



# Bringing Depth and Meaning to Perinatal Quality Improvement by Partnering With Patients

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**Abstract:** The quality of maternal care in the United States has garnered attention as the public has been made aware of outcome data and stories of patients' experiences. Calls to action from national leaders include a focus on evidence-based clinical practice and on interventions that meaningfully include patients and their families in their own care and in identifying promising practices to fill existing gaps. This article provides a look at the methods to identify needs from the patient and family perspective to help improve the quality of maternal care.

**Key words:** maternal morbidity, patient and family engagement, quality of care

## Introduction

Over the past decade, there has been mounting pressure in the United States

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regarding the need to improve maternal morbidity and mortality, which is the worst in the world among high-resource countries.<sup>1</sup> Programs such as the Alliance for Innovation on Maternal Health have been developed to help elevate and spread community and hospital-based strategies to better the care of pregnant women.<sup>2</sup> These strategies and others have been adopted by state perinatal quality collaboratives across the country, whose focuses have been on the design, implementation, and evaluation of hospital-based quality initiatives to improve outcomes and prevent serious maternal events.<sup>3</sup>

Alongside these efforts has been a recognition that the informational and emotional support of patients and families should be a primary driver in any initiative designed to reduce maternal

morbidity and mortality.<sup>4</sup> However, the call to action has remained vague, providing little in terms of change ideas and resources for effectively engaging patients and families beyond the provision of patient education resources.

Neonatal intensive care units have long used patient and family engagement (PFE) practices as a way to drive quality performance.<sup>5</sup> In particular, the Vermont Oxford Network (VON) developed national guidelines for engaging families to improve outcomes and require hospital-based teams to partner with family members in the design and implementation of VON-sponsored quality projects.<sup>6</sup> Yet, this approach has lagged in obstetric quality improvement. There are few published articles discussing potential methods or benefits of effectively engaging patients and families to improve maternal outcomes, leaving perinatal quality collaboratives to derive PFE strategies from nonobstetric examples.

In this article, we will discuss efforts by the Perinatal Quality Collaborative of North Carolina (PQCNC) to draw from examples of PFE across health care to execute a maternal initiative that integrated patient and family partnership into both project design and care at the bedside.

### ***PQCNC Model for PFE***

The PQCNC is a statewide organization composed of stakeholders in perinatal care from across North Carolina. Members include providers of all types (nurses, doctors, midwives, nurse practitioners) across all specialties (obstetrics, pediatrics, and neonatal intensive care), patients and families, hospital administrators and quality leaders, state leaders (public health and legislative), payers (Medicaid and Blue Cross Blue Shield North Carolina), and the North Carolina Healthcare Association. Since 2009, PQCNC has conducted 9 statewide

perinatal hospital projects in 65 hospitals covering two thirds of the births in North Carolina.

The PQCNC mission is to make North Carolina the best place to give birth and be born. PQCNC pursues this mission by selecting quality improvement projects that are based on value, defined as: (1) spread of best practices and reduction in unnecessary variation, (2) patient and family partnership, and (3) resource optimization. As is evident from the value proposition, the role of patients and family members is considered vital in improving care. Through the sharing of their perspectives, patients and family members are understood to bring unique insight and knowledge to improvement teams that no other member can provide. Embedded at every level of the organization and in all stages of clinical initiatives, patients and family members have been strong catalysts for change in PQCNC's neonatal and maternal initiatives.

Statewide quality projects, both in the newborn and obstetric arenas, go through a nominating and vetting process. Stakeholders from around the state, including individual hospital units, individual providers, patients and family members, or pairs, are asked to submit ideas for potential projects. These projects are then voted on by all participants at our annual leadership meeting. These participants include the vast array of hospital personnel, both government and private statewide organizations, and the patients and families themselves, involved in women's health across the state. Each participant has an equal vote when selecting projects.

When a quality initiative has been selected an expert team is convened. Expert teams consist of providers, patients and family members, public health groups, payers, hospital and health system leaders, and any other stakeholder who feel that they can provide input into

the development of the initiative. Each expert team includes patient/family partners who help develop the action plan, the key driver diagram, vet any patient/family engagement or educational tools that will be used in the project, and identify the data elements needed to drive the project.

