
Social Media, Power, and the Future of VBAC

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ABSTRACT

The Internet has been called a disruptive technology because it has shifted power and altered the economics of doing business, whether that business is selling books or providing health care. Social media have accelerated the pace of disruption by enabling interactive information sharing and blurring the lines between the “producers” and “consumers” of knowledge, goods, and services. In the wake of the National Institutes of Health Consensus Development Conference on Vaginal Birth After Cesarean (VBAC) and major national recommendations for maternity care reform, activated, engaged consumers face an unprecedented opportunity to drive meaningful changes in VBAC access and safety. This article examines the role of social networks in informing women about VBAC, producing low-cost, accessible decision aids, and enabling multi-stakeholder collaborations toward workable solutions that remove barriers women face in accessing VBAC.

The Journal of Perinatal Education, 19(3), 43–52, doi: 10.1624/105812410X514431

Keywords: vaginal birth after cesarean, social media, shared decision making, informed consent, childbirth, childbirth education

In 2006, *Time* magazine famously acknowledged the cultural, political, and economic importance of online social media by declaring an unconventional Person of the Year: “You.” *Time* editor, Lev Grossman, noted in his editorial introducing the “You” issue that the sudden emergence of social media is “a story about community and collaboration on a scale never seen before. . . .It’s about the many wresting power from the few and helping one another for nothing and how that will not only change the world, but also change the way the world changes” (Grossman, 2006, para. 2). Expert media

technologist, Deanna Zandt, echoes Grossman’s claim, saying, “Technology isn’t a magic bullet for solving the world’s problems, but it’s certainly a spark to the fastest fuse to explode our notions of power that the world has seen in a thousand years” (Zandt, 2010, pp. ix–x). Social media are defined and common tools are described in Table 1.

The superlative claims about the potential for social media to upend traditional power structures continue when the social media gaze shifts to health care. A landmark white paper on the influence of “networked e-patients” on health care states that

TABLE 1
What Are Social Media?

Definition	The web-based, collaborative encyclopedia, Wikipedia, itself a well known example of social media, defines social media as (emphasis added): “. . . media for <i>social interaction</i> , using highly accessible and scalable publishing techniques. Social media use web-based technologies to <i>transform and broadcast media monologues into social media dialogues</i> . They support the <i>democratization of knowledge</i> and information and transform people from content consumers to content producers” (Wikipedia, 2010).
Common Social Media Tools	<p><i>Blogs</i> – Websites that allow individuals or groups to provide content (essays, personal reflections, videos, calls to action, etc.). Readers participate in discussion by leaving comments on individual blog posts.</p> <p><i>Facebook and LinkedIn</i> – Allow users to create profiles, connect with friends and colleagues, and share photos, videos, websites, and other content. Connections are generally closed (i.e., two individuals must agree to be connected in order to have access to each other’s content).</p> <p><i>Twitter</i> – Often referred to as “microblogging” because posts are limited to 140 characters. Allows users to follow other users, but connections are not necessarily mutual. Users may broadcast to all followers, engage in conversation with individual users, or participate with many users in chats, with all “tweets” being public unless proactively made private.</p> <p><i>Forums</i> – Allow ongoing discussion in multiple topic “threads.” Users can also connect directly with other users.</p>

“this massive, complex, unplanned, unprecedented, and spontaneous medical empowerment of our lay citizens may turn out to be the most important medical transformation of our lifetimes” (Ferguson & e-Patients Scholars Working Group, 2007, p. V).^{*} If Ferguson et al. and countless other authors and thinkers are correct, power is up for grabs in our new connected world, and individuals who have traditionally been disempowered in health care—most notably, health-care consumers—are in a better position than ever to claim their rightful share of power in health-care decisions.

Perhaps nowhere in the U.S. maternity care system is power more clearly out of balance than in decisions about the care of childbearing women who have undergone prior cesarean surgery. The recent National Institutes of Health (NIH) Consensus Development Conference on vaginal birth after cesarean (VBAC) concluded that VBAC is a “reasonable option for the majority of women” (NIH, 2010, p. 17) because the absolute risk of an adverse outcome is low regardless of planned birth route and, while poor fetal/neonatal outcomes (including death) are higher with a planned VBAC, poor ma-

