Development and Dissemination of Potentially Better Practices for the Provision of Family-Centered Care in Neonatology: The Family-Centered Care Map

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OBJECTIVE. Family-centered care has become integral to the provision of quality neonatal intensive care. However, practices that reflect the core principles of family-centered care have not been described fully in the literature or implemented and evaluated consistently within newborn intensive care. The objective of this study was to create a family-centered care map that enhances the ability of the health care team to work with families to coordinate and deliver care in a holistic manner to meet the developmental, physical, and psychosocial needs of NICU patients and their families.

METHODS. Potentially better practices were developed for sequential clinical phases by using standardized methods. These included focus groups with families, brainstorming sessions with staff, literature review, and input from established family advisory groups and family-centered care experts. Potentially better practices then were integrated into the family-centered care map that was configured in a Web-based format. Overall utility will be evaluated by determining the effect of the family-centered care map on length of stay, parental satisfaction, and family-centered care beliefs and practices among NICU staff.

RESULTS. Sixty-three potentially better practices were identified for 7 clinical phases and 3 variations that were believed to characterize the clinical course of a typical NICU patient. A prototype of the Web-based family-centered care map that illustrates the clinical phases with links to the related potentially better practices, operational processes, and case studies was created. Baseline data from a care provider survey, from a family satisfaction survey, and on length of stay have been collected.

CONCLUSIONS. Quality improvement methods and collaboration among 3 centers led to the development of an innovative Web-based resource to assist individual care providers and family advisors to provide comprehensive family-centered care to
infants and families. Implementation of the family-centered care map has potential to affect positively the quality of newborn intensive care and lead to improved long-term outcomes.

**Potential Benefits of Family-Centered Care (FCC) in the NICU**

The involvement of families in the decision-making processes and the care of their infants has become an area of focus for NICU care providers worldwide. There is a growing list of professional organizations that are promoting meaningful integration of family-centered principles into their standard practices and guidelines. There is evidence that FCC in the NICU can lead to shorter lengths of stay, fewer readmissions, enhanced breastfeeding outcomes, reduced parental stress, increased parental confidence after discharge, and increased staff satisfaction. In addition, family participation in infant care leads to greater family satisfaction with the health care experience. Ultimately, FCC might be expected to enhance attachment between an infant and the family and result in improved long-term outcomes for both.

FCC is characterized by the following principles:

- People are treated with dignity and respect.
- Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
- Patients and family members build on their strengths by participating in experiences that enhance control and independence.
- Collaboration among patients, family members, and providers occurs in policy and program development, professional education, and the delivery of care.

As part of a previous Vermont Oxford Network (VON) Neonatal Intensive Care Quality Improvement Collaborative, 11 NICUs formed an exploratory group that focused on FCC. This group developed and provided evidence for 10 potentially better practices (PBPs) to support FCC. Although each of the PBPs is important to help guide protocols and practices to improve the provision of FCC at an organizational level, individual practitioners could benefit from prompts to trigger specific strategies to support FCC in their daily interactions with families. The “Family Matters” exploratory group of Neonatal Intensive Care Quality Improvement Collaborative 2002 (NIC/Q 2002) attempted to meet this need through the development of an FCC map.

**METHODS**

The “Family Matters” exploratory group was formed at the outset of the VON NIC/Q 2002 to explore ways to advance FCC and build on the work of the previous collaborative. Two centers initially came together to develop this theme. In 2003, a third hospital joined the group was provided with support from the Institute for Family-Centered Care. A parent who had an infant in a NICU and has experience working with quality improvement projects also joined the team. Technical support was provided throughout by the VON NIC/Q 2002 project faculty.

Group members decided that a Web-based FCC map would be a valuable resource. They committed to the development of this tool as the main goal for the collaborative project. The overall aim statement of the group was created to capture the key elements of the project: “To create a family-centered care map that enhances the ability of the health care team to work with families to coordinate and deliver care in a holistic manner to meet the developmental, physical, and psychosocial needs of NICU patients and their families.”

