Family Involvement in Quality Improvement

From Bedside Advocate to System Advisor

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KEYWORDS

- Family advisors • Quality improvement (QI) • Family centered care (FCC)
- Quality improvement collaborative • Family integrated care
- Patient and family engagement (PFE) • Family engaged care (FEC) • Family leaders

KEY POINTS

- Involving families in neonatal intensive care unit (NICU) quality improvement is not a new concept, but recent developments in this partnership model have helped to shape the depth and breadth of family involvement in quality improvement.
- Families are more than stakeholders in NICU quality improvement and can serve as active partners in system design and improvement.
- Opportunities exist to enhance partnerships with families, and seeking to improve this key relationship is imperative to nurture a culture that ensures the best possible neonatal outcomes.

Video content accompanies this article at http://www.perinatology.theclinics.com.

INTRODUCTION

In 1992, Helen Harrison gathered a group of parents and physicians to initiate a dialogue addressing obstacles to meaningful participation for families of critically ill infants. This interaction resulted in the proclamation of 10 principles of family

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centered neonatal care, which, to this day, serve as the foundation for our understanding of patient and family centered care.

These guiding principles also serve as a context for delineating the potential impact family members who have the unique experience of care can have on the system of care. Family advisors can impact health care outcomes through meaningful and systematic engagement in quality improvement.[1]

Despite the dialogue that was initiated almost 25 years ago, potential remains for deeper and farther-reaching impact of family advisors as quality improvement agents in newborn intensive care. In this article, the authors review their experience as a field with family advisors in neonatal intensive care and particularly with regard to family involvement in quality improvement. After a brief historical context, the authors provide examples of opportunities for family engagement in neonatal care outside of quality improvement. The authors then outline different approaches and strategies for engaging families as partners in neonatal intensive care unit (NICU) quality improvement efforts. In much of this article, the authors use the experience of Vermont Oxford Network (VON) to illustrate principles of family engagement in quality improvement; although they recognize many other groups have made landmark contributions to this field, the authors are not reviewing those in detail.

Historical Perspective

Harrison's gathering of past NICU families with physicians in 1992 was instrumental in setting the stage for future quality improvement work. This gathering resulted in what has been called the Lake Champlain Manifesto because it was held in Burlington, Vermont. It was attended by several prominent neonatologists, including Dr Jerold F. Lucey, then Editor in Chief of *Pediatrics*, and Dr William Silverman who helped organize the meeting. The principles of family centered care were shared and are still relevant today. These principles and ideas include the following:

- There should be open and honest communication between families and health care professionals.
- Decision-making should be informed and balanced and decisions based on information that is unbiased and helpful to families.
- Parents and the health care team should work together to minimize pain in the neonate.
- The physical environment of the NICU should be as safe and developmentally appropriate as possible.
- Parents and professionals should ensure that medical interventions are effective and safe.
- Parents and professionals should collaborate on NICU policies and ensure parents' role is valued and supported.
- The follow-up of at-risk infants should be ensured.
- Shared decision-making, especially related to invasive and painful treatment options, should be carefully considered and health care outcomes shared with families.[1]

The group's broad-brush recommendations for a developmentally supportive environment for the infant and psychologically supportive environment for families were reinforced by suggestions that families and health care professionals work together to operationalize these principles and systematically apply them.

In 2001, the Institute of Medicine released its report on requirements to achieve quality in health care. It identified 6 aims for improvement, including patient-centered care.[2] The Institute for Patient- and Family-Centered Care (IPFCC) developed core concepts of patient and family centered care.[3] These core concepts are described in **Box 1** and mirror many of the concepts suggested earlier by Harrison.

Family Involvement in Neonatal Intensive Care Unit Improvement (via Methods Other than Quality Improvement)

Although the focus of this article is family engagement in quality improvement, there are numerous other ways in which families have played and can play essential roles in helping to define and shape clinical care of their infant.