PQCNC uses semiannual learning sessions which are opportunities for the hospital teams to collaborate and share their experiences. Patients and families participate in the learning sessions as both presenters and joining hospital teams when they do tabletop exercises to brainstorm tactics for their home institutions. The consistent feedback from our hospital teams is how valuable the sharing of personal stories impacts their practice and how the patient and family perspective frames issues clinicians would otherwise misconstrue.

Every participating hospital is expected to have active participation of patients and families on their local perinatal quality improvement teams (PQIT). Some hospital teams have encountered barriers to do this effectively. These include identifying patient/family partners, coordinating the schedules of busy patients and family members who are usually parents of young children, as well as navigating perceived legal hurdles of having patients and families involved in the discussion of hospital operations. Highly functioning hospital teams have been able to actively engage individual patients or family members as members of their PQIT, whereas others have used preexisting hospital patient and family advisory boards to assist in this work.

### ***PQCNC Obstetric Hemorrhage (OBH) Story***

OBH is a major cause of maternal death and morbidity in North Carolina.

Approximately 3% to 5% of obstetric patients will experience postpartum hemorrhage.<sup>7</sup> These preventable events are the cause of 12% of maternal deaths in the United States.<sup>8</sup> In August 2017, PQCNC partnered with the Alliance for Innovation on Maternal Health to address these sobering statistics and facilitate widespread adoption and implementation of the OBH bundle.<sup>9</sup> This bundle, made up of a collection of 13 best practices vetted by experts for preventing, preparing for, and responding to OBH, included the following guidance related to patient and family support—to respond to every hemorrhage by providing a “support program for patients, families, and staff for all significant hemorrhages.”

To understand what would constitute support from the patient and family perspective, PQCNC invited OBH survivors to share their experiences and help identify and prioritize meaningful support practices, which would then be developed into resources that would be shared with hospital teams. The following section outlines the steps taken to engage these patient partners and to create coproduced tools to be adopted, adapted, and implemented across the state.

### ***Partnering With Hemorrhage Survivors to Create Meaningful Resources***

Although the term PFE is commonly used in health care, it can mean different things to different people. Broadly defined, PFE is the active partnership between patients, families, and caregivers working together to improve health care delivery.<sup>10</sup> This partnership can occur at the individual patient and family level, the clinic/unit or organizational level, and the policy level.<sup>11</sup> Over the course of the PQCNC OBH initiative, a multilevel approach was utilized

to ensure patients and families were not just engaged at the point of care, but that they were key drivers in the design of improvement strategies. At the outset of the work, 2 OBH survivors were invited to serve as subject matter experts for the initiative, providing critical insight and guidance related to the patient and family experience. They were given background documents and were asked to address the OBH bundle item regarding patient and family support by reflecting on their personal experiences and sharing suggestions for how patients and families could best be supported when OBH occurs. The result was a list of 9 potential change ideas, which were summarized and shared with a virtual support group for maternal near miss survivors. Members of the group who experienced OBH were asked to review the change ideas and select 5 that they felt would be most impactful for providing informational and emotional support to patients and families. Fifteen hemorrhage survivors provided feedback and, with their guidance, a list of 5 essential patient and family support practices following OBH was created (Table 1).

These practices were then put into a baseline survey that was distributed to all hospital teams participating in the OBH initiative. For each item, teams were asked to indicate whether or not the

practice was in place. Results indicated that hospitals lacked the resources for practices 3, 4, and 5.


On the basis of this information, the 2 OBH survivors serving as subject matter experts were asked to assist with the development of relevant resources that could be shared with participating hospital. Each resource was codesigned with the subject matter experts and reviewed by additional OBH survivors through the aforementioned virtual support group. These women helped ensure that the language used throughout the resources were sensitive and understandable and that the examples provided and topics addressed thoroughly covered a range of OBH experiences. The result of these partnerships included the spread of 2 resources. The first, *Life After Postpartum Hemorrhage* (Fig. 1), provides women and their families with information about what to expect and what symptoms to be aware of when they go home. The form includes a place for women to indicate which topics they would like more information about and addresses issues related to physical recovery, emotional recovery, and when to seek care. Upon reviewing the resource, one OBH survivor commented, "This is wonderful. I actually cried while reading it. I developed a severe postpartum mood disorder and I know that my hemorrhage played a big role. I wish I had been sent home with this colorful and insightful document." The second resource, titled, *Resources for Postpartum Hemorrhage Survivors*, includes a selection of annotated websites and online support groups that were identified as sources of informational and emotional support by the OBH survivors (Fig. 2). Although not meant to take the place of the care provided by licensed professionals, these resources were found to fill a gap for those in rural areas without ready access to specialists or mental health professionals, as well as those who found themselves with significant appointment delays needing timely resources.

