not all families received a card and/or photograph.

Rapid cycle improvements resulted in redesign of the cards, development of a card supply system, purchase of 2 digital cameras with portable printers, and training on use of new cameras. This has improved the consistency with which families receive photograph cards as reported by families on follow-up questionnaires. In addition, the families of inpatients have benefited from the availability of quality photographs.

**PBP: Establish Contact Between the Family and Members of the NICU Team and/or Other Support Individuals Before the Birth of the Infant (Map Phase: Golden Hours)**

Multiple care providers are present at the delivery of a high-risk newborn. Frequently, families are not introduced to individual team members. After delivery, the infant is transferred to the NICU and cared for by other team members. Families have expressed isolation and fear regarding those first hours.
**Case Study: Family Visit by NICU Admission Nurse (SWC)**
Focus groups were held with graduate families to explore their experiences during the hour before and the hour after their infant’s birth. They revealed that the Golden Hours phase was an extremely stressful time for most families. A visit to the family by a member of the NICU admission team before the birth was suggested as a way to alleviate the stress.

Five nurses volunteered to participate in the trial. Nine of the 10 families expressed that the visit was helpful. One mother stated that she was unsure whether the visit was helpful because of the numerous visits that she had received from medical staff. All 10 families agreed that the visit would be helpful for other families.

**PBP: Create Opportunities to Dialogue About the Infant’s Condition and the Family’s Concerns and Observations (Map Phase: Acute)**
Family participation is an essential component of FCC. Families often contribute significantly to clinical observations and assessments. Potential strategies for facilitating family participation and incorporating family decision-making include family participation in rounds, family calling schedules, and documentation tools for families. Although family participation in medical rounds has been addressed in the FCC literature, much of it is not specific to the NICU setting.

**Case Study: Families on Rounds (Joe DiMaggio Children’s Hospital, Vermont Children’s Hospital at Fletcher Allen Health Care)**
Traditionally, families at the Joe DiMaggio Children’s Hospital (JDCH) NICU have been asked to leave the unit during rounds. The concept of including families during weekly multidisciplinary rounds was met with resistance by the majority of the health care team; many anticipated that this would impede the rounding process. After discussion with members of NIC/Q 2002, some staff agreed that it would be beneficial to include the family on rounds, thereby improving the trust between family and staff. Before initiating the Family on Rounds program, a Family-Centered Care Team that included family advisors surveyed the family and staff.

Families welcomed the opportunity to be present during rounds, and staff agreed that families should have access to and understanding of all information that is pertinent to their infant’s care. The main concerns of staff were (1) patient confidentiality, (2) time on rounds, and (3) completeness of information discussed with the family present.

The current rounds process was altered as little as possible. To avoid delays, all family members were asked to save specific questions for later in the day, when the physician had adequate time. Confidentiality was maintained by asking families of infants who were not being discussed to leave the room temporarily.

Families indicated that being present for rounds gave them a better understanding of their infant’s condition and an opportunity to be more involved in their infant’s care. Surveys of staff showed that many of the fears that were expressed before Family on Rounds were not an issue; however, the disruption of moving family members in and out during rounds was. Families of infants who are not being discussed are now permitted to remain in the unit; confidentiality is protected by avoiding discussion of patients within earshot of other families. Although the Family on Rounds initiative is still in its early stages, it seems to have had a positive impact. Both family and staff view it as a giant step toward improved FCC.

At Vermont Children’s Hospital at Fletcher Allen Health Care (VCH), families have been accepted on daily rounds for several years, despite similar concerns about patient confidentiality. The VCH team decided to explore the level of family participation in rounds and opportunities for improvement.

Baseline data demonstrated high family satisfaction with rounds; however, they learned about rounds hap-hazardly through a variety of sources. Some families never learned of their existence. Plans for improvement include increasing family awareness of rounds through easily accessible written materials, acquainting staff with recommendations from the Institute for Family-Centered Care on bedside rounds, instituting a “Jargon-Buster” flag for families to alert the team when they are using medical jargon, and creating a Confidentiality Statement for families.

**PBP: Promote and Support Lactation (Map Phase: Growing Stronger)**
The early establishment of breast milk production is associated with prolonged breastfeeding success. There are known medical and neurobehavioral benefits of breast milk. Many families recognize that breast milk is something unique that only they can provide for their infant.

**Case Study: Got Milk (JDCH)**
The purpose of the “Got Milk—Breast Milk is Best” program was to support the maximum growth potential of the extremely low birth weight (ELBW) infant through evidence-based nutritional practices. In collaboration with families, protocols were developed and mandatory in-service sessions were provided to nurses, neonatologists, and neonatal nurse practitioners.

The components of the program included (1) education of staff and families regarding the components of breast milk, (2) guidelines outlining the handling and feeding of breast milk, and (3) the benefits of “kangaroo care.” A “Mother’s Milk Club” offered families an opportunity to “compare notes” on a weekly basis. The meeting was facilitated and supported by the NICU Family.
Educator/Lactation Consultant. Weekly assessments of weight and head circumference of ELBW infants were recorded; infants with hydrocephalus were excluded.