Two key assumptions guided the development of the FCC map: (1) the clinical course of a NICU infant and family can be divided into distinct phases, and (2) the experiences and needs of infants and families vary over time and in relation to clinical phase and stage of development. It was the goal of the group to develop PBPs that were specific to a particular clinical phase and could be applied to enhance FCC through the development of new protocols, introduction of tools, and application of specific interventions when interacting with families. Specific operational processes were developed for each PBP. The FCC map was populated with case studies from each of the teams that could be used to demonstrate an effective implementation strategy.

A Web-based tool was believed to be the ideal medium for the illustration and dissemination of PBPs, operational processes, and case studies. This format offers individual practitioners a timely, easily accessible, and useful tool to enhance their own practice. The dynamic nature of a Web-based format allows for future expansion as new evidence becomes public and NICUs develop additional PBPs, operational processes, and case studies.

Several steps were required before the FCC map could be used. Goals, project scope, and procedures to be followed were determined early in the project. Measurable outcomes that could be used to evaluate the utility of the map were identified and either implemented or created. The appearance and the architecture of the Web-based map were established by consensus with input from VON support personnel. Each center assumed responsibility for populating individual map phases with PBPs, operational processes, and case studies. Revisions to the draft phases were made after review by the whole team, which included a parent representative and a recognized expert from the Institute for Family-Centered Care. Ongoing collaboration and communication were achieved.
through attendance at NIC/Q 2002 meetings, telephone conferences, and use of a listserv.

Before PBP development, it was necessary to establish the framework and principles that would inform the process. First, the “backbone” of the map was created by determining the clinical phases that would anchor it (names, start and end points, variations; Fig 1A). Second, the key domains of FCC that would be used to guide PBP development within each clinical phase were determined. The principal PBP was access to and use of an FCC map by members of the NICU team and families will improve the delivery of care in the following domains:

- Building a trusting relationship between the family and the health care team
- Achieving optimal parental 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 believe that their infant is safe
- Preparing the family for life outside the hospital
- Facilitating infant–family attachment

In all cases, participants were asked to refer to these domains when crafting PBPs and operational processes. Teams that worked on the various map phases followed the following sequence for PBP development:

- Conduct focus groups with families
- Conduct brainstorming sessions with staff
- Review pertinent literature
- Develop draft PBPs
- Circulate draft PBPs within exploratory group for input
- Circulate draft PBPs to established family advisory groups and experts in FCC for additional input and validation

The PBPs that were created through this process were listed (Table 1) and connected to the appropriate clinical segment on the Web-based FCC map, where they can be accessed by providers of neonatal intensive care.

**Outcome Measures**

The effectiveness of the FCC map to support FCC was to be determined by several measurement tools. The group reviewed the assessment tools that were being used at their centers to determine which, if any, might be applicable for this purpose. In addition, the “We Are Family” exploratory group from NIC/Q 2000 had developed several measurement tools to assess parent-reported outcomes and staff beliefs and practices that could be applied to assess the effectiveness of the map.

One of the most important indicators to track was the satisfaction and confidence of families. Two existing tools were appropriate for this purpose: Howsyourbaby.com and the Family Satisfaction Survey used by Vermont Children’s Hospital. An additional tool was developed during the project to evaluate the effectiveness of a NICU in meeting the needs of families in the 7 quality domains identified for the project (Appendix). The impact of FCC map availability on the attitudes of NICU care providers was assessed by using the NICU Care Provider Questionnaire that was developed during NIC/Q 2000. Length of stay of NICU infants also was considered an important outcome and was available through the VON database. Finally, if the FCC map were truly effective in enhancing FCC in a meaningful way, then the team felt that a tool to assess parent–infant attachment postdischarge would be extremely valuable.

The team at Sunnybrook and Women’s Health Sciences Centre planned to use the Nursing Child Assessment Satellite Training and Parent–Child Interaction Feeding and Teaching Scales for this purpose.

