WOMEN'S EXPERIENCE OF OBSTETRIC HEMORRHAGE: INFORMATIONAL, EMOTIONAL AND PHYSICAL HEALTH NEEDS

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EXECUTIVE SUMMARY

- Women and families need information and emotional support during and after an obstetric hemorrhage.
- Women need to experience being listened to and have their experience acknowledged from their own, rather than the clinicians' perspective.
- Women need to know what happened to them, and why. Formal discussions about their experience and prognosis should occur throughout their hospitalization and during postpartum follow up visits.
- After a severe hemorrhage, maternity clinicians should be alert for behavior or emotional states in women that are outside the normal range of postpartum responses. Such reactions may include detachment, dissociation, and intrusive thoughts.
- The experience of traumatic birth after hemorrhage is individual; not all women respond the same way. Factors affecting the development of traumatic reactions may include the woman's sense of threat to her or her baby, loss of control, or loss of trust in caregivers. Women's reactions may not correspond with clinicians' perception of the level of the severity, or resolution of the complication.
- Tailored and specific discharge planning for women and their families who have experienced hemorrhage should include assessment for women's physical and emotional recovery, and referrals for counseling and support in the community.

BACKGROUND AND LITERATURE REVIEW

There is little research on women's experience of hemorrhage in the United States. However, international research and published first person narratives provide insights into women's experience of severe maternal morbidity. These insights suggest we can better meet the needs of women and families regarding information and emotional support during and after a severe maternal hemorrhage.[1-8,11]

After a traumatic birth event, women seek to understand what happened to them, make sense of the reasons behind their experience, and think about implications for their long-term health and possible future childbearing. Research on women's experience of

obstetric hemorrhage from studies conducted in Australia, the United Kingdom and other countries shows that a significant proportion of women report not receiving adequate information about their condition and recovery.[2,3,9] While women report feeling grateful to health professionals for the life saving care provided to them and their babies, women often report feelings of anger and frustration at not receiving sufficient information and/or at the quality of the emotional care they received.[4,5]

In a study of 206 Australian women who had significant postpartum hemorrhage, twenty percent of the women reported they did not receive care that consistently met their needs for acknowledgement, reassurance, and information while in the hospital[7], and 37% believed the hemorrhage might have been prevented with different care. A participant in an ongoing study of U.S. women's experiences of maternal complications recalled:

> *I must have used the portable toilet four times in that Emergency Room. The nurse never weighed that blood. And that's a common thing: people don't realize you're hemorrhaging because they don't even keep track. (Beth)* [10]

These and other findings suggest that women are attuned to delays in recognition of and response to hemorrhage, and may be further traumatized by perceptions of sub-optimal care. Such experiences may intensify the need for a formal discussion, including review of events and prognosis, with a health care provider who was present during the event.

In the case of language barriers, provision should be made for professional (non-family) translators, preferably with experience in obstetrics. A study of Swedish immigrant women's experience of maternal morbidity found that women felt health care providers underestimated their complaints, did not provide women with adequate information about their diagnosis and treatment options nor their risks for the complications they experienced, and this was especially marked among women with low education levels [11].

After a significant morbidity, referral for follow-up counseling and mental health services is also recommended.[2] Physician and nursing providers may not know how women have perceived their experience, thus assessment and discharge planning for follow-up care are essential for all women who have experienced severe hemorrhage or other potentially traumatic birth experiences.

Finally, it is important to note that there are no specific organizations that support the unique needs of women who have experienced a severe obstetric hemorrhage but there are resources that address medical crises and the impact of trauma in childbirth.

INFORMATIONAL, EMOTIONAL AND PHYSICAL HEALTH NEEDS

Key informational, emotional and physical health needs particular to specific time periods are summarized in Table 1 (found directly before the references) and briefly elaborated below.

Before the Critical Event

Women who communicate with providers or present to care with a concern about their symptoms should be listened to respectfully and given full, complete information about their concerns. All women who have been identified to be at high risk for obstetric hemorrhage should be counseled early in their prenatal course about the likelihood of blood transfusions. The discussion, patient preferences and plan regarding treatment should be documented and communicated to the facility where the woman will give birth. In complex cases, the primary maternity provider should ensure that all relevant disciplines (e.g. anesthesia, nursing, and sub-specialty services as appropriate to the woman's condition) are included in care planning.