Follow-up measurements of head circumference and weight were substantially improved (Fig 3). ELBW infants with discharge weights >50th percentile increased from 8.8% to 14.8%; discharge head circumferences >50th percentile increased from 20.6% to 25.9%. Families and staff reported satisfaction; in particular, families expressed a sense of empowerment.

PBP: Provide Anticipatory Guidance Regarding the “Ups and Downs” Experienced by Many Infants and Families (Map Phase: Growing Stronger)

The typical NICU clinical course is never linear. Infants have periods when they make steady progress and then suddenly show signs that they are not doing so well. Staff are familiar with this process and expect it; families are not and may be devastated with these “ups and downs.” Educating families to recognize this as a normal process is critical. Strategies include support groups, family-oriented care maps, and frequent assessments of the family’s perceptions.22–24

Case Study: Watch Me Grow (JDCH)

The initial purpose of the Watch Me Grow support group was to serve as a weekly scrapbook/photograph album club. Family members took photographs of their infants weekly, brought them to the meeting, and discussed the events surrounding the photographs. The scrapbook format was successful; however, funding for the materials was limited and supplies eventually were depleted. Despite this, attendance continued to increase and a greater amount of sharing took place among the participants.

Currently, Watch Me Grow is held weekly in the early evening during nursing shift change. A light meal is provided, and all family members are encouraged to attend. A social worker and a NICU nurse facilitate the group. Each family is asked to introduce themselves and talk a little about their infant. This generally opens the floor for families to discuss their personal experiences in the NICU with one another.

Family members are informed about Watch Me Grow on admission via the Family Handbook, a 20" × 40" sign over the entrance area scrub sinks, and word of mouth from staff members. Attendance fluctuates with unit census. Greatest attendance occurs when participants...
recruit new NICU families. This method also facilitates an informal parent-to-parent buddy system.

Recently, an evaluation tool was developed to determine the effectiveness of Watch Me Grow as a support mechanism for the NICU families. Twenty-four recent Watch Me Grow participants responded to a 10-item survey. Results showed an overall satisfaction rating of 95.3%.

In summary, the benefits of a family support group are evident. Participants have stated that speaking with others who are experiencing or have experienced similar events is reassuring. A number of long-term relationships have been established among NICU families. For these reasons, the Watch Me Grow weekly meetings will continue. Table 2 shows a list of the PBPs that were implemented at each center. A complete listing of the PBPs is provided in a companion article in this supplement.12

RESULTS

Hospital LOS for very low birth weight infants who were discharged to home decreased from 73 to 60 days at VCH (Fig 4). In 2001, LOS at VCH was at the 83rd percentile rank (VON data); this decreased to the 50th percentile rank in 2003. Measures of family satisfaction at VCH revealed improvements in FCC. In response to the statement, “Your participation in planning your infant’s care,” very good and excellent ratings increased from 76% to 93% during a 3-year period. “How well you were helped to feel like a parent” increased from 76% to 88% (Fig 5).

Measures of growth in ELBW infants at JDCH demonstrated improvement during a 2-year period. The percentage of infants with a discharge weight >50th percentile increased from 8.8 to 14.8; discharge head circumference >50th percentile increased from 20.6 to 25.9.

DISCUSSION

Addressing FCC through the creation of a Web-based tool has been both rewarding and challenging for the participating institutions. Difficulty in the measurement of outcomes, low levels of evidence in the existing literature, and staff attitudes all have contributed to the challenge. Many practices that enhance FCC also may increase the need to be proactive about maintaining patient confidentiality. The lack of adequate family support spaces and infant bed space, so prevalent in the NICU setting, presents another challenge when persuading staff to adopt these practices.

During the development of the FCC map, clinical outcomes, satisfaction, and financial improvements were observed. At JDCH, an FCC initiative resulted in substantial improvements in growth parameters at discharge. This initiative included hiring a hospital-wide director for FCC and other efforts evidencing a commitment to FCC at the hospital leadership level.

VCH reported improved family satisfaction in conjunction with an impressive decrease in LOS. The decrease in LOS was attributed not only to the efforts to improve FCC, but also to being a direct result of several practice changes that were implemented at the same time. These included setting a projected discharge date on admission, frequent discussion of this date with families during rounds, anticipatory scheduling of predischarge procedures (hernia repair, circumcision, and ophthalmology examinations), improved resources for lactation support, and consistent implementation of enteral feeding guidelines.

SWC created and implemented a postdischarge telephone survey that addressed the map domains. In response to the statement, “Rate your family’s involvement in your infant’s care,” 93% indicated that it was “just right” (155 responses). The FCC map, in its current iteration, applies primarily to the infant who is born...
preterm. Although aspects of it may be adapted for term and near-term infants, it is anticipated that the FCC map will be most useful in caring for the preterm infant.

CONCLUSIONS
There are predictable points during the NICU experience that provide opportunities to apply PBPs for FCC. The FCC map represents the typical course of an infant’s and a family’s relationship with the NICU team. Access to and use of the FCC map by members of the NICU health care team as well as others, including families who serve as advisors, will improve the delivery of FCC. The FCC map has potential for application to multiple user groups, including family advisors, “paid parents,” and families themselves. Evaluation of the PBPs is ongoing and dynamic; the collaborative will continue to explore the operational processes that are associated with these practices.

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