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# Implementing Family-Integrated Care in the NICU

## *Engaging Veteran Parents in Program Design and Delivery*

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### ABSTRACT

The purpose of this article is to describe and evaluate how “veteran” parents were engaged as experts in the design and implementation of a family-integrated care program in a Canadian neonatal intensive care unit (NICU). Three parents of preterm infants previously discharged from the NICU participated in the design and implementation of a family-integrated care pilot program. The steering committee for the program included 5 staff members (a physician, a NICU nurse, a parent education nurse, a lactation consultant, and a social worker) and the parent volunteers. This article includes a total of 42 mothers of infants born at 35-week gestation or less were enrolled in the pilot program. A detailed description and qualitative evaluation of the engagement of veteran parents in the design and implementation of the family-integrated care program. The effectiveness of engaging veteran parents in developing this model of care was evaluated by written feedback from the veteran parents and the other steering committee members. In addition, a structured interview at discharge with the 42 mothers enrolled in the pilot study was used to assess their experiences of the peer-to-peer support provided by veteran parents. Veteran NICU parents brought a wealth of wisdom and expertise developed through personal experience to the design and implementation of the family-integrated care program. The veteran parents played a significant role in both the initial development of the program and in the provision of peer-to-peer support during program implementation. Engagement of parents with prior experience of the NICU care environment is a critical step in the design and implementation of a program of family-integrated care.

**KeyWords:** family-centered care, family-integrated care, NICU, parent engagement, patient engagement

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The engagement of parents in the neonatal intensive care process can be impeded by their feelings of anxiousness about the well-being of their infant and intimidation by the complex technologies of the neonatal intensive care unit (NICU) environment.<sup>1</sup> Although healthcare providers aim to benefit their patient's best interests, a patient's perspective on what is most beneficial to him or her may not be what the provider expects.<sup>2</sup> The NICU healthcare professionals who value parents' unique expertise and have integrated it into their medical practice report that parents feel their perspectives are respected and that this translates into less conflict with healthcare professionals and a higher overall satisfaction with the NICU experience.<sup>3</sup> Mothers paired with a "parent buddy" also report experiencing less parental stress in the NICU, less depression after 4 months, and greater social support.<sup>4</sup> Furthermore, 96% of mothers surveyed rated a parent buddy program as being very helpful in the areas of shared similar experiences, reduction of feelings of isolation, validation of feelings, normalization of experience, increase in comfort interacting with medical professionals, and improvement with coping in the NICU.<sup>5</sup>

The importance of parent engagement in care processes had previously been established in our NICU through successful initiatives, such as a parents' association, parent advisory committee, parent buddy program, and parent education support nights, as well as many quality improvement initiatives. On the basis of these outcomes, the NICU care team was eager to explore further progressive family-centered care models. One such model is the Humane Neonatal Care Initiative in Tallinn, Estonia.<sup>6,7</sup> In this model, once infants are stable and off ventilators, their mothers are enlisted to provide most of the infants' care until discharge from the unit. The initiative has been reported to result in an increase in weight gain, reduction in infection rates, decrease in the duration of intravenous infusion and antibiotic therapy, and improvement in neurological outcomes.<sup>6</sup>

To further understand the family-centered care process, a multidisciplinary team from our unit, with a parent representative from the parent advisory committee, visited Tallinn to observe the Humane Neonatal Care Initiative in action. On the team's return from Estonia, involvement of additional parents was sought to help adapt and translate the Tallinn model to the Canadian NICU environment. The resulting care model, "Family Integrated Care" (FICare), incorporates parents into the NICU care team as an integral part of the team and treats the mother-baby unit as one.<sup>8</sup> The parents provide most of the primary care for their infants, with the exception of intravenous procedures and medications, whereas the nurses' role becomes supervisory

and educational in nature. This represents a significant paradigm shift from existing family-centered care models.

The purpose of this article was to describe and evaluate (1) how veteran parents were engaged in the design of the FICare program and (2) the peer-to-peer support that veteran parents provided for parents enrolled in the pilot study. The insights gained from this discussion will assist other NICUs in developing family-integrated care programs.