**TABLE 1. Five Essential Patient and Family Support Practices Following Obstetric Hemorrhage**


1. Ensure that every patient has contact with her baby as soon as she is alert and medically stable
2. Assess every patient's desire to begin breastfeeding and/or pumping as soon as she is medically stable, regardless of the inpatient unit
3. Address the emotional trauma of the event with every patient by normalizing emotional symptoms and providing resources for assisting both patient and family
4. Ensure that every patient receives thorough discharge education, specific to hemorrhage
5. Offer every patient and family a postdischarge debrief following a hemorrhage event

# Life After Postpartum Hemorrhage

Use this tool to learn what to expect and to identify topics you would like more information on.



Insert Hospital  
Logo Here



		I Would Like More Information About This Topic
Key Points about Postpartum Hemorrhage (PPH)	Losing a lot of blood quickly can cause a severe drop in your blood pressure. It may lead to shock and death if not treated.	<input type="checkbox"/>
	Quickly finding and treating the cause of bleeding can often lead to a full recovery.	<input type="checkbox"/>
	Postpartum hemorrhage can occur up to 12 weeks after birth. Talk to your healthcare provider about your risk and symptoms to watch for.	<input type="checkbox"/>
Physical Recovery	Losing a lot of blood can leave you feeling tired and weak. Your provider may want to do tests to find out how your body is coping with blood loss. This will help them decide what treatment to recommend.	<input type="checkbox"/>
	When your body is having trouble coping with blood loss, it is normal to:	
	<ul style="list-style-type: none"> <li style="width: 50%;">Feel weak and get tired more easily</li> <li style="width: 50%;">Look very pale</li> <li style="width: 50%;">Feel dizzy</li> <li style="width: 50%;">Feel out of breath</li> <li style="width: 50%;">Be grumpy, cranky or angry</li> <li style="width: 50%;">Have trouble focusing or concentrating</li> <li style="width: 50%;">Have headaches</li> <li style="width: 50%;">Have ringing in ears</li> </ul>	<input type="checkbox"/>
	If you have any of the symptoms listed above, your healthcare provider may want you to take iron. If your iron levels are very low, you may be offered iron by injection, IV or even a blood transfusion.	<input type="checkbox"/>
	Even if you are taking iron pills, your diet can be an important source of iron. Examples of iron-rich foods include: beef, shrimp, spinach, lentils, and almond butter.	<input type="checkbox"/>
Emotional Recovery	The “baby blues” and postpartum depression and anxiety can affect anyone. You may be more likely to have postpartum depression, anxiety or even post-traumatic stress disorder (PTSD) after a postpartum hemorrhage.	<input type="checkbox"/>
	Some symptoms of postpartum depression, anxiety and PTSD include:	
	<ul style="list-style-type: none"> <li style="width: 50%;">Feeling low (depressed mood) or angry most days</li> <li style="width: 50%;">Loss of confidence or self esteem</li> <li style="width: 50%;">Loss of interest in activities that you used to enjoy</li> <li style="width: 50%;">Loss of appetite or overeating</li> <li style="width: 50%;">Having trouble concentrating</li> <li style="width: 50%;">Recurrent thoughts of suicide or death</li> <li style="width: 50%;">Having trouble falling asleep or staying asleep</li> <li style="width: 50%;">Reliving the event</li> <li style="width: 50%;">Anxiety or excessive worry</li> <li style="width: 50%;">Feeling unable to take care of your baby</li> </ul>	<input type="checkbox"/>
	If you have any of the symptoms listed above, contact your healthcare provider right away.	<input type="checkbox"/>
	Whether you’ve had a hysterectomy or face a higher risk of postpartum hemorrhage with future pregnancies, there is often a grieving process to work through. Talk to your healthcare provider about support available.	<input type="checkbox"/>