ternal outcomes (including death) are higher with a planned repeat cesarean, especially in women who go on to have subsequent pregnancies. Despite this apparent equipoise, practitioners, hospitals, and insurance companies often restrict the option to attempt a VBAC before the patient is consulted about her preferences for mode of giving birth (American College of Obstetricians and Gynecologists, 2009; Roberts, Deutchman, King, Fryer, & Miyoshi, 2007). In a national survey of women who gave birth in U.S. hospitals in 2005, 57% of mothers who had previous cesareans and were interested in a VBAC were denied the option of a VBAC, most often due to unwillingness of their caregiver (45%) or the hospital (23%), with only 20% citing a medical rationale for denial (Declercq, Sakala, Corry, & Applebaum, 2006). While rare, some hospitals have resorted to court orders to compel women to comply with repeat cesarean surgery (Cohen, 2009). As a result of trends that discourage or deny VBAC, the U.S. rate of vaginal birth among women with prior cesarean surgery ranges from 2.5% to 20.9% across American states, and the national rate is at a historical low (Guise et al., 2010).

Even where VBAC access is not restricted, women may face intense pressure from health-care providers, as well as family and friends, to undergo repeat cesarean surgery. Care providers may offer

^{*}The “e” in “e-patients” refers to “individuals who are equipped, enabled, empowered and engaged in their health and health care decisions” (Ferguson & e-Patients Scholars Working Group, 2007, p. II).

a choice but may frame it in such a way that makes repeat cesarean the default and presumably “better” choice over VBAC (Goodall, McVittie, & Magill, 2009). Sometimes, these care providers, having initially offered the woman the option to have a VBAC, may unilaterally revoke the woman’s “candidacy” for VBAC later in pregnancy, based on arbitrary guidelines or results of unreliable but compulsory screening tests. Also, despite strong evidence favoring the health and safety of VBAC, even well-supported women who remain good candidates for VBAC at the end of pregnancy may choose repeat cesarean surgery because they have internalized cultural messages suggesting that a cesarean is safer than a VBAC and that a planned VBAC merely values the mother’s birth “experience” over safety (Transforming Maternity Care Consumers and Their Advocates Stakeholders Workgroup, 2010).

Reflecting on VBAC restrictions and other trends in maternity care, a multi-stakeholder collaboration of leaders across the health-care system recently issued recommendations for improvement, including increased choice and autonomy in maternity care. In the Childbirth Connection’s report, *Blueprint for Action: Steps Toward a High-Quality, High-Value Maternity Care System*, the collaborative group states that system goals should include “activated and informed consumers [fostering] maternity care quality improvement and system performance” (Angood et al., 2010, p. S40).

The recent findings of the NIH consensus panel that confirmed planned VBAC is a reasonable, evidence-based option for most women, coupled with major national recommendations that highlight the importance of women’s choice and autonomy in improving the quality and safety of U.S. maternity care, present an unprecedented opportunity to call for mother-friendly policies and practices, including safe and accessible care for women who want a VBAC. However, implementing mother-friendly policies will require a major redistribution of power in maternity care. This article examines the potential of the current social media-enabled consumer movement to be the disruptive force that drives the redistribution of power in health care. Using the framework of patient-driven health care put forth in the landmark White Paper, *e-Patients: How They Can Help Us Heal Health Care* (Ferguson & e-Patients Scholars Working Group, 2007), we review contemporary examples of how networked VBAC advocates are altering the maternity care landscape by raising consciousness; giving individ-

uals unprecedented access to information, support, and community; and enabling collaboration toward workable solutions to remove the barriers women face in accessing VBAC.

PATIENT-DRIVEN HEALTH CARE: SEVEN PRELIMINARY CONCLUSIONS

Evidence is emerging from other health-care disciplines that consumer-driven system disruption is well underway. The White Paper, *e-Patients: How They Can Help Us Heal Health Care*, was published in March 2007 by a group of patients, clinicians, and researchers who have since incorporated as the Society for Participatory Medicine (Ferguson & e-Patients Scholars Working Group, 2007). The paper describes how the Internet in general and social networking tools in particular have fueled a new era of patient engagement in which access and innovation are transforming patients from passengers to responsible drivers of health care. The authors argue that, properly leveraged, these changes have the potential to “create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients” (Ferguson & e-Patients Scholars Working Group, 2007, front matter). While the authors recognize that the impact of these cultural and technological shifts has only begun to be realized, they offer seven preliminary conclusions:

1. e-Patients have become valuable health-care resources, and providers should recognize them as such.
2. The art of “empowering” patients is trickier than we had thought.
3. We have underestimated patients’ ability to provide useful online resources.
4. We have overestimated the hazards of imperfect online health information.
5. Whenever possible, health care should take place on the patient’s “turf.”
6. Clinicians can no longer go it alone.
7. The most effective way to improve health care is to make it more collaborative.