During the Critical Event

Families and other close support persons are an integral part of the birth process, often providing strength and support for patients in managing unexpected health crises. During childbirth, health crises are especially unexpected and family members need information and support; they may wish to stay with their loved one throughout the course of care. Health care providers are often uncomfortable with family presence during procedures and resuscitation due to fears of distraction, interference by family members, psychological distress for family members and liability concerns.[12-14] However, studies suggest these fears are unfounded, and family members, patients and clinicians benefit from family presence, even during resuscitation.[15-21] Survey data revealed patients and families overwhelmingly wanted the option of family presence at resuscitations.[22] There is no evidence to support health care providers' perceptions or concerns that family members are disruptive during invasive procedures or resuscitations, or that family presence increases malpractice risk.[17,20,22] A recent clinical trial suggests psychological benefit for family members present during CPR.[20,22,23] Support for family presence during invasive procedures and resuscitations is formally endorsed by the Society for Critical Care Medicine, American Academy of Pediatrics, American College of Emergency Physicians, American Association of Critical Care Nurses, and the Emergency Nurses Association.[22,24-26]

Patient and family expectations and desires for presence during urgent medical care and resuscitation should be ascertained and supported.[27] It is generally appropriate for a family member or other close personal support person to remain with the patient during resuscitation if they wish to do so. Family members who witnessed resuscitations in patients who ultimately died reported easier adjustment to death and grieving and felt

their presence was beneficial to their loved ones. Patients who have survived resuscitations witnessed by family members also report this was beneficial.[12,13,18,20,22] Hospitals should have a clear, formal policy for family presence during emergencies and resuscitations in obstetric units. Such policies should include a designated support person for the family member.[19,26]

Recovery after the Critical Event (In hospital)

Although clinicians may feel relief that the clinical situation was successfully managed, it is important to remember that the patient has a potentially long and challenging recovery ahead of her, as well as the need to care for her new baby. If she is in a critical care unit, it is important to create a calm, healing environment. When the prognosis is relatively positive, clinicians can sometimes lose focus and talk about their own reactions or chat about extraneous events while providing clinical care. This can have the effect of denying the humanity of the patient and her current reality. Michelle Flaum Hall remembers feeling erased as a person when a clinician chatted casually about weekend plans while hanging a bag of blood:

> *I needed my providers to maintain a caring and professional focus on me, which means not allowing one's own "stuff" to get in the way of sensitive and respectful communication. Experiencing medical trauma can be dehumanizing; treating patients as competent, resilient people restores their humanity.*[4]

It is critical that health care providers be especially careful in the manner and language used to communicate with women after a critical event, especially when there has been an unexpected or unwanted outcome, such as a hysterectomy.

> *I can remember waking up and feeling…I was just mad. I was angry that it [a hysterectomy] had happened. I don't remember how I knew that everything had happened. I was told that a nurse had told me. She didn't know that I didn't know, that I wasn't going to be able to have any more kids. I had no clue what she was talking about and no one wanted to tell me at that point because I still wasn't stable and I guess this nurse kind of messed up and told me. And apparently I screamed and I was angry and I made her cry. (Jennifer)*[10]

An unexpected physical trauma may affect women's preferences regarding self and newborn care. As with all support, it is important to follow women's lead. For example, some women are grateful for breastfeeding assistance, such as pumping, in the ICU; others report difficulty in obtaining appropriate support. Still others may be worried about how lactation may affect their own healing, or may find that the physical challenges of healing supersede their prior preferences. It is important not to make assumptions about what women need, can, or "should" do during this time. Shared decision-making using

high quality information should be used to support the mother in her decisions and actions regarding feeding and other newborn care.

Maternity clinicians should assess women's emotional state and pay attention to signs of trauma and negative emotional states, such as depression or dissociation. If available at the facility, on-site referrals to mental health professionals may be useful. Clinical counselor Michelle Flaum Hall developed a sample tool for maternity clinicians to assess women's acute stress levels after a severe morbidity (see Appendix G, page 172-176).

Recovery after the Critical Event (At home)

Women with moderate or severe morbidity related to an obstetric hemorrhage are faced with their own physical recovery needs but also the responsibility of caring for a newborn at home. It is important to assess women's needs for, and access to, in-home support and care. Women who have experienced a significant morbidity as a result of childbirth should receive specific discharge planning reflecting their needs for physical and emotional recovery in addition to the routine discharge planning and teaching regarding care of themselves and newborn(s). A sample discharge planning tool is available on page 139-140.