**FIGURE 1.** “Life After Postpartum Hemorrhage” resource created by OBH survivors.

### ***Implementing Patient and Family Support Resources***


To underscore the need for patient and family support resources, 3 OBH survivors were asked to share their personal

experiences during an in-person learning session with PQCNC hospital-based OBH teams. While sharing their stories, the women connected their lived experiences to the 5 essential patient and

	I Would Like More Information About This Topic
Call Your Healthcare Provider	If you have heavy bleeding that soaks 1 maternity pad in an hour for 2 hours in a row. <input type="checkbox"/>
	If you pass large blood clots. <input type="checkbox"/>
	If you are breathing faster than normal, or your heart is beating faster than normal. <input type="checkbox"/>
	If you are urinating less than usual, or not at all. <input type="checkbox"/>
	If you feel dizzy. <input type="checkbox"/>
	If you have questions or concerns about your condition or care. <input type="checkbox"/>
Go to the Emergency Department	If you have heavy bleeding that soaks 1 maternity pad in 15 minutes or less. <input type="checkbox"/>
	If you are suddenly short of breath and feel lightheaded. <input type="checkbox"/>
	If you have sudden chest pain. <input type="checkbox"/>


Some women find it helpful to speak with their healthcare provider about the events surrounding their hemorrhage after they have had time to heal. Having this opportunity after you leave the hospital can help you fill in gaps of time you don't remember and allow for answers to questions that didn't come up until after you've spent some time at home. If you would like an opportunity to meet with your healthcare provider, we encourage you to call his or her office to schedule an appointment when the time feels right to you. Be sure to let the scheduler or your provider's nurse know what information you would like to receive during the appointment, so that your healthcare provider can come prepared to answer your questions.

## Your Steps to Success




**BUILD**

Build a team to support you that includes trusted providers, friends and family, and peer support.




**LEARN**

Learn what to expect and what you can do to advocate for your physical and emotional health and well-being.



**SHARE**

Share your informational and emotional support needs with your healthcare provider.



**SUCCEED**

Partner with your support team to make a plan for addressing your physical and emotional needs.

Visit [www.pqcnc.org](http://www.pqcnc.org) to learn about North Carolina's Postpartum Hemorrhage Initiative (AIM OBH) and to find out how patients and families are partnering with healthcare providers to help make North Carolina the best place to give birth and be born.




FIGURE 1. (Continued)

family support practices that hospitals had previously reported on; they highlighted how support might have been more effective if the identified practices

and relevant resources had been in place. The PQCNC team then shared the codesigned resources and described how hospitals would be able to access



# Resources for Postpartum Hemorrhage Survivors



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Women who have had a Postpartum Hemorrhage (PPH) often have many informational and emotional needs after they leave the hospital. This list of resources was compiled by women who have experienced a hemorrhage following the birth of their child. It includes a selection of websites and online support groups that they have found helpful.

**After the ICU:** <http://www.aftertheicu.org/>

This site was created by a group of doctors, former patients and other healthcare professionals, working together to provide Intensive Care Unit (ICU) patients, their families and other medical professionals with information about the road to recovery after critical illness. Resources are provided that address physical, emotional and cognitive needs following an ICU discharge.

**After Trauma:** <http://www.aftertrauma.org/>

This site is meant to provide a community for survivors of traumatic injury and their families to support and connect with one another. Information and resources are also provided to help survivors and families on the recovery journey.

**Amniotic Fluid Embolism Foundation:** <http://afesupport.org/>

This site includes resources for family members (caregivers), survivors, and those who have experienced a loss related to Amniotic Fluid Embolism (AFE). Guides and resources help survivors and families from the crucial moments after AFE, through the hours, days and weeks following.

**Birth Trauma Association:** <http://www.birthtraumaassociation.org.uk/>

Resources on this site are meant to support women who have suffered difficult births by offering information, advice and peer support to all women who are finding it hard to cope with their childbirth experience.