## THE ROLE OF VETERAN PARENTS IN DESIGNING THE FICARE PROGRAM

The 3 veteran parents who participated in the design and implementation of our FICare program had previous working relationships with NICU staff and were selected on the basis of their (1) ability to reflect on their personal experience and articulate it in a way that would assist with shaping program design; (2) knowledge of the NICU environment, culture, and care practice; and (3) demonstrated ability to create positive working partnerships with healthcare providers. The development of the FICare program from conception to implementation took approximately 12 months. The steering committee that oversaw the design and implementation process consisted of the 3 veteran parents, a NICU physician, a NICU nurse, a parent education nurse, a lactation consultant, and a social worker.

Following reflection on the visit to Estonia, a literature review of other models of care that adopted the same principles was performed. With support and guidance, the veteran parents were active participants in the review and the resulting discussions. The goals of the program and supports needed to make it successful were then delineated. Brainstorming what a "day in the life" of a parent or nurse working in the FICare program would involve helped focus the discussion on what needed to be included in the program. Three teams, each coled by a veteran parent, worked on the research, education, and support aspects of the program. These multidisciplinary teams worked collaboratively to provide tools and solutions for each part of the program. For example, the research team wrote the research ethics board application and developed consent forms and charting tools. The education team developed the education program for staff and parents, which included developing curricula for both nurse<sup>9</sup> and parent education sessions.<sup>10</sup> The support team worked on identifying what supports and modifications needed to be provided in the NICU, which included planning, budgeting, and sourcing items.

When obstacles such as nurses' fears about how the FICare model might impact their job security were encountered, the committee was able to

address their concerns and reiterate our shared philosophy. In that specific example, the veteran parents were able to validate for the nurses their true appreciation of the nurses' role and how the project would not devalue that in any way. As a pilot study of the FICare program began, the same collaboration guided the response to staff and parent feedback. The common goal was that the program should work for everyone involved, from the healthcare staff to the parents of infants in the NICU.

## EVALUATION OF THE VETERAN PARENT ROLE IN PROGRAM DESIGN

After completion of the pilot project, 2 aspects of the veteran parent role in the design of the FICare program were assessed: (1) The value of veteran parent engagement and the way veteran parents were engaged in program design and (2) the specific factors that contributed to maintaining veteran parent involvement. The goal was to use the insight gained from the evaluation to assist with informing and shaping future practice.

The 8 FICare steering committee members were asked: "What is your perception of veteran parent engagement, contribution, and future considerations in program design," and "What factors contributed to maintaining veteran parent involvement throughout this pilot project?" All of the steering committee members reported positive experiences with the veteran parent role and highlighted that the FICare program was enhanced by the parents' personal experience and expertise. As one steering committee member stated:

Parent participation in the [FICare] model of care (from conception, implementation, and day-to-day [operations]) was imperative in that their experiences contributed, and continues to do so, to the foundation of the program. They have walked the walk and truly understand what it is like to have an infant in the NICU and the needs of families.

Using thematic analysis,<sup>11</sup> key words and phrases from the responses of the steering committee members were coded into 3 categories: engagement and contributions, future considerations, and factors supporting parental involvement. From the responses to the question regarding parent engagement and contributions, 3 themes were identified: prior NICU experience, sustained involvement, and parent background and skills. Two further themes identified under future considerations were setting clear expectations/providing training and support, and cultural diversity. Responses in the category of factors supporting parental involvement were used to generate a list of 10 strategies that are key to engaging parents in the design and implementation of a program such as FICare (see Table).

**TABLE. Key Parent Engagement Strategies**

Invite parents as key members at the very beginning to translate the idea into practice
Create a meaningful experience where parents have specific roles in the process
Allow parents to use their professional skills
Provide a formal structure, such as a steering committee and workgroups, with a parent lead in each group
Have an active, responsive, and integrated steering group
Build positive relationships between staff and parents
Identify staff to support parent involvement
Create a flexible work structure
Provide parents with a choice of feedback mechanisms
Provide some financial compensation, such as a stipend or parking reimbursement

## Veteran Parent Engagement and Contributions

### *Prior NICU Experience*

The value of including the veteran parents' prior experiences of the NICU was a strong theme among committee members' responses. Many spoke of the importance of embracing the parent experience and strongly believing in the philosophy that the "users" of the service can offer various insights that help inform a more holistic program design. For instance:

Parents' past experiences and idea generation ... was very helpful in implementation planning for rollout of the project (ie, what they were going through, how to best approach parents, with what, when, what would be realistic to expect from parents, etc).