Some women fear being alone at home with the baby, especially if the hemorrhage began during the postpartum period and they remember passing out or calling paramedics.[10] Many women may be physically weak and require additional help at home. Family members may not live nearby, and those who came from a distance for the birth may be unable to extend their stay. Partners may have to work and may not have sufficient time off to stay with women after they are discharged home.

Women who have experienced a life-threatening event experience an existential crisis as well as a medical one.[2,3,9,10] They need to process the event yet often find that family members and friends wish to put the ordeal behind them.

> *There are times…when people say, "Oh, you should just be thankful you're alive." Well, I totally agree with that, but there are times you still…you know, it's hard. I guess every once and awhile you need a pity party and just to feel bad because I would've had more children. I feel like I was cheated in that way. (Jennifer)*[10]

Family members and friends are often emotionally overwhelmed and can be unable or uncertain how best to provide support once the woman has been discharged home. Lack of support from family members can create lasting rifts:

And my father-in-law said, "What happened to you was obviously supposed to. Beth, you need to move on." And I was thinking, "Oh my god, if I was talking about this three years later, maybe someone should say that. But this has been three weeks. I've had two major abdominal surgeries in eight days of each other. I almost died and that's your response?" (Beth)[10]

Even with the highest quality of care, women may be at risk of developing traumatic stress reactions and acute stress disorder after a severe hemorrhage. These stress reactions may occur when people experience events in which there was an actual or perceived threat of death or severe injury. While not all women who have an obstetric emergency experience will develop PTSD, when it does develop, it can be debilitating and greatly impair functioning in many life domains.[2,28] Women and their families should be informed of the signs and symptoms of PTSD (for both the woman and her partner) and provided with referrals for counseling before they leave the hospital. Sensitive care may support resiliency and reduce the development of severe emotional distress if staff understand that the experience of traumatic birth is individual and may be more related to the woman's sense of threat, loss of control, loss of trust in caregivers, or other factors rather than the clinical severity or clinical resolution of the complication. This is why it is essential to assess for signs of trauma reaction before discharge, and to provide referrals and resource lists for all women who experience severe morbidity. See the Educational Tool #1 for a list of resources for birth and general trauma support and resiliency models.

RECOMMENDATIONS

1. Women who experience obstetric hemorrhage need to be
    a. Given full information about their medical condition as it happens and their prognosis;
    b. Observed for signs and symptoms of acute trauma and referred to psychological counseling resources while in hospital and/or post discharge.

2. Families and support persons should be given the opportunity to remain present during resuscitation efforts, and be given information and emotional support.

3. More research is needed on women's experience. There is little research on women's experience of obstetric hemorrhage and no research investigating predictors of trauma experience following hemorrhage or factors contributing to or interfering with emotional healing after obstetric hemorrhage with or without peripartum hysterectomy.

EDUCATIONAL TOOLS, SAMPLE DOCUMENTS

1. Educational Tool #1: Resources For Women, Families and Clinicians After and Obstetric Emergency and Resources for Maternity Clinicians after a Severe Maternal Morbidity.
2. Educational Tool #2: Discharge Planning For Women With Complications During The Birth Hospital Stay.
3. A Guide to Recognizing Acute Stress Disorder in Postpartum Women in the Hospital Setting (Appendix G).

TABLE 1:
INFORMATIONAL, EMOTIONAL & PHYSICAL HEALTH NEEDS AMONG WOMEN (AND THEIR FAMILIES) WHO EXPERIENCE MATERNAL HEMORRHAGE

	PRENATAL/ before critical event	INTRAPARTUM/ during critical event	POSTPARTUM/ in hospital recovery	DISCHARGE	POSTPARTUM/ at HOME
	Information needs				
Women	○ What is normal bleeding postpartum ○ When to seek medical care and where to go ○ **IF HIGH RISK:** Develop a plan and include information about blood donation ahead of time ○ Provide professional translator, when applicable	Factual data: ○ What is happening ○ What is being done ○ Orient to hemorrhage as emergent event ○ Provide professional translator, when applicable throughout hospital stay	○ Read the chart! Know the facts before speaking to patient ○ Sensitively and empathetically provide information about what has happened and her current condition ○ Keep focused on patient needs; avoid personal or social conversations with colleagues while with patient	○ Formal discussion: chain of events; what caused hemorrhage ○ Balance women's need to know with hospital policy around disclosure ○ Recognize possible conflict of interest ○ Provide referrals to psychological counselor or social worker	○ Risks in future pregnancy (if applicable) ○ Formal discussion about what happened and prognosis at follow up postpartum visit
Partner, Family, Support team	Same as above	Same as above, and ○ Assign support to Partner ○ Keep updated frequently ○ Keep in the room, even during emergency care if the person wishes to stay	Same as above, and ○ Assign support to Partner ○ Keep updated frequently	Same as above	Same as above

