Creating a Culture of Consumer Engagement in Maternity Care

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ABSTRACT

In this column, the author reprises recent selections from the Lamaze International research blog, *Science & Sensibility*. Each selection discusses opportunities to establish a culture of consumer engagement in maternity care. The author demonstrates how improving health literacy, ensuring multi-stakeholder participation in the development of clinical guidelines, and supporting comparative effectiveness research of woman- and family-centered care practices may improve maternity care.

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Lamaze International's research blog, *Science & Sensibility*, is intended to help childbirth educators and other birth professionals gain the skills necessary to deconstruct the evidence related to current birth practices. Visit the Science & Sensibility Web site (www.scienceandsensibility.org) to stay up to date and comment on the latest evidence that supports natural, safe, and healthy birth practices.

Amy Romano, host of the *Science & Sensibility* research blog, invites readers to respond to the posts reprinted in this article. Go to the URLs presented in the corresponding footnote for each section's main heading and post your response.

In January, a multi-stakeholder group of leaders from across the U.S. health-care system issued recommendations for transforming maternity care (Angood et al., 2010). With consumers and their advocates at the center of the process, the leaders articulated a vision for a woman- and family-centered, community-based, integrated primary care system and offered specific recommendations in 11 critical focus areas. "Decision Making and Consumer Choice" was one of these areas, and the recommendations in this area were as follows:

1. Expand the opportunities and capacity for shared decision-making processes, and tools and resources to facilitate informed choices in maternity care.
2. Design system incentives that reward provider and consumer behaviors that lead to healthy pregnancies and high quality outcomes.
3. Revive and broaden the reach of childbirth education through expanded models and innovative teaching modalities.

4. Promote a cultural shift in attitudes toward childbearing. (Angood et al., 2010, p. S20)

These recommendations acknowledge what many in the childbirth education community already know: Engaging consumers is more than just providing education. Women are "educated" about birth from a young age through cultural messages, make decisions about their care in the context of a system that values institutional routines over individual preferences and needs, and sometimes lack the ability to exercise informed consent and refusal. Creating a culture of consumer engagement in maternity care will take a broad effort at every level of our system.

Recently on Lamaze International's research blog *Science & Sensibility*, we have been exploring these issues. Recent posts about creating a culture of consumer engagement address childbirth literacy and cultural messages, the potential role of consumers to influence policies related to vaginal birth after

cesarean (VBAC), and the need for more research that evaluates consumer engagement strategies and family-centered care.

CHILDBIRTH LITERACY: WHAT WE'RE UP AGAINST¹

If anyone is wondering whether good quality childbirth education is necessary in our “information age,” the past month offers three compelling reasons to think that women remain profoundly in need of a trustworthy, reliable resource for learning how to have safe and healthy birth experiences.

1. The December issue of *Obstetrics & Gynecology* reports results of a survey by UnitedHealthcare of 650 insured women who had given birth to their first child within the previous 18 months (Goldenberg, McClure, Bhattacharya, Groat, & Stahl, 2009). Researchers asked the mothers, “At what gestational age do you believe the baby is considered full term?” (p. 1254). Nearly 1 in 4 mothers (24%) chose 34–36 weeks, half chose 37–38 weeks, and the remaining quarter chose 39–40. Researchers also asked, “What is the earliest point in the pregnancy that it is safe to deliver the baby, should there be no other medical complications requiring early delivery?” (p. 1254). More than half (52%) of the new mothers chose 34–36 weeks, while fewer than 10% chose 39–40 weeks. For neither question did women’s responses vary significantly by age, ethnicity, marital status, education, region of the country, or income.

The researchers did not report which women took childbirth education classes and whether responses were more accurate among women who did. But another research team reported that childbirth classes that include specific content focusing on risks of elective induction are effective at reducing demand for such inductions (Simpson & Newman, 2008). Now that hospitals face Joint Commission core quality measures for perinatal care that include refraining from elective deliveries prior to 39 weeks, the results of UnitedHealthcare’s survey strongly suggest that educating women about the risks of cutting a healthy pregnancy short will play an important role in helping hospitals comply.