**Healthtalk.org:** <http://www.healthtalk.org/peoples-experiences/pregnancy-children/conditions-threaten-womens-lives-childbirth-pregnancy/topics>

This section of healthtalk.org addresses the experience of conditions that threaten women's lives in pregnancy and childbirth by seeing and hearing people share their personal stories on film. The Teaching Resources area of the site includes key learning messages from interviews with patients who have experienced a near miss.

**Hope for Accreta:** <http://www.hopeforaccreta.org/>

This site includes photos and stories submitted by Accreta survivors, as well as helpful links and ways to connect with peers both virtually and through local chapters.

**March of Dimes:** <http://www.marchofdimes.org/pregnancy/postpartum-hemorrhage.aspx>

This section of marchofdimes.org discusses the signs and symptoms, risk factors and treatment of postpartum hemorrhage. Information regarding related conditions is also provided.

**FIGURE 2.** Resources for postpartum hemorrhage survivors created by OBH survivors.

them. Over the following months, the PQCNC staff, including process improvement and PFE coaches, maintained regular contact with the

hospitals and provided guidance regarding implementation and evaluation of the patient and family support resources. In particular, teams were guided

**Medically Induced Trauma Support Services:** <http://www.mitss.org/>

The Medically Induced Trauma Support Services (MITSS) site includes a section devoted to patients and families. Resources focus primarily on therapeutic needs and support. In addition to accessing informational support, visitors to the site can read or watch videos of patient and family stories and connect to online support groups.

**Postpartum Support International:** <http://www.postpartum.net/>

The site provides links to information about perinatal mood and anxiety disorders, including risk factors, symptoms and treatments. Visitors to the site are able to identify local resources, chat with an expert or join an online support group. Highlights include resources for special groups such as military families, women of color, fathers, and more.

**Preeclampsia Foundation:** <https://www.preeclampsia.org/get-support>

This site includes multiple resources on preeclampsia and other hypertensive disorders of pregnancy. Visitors can link with health experts for advice and connect with other preeclampsia survivors through the Community Forum or Share Your Story thread.

**Prevention and Treatment of Traumatic Childbirth (PATTCh):** <http://pattch.org/>

Information on this site helps explain the components of traumatic birth and describes the symptoms, risk factors, treatment and prevention of traumatic birth.

**Solace for Mothers:** <http://www.solaceformothers.org/>

The resources available through this site are meant to offer immediate, personal support to mothers and others who are struggling with birth trauma, PTSD after childbirth and anxiety caused by their birthing experiences.

**Facebook Support Groups****HFA Hysterectomy due to Childbirth Support Group:** <https://www.facebook.com/groups/787583127981280/>

This is a Facebook Group for women who required a hysterectomy due to childbirth.

**Maternal Near-Miss Survivors:** <https://www.facebook.com/groups/maternalnearmiss/>

This Facebook Group is designed to be a safe place where survivors of a maternal near miss find comfort and offer support to one another. A maternal near miss is defined as an event where a woman nearly dies due to pregnancy or childbirth related complications.

**Postpartum Hemorrhage:** <https://www.facebook.com/groups/pphsupport>

This Facebook Group is for people who have experienced a postpartum hemorrhage or excessive blood loss following childbirth. Members include parents, birth workers and health providers.

**Postpartum Hemorrhage and Hysterectomy:** <https://www.facebook.com/groups/55913304922/>

This is a Facebook Group for women who have experienced a postpartum hemorrhage and hysterectomy.

**Unexpected Project:** <https://www.facebook.com/UnexpectedProject/>

This Facebook Page is a place for the survivors and loved ones of pregnancy-related death and near-death in the USA to share their stories and raise awareness. Members include women who survived a near-miss, individuals who support near-miss survivors, and loved ones who lost a woman due to complications of pregnancy.

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**FIGURE 2.** (Continued)

toward the adoption of processes that would consistently ensure that patients experiencing OBH would be identified and successfully receive resources before discharge from the hospital. Emphasis was


on ensuring that there was an opportunity for the patient and family to review the resource and verbalize understanding of the material or gain clarity from clinical staff if questions arose.



## Patient Feedback Questions for Obstetric Hemorrhage



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Receiving feedback from patients to understand the OBH experience from their perspective is vital for improving quality and safety. Use the questions below to guide you through conversations with your OBH patients. Consider providing follow-up with patients by phone within 10-14 days of discharge. Before they go home, let them know to expect the call – it will increase the likelihood of connecting.