**RESULTS**

Sixty-three PBPs were developed for 7 clinical phases and 3 variations. The clinical phases represent the sequential clinical course for a typical NICU patient (ie, very low birth weight infants). The variations were added to acknowledge regional differences in models of care and to capture common variations in the clinical courses of infants that can occur. These variations account for outborn infants, those who are transferred to another center for some of their care, and those who die. Currently, not all PBPs have been tested by established family advisory groups, and additional revisions are expected. A prototype of the Web-based FCC map has been produced, but a complete FCC map has not yet been finalized or field-tested (Fig 1).

Baseline measurements for the outcomes of interest have been acquired. All 3 centers have administered the NICU Care Provider Questionnaire. Variable success has been achieved in implementing the Howsyourbaby.com survey and the postdischarge telephone survey. Individual centers have reliable family satisfaction surveys in place, but no consistent tool has been used at all 3 centers. Length-of-stay data are being captured at each site as part of the VON data-collection process. Sunnybrook and Women’s Health Sciences Centre was unable to acquire adequate resources to implement routine Nursing Child Assessment Satellite Training testing.

The level of evidence from the literature to support the PBPs was considered low according to traditional rating scales. Few randomized trials or cohort studies that evaluate the effect of interventions that are designed to support FCC could be identified. However,
FIGURE 1
there is a rich body of qualitative research and descriptive literature discussing the psychosocial impact of the NICU experience on infants and families with suggestions for changes in policies and practices that support infants and families. Several groups have championed a greater emphasis on FCC and demonstrated positive results in the form of improved family satisfaction and adjustment.6,13,14 Families have made proposals for changes to the system or approaches to the provision of care that they would have found beneficial. The available literature and the input from experienced health care providers and families formed the basis for most of the PBPs described in this article.

DISCUSSION

Progress of FCC

The “Family Matters” team represents the second time that an exploratory group that is part of a VON quality improvement collaborative has chosen to focus on FCC. The articles and resource kit that were developed by the previous exploratory group allowed group members to build consensus quickly about the project’s goals, scope, and processes. Two measurement tools that the previous group developed, piloted, and implemented were considered to be useful in the evaluation of this project. The 10 PBPs that were developed within the previous collaborative were seen to be critical in providing the framework for establishing a system-wide model of FCC. However, the current group wanted to further the integration of FCC practices by concentrating on 2 particular PBPs: “care processes are designed and followed with attention to the experience of the infant and the family” and “families are supported to participate in the care of their infant/s to the level they desire.”17 Members believed that individual providers and family advisors would benefit from a resource that could provide guidance on how to promote FCC throughout their daily interactions with infants and families.