First, family involvement may help ensure the clinical environment of the neonate provides the optimal setting and best possible long-term outcome for the infant and family. NICUs were historically designed in open bays, reminiscent of traditional multi-bed wards. Inadequate space at the bedside and lack of privacy are 2 of the barriers cited by staff to achieving family centered care. Recent designs have embraced single rooms and small pods that encourage family presence, which, given a supportive culture, may facilitate their participation in all aspects of care. The perspective and participation of graduate families is recommended in the design of NICUs.[4]

In 2004, Dr Robert White of Memorial Hospital in South Bend, Indiana, a champion of family centered NICU design, challenged the neonatal care community to move the locus of care from the isolette to the mother's arms.[5] In a NICU in Sweden, at Akademiska Barnsjukhuset University Children's Hospital, Uppsala, each care space includes an adult bed, located immediately adjacent to the intensive care equipment ensuring infants can be cared for in their parents' arms or while kangarooing (Video 1). In 2014, Dr Uwe Ewald partnered with VON, Burlington, Vermont, to create a virtual video visit to their Care by Parent NICU. In step-down care, parents provide most care to their infants (Video 2).

Box 1
Core concepts of patient- and family-centered care

Respect and dignity

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

Information sharing

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

Participation

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

Collaboration

Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education as well as in the delivery of care.

From Johnson BH, Abraham MR. Partnering with patients, resident and families: a resource for leaders of hospitals, ambulatory care settings, and long-term care communities. Institute for Patient- and Family-Centered Care; 2012. Available at: http://www.ihi.org/education/conferences/APACForum2012/Documents/I1_Presentation_Johnson.pdf. Accessed July 10, 2017.

Skin to skin or kangaroo care is a family centered practice that has been the focus of recent quality improvement projects and is a core care concept in the Uppsala NICU (Video 3). The role of NICU fathers is less often reported on and supported. In the Uppsala unit, fathers are active in the care of their infants and report feeling more like parents (Video 4).

Participation in the design of research presents a second example of the impact of families' roles in achieving improvement. The Family Integrated Care (FICare) research project in Canada included graduate families as partners in its design. Families enrolled in the study were encouraged to provide their infants' care and were fully engaged as decision-makers. Ongoing educational opportunities reinforced their role as caregivers. Graduate parents were key participants in the design of the FICare program and also provided peer support.[6]

THE CURRENT PRACTICE

What Has Been Achieved for Family Involvement in Quality Improvement

Numerous groups have developed resources to help define and guide potentially better practices for family involvement in quality improvement. Here, the authors focus on the work done by VON and then share resources developed by other national organizations.

In 2004, the IPFCC partnered with VON to develop a self-assessment resource for teams to help determine their status related to family advisor engagement in quality improvement. Teams, including family advisors, were encouraged to assess their culture and jointly develop strategies to improve. The goal was to deepen and enhance the involvement of families in quality improvement.[7]

VON modeled this collaboration by not only encouraging quality improvement teams to identify family advisors but also appointing family faculty to partner with faculty from other disciplines to lead quality improvement collaborative groups. Each family leader coleads the improvement activities with the other faculty from unique disciplines to ensure comprehensive representation. A family advisor has also served on the overarching advisory board to shape future collaboratives.

The 2007 VON e-book *NICQ 2007 Improvement in Action*[8] highlights some key findings from the quality improvement work not only within VON but also from publicly available examples of innovative projects and methods of partnering with families.

In the most recent VON intensive quality improvement initiative, NICQ Next[2], it has been a goal to ensure every test of change includes a measurement of its impact on families because every change impacts the family, either directly or indirectly. The family faculty (family leaders) within each group of hospitals work closely with the participating teams to identify measures to assess the impact of tests of change on families and to explore opportunities to codesign quality improvement projects. Family advisors may be able to identify opportunities that the clinical team members might not consider, thus, allowing for more robust improvements.