**Postpartum Hemorrhage/Bleeding Questions for Patients**

Introduce the questions by letting the patient know you are reaching out because your hospital is working to ensure that women who experience hemorrhage/significant bleeding after delivery receive all of the support they need. Let her know that hearing about her experience will help your team understand what they are doing well (and should keep doing) and what they should consider doing differently. If she agrees to help, proceed with the following questions...

1. Can you tell me about your delivery and postpartum experience? (Let the patient tell her story. Allow the patient to talk for as long as she wishes.)

Possible follow-ups:

- Were you alone or was someone there with you? Who? What have they told you about the experience?
- Did you know you were at risk for postpartum hemorrhage/bleeding?
- Was your C-section/hysterectomy/etc. planned?

2. What do you remember being told about hemorrhage/bleeding before being discharged?
3. Did you have any concerns about going home? Did you develop any concerns once you were home?
4. What information do you wish you had received before going home?
5. What could we have done better to support you before, during, or after your hemorrhage/bleeding?
6. Would you be interested in meeting with your doctor to learn more about what happened during your hemorrhage/bleeding?
7. What else would you like for me to know?
8. Do you have any questions for me?

**FIGURE 3.** Script to assist hospital staff when having follow-up conversations with OBH survivors.

### ***Pursing Patient and Family Feedback to Improve Quality and Safety***

As few teams had recruited patient partners to serve on their OBH team to assist with

the implementation process, hospitals were asked to contact recent OBH survivors following discharge to ask for feedback on their patient and family support experience following OBH. Teams were advised to inform patients, while still in the hospital,

that a follow-up phone call should be expected between 10 and 14 days following discharge, increasing the likelihood of connecting with the mother and allowing her time to reflect on her experience before giving feedback. Although promoting PFE in individual care is a familiar practice, PFE at the unit or organizational level is less understood.<sup>12</sup> For this reason, the PQCNC staff created a tool to guide clinical staff instructing them on how to perform the follow-up call (Fig. 3).

Many of the insights gained from these calls included missed opportunities to partner with patients. Many stories highlighted delayed, absent, or unclear information-sharing, especially around the assessment of patient risk for OBH. Completing an evidence-based risk assessment upon admission to the birthing center was an intervention many teams adopted during our initiative. However, most teams were completing this form independent of the patient, utilizing information documented in the electronic medical record or prenatal records. Unfortunately, it was not uncommon for previous documentation to be incorrect, indicating no previous OBH when in fact I had been experienced. The feedback calls illuminated the need to change this process, partner with patients, and use this opportunity to obtain vital information measuring a patient's risk as well as educate them simultaneously on what puts them at risk—not only with this pregnancy but with subsequent pregnancies.

## Conclusions

In a March 6, 2018 speech to an audience at the Healthcare Information and Management Systems Society conference, Centers for Medicare and Medicaid Services administrator, Seema Verma stated, "Let me be clear, we will not achieve value-based care until we put the patient at the center of our health care system."<sup>13</sup> This manuscript outlines several approaches to achieving this goal. One is to meaningfully

partner with, value, and act on the opinions of patients and families in the selection, design, and implementation of statewide perinatal quality improvement projects. Another is to ensure the critical perspective of patients and family members addresses engagement at both the individual and organizational levels. Connecting the voices of hemorrhage survivors to frontline staff in hospitals across North Carolina delivered the reason implementing a hemorrhage bundle was vital to safe patient care. The patient voice elevated engagement and provided the reason why working hard to recognize and respond quickly to those patients at-risk was a responsibility that could not be ignored.

Though difficult to measure, the voice of the patient and their families is worth finding, embracing, and infusing in all quality improvement projects. The value of patient and family partnership described in this manuscript echoes experiences of others working in perinatal quality improvement where the value of PFE is inferred. If the implied benefit is measurable, is it a dose-response relationship or is there a critical threshold that needs to be met to demonstrate the value? We encourage perinatal quality collaboratives and other organizations to continue to identify methods that will capture the impact of PFE and glean value in what we feel provides optimal, safe patient care.

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