A Web-based FCC map was believed to be an ideal medium for illustration and dissemination of the PBPs. In this format, PBPs are easily accessible and can serve as real-time prompts to members of the health care team and family advisors. In addition, the format is seen to have value for the process of quality improvement in general. By using a Web-based tool, deeper exploration into a topic can be embedded and quick access to a wealth of resources for individuals and units that engage in quality improvement can be provided. Operational processes can be linked to applicable case studies, either within the FCC map or among those collected on the VON’s nicq.org Web site. These case studies and operational processes also can be connected to relevant references, hospital Web sites, and other online resources. The adaptive and dynamic nature of the Web-based format allows for continuous revisions as new literature is published and new PBPs are identified. In the case of
<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Family Matters PBPs</th>
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<tbody>
<tr>
<td><strong>Preadmission (inborn)</strong></td>
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<tr>
<td>1. Collect and record information about the family’s psychosocial history, cultural background, spiritual beliefs, and learning needs</td>
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<tr>
<td>2. Ensure that a medical consultation by an experienced practitioner takes place in a timely manner</td>
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<tr>
<td>3. Use unit-based guidelines for management of threatened delivery at borderline of viability</td>
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<tr>
<td>4. Individualize the approach to and content of antenatal consultations to meet the family’s needs</td>
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<tr>
<td>5. Provide access to a variety of resource materials regarding conditions discussed</td>
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<tr>
<td>6. Provide options for NICU staff and experienced families to support the family</td>
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<tr>
<td>7. Familiarize the family with the NICU environment, unit care philosophies, and team</td>
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<tr>
<td>8. Establish an individualized plan with the family for ongoing consultation</td>
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<tr>
<td><strong>Preadmission (outborn)</strong></td>
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<tr>
<td>1. Provide referral hospitals with family-centered resource materials</td>
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<tr>
<td>2. Collect and record information about the family’s psychosocial history, cultural background, spiritual beliefs, and learning needs before transfer</td>
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<tr>
<td>3. Maintain family—infant contact before and after transport</td>
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<tr>
<td>4. Support the family’s initiative to envision and record their infant’s story</td>
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<tr>
<td>5. Welcome the family to the NICU on arrival</td>
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<tr>
<td><strong>Golden hours</strong></td>
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<tr>
<td>1. Provide neonatology consultation or repeat consultation before the birth of the infant</td>
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<tr>
<td>2. Establish contact between the family and members of the NICU team and/or other support individuals before the birth of the infant</td>
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<tr>
<td>3. Maintain infant—family contact throughout the admission process</td>
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<tr>
<td>4. Ensure that the family is fully informed of their infant’s condition</td>
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<tr>
<td>5. Welcome the family to the NICU</td>
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<tr>
<td><strong>Acute</strong></td>
<td></td>
</tr>
<tr>
<td>1. Maintain infant—family contact</td>
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<tr>
<td>2. Provide care and support that is appropriate to the family’s spiritual and cultural beliefs and individual needs</td>
<td></td>
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<tr>
<td>3. Orient the family to the NICU and relevant policies</td>
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<tr>
<td>4. Create opportunities to dialogue about the infant’s condition and the family’s concerns and observations</td>
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<tr>
<td>5. Promote and support the initiation of lactation</td>
<td></td>
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<tr>
<td><strong>Growing stronger</strong></td>
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<tr>
<td>1. Increase participation of the family in the provision of care to their infant</td>
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<tr>
<td>2. Educate the family to prepare them to assume responsibility for monitoring and responding to infant cues</td>
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<tr>
<td>3. Promote and support lactation</td>
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<tr>
<td>4. Provide anticipatory guidance regarding the “ups and downs” experienced by many infants and families</td>
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<tr>
<td>5. Recognize and celebrate achievements and milestones</td>
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<tr>
<td><strong>Breathing/feeding/growing</strong></td>
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<tr>
<td>1. Involve the family in the assessment of and response to their infant’s feeding cues</td>
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<tr>
<td>2. Involve the family in the interpretation of and response to their infant’s behavioral cues</td>
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<tr>
<td>3. Involve the family in assessment of and response to their infant’s breathing patterns</td>
<td></td>
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<tr>
<td>4. Provide individualized education/support for families who have infants with special needs</td>
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<tr>
<td>5. Provide opportunities for extended family members and/or friends of the family who will provide support at home to participate in the infant’s care</td>
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<tr>
<td><strong>Transfer</strong></td>
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<tr>
<td>1. Offer the family the option of continuing care in the present health care facility or transfer to another facility</td>
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<tr>
<td>2. Ensure that the family is actively involved and well informed regarding the process of planning for their infant’s transfer</td>
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<tr>
<td>3. Facilitate the transfer for the family, the referring hospital, and the alternative health care facility</td>
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<tr>
<td>4. Facilitate communication among the family, the referring hospital, and the alternative health care facility</td>
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<tr>
<td><strong>Transition to home</strong></td>
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<tr>
<td>1. Collaborate with the family on a target date for discharge</td>
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<tr>
<td>2. Establish the infant’s “medical home”</td>
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<tr>
<td>3. Assist the family with celebration of their infant’s discharge home</td>
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<tr>
<td>4. Assist the family with making preparations at home for the arrival of their infant</td>
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<tr>
<td>5. Familiarize the family with guidelines for communicating with staff after their infant goes home</td>
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<tr>
<td><strong>Postdischarge</strong></td>
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<tr>
<td>1. Ensure continued access to specialized diagnostic and therapeutic services</td>
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<tr>
<td>2. Offer the family options to become involved with ongoing NICU programs, including peer-to-peer support</td>
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<tr>
<td>3. Celebrate the family’s successful graduation to the community</td>
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<tr>
<td><strong>Bereavement</strong></td>
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<tr>
<td><strong>Anticipatory phase</strong></td>
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<tr>
<td>1. Inform the family of the serious nature of their infant’s condition in a timely and sensitive manner</td>
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<tr>
<td>2. Assist the family to identify and access their support network</td>
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<tr>
<td>3. Conduct discussions regarding treatment options that affirm the family’s primacy in the decision-making process</td>
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<tr>
<td>4. Assist the family to determine the most appropriate course of action by exploring the family’s value systems, cultural background, and spiritual beliefs</td>
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<tr>
<td><strong>Preparatory phase</strong></td>
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<tr>
<td>1. Prepare and support the family for the anticipated death of their infant</td>
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<tr>
<td>2. Offer the family choices about and ensure availability of support</td>
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<tr>
<td>3. Assist the family in creating a plan for the death of their infant</td>
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<tr>
<td>4. Provide for the physical comfort of the family during this time</td>
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</table>
the FCC map, it can reflect the most current understanding of family-centered newborn intensive care.