Veteran parents are able to bring a valuable and much-needed family-centered viewpoint to discussion at steering, which kept the team on track with the values which are required for this project.

[Veteran parents] added a different perspective to all the discussions as we tried to anticipate a day in the life of a parent in [the FICare program], the physical supports required to facilitate the parents' presence at the bedside, the psychological supports needed to support the program, the charting tools, the education program for the parents, and the education program for the nurses.

One important facet of this theme was that the input of the veteran parents was respected and always taken into consideration in all aspects of the

project. This was noted by several steering committee members.

[I was] struck by how much respect and consideration the medical and interdisciplinary professional healthcare team seemed to give to the opinions and insights that the parents brought with them.

I feel that when there was a difference of opinion among staff that parents were looked to almost as the deciding factor.

When parents challenged elements of the project, their feedback was listened to and incorporated.

### **Sustained Involvement**

To ensure that the parents' experiences were fully incorporated into the design and implementation of the FICare program, it was recognized that they had to be involved in all stages of the project. In particular, most committee members stated that it is crucial to invite veteran parents to be involved in program design in the early stages and to ensure their continued contribution to the project. The early and active involvement of veteran parents "sent a strong message that parental involvement was important," provided "a variety of perspectives and backgrounds to help expand the project," and ensured that the team members "were all on the same page" in terms of the program's objectives. It was also clear that involving parents in this project was not mere tokenism but rather a serious and valued integration of NICU families. The success of this FICare pilot project<sup>8</sup> speaks to the holistic and robust knowledge gained from incorporating the experiences of both NICU healthcare professionals and families into the program design.

### **Parent Background and Skills**

Including veteran parents with different professional backgrounds and specific skills was also a strong theme among the committee members' responses. Many stated that, in addition to their experiences in the NICU, the veteran parents contributed unique skills and professional expertise that greatly strengthened the design and implementation of the FICare program. Their varying skill sets allowed them to be able "to do more for the project than just be advisors" and "strengthened this project and helped resources go further." The fact that the veteran parents took on leadership roles and provided services and resources that would not have been available without their involvement was mentioned by several committee members.

I certainly felt that [the veteran parents] had a real role in designing the "care model" ... not least because they were coleads on all the working groups.

When [veteran parents] participate/colead the education program, they bring a richness of experience that enhances the education/information.

In fact, a combination of veteran parent and staff as coleaders in an education session provides the necessary information whilst well supported by the emotion and experiences.

[Veteran parents were] invaluable resources to take on certain elements of project work where their expertise would allow, many project related items/documents would not have been created, or to the current standard, without parent involvement.

### **Future Considerations**

Two areas that were identified as requiring further development and inclusion in future projects were (1) setting expectations and providing training and support for the veteran parents and (2) expanding the cultural diversity of the parent volunteers to reflect the patient population. Although the veteran parents were heavily involved in the design, implementation, and ongoing development of the FIC project, it was suggested that "the expectations and time commitment should be clear from the beginning ... so that everyone would feel comfortable participating." Feedback also indicated the need to ensure that the veteran parent role has a defined focus and that parents are empowered.

At times, [veteran] parents were asked to do things like organize paperwork or clean/prepare family areas. Especially considering the quasi-volunteer nature of their role, these requests weren't really appropriate.

Perhaps assign more responsibility to parent cochair of project/steering, so that they are able to take on more ownership over the project and think of strategic future implementation. Additional empowerment of this group would lead to even greater success.

In concert with defining the role and expectations placed on veteran parents, a requirement for additional and ongoing training and support was highlighted. Areas of additional training identified by one parent included "infection control, privacy policies, and cultural competency training." Appreciation and mentorship were also seen as imperative and vital to maintaining veteran parent involvement in program design.