2. In the current issue of *Birth*, a team of midwifery researchers report findings from a qualitative study of 10 top-selling childbirth advice books (Kennedy, Nardini, McLeod-Waldo, & Ennis, 2009). The researchers used discourse analysis to gauge such factors as how the woman’s role was portrayed, whether language emphasized risk, how birth settings and providers were described, how pain and coping strategies were discussed, and whether the books provided full disclosure of best scientific evidence. While a few books provided evidence-based information, normalized the process of birth, and situated the mother at the center of decision-making, others painted birth as scary, risky, foul, and debilitating, or reinforced messages that women should cede their power to doctors and modern medicine. The researchers conclude:

The U.S. medical and obstetrical community presents itself as practicing according to best scientific evidence. However, many of the books examined, 70 percent of which were endorsed, reviewed, and/or written by physicians, did not systematically present data to support or refute common maternity practices. Why? Does evidence counter or conflict with common obstetrical practice? Will women become “too” demanding or make decisions for which they are deemed unqualified? (Kennedy et al., 2009, p. 323)

3. RH Reality Check just posted an interview with childbirth educator Vicki Elson, whose documentary film, *Laboring Under an Illusion*, explores another way people in our culture learn about birth: on television (Newman, 2009). Elson presents 100 clips from sitcoms, “reality” birth TV shows, movies, and childbirth education videos to juxtapose real births with fake births and “let people make up their own minds” (Newman, 2009, para. 10). Elson describes her impetus for making the movie:

I was doing a workshop for nurse-midwives at a local hospital when a particularly ghastly and unrealistic (and Emmy-winning) episode of “E.R.” came out. The midwives said their phones were ringing off the hooks because moms were scared that they could die like the lady on TV. Meanwhile, Murphy Brown was America’s liberated TV mom who could anchor the news and stand up to Dan Quayle. But in labor, she was wilted and powerless,

¹ Posted December 21, 2009, at <http://www.scienceandsensibility.org/?p=897>

except when she was strangling men by their neckties. I wanted my kids and their friends to grow up with realistic, nourishing imagery about the power of their bodies to do normal things like have babies. I was working with midwives Rahima Baldwin Dancy and Catherine Stone on a workshop called "Empowering Women in the Childbearing Year," and we started collecting clips to show childbirth educators what they were up against from the culture. It's still a struggle to compete with compelling but unrealistic imagery that sticks in people's minds. I expanded on that project to write my master's thesis 10 years ago, and when the kids grew up I finally got around to updating the project and putting it on DVD so it's more useful and accessible. (Newman, 2009, para. 8)

delivery in the United States?" The panel will certainly look to Centers for Disease Control and Prevention data for this question, and will see the all-to-familiar curve that shows VBAC rates increasing steadily through the mid-1990s and then plummeting (Hamilton, Martin, & Ventura, 2007).

I would suggest the following additional sources:

The Listening to Mothers II survey, a nationally representative survey of women who gave birth in U.S. hospitals in 2005 (Declercq, Sakala, Corry, & Applebaum, 2006). The researchers found:

Among those women who had had a cesarean in the past, 11% had a vaginal birth after cesarean for the most recent birth, while 89% had a repeat cesarean. Of women with a previous cesarean, 45% were interested in the option of a VBAC, but most of these women (57%) were denied that option. The most common reasons for the denial of the VBAC were unwillingness of their caregiver (45%) or the hospital (23%), followed by a medical reason unrelated to the prior cesarean (20%). (Declercq et al., p. 27)

The Database of Hospital VBAC Bans produced by volunteers from the International Cesarean Awareness Network (<http://ican-online.org/vbac-ban-info>). The database lists all hospitals with official policies banning VBAC as well as those with "de facto bans," in that the hospital allows VBAC but none of the providers practicing there offer the option to their patients. According to a press release about the database, the number of hospitals banning VBAC has increased 174% since 2004 (International Cesarean Awareness Network, 2009).

Evidence that hospitals are relying on court-ordered cesareans to enforce VBAC-bans, resulting in high-profile cases, such as that of Joy Szabo, who traveled hundreds of miles to another hospital to avoid the court-ordered repeat cesarean (Cohen, 2009), and Laura Pemberton, who planned a home birth in an unsuccessful attempt to avoid a court order (National Advocates for Pregnant Women, 2009).

ARE CONSUMERS AT THE BOTTOM OF THE EVIDENCE PYRAMID?³

I have argued before on this blog and elsewhere that strategies that involve increased participation by

LET YOUR VOICE BE HEARD AT THE VBAC NIH CONSENSUS DEVELOPMENT CONFERENCE²

I arrived home from my holiday vacation to a stack of mail that included an invitation from the National Institutes of Health (NIH) to attend the Consensus Development Conference on Vaginal Birth after Cesarean this March. The conference is free and open to the public and will be broadcast by live webcast. Invited experts will present findings from a systematic review of the scientific evidence, consider several key questions, accept public comment, and ultimately prepare a consensus statement.