The Web-based format also influenced the way that the group conceptualized the map; opportunities for NICU staff and advisors to promote FCC were not perceived within the strict parameters of time of admission to discharge. Instead, the group was able to conceive of the potential to support an infant and a family before birth and into the postdischarge period.

Increasing connections to resources and collaboration with colleagues within antepartum units, obstetrics, and the community were easy to visualize. Unlike the static format of a written resource, the Web-based format offers the potential to illustrate a “typical” clinical course with both anticipated and unanticipated variations that disrupt a linear path. Engaging in creative brainstorming sessions and talking with families helped the team to see the clinical course from the perspectives of families and accurately reflect their experience and expressed needs.

A key lesson learned during the project was the benefit of incorporating the family perspective into the quality improvement process. A parent advisor became a member of the group and was able to provide critical insight and feedback. Not all of the members had the same level of understanding of FCC. None of the 3 centers had family advisory councils before the start of this project. However, the centers became increasingly comfortable in asking for family input. The benefits of incorporating families as advisors became apparent as the group struggled with conceptualizing aspects of the map that were not clear-cut. All have begun steps to establish family advisory councils.

Establishing meaningful partnerships with families in quality improvement initiatives as well as in direct care reflects a key principle of FCC. Future projects would benefit from including families as key members of the quality improvement team from the start. In addition, future endeavors would be helped by having individuals or centers from earlier projects that had focused on FCC to serve as a formal resource to improve consistency and coordination.

Family-centered practice in newborn intensive care still is relatively young. Standard practices and measurements are not well defined. Unlike the groups that focused on clinical areas, this team had to spend a great deal of time finding and adapting measurements and identifying PBPs. The group believed that they did not have adequate time to develop case studies and to implement and evaluate the map fully. However, participation in this project resulted in an increased appreciation of the critical importance of FCC by team members and supported the development of unit cultures that are receptive to improvements in this area.

To finalize the FCC map, additional case studies, references, and online resources will need to be added. The 3 centers have committed to putting the FCC map through a thorough review by family advisors before making it available online. The map then will be piloted at the 3 centers and revised as needed. Baseline data have been collected, but follow-up evaluation cannot occur until the map is implemented. All 3 centers have committed to continuing their efforts.

**PBPs and Level of Evidence**

FCC is an approach to health care that is beginning to be applied in newborn intensive care. Although it is relatively new to health care, FCC has been implemented and investigated in the past several decades within the fields of education and other social sciences. Investigators just recently have begun to research systematically the evidence base for practices within the social sciences. However, it has become apparent that the standard models for determining the evidence base within medicine pose significant challenges when applied to approaches such as FCC that derive their conceptual frameworks from fields other than medicine. Researchers in the social sciences are discussing these challenges and exploring potentially appropriate models for determining the evidence base for FCC.