	PRENATAL/ before critical event	INTRAPARTUM/ during critical event	POSTPARTUM/ in hospital recovery	DISCHARGE	POSTPARTUM/ at HOME
	Emotional support				
Women		Reassurance: ○ Baby: Where is the baby; How is the baby ○ Provide pictures of the baby if separated for medical reasons ○ Woman: "*We are doing everything to take care of you*"	○ It may be helpful to minimize loud noises, bright lights if possible. Take the patient's lead regarding TV, visitors, etc. ○ Pay attention to signs of trauma, depression. Seek consultation with a mental health professional if necessary ○ Present information of trauma behaviors, ways to support herself in a caring, nurturing manner	○ Normalize postpartum experiences without discounting severe event	○ Pay attention to signs of trauma, depression ○ Seek consultation with a mental health professional if necessary
Partner, Family, Support team		Same as above	○ Ask how partner/family members are doing ○ Remember the partner is also processing the experience ○ Present information of trauma behaviors, ways to support mother and family in a caring, nurturing manner	○ Referral to postpartum care needs ○ Counseling and PTSD warning signs for self and woman	○ Referral to postpartum care needs ○ Counseling and PTSD warning signs for self and woman

	PRENATAL/ before critical event	INTRAPARTUM/ during critical event	POSTPARTUM/ in hospital recovery	DISCHARGE	POSTPARTUM/ at HOME
	Physical/Health Care				
Women		○ Keep mom and baby together if possible	○ Support breastfeeding if desired and provide breast pump and certified lactation consultant ○ Don't assume medications make breastfeeding contraindicated ○ Assess strength and ability to perform activities of daily living	○ Refer to Outpatient lactation support ○ Referral to physical therapy as indicated	○ Postpartum follow up within 10 days; formal discussion about what happened and prognosis
Partner, Family, Support team		○ Comfortable place to sleep ○ Private place to make calls for additional support and updates	○ Comfortable place to sleep ○ Private place to make calls for additional support and updates	○ Counsel about need for extra physical support for woman at home	○ Counsel about need for extra physical support for woman at home

REFERENCES

1. Callister LC, Holt ST, Kuhre MW. Giving birth: The voices of Australian women. *J Perinat Neonatal Nurs.* Apr-Jun 2010;24(2):128-136.
2. Elmir R, Schmied V, Jackson D, Wilkes L. Between life and death: Women's experiences of coming close to death, and surviving a severe postpartum haemorrhage and emergency hysterectomy. *Midwifery.* Apr 2012;28(2):228-235.
3. Furuta M, Sandall J, Bick D. Women's perceptions and experiences of severe maternal morbidity - A synthesis of qualitative studies using a meta-ethnographic approach. *Midwifery.* Feb 2014;30(2):158-169.
4. Hall MF. The psychological impact of medical Trauma: One woman's childbirth story. *Nurs Womens Health.* Aug-Sep 2013;17(4):271-274.
5. Pil T. Babel: The voices of a medical trauma. In: Gross P, Guernsey D, eds. *Pulse: Voices from the heart of medicine*. New Rochelle, NY: Voices from the Heart of Medicine, Inc.; 2012:158-167.
6. Souza JP, Cecatti JG, Faundes A, et al. Maternal near miss and maternal death in the World Health Organization's 2005 global survey on maternal and perinatal health. *Bull World Health Organ.* Feb 2010;88(2):113-119.
7. Thompson JF, Ford JB, Raynes-Greenow CH, Roberts CL, Ellwood DA. Women's experiences of care and their concerns and needs following a significant primary postpartum hemorrhage. *Birth.* Dec 2011;38(4):327-335.
8. Tuncalp O, Hindin MJ, Adu-Bonsaffoh K, Adanu R. Listening to women's voices: The quality of care of women experiencing severe maternal morbidity, in Accra, Ghana. *PLoS One.* 2012;7(8):e44536.
9. HealthTalk Online. Conditions that threaten women's lives in childbirth and pregnancy. *HealthTalk Online: People's Experiences 2014* 2014; http://healthtalkonline.org/peoples-experiences/pregnancy-children/conditions-threaten-womens-lives-childbirth-pregnancy/topics.
10. Morton C, Nack A, J B. The social invisibility of maternal morbidities in US motherhood narratives: Giving voice to lived experience. Motherhood Conference; March 6-8, 2014, 2014; New York City.
11. Jonkers M, Richters A, Zwart J, Ory F, van Roosmalen J. Severe maternal morbidity among immigrant women in the Netherlands: patients' perspectives. *Reprod Health Matters.* May 2011;19(37):144-153.
12. Critchell C, Marik P. Should family members be present during cardiopulmonary resuscitation? A review of the literature. *Am J Hosp Palliat Care.* 2007;24(4):311-317.
13. Duran C, Oman K, Abel J, Koziel V, Szymanski D. Attitudes toward and beliefs about family presence; a survey of healthcare providers, patients' families, and patients. *Am J Crit Care.* 2007;16(3):270-279.
14. Sak-Dankosky N, Andruszkiewicz P, Sherwood PR, Kvist T. Integrative review: nurses' and physicians' experiences and attitudes towards inpatient-witnessed resuscitation of an adult patient. *J Adv Nurs.* Oct 24 2013.