Each comprehensive toolkit created to support the improvement projects included family leaders as coauthors. Many participating teams developed at least one aim focused explicitly on family centered care or enhancing the culture to support a family centered approach to care. Some of the potentially better practices authored include

- Ensure family integration in care to improve outcome, build confidence, and promote attachment.
- Develop, test, implement, and continually refine standardized processes designed to integrate family centered care into all documented protocols for surgical care.

In September 2016, VON NICQ Next[2] teams gathered in Chicago to advance their collaborative improvement work. Of 61 teams attending, 59 acknowledged in their quality improvement abstract the inclusion of at least one family advisor as a member of their VON team and 36 teams sponsored the attendance of a family advisor at the meeting. More than 250 quality improvement posters were presented, and attendees assessed the 26 family advisor stories as exceptionally impactful. Families identified opportunities for future improvement by including the section *what I wish I had known* when their infants were in the NICU. See Box 2 for a summary of themes that emerged.

Box 2
Reflection on neonatal intensive care unit experience by quality improvement family advisors: a few excerpts

> *What I Wish I Had Known While in the NICU*
> *—Vermont Oxford Network Annual Quality Congress Poster Fair, Chicago 2016.*

That my presence makes a difference to my baby (Family presence, participation, and caregiving are valuable variables to the outcome of infant and parents desire knowledge about their value to the team.)

- "{I wish I had known} what I could do to help my babies and why my presence mattered."
- "{I wish I had known} that my presence in the NICU was important."
- "{I wish I had known} that my loving touch was actually therapeutic and meaningful. For both of us!"

How it could feel to be a parent in the NICU (Parental roles can feel tenuous and need to be supported/encouraged.)

- "I wish I would've felt like a mom sooner than I did."
- "I wish I would've felt confident enough to ask for help—help in understanding what was happening to my babies, help in navigating the NICU, and help with how to feel like a parent."
- "{I wish I had known} that it was my right and responsibility to advocate for my children."
- "I wish I would have known that it was okay to request to touch, kiss, hold or assist in providing daily care, without fearing that I was interfering or that I would do something wrong."
- "I wish I would've known that I wasn't as powerless as I felt."

That I would experience so much guilt (Parental guilt can be an overriding emotion, and psychosocial support is crucial throughout the journey, including after discharge from the NICU.)

- "{I wish I had known} years later I would still feel at fault for his early delivery."
- "{I wish I had} felt less guilty and believed this wasn't my fault."
- "I wish my daughter would have felt comfort during painful care procedures."
- "I wanted to cry, yet I didn't know if my tears were supposed to be tears of joy or tears of sorrow. Or did I have no right to cry at all; was this somehow all my fault?"
- "I experienced PTSD from everything I had gone through, and have had dreams and flashbacks of my hours spent by his bedside. I wish I had known that his first birthday, and even his second, would be an extremely difficult and emotional day and not one I would want to celebrate like most other moms."

That I too would be the subject of assessment (Parents have a keen awareness of environment.)

- "They Talk About Parents, Too –change of shift is used for more than just reporting on the medical status of the patient."

That the journey can be full circle and serve as a way to improve others' experience

- "{I wish I had known}…that someday we would embrace our journey and use it to help others."

Abbreviation: PTSD, posttraumatic stress disorder.

In 2013, the Agency for Healthcare Research and Quality (AHRQ) developed a guide to achieve patient engagement as a means to advance hospital quality and safety. This guide provides specific recommendations, including evidence on how families can enhance quality and safety efforts. Best practices are identified, including tips for leadership on ensuring a collaborative environment to enhance patient partnerships, including transitions of care.[9]

In 2015, the National Perinatal Association partnered with parents and interdisciplinary representatives to establish recommendations for the psychosocial support of NICU families. The recommendations are supported by a series of principles, including interdisciplinary collaboration, continuity of care, varied family responses to traumatic events, and an imperative for a universal level of support for all families with additional supports where accessible.[10]

Examples of Family Involvement in Quality Improvement Achieved

The authors provide examples based on the *Framework for Family Involvement in Quality Improvement*, developed by the IPFCC and a VON family advisor and detailed in **Boxes 3** and **4**.[7]

Box 3
Framework for family involvement in quality improvement

Level I

Families complete surveys or engage in other evaluative activities as respondents (for example, focus groups). The level of participation is time limited and may be cursory but can be helpful to guide practices and identify needs and themes that improvement teams can then address. This level of involvement may be appealing for those families interested in sharing their insight, yet may not wish to commit to long-term projects.