Given that consensus about an operational definition of evidence-based practices within education and social sciences has not been achieved, the authors can report only on the current standards. The majority of the literature that informed the development of the FCC map
would fall within level 5 according to the Muir-Gray Classification System: opinion of respected authorities, based on clinical evidence, descriptive studies, or reports of expert committees. An exception to this classification would be for the PBPs related to promoting and supporting breastfeeding in newborn intensive care, which fall in higher levels.

Access to the most recent draft of the Web-based FCC map and to the most current bibliography related to the FCC map can be arranged by contacting the corresponding author, Michael S. Dunn, MD. Access to the most current bibliography for FCC in newborn intensive care can be downloaded at www.familycenteredcare.org.

CONCLUSIONS

Three centers formed an exploratory group as part of the VON NIC/Q 2002 to advance FCC in newborn intensive care. The team created a Web-based FCC map that guides health care providers and family advisors to work with families to coordinate and deliver care in a holistic manner to meet the developmental, physical, and psychosocial needs of infants and their families. The FCC map parallels the clinical course of an infant and provides 63 PBPs that reflect the core principles of FCC. Baseline data have been collected; follow-up evaluation is pending full implementation of the FCC map. This exploratory group believes that the FCC map has the potential to affect positively the quality of newborn intensive care and lead to improved long-term outcomes.

ACKNOWLEDGMENTS

We acknowledge the contributions of the members of the Family Matters exploratory group (Joe DiMaggio Children’s Hospital, Hollywood, FL: core team Dawn Hawthorne and Robert Hoopes; Sunnybrook and Women’s College Health Sciences Centre, Toronto, Ontario, Canada: core team Michael Dunn, Maureen Reilly, and Denise Zayack; and Vermont Children’s Hospital, Burlington, VT: core team Michele Bouchard, Candice Bullock, Merja Cahoon, Anne Johnston, Charles Mercier, and Deborah Rowell); Julianne Nickerson (parent advisor), and Nick Masi Jr (consultant) for manuscript review; Jim Handyside for technical support; and the many families who provided valuable guidance and input.

REFERENCES

7. Preyde M, Ard F. Effectiveness of a parent “buddy” program for mothers of very preterm infants in a neonatal intensive care unit. CMAJ. 2003;168:969–973
APPENDIX: POSTDISCHARGE TELEPHONE SURVEY

SECTION 1

Baby’s name: ____________________________  boy □  girl □
Chart #: ________________________________
Telephone #: ____________________________
Mother’s name: __________________________  Father’s name: __________________________
Conversant in English:  □ Yes  □ No
If no, primary language: _________________
DOB (yyyy/mm/dd): _______________________
DODischarge (yyyy/mm/dd): _______________
DODeath (yyyy/mm/dd): ___________________
Multiple birth:  □ Yes  □ No
Names of siblings in NICU:  □ alive  □ dead
□ alive  □ dead
□ alive  □ dead
Gestational Age at birth: _______ weeks
Birth Weight: ________________ grams
Discharge:  □ Home  □ Other hospital □  Specify: _______________________________
Corrected GA: ________________ weeks
Discharge Weight: ________________ grams

Problem list (at discharge):  1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________

Follow-up clinic appointment: ________________________________

Other appointments: ________________________________

Significant Social issues: ________________________________

Social worker: ________________________________

SECTION 2 - Calls to Family

1. Date of call: ____________  Time on: _______ Time off: _______
   (yyyy/mm/dd)
   Person who answered the phone: ________________________________

2. Date of call: ____________  Time on: _______ Time off: _______
(yyyy/mm/dd)
Person who answered the phone: ________________________________

3. Date of call: ________ Time on: ________ Time off: ________
   (yyyy/mm/dd)
   Person who answered the phone: ________________________________
Survey completed: Yes ☐ No ☐
If yes, name and profession:
________________________________________________________________
If no, reason: __________________________________________________