... Ongoing guidance, support, respect, and time need to be provided with the increasing expectations [placed on veteran parents], not only in meetings but contributions within the pilot itself, (remembering that they are volunteers).

As staff, we work within the hospital policies, guidelines, budget, and limited time. As parents, their experiences of the healthcare system are remarkably different. Marrying the two takes time, consideration, mentoring and care. ... To ensure that [veteran parents] feel valued, *time* needs to be allotted to a staff member to be able to provide this ongoing support.

The other area identified as needing to be addressed for future program development was the inclusion of parents who are truly reflective of the patient population, which was noted by several committee members.

We chose parents who are well educated, articulate, and had the resources enabling them to dedicate their time. However, I do not feel they were a true representation of our parent population.

Depending on the goals of the program, the selection of veteran parents should, if possible, be a cross-section of cultural and different NICU experiences.

In the future, it would be beneficial to have parents from different ethnic backgrounds and socioeconomic groups to help us design a program that would work for more of our patient population.

However, it was also noted that this concept could, in certain circumstances, be at odds with the needs of the project in terms of the skills and expertise that veteran parents are able to bring to the project. As stated by one committee member:

[Bearing in mind] the nature of the work the veteran parents need to do, there does have to be a standard level of professionalism, insightful and critical thinking skills, and a level of experience of articulating and translating ones' experience into an applicable influence in moulding and shaping project design. These skill sets are usually acquired through higher levels of education and professional jobs (though not exclusively), but which may present a barrier to veteran parent diversity that is truly reflective of the NICU.

### Specific Factors for Maintaining Parent Involvement

The 10 most common factors that the steering committee provided as contributing to the maintenance of veteran parent involvement are presented in the Table. Unsurprisingly, there is much overlap between these strategies and many of the reflections already presented. In particular, it was recognized that veteran parents are key to program design and implementation and as such should be invited to take part at the beginning of the process, have specific roles, work within a formal structure, and have the ability to use their professional skills. In addition, the conditions within which the veteran parents worked were also seen as very important for maintaining their involvement. This included the provision of financial compensation as appropriate (stipend or parking reimbursement), a flexible working environment, and the opportunity for feedback through multiple mechanisms, as well as the development of positive relationships between hospital staff and parents.

## THE VETERAN PARENT ROLE IN PEER-TO-PEER SUPPORT DURING PROGRAM IMPLEMENTATION

The 3 volunteer veteran parents were trained parent buddies<sup>4</sup> but required an additional 3-hour training program focused on providing in-hospital, small-group support. In the session, a social worker and parent support nurse helped provide some understanding of the parameters of the new veteran parent peer-to-peer support role, specifically regarding privacy, confidentiality, appropriate boundaries, and advocacy. Given the scope of this volunteer role, it was essential to ensure that these skills were in place before program implementation began. The veteran parents' reflections on this training were also used to inform future training sessions.

The FICare pilot program initially started out with 3 veteran parents visiting the NICU for 3 half days per week. The 3 veteran parents gave general overviews of their visits to each other via e-mail. As the project progressed, ongoing feedback from the veteran and NICU parents indicated that one session of peer-to-peer support a week was sufficient and the veteran parent visits were reduced to 1 half day per week. The needs of NICU parents for specific support and education regarding their infant's medical care and other related issues were met by healthcare professionals within the unit. There was an expectation that parents would commit to participate in the FICare program for at least 1 year; however, during the course of the pilot study, 2 parents modified their commitment because of life changes, and one new parent was introduced to the program. It is important to note that the steering committee meetings continued biweekly throughout the project, with all 3 veteran parents continuing to participate actively on this committee.

Supervision of the veteran parents involved in the FICare program was overseen by a social worker and a parent education nurse. During the NICU visits, the veteran parent either led or coled (with a parent education nurse) the education session scheduled for that particular day.<sup>10</sup> The veteran parents were also involved in the education of nursing staff and supporting staff involvement in the program. In a separate part of the pilot study, the nursing staff evaluated their experiences with the FICare program and the education provided to nurses by the veteran parents was identified as being very important.<sup>9</sup>

In addition, each veteran parent also facilitated a recreational activity such as arts and crafts or a coffee hour to develop a sense of community among the participants in the FICare program. At times, the veteran parent also acted as a liaison between the FICare families and the healthcare staff. Issues such as nursing assignments, use/misuse of the dedicated FICare parent room, personal concerns with anxiety,

or family members were sometimes disclosed to the veteran parents, who were then able to mediate these concerns to the healthcare team. The veteran parents also became advocates for what they felt parents would need to be fully engaged in the program.