Level II

Family advisory councils serve as a resource to the quality improvement team (for example, review projects, documents). Having an established advisory council as well as sustaining the council is a prerequisite to this type of collaboration. This level can provide a more cohesive and consistent approach to gathering feedback from family advisors.

Level III

Families participate as occasional reviewers and consultants during an improvement project. Identifying family advisors to serve as consultants and engaging them throughout the project can be a way to enhance patient- and family centered care practices. Families can be called on to help identify opportunities as well as inform practice changes and enhancements.

Level IV

Families participate as active members of improvement teams and/or may serve on unit-based task forces and committees and faculty for staff and clinician education. Identifying family advisors to serve as ongoing full members of the team is a requirement. Sustaining this involvement by providing diverse and flexible opportunities to participate can be a way to ensure consistent and ongoing involvement.

Level V

Families are coleaders of improvement initiatives. At this level, family advisors are on equal footing with other leaders of quality improvement initiatives. Families have equal responsibilities related to leadership of quality improvement projects. Compensation would be comparable with other leaders at this same level.

From Abraham M, Nickerson J. Framework for involving patients and families in research. Institute for Patient and Family-Centered Care. October 20, 2009; with permission. Available at: http://www.ipfcc.org.

Box 4
Requirements to establish level V family advisor involvement

Recognize the family as an essential partner in CARE and support quality improvement efforts:

- Support families at the bedside (at the clinical level of care).
- Ensure the parental role is honored and supported through education and peer support.
- Ensure family presence is supported with open and unrestricted NICU access and clarify that families have the opportunity to designate who they consider to be family.
- Consider the importance of the physical space that provides the best developmental environment for the baby and also allows for privacy and family bonding time (ie, kangaroo care and so forth).
- Provide educational information that is helpful, timely, and affirming.
- Ensure a feedback loop is provided to assess the care experience of families.

Recognize the family as an essential partner on the QUALITY IMPROVEMENT team:

- Support families in a family advisor role in quality improvement.
- Establish visual identification of family advisors (ie, name tags that are different color, recognition at plenary sessions) at meetings and conferences.
- Ensure introductions of family advisors to the team and vice versa.
- Consider providing stipends for volunteer family advisors on the team.
- Consider identifying more than one family advisor for each project/committee.
- Develop systems, such as advisory councils, that ensure continuity and sustainability of family advisors.
- Provide similar quality improvement training for family advisors as for other disciplines.
- Provide opportunities for family advisors to engage in peer networking and support.

Recognize the family as LEADERS OF QUALITY IMPROVEMENT INITIATIVES:

- Support families as leaders in quality improvement.
- Establish paid faculty roles for family leaders to coordinate family related activities.
- Provide a feedback loop (ie, advisory board) to gather ideas and inform future direction of quality improvement work.
- Provide opportunities for presenting the family perspective at any and all presentations.
- Provide authorship opportunities for materials and articles.
- Engage family advisors in research opportunities.

Recognize the role and responsibility of the quality improvement LEADERSHIP TEAM: establish principles and consistent processes to guide teams

- Set the expectation that every team will include at least one family advisor as a fully supported and realized quality improvement team member.
- Provide resources to teams and family advisors to achieve role clarity and understanding.
- Follow through on expectations and provide consultative support to teams that are challenged in achieving family inclusion goals.
- Embed family centeredness in clinical quality improvement projects by measuring the impact of tests of change on families, partnering with families to codesign tests of change and collaborating with families who will lead tests of change.