SECTION 3

We are interested in hearing about how you feel about the experience that you and your family had while your baby was in the NICU at Sunnybrook and Women's. Please let us know how you felt about:

1. Your family's involvement in your baby's care.
   Not enough ☐ Just right ☐ Too much ☐
Comments:

2. The exchange or sharing of information between our health care team and your family.
   Poor ☐ Fair ☐ Good ☐ Very Good ☐
   Excellent ☐
Comments:

3. The emotional support you received.
   Poor ☐ Fair ☐ Good ☐ Very Good ☐
   Excellent ☐
Comments:

4. How well did we prepare you and your infant(s) for your life after discharge or transfer from this hospital?
   Poor ☐ Fair ☐ Good ☐ Very Good ☐
   Excellent ☐
Comments:

5. Please let us know how you felt about the degree of trust you developed in your relationship with the health care team.
   Poor ☐ Fair ☐ Good ☐ Very Good ☐
   Excellent ☐
6. While under our care, did you feel that your baby was safe and in good hands?
   Never □  Sometimes □  Frequently □  Most of the time □  Always □
   Comments:

7. How emotionally connected/attached did you feel to your baby at discharge?
   Poor □  Fair □  Good □  Very Good □  Excellent □
   Comments:

8. What is your attachment at the present time?
   Poor □  Fair □  Good □  Very Good □  Excellent □
   Comments:

9. Overall, how would you rate your family’s satisfaction with their NICU experience?
   Poor □  Fair □  Good □  Very Good □  Excellent □
   Comments:

SECTION 4
There is another survey that we ask parents to fill out while their baby is still in our hospital called “How’s your baby.com”?

   Did anyone in your family fill it out?  Yes □  No □
   If no, could you tell us why? (Did you know that you could still complete it?)
   If the family would like to complete the survey on the internet:

   Web page:  www.howsyourbaby.com
   Password:  XXXXXXXX

If the family would like a paper copy of the survey to complete (please forward family information, i.e. Name and address) to:

SECTION 5 – Referrals/Follow Up

□  Feeding issues:
Specify: ________________________________

☐ Breast feeding clinic:

Specify: ________________________________

☐ Follow-up Clinic:
  for developmental issues
  6-week appointment

Specify: ________________________________

☐ Paediatrician
  medical issues
  should see within 4 weeks of discharge

Specify: ________________________________

☐ Family Doctor
  medical issues

Specify: ________________________________

☐ Public Health
  for Infant Development
  program and
  Community resources

Specify: ________________________________

☐ TeleHealth
  assessed as more urgent

Specify: ________________________________

☐ Ontario Early Years Centres
  for medical resources that normalize
  the experience of their child’s birth

Specify: ________________________________

Follow-up:
☐ Bereavement or spiritual support (Chaplain)
☐ Social workers
☐ Patient Advocate

Specify: ________________________________

☐ NICU Manager

Specify: ________________________________

☐ Chief of Department

Specify: ________________________________

☐ OBS Manager
SECTION 6
Call Process Evaluation
What was your overall feeling about the call you’ve just completed?
☐ Positive    ☐ Negative
Did the call stay within the confines of the survey?
☐ Yes         ☐ No
If no, what took the call into other areas:
☐ request for health information
☐ identification of positive findings (triage)
☐ call became conversational
☐ other (please describe)
Were you prepared to deal with the manner in which the call transpired?
☐ not at all prepared
☐ somewhat prepared
☐ moderately prepared
☐ very prepared
What would have helped you to feel more satisfied with the way the call transpired?
☐ parents aware of survey
☐ more education for caller
☐ availability of translator
☐ call criteria more than 96 hours
☐ other please explain
Do you feel that you are starting to identify certain “trends” between the calls you’re making?
☐ Yes         ☐ No
If yes, please describe:

________________________________________________________

Do you feel that this call would have been beneficial to the family if a supportive aspect was included?
☐ Yes         ☐ No
Are there any additional findings from this call that you would like to share?

________________________________________________________
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