15. Merlevede E, Spooren D, Henderick H, et al. Perceptions, needs and mourning reactions of bereaved relatives confronted with a sudden unexpected death. *Resuscitation.* Jun 2004;61(3):341-348.
16. Meyers T, Eichhorn D, Guzzetta C. Do families want to be present during CPR? A retrospective survey. *J AEmerg Nurs.* 1998;24(5):400-405.
17. Sacchetti A, Paston C, Carraccio C. Family members do not disrupt care when present during invasive procedures. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine.* May 2005;12(5):477-479.
18. Wagner JM. Lived experience of critically ill patients' family members during cardiopulmonary resuscitation. *Am J Crit Care.* Sep 2004;13(5):416-420.
19. Doolin CT, Quinn LD, Bryant LG, Lyons AA, Kleinpell RM. Family presence during cardiopulmonary resuscitation: Using evidence-based knowledge to guide the advanced practice nurse in developing formal policy and practice guidelines. *Journal of the American Academy of Nurse Practitioners.* Jan 2011;23(1):8-14.
20. Jabre P, Belpomme V, Azoulay E, et al. Family presence during cardiopulmonary resuscitation. *N Engl J Med.* Mar 14 2013;368(11):1008-1018.
21. Porter JE, Cooper SJ, Sellick K. Family presence during resuscitation (FPDR): Perceived benefits, barriers and enablers to implementation and practice. *International emergency nursing.* Apr 2014;22(2):69-74.
22. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Crit Care Med.* Feb 2007;35(2):605-622.
23. Geshman J. Health cut hits hurdle: Plan to reduce spending by discouraging C-sections falters after hospitals balk. *Wall Street Journal.* July 13, 2011, 2011.
24. American Association of Critical-Care Nurses. Family presence during CR and invasive procedures. *AACN Practice Alert* 2010. http://www.aacn.org/wd/practice/docs/practicealerts/family presence 04-2010 final.pdf. Accessed January 22, 2014.
25. American Academy of Pediatrics Committee on Pediatric Emergency M, American College of Emergency Physicians Pediatric Emergency Medicine C, O'Malley P, Brown K, Mace SE. Patient- and family-centered care and the role of the emergency physician providing care to a child in the emergency department. *Pediatrics.* Nov 2006;118(5):2242-2244.
26. Emergency Nurses Association. *Family presence during invasive procedures and resuscitation.* Des Plains: ENA;2012.
27. Lederman Z, Garasic M, Piperberg M. Family presence during cardiopulmonary resuscitation: Who should decide? *Journal of medical ethics.* Apr 10 2013.
28. Elmir R, Schmied V, Wilkes L, Jackson D. Women's perceptions and experiences of a traumatic birth: A meta-ethnography. *J Adv Nurs.* Oct 2010;66(10):2142-2153.