Data from Pragmatic tips to structure and systematically integrate family involvement in quality improvement – lessons from Vermont Oxford Network collaboratives, 1999–2016.

Examples of Level I Family Involvement in Quality Improvement

Families complete surveys or engage in other evaluative activities as respondents (for example, focus groups)

There are numerous examples of level I participation, including focus groups and surveys.[11,12] Providing an opportunity for families to share their experiences can lead to a better understanding of the health care system and identify opportunities for improvement. A recent qualitative research project to explore the hospital experience of families with infants being treated for neonatal abstinence syndrome (NAS) led to key insight in the treatment of this group of infants and their families. Through interviews with the research team, families articulated their clear desire to be part of the care team; desired clear communication with the health care team, especially during care transitions; and valued education that reinforced their role as parents and decision-makers during the course of their stay.[13]

Examples of Level II Family Involvement in Quality Improvement

Family advisory councils serve as a resource to the quality improvement team (for example, review projects, documents)

Family advisory councils composed of family members whose children had been cared for in the NICU are in place in many hospitals.[14] The councils typically provide feedback on proposals and projects that are initiated by members of the NICU staff. Quality improvement projects may be presented for review and the irreplaceable perspective of NICU families sought.

During the most recent VON quality improvement collaborative, NICQ Next[2], a team from the UMass Memorial Medical Center, was seeking to improve the rates of human milk provision for oral care to infants in their NICU. The team developed a multifaceted approach to improving this, including the development of colostrum collection kits to be distributed to mothers. When the NICU Parent and Family Advisory Council was presented with the proposed project, the group of graduate parents rejected the wording on the kits, offering valuable feedback and suggestions. The value of engaging a family advisory council is directly aligned with the humility of those seeking its feedback.

Examples of Level III Family Involvement in Quality Improvement

Families participate as occasional reviewers and consultants during an improvement project

VON's quality improvement collaboratives have provided many examples of family advisor participation as reviewers and consultants. Some improvement collaborative teams included families who provided feedback on multiple projects. One that focused specifically on family centered care was the creation and pilot implementation of a family centered care map (FCC map) providing potentially better practices with examples aligned with phases of care in the NICU (http://www.fccmap.org/).[15,16]

In a different setting, family advisors participated in the refinement of a survey to be administered to graduate NICU families to better understand and design services based on family perceptions of barriers to fully assuming their roles in the NICU.[17]

Examples of Level IV Family Involvement in Quality Improvement

Families participate as active members of improvement teams and/or may serve on unit-based task forces and committees and faculty for staff and clinician education

Families as full participants in quality improvement are evidenced in unit-based projects and as regular committee members at all levels within organizations. One example of level IV work is family advisor participation on patient safety committees.[18]

Family advisors bring fresh eyes to patient safety rounds and powerful advocacy for future infants and families.

From 1998 to 2000, a VON quality improvement collaborative, with faculty from The IPFCC developed potentially better practices for NICU family centered care.[19] Family advisors were full members of the team that evaluated practices and made site visits to centers with strong self-reported family centered care. Among the important assessments made was that collaboration with NICU families depends less on the physical facilities and depends more on the attitudes of the staff. Readiness to advance family centered care often hinged on cultural prerequisites, such as cohesive multidisciplinary teamwork.

A team at The Children's Hospital at Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire conducted a quality improvement project from 2013 to 2015 focused on NAS. This project included a family advisor on the team and sought feedback repeatedly from families to improve iterative tests of change. By supporting families rooming-in with their NAS newborns, the use of pharmacologic agents and length of stay were decreased while optimizing family centered care.[20]

A systematic review of family involvement in health care systems revealed that collaboration at this level led to changes in the health care delivery systems in several different ways. Results varied, but some reported outcome improvements and improvement related to access to services.[21]

Examples of Level V Family Involvement in Quality Improvement

Families are coleaders of improvement initiatives

At level V, families are fully integrated as critical members of the quality improvement team at all levels. One example at the NICU level was achieved by the family advisor at Helen DeVos Children's Hospital in Grand Rapids, Michigan. As a member of VON's NICQ Next[2] quality improvement collaborative, the family advisor codesigned and led tests of change for staff education. The family advisor and nurse educator designed a very impactful educational module in support of their team's Small Baby Unit, addressing the needs of micropremature infants. Graduate families contributed to informed conversations, included in a staff education video providing parental insight into the NICU experience and life after the NICU.