## EVALUATION OF THE PEER-TO-PEER SUPPORT PROVIDED BY VETERAN PARENTS

At discharge, the 42 mothers enrolled in the FICare pilot study were interviewed regarding the effectiveness of the veteran parent role. The 3 themes that emerged from the interviews were (1) comfort and hope gained from shared experiences; (2) facilitation of bonding and provision of psychological support; and (3) increased confidence in caring for their infant through parent-to-parent education.

NICU veteran parents brought a wealth of wisdom developed through personal experience to their role in the FICare program. All of the families surveyed had positive experiences with the veteran parents, with many stating that communication was easier to initiate with a peer rather than with clinical staff and that it gave them a different perspective.

I think it's easier to talk to [the veteran parents] than it is to talk to a [nurse] ... simply because they've gone through it and even though we've only just met, there's that connection that no one else can have.

Hearing stuff from [veteran parents] provides you with ... a different type of reassurance than a doctor.

Because of their unique perspectives, there seemed to be an immediate bond between veteran parents and the new NICU families based on shared common experiences. This was particularly important, as having a premature infant can be a frightening occurrence and is very different from delivering a fully developed baby, as recognized by one mother, who stated: "My sisters or my mom, they had babies, but all of them had full-term babies; they didn't have babies in the hospital. So dealing with a small baby in the hospital, it's a completely different experience." Indeed, most participating families credited the similar experiences that veteran parents had to their own as bringing them much-needed comfort and hope and decreasing their anxieties.

Talking to someone who had the same experience—they understand you. Her baby went through the same thing. So it made me feel better.

[Knowing] how [they] handled it, what happened three years later, and knowing that it wasn't the end of the world, and they were able to cope, gives me more hope that I can deal with it.

It helped me calm down. It was nice to talk to someone who's been in your shoes for sure ... just reassurance that there is light at the end of the tunnel.

Furthermore, parents felt that the veteran parent role helped facilitate camaraderie and bonding between other families in the NICU.

We all kinda had tunnel vision; we were there for our babies. We would say hi, look after our babies, and we leave. It worked out well that [veteran parents] were there to help us connect [to other families].

[The veteran parents] facilitated some bonding between the moms in the group.

The general parent-to-parent support made an impact and was appreciated by many.

I shared some of the things with them that bothered me and they said they had the same feelings, so it's not that I'm going crazy. ... [T]his is a feeling that everybody's going through.

Many parents also felt that the education that the veteran parents provided was very valuable and it helped them increase their confidence.

[The veteran parents] were always very helpful, supportive, answered any questions, and answered questions that I didn't know I wanted to ask.

We learned how to take care of our baby. I was much more comfortable with what I was doing.

Most mothers spoke about the uniqueness of the veteran parent role, and some reflected on the depth of understanding that only someone who has been through the experience can bring to the interaction.

I feel like the veteran parents still had a unique role to play ... [they] still know a lot more than we do.

I've spoken to [veteran parent] once or twice and both times I've done it, I sort of feel like I know her family as much as she knows my family.

Overall, having someone in the unit who has also had personal experience of being a mother of an infant in the NICU was key to the FICare parents' general experience of the NICU. As stated by one mother: "I was talking to someone who knew what I had been through, I think this is necessary." Oftentimes, the attributes of a comprehensive and refined supportive role are seen and felt in nuanced ways, as evidenced by the themes reflected by the families involved in the FICare program. The feedback from families working with the veteran parents attested to the provision of authentic and sincere support that benefited families with infants in the NICU. Without the support veteran parents provided to these families, the rich and holistic advantages attributed to this study would not have been realized.

## DISCUSSION

Many insights were gained from this qualitative evaluation of the engagement of veteran parents in the FICare pilot study, most significantly how instrumental the parent voice was in shaping this project.