The 2006 so-called "Cesarean Delivery on Maternal Request" NIH conference was deeply flawed and yet legitimized the tiny number of truly elective primary cesareans on the basis of maternal autonomy (Childbirth Connection, 2008). NIH consensus conferences can influence policy and practice, so as advocates for safe and healthy birth choices and for patients' rights to informed consent and refusal, it is in our interest to see that the upcoming VBAC conference brings together the best possible evidence on all birth choices for women with prior cesareans.

Here at *Science & Sensibility*, we plan to offer our thoughts on sources of data for the conference's key questions, focusing on sources that are likely to be missed, ignored, or undervalued by the panel. The first key question is, "What are the rates and patterns of utilization of trial of labor after prior cesarean, vaginal birth after cesarean, and repeat cesarean

To view the full proceedings and read the evidence report from the NIH Consensus Conference on Vaginal Birth After Cesarean, visit <http://consensus.nih.gov/2010/vbac.htm>

² Posted on January 4, 2010, at <http://www.scienceandsensibility.org/?p=908>

³ Posted January 17, 2010, at <http://www.scienceandsensibility.org/?p=921>

women and families in maternity care hold major potential for improving our rather dismal maternal and infant health outcomes.

A study reported in the current issue of the *International Journal of Gynecology & Obstetrics* highlights a major obstacle to implementing consumer-led health strategies: lack of comparative effectiveness research supporting their use (Belizán et al., 2010). The researchers analyzed all Cochrane Systematic Reviews addressing pregnancy, childbirth, newborns, or children up to 5 years old. They categorized each systematic review by the level of consumer involvement versus health-care system involvement that the intervention required. They found that 62% of pregnancy and childbirth reviews, 94% of neonatal reviews, and 71% of children's health reviews addressed interventions that involved no consumer participation, such as cesarean surgical techniques or intensive care treatments. Interventions that could be implemented within the community (such as nutritional programs) or that involved woman- or family-centered health care (e.g., labor-support techniques, family-centered pediatric approaches) were far less likely to be studied. The researchers concluded:

The vast majority of research is performed on interventions that are solely in the realm of the providers. Maternal and child health research needs to be directed toward innovative interventions involving consumer participation, particularly those that can be implemented in middle- and low-income countries where the accessibility and quality of the health systems are poor. (Belizán et al., 2010, p. 155)

This study highlights one of the major systemic biases we see in research. When so much of our research comes from academic medical institutions, what happens outside of those institutions—even if it has a far greater potential impact on the health and wellbeing of the institution's beneficiaries—does not get studied much. Nor do interventions that can happen within institutions (e.g., doula support in labor) but challenge the institutional hierarchy, which too often puts patients and families at the bottom.

One area in which we need far more research is perinatal education. Few studies evaluate strategies to educate, engage, and inform women. In addition, according to a review in the fall 2009 issue of *The Journal of Perinatal Education*, even when researchers do evaluate perinatal information giving

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and education, they tend to evaluate approaches that accommodate medical concepts of efficiency (e.g., leaflets or DVDs) rather than meet women's own stated needs and preferences (e.g., opportunities to discuss options in depth with their care providers or in small peer groups facilitated by knowledgeable professionals) (Nolan, 2009).

Pregnant women and new mothers are avid seekers of health information—online, in childbirth education classes, from health-care providers, and in their communities. This natural impulse to take responsibility for their health, connect with other women, and engage in their care is currently being overwhelmed by the application of one-size-fits-all maternity care policies, including mandated cesarean surgery for women with risk factors or more subtle threats to autonomy such as restricting mobility, denying access to food and drink, and excluding family members and other support people from care settings.

Empowered, informed, engaged consumers, individually or collectively, can be effective at overcoming these barriers to safe, effective care. In fact, it sometimes seems to be the only force driving meaningful change. Fifty years ago, the American Society for Psychoprophylaxis in Obstetrics (now Lamaze International) helped lead a charge to let fathers into the delivery room and challenged the harmful, demeaning childbirth routines that prevailed as standard practice. Just last year in December 2009, CNN reported the happy outcome for a woman who avoided cesarean surgery she did not need or want (Cohen, 2009). In advocating for her own care, she has inspired a generation of other women facing vaginal birth bans in their own communities.

Consumers are the least powerful contingent in the health-care system, even though our knowledge, attitudes, and actions could be the most important influence on our own health and safety. It's time for major paradigm shifts in research, policy, and practice.

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To view each of the six Lamaze Healthy Birth Practices and to read about the evidence-based research that supports these practices, visit the Lamaze Web site (www.lamaze.org).

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