All staff who viewed the educational video assessed it as extremely impactful. Some reported intentions to change their practice of interaction and use of language with families. An excerpt of the video is provided (Video 5).

MAJOR RECOMMENDATIONS

Socioeconomic determinants of health impact infants as the trajectory of their lives is directly impacted by the degree to which they establish and maintain physical, psychological, and emotional well-being.[22] It is critical to facilitate, support, and deepen involvement of families in quality improvement. Family members who have the unique experience of newborn intensive care see the health care system through a different lens. By collaborating with families serving as equal partners in quality improvement, opportunities for improvement can more readily be identified and acted on.

The Model for Improvement[23] prompts the following question: What are we trying to improve? Clinicians have valuable insight into the physiologic requirements of the infant's care. Families have exclusive insight into the needs of their family unit. Everything that happens to an infant in the NICU impacts the family. That impact should be acknowledged, respected, and measured. Some organizations have done this on a system level, such as the Institute for Healthcare Improvement, VON, AHRQ, Patient-Centered Outcomes Research Institute, and others. The IPFCC published a resource highlighting tangible examples of partnerships at all levels of involvement.[24]

The authors suggest a model whereby engaged family advisors are active at every level and in every aspect of the hospital system. The levels of engagement enable teams to build on their achievements, thus, ensuring different opportunities and mechanisms for partnership. At level V, for example, families are codesigning and coleading quality improvement projects and have representation on committees and may leverage advisory councils for feedback and assistance. They are members of organization-wide planning and review teams, and the quality of care and interactions are being continuously improved through repeated feedback and individualization of care planning and assessment with every family entering the nursery.

The Controversies

Barriers

As a sociologic imperative, infants will thrive as members of strong, loving, supportive, and supported families. Failure to establish this as the goal of neonatal intensive care limits the contributions the dedicated professional team is able to make. Effective neonatal care requires clinical excellence, psychosocial support and services, family education, staff support and education, and a culture that includes a shared vision and a commitment to respect and empathize with every interaction.

Researchers have observed that conditions in the NICU fail to invite and support families in full participation and care of their infant. Barriers include lack of privacy, inadequate space for families to remain with their infant, priority given to technical activities, inadequate educational support provided to families, staffing constraints, and unit culture.[25]

Competing interests

Demands on the clinical health care team impact family centered care. Staffing may be determined based solely on technical requirements for care and fails to provide time and educational resources to mentor families in the care of their infant. Budgetary constraints impact on funded family advisor roles and provision of psychosocial support. The participation of senior leaders is critical to aligning organizational goals with leveraging of resources. Length of stay and family satisfaction are key organizational indicators, both of which can be positively impacted with family centered resources and staffing ratios.

In an evaluation of NICU family presence on rounds, medical trainees were least supportive, as it was interpreted as interfering with the pattern of education on rounds.[26] Family presence and participation on rounds presents unique educational and learning opportunities. Physician mentors have the opportunity to model family centered rounds by demonstrating effective communication and resultant shared decision-making, which contributes to empowered, functional families.

Changes in Practices That Are Likely to Improve Outcomes

What is required to establish level V

All neonatal care providers should seek to establish level V family advisor involvement. In **Box 4**, the authors offer detailed steps that will help an institution achieve level V using the framework described earlier. Here, the authors offer an additional framework for achieving full family centered care as a health care system.