During translation of the FICare model to other sites or the development of similar models of care, the veteran parent voice should be highly valued and given scrupulous consideration at both the design and implementation stages. Without the comprehensive efforts of the veteran parents, the FICare program would not have been a holistic reflection of the familial needs of NICU infants. The contributions and collaborations of the 3 veteran parents were very beneficial, as each parent brought to the role unique strengths and transferable professional skills, as well as diverse life experiences. This also speaks to the advantages of engaging more highly educated parents who have the ability to articulate their experiences and assist in project design. During the implementation phase of the pilot study, the small group peer-to-peer support provided by the veteran parents along with their participation in the education sessions provided to NICU parents was a key factor in the success of the FICare program.<sup>10</sup> The additional involvement of the veteran parents in educating nursing staff was also seen as an overwhelmingly positive experience.<sup>9</sup>

The actual process of how to engage patients or families in the redesign of healthcare delivery systems and how to evaluate the effectiveness of that process, although supported in theory, is not well described in the literature.<sup>12</sup> The most established framework for evaluating public engagement is that proposed by Rowe and Frewer,<sup>13</sup> who have defined 5 “acceptance” criteria (representativeness, independence, early involvement, influence, and transparency) and 4 “process” criteria (resource accessibility, task definition, structured decision-making, and cost-effectiveness) that should form the basis for effective public engagement. Our evaluation shows that parent engagement in this pilot program was well aligned with these criteria, particularly in the areas of independence, early involvement, influence, transparency, and structured decision making.

Another key finding in the public engagement literature is the role of contextual influences over the goals, processes, and outcomes of public engagement in the development of healthcare programs and policies. In particular, a critical synthesis of the literature by Abelson et al<sup>12</sup> in 2010 indicated that organizational commitment is a very important determinant of successful public engagement. The specific strategies identified here as being key to parent engagement, such as the need to provide staff support for the veteran parents, a stipend for parking, clear levels of accountability, and a clearly identified process for debriefing, are indicative of the commitment of our organization and in keeping with the research findings. Of additional interest, the report by Abelson et al<sup>12</sup> also identified that the skills required to support engagement with the public can be learned in a supportive organizational

environment, giving merit to the idea that we can assist in translating the information gained from this pilot program into a larger more comprehensive program and also to other sites.

## LIMITATIONS

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Although it was noted that the veteran parents were not culturally and socioeconomically representative of the NICU parent population, this did not appear to limit the FICare program in any way. During their parent buddy training, the veteran parents were taught to focus on the commonalities rather than the differences that bring parents together in the NICU. Veteran parents were also taught to be mindful of the cultural implications of their work and actions. As such, the shared experience of having an infant in the NICU and being part of the FICare program was a stronger influence than any cultural or socioeconomic differences.

One particular feature of our NICU that aided in the design and implementation of this pilot study of FICare was that it already had a source of veteran parents who were engaged with the hospital in some way. However, the experience of designing and implementing a healthcare program were at the same time new for all our veteran parents. For sites where parents may not already be involved in ongoing programs such as parent buddy programs or parent associations, additional attention might be needed to enable the engagement of parents, such as implementing parent training/buddy programs and changing the organizational culture of the unit or hospital. Although the design and implementation of a program such as FICare may seem like a big step, successful integration of parents into any hospital project, however small, can lead by example to organizational change and improved outcomes.

## CONCLUSION

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There is an increasing recognition of the importance of actively involving patients and their families in the provision of their care and the redesign of care processes. This study shows how essential parent involvement was to the design and delivery of a pilot program of FICare, a program we will continue to expand and evolve with their help. This evaluation also provides guidance as to how to continue to support the engagement of parents in our NICU and how to support parents at other sites that may wish to adopt the FICare model as it evolves into a larger program. Clearly, a committed and receptive interdisciplinary clinical team that supports parent engagement is also critical. The establishment and continued expansion of the FICare program, along with the use of the expertise of veteran NICU families, will advance the practice of patient- and family-centered

care, as well as facilitate the development of partnerships with patients and families. We hope that the insights offered here will be helpful in establishing the FICare model in other healthcare centers.

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