Microsystem (the neonatal intensive care unit)

In 1992, Helen Harrison provided us with the building blocks to support family involvement in quality improvement by noting that family-staff partnership was necessary to establish and develop programs, which include quality improvement. The features of interdisciplinary collaboration, effective communication, shared goals, and conflict resolution processes all contribute to patient outcomes in the NICU.[27,28] All of these features coalesce in unit culture. When the culture includes accountability for the patient and family experience, the health care team is free to partner effectively with those it serves to improve the quality of care and experience.

Fully implementing family centered care will enable family integrated care wherein parents provide both the locus for care and most of the care itself. Newborn intensive parenting units will become the new norm. Fully supported and integrated families will both inform bedside quality improvement and demonstrate it.

Mesosystem (the program level = perinatal/neonatal-obstetrics/mother-baby, as examples)

Opportunities for families to participate in neonatal quality improvement begin with their first interaction with the perinatal team. Some pregnancies are identified as high risk; expectant mothers are referred to obstetric specialists, genetic counselors, or diagnostic services. In cases whereby the mother is hospitalized antenatally, regular communication between the obstetric and neonatal team should occur with the family and families should be educated and oriented to the NICU. Understanding and respecting the unique needs of families before admission to the NICU facilitates an optimal transition of care.

Macrosystem (the organization)

The Institute of Medicine identified in *Crossing the Quality Chasm* that although organizations make the commitment to embrace rules and principles to achieve quality, there must remain a commitment to individualize care based on patient preference and informed choice.[2]

Although much of the work to design NICU environments occurs within the microsystem (NICU), the expectations and guiding principles are determined at the level of the organization and its charter sponsored by senior leaders. Ensuring those principles are respectful of family centered care will invite family partnership and tests of concept.[29]

Metasystem (networks, health systems, and collaboratives)

In addition to ensuring family involvement throughout the organization, family centered care is fostered by considering metasystems beyond the hospital. These metasystems include metasystems around the individual patient, focused on care after neonatal hospitalization, and metasystems around the individual hospital, such as state and national collaboratives.

At the individual patient level, metasystems must recognize the family's needs beyond the hospital setting to achieve the highest quality care, particularly for NICU graduates. Neonatal follow-up programs provide standardized developmental assessments and service referral, but this commitment is not sufficient. In 2002, the American Academy of Pediatrics redefined its policy statement on the medical home.[30] In addition to other aspects of family centered care, key recommendations are for provision of care coordination and the maintenance of a central record. Families face recurring challenges in effectively navigating the health service environment, advocating for their NICU graduate children. For those children with complex needs, quality care may be supported by pediatric mental health models, such as high-fidelity wraparound care, which operationalizes care coordination and individualization to meet underlying needs.[31] Given that the relationship between the professional team and the family is unquestionably focused on the best possible outcome for the infant, fulfilling that commitment requires a reset from the provision of traditional follow-up to follow through.

Perinatal/neonatal quality improvement collaboratives are metasystems that involve families in the design, testing, and evaluation of care improvements at health system, state, and multi-state levels. The Ohio Perinatal Quality Collaborative (https://www.opqc.net/) provides relevant patient resources as well as an open invitation for patients and families to become engaged in the quality improvement work. The Perinatal Quality Collaborative of North Carolina is an example of a statewide quality improvement collaborative that has engaged family advisors. Videos with family stories are included as part of the resources shared publicly for many of the initiatives (PQCNC initiatives).

SUMMARY STATEMENT

A culture of accountability to those served is required at the highest levels, manifested by partnership with families in the design, assessment, and prioritization of quality improvement. Intending to serve is not sufficient. Without the fully empowered voice of the family recognized from the bedside to the boardroom at the organization and health system level, all efforts in the programmatic and NICU milieu are diminished in legitimacy.

As caregivers, providers, administrators, and supporters, we are challenged to demonstrate a noble commitment the interests of those we serve, over our own desire for control. Advances continue to be made in family centered, family integrated, and family engaged care. If quality improvement is a method we embrace, learning what is important to those served is vital to achieving quality. Partnering with families to improve quality will optimize our success at every level of the health care system.

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