The authors of the e-Patients White Paper did not address e-patient behaviors of maternity care consumers or explore the implications of social technologies for childbearing women. Nor have the institutions that track online health behavior surveyed expectant or new mothers (Fox, 2008). The small body of evidence that does exist, however, suggests


Read Rima Jolivet and Maureen Corry’s article, “Steps Toward Innovative Childbirth Education” on pages 17–20 of this issue of the journal to learn more about Childbirth Connection’s multi-stakeholder “Transforming Maternity Care” initiative and published report, *Blueprint for Action: Steps Toward a High-Quality, High-Value Maternity Care System*.

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that frequent and intensive use of the Internet is the norm among the childbearing population. In a survey of women who gave birth in U.S. hospitals in 2005, women reported an average of 20 visits online to get pregnancy and birth information during pregnancy. However, nearly 1 in 5 (19%) reported at least 100 such Internet visits during pregnancy (Declercq et al., 2006). A more recent survey conducted among visitors to 23 websites that offered general pregnancy information collected data on women's use of the Internet for various health-related activities (Lagan, Sinclair, & Kernohan, 2010). Significant majorities of women reported going online 10 times or more during pregnancy to participate in an online support group (65%), participate in an online discussion (80%), research a pregnancy-related product (72%), or seek general information (88%). Women also reported going online at least once to seek a second opinion (67%), find information about prescribed treatments (59%), learn about a specific pregnancy-related condition (94%), and purchase pregnancy-related products (80%).

SHARED DECISION MAKING IN A HOSTILE SYSTEM: THE ROLE OF SOCIAL NETWORKS

In the draft statement released by the consensus panel after the NIH Consensus Development Conference on VBAC, the panelists urged, "When [planned VBAC] and [planned repeat cesarean] are medically equivalent options, a shared decision-making process should be adopted and, whenever possible, the woman's preference should be honored" (NIH, 2010, p. 36). However, as Godolphin (2009) argues, shared decision making rarely happens in health care because it is difficult and time-consuming, clinicians are not taught the necessary skills, and a clear imbalance of power exists between providers and patients. These problems are magnified in the VBAC decision-making process because providers lack the evidence to provide individualized risk assessments to women, may perceive VBAC to be riskier and repeat cesarean safer than the available evidence suggests, and have financial incentives to steer women toward repeat cesarean. In short, they may not share the definition of "medically equivalent" with patients, and even when they do, they may lack the skills or time necessary to

communicate risks and benefits to the women in their care.

Moreover, there is little evidence that traditional models of shared decision making are effective. The e-Patients White Paper reviews evidence that when medical information flows from "experts" (i.e., medical professionals) to patients, whether in a health-care setting or over the Internet, health outcomes do not improve and may in fact worsen (Gibson et al., 2002; Murray, Burns, See Tai, & Rai, 2004). Making matters worse, this top-down approach to information sharing may compromise patients' satisfaction with care and feelings of control (Kukla et al., 2009; Lysterly et al., 2007). In an essay titled "Finding Autonomy in Birth," Kukla and colleagues (2009) reference qualitative research that demonstrate how offering choices without providing social context and without relating them to the values that are important to the patient actually decreases the patient's feelings of autonomy, control, and satisfaction with care. The authors argue that providing the options as equal choices in a list, or worse, with a paternalistic bias toward a mode of birth preferred by the practitioner, can be overwhelming and ethically problematic.

Finally, even if decision support tools will someday overcome these barriers and provide meaningful, individualized guidance about VBAC, a woman pregnant today with a cesarean scar on her uterus cannot benefit from such tools because they have not been developed yet. The NIH consensus panel recommended "interprofessional collaboration to refine, validate, and use in clinical practice decision-making and risk assessment tools as well as informed consent templates that are informative, reliable, and documentable, focusing on communicating absolute risk in easily understood terms" (NIH, 2010, p. 17). Yet the widespread application of such rigorously tested decision support tools, though a laudable goal, is likely to be years if not decades away, given the typical pace with which studies are designed and funded, participants recruited, findings published, and evidence integrated into practice. Moreover, if, as the NIH recommends, the tools are conceived and developed by professionals and implemented in clinical practice settings, the years-long wait may yield tools that are ineffective because of the fundamental limitations of the provider-centric approach already discussed.

Our health-care system has one untapped resource that can contribute to resolving all of these shortcomings in the existing shared decision-making framework: engaged consumers. By forming

social networks, women can consider their choices with access both to information and to the perspectives and experiences of other women with similar priorities and concerns. When, in the context of that social interaction, women identify unmet needs for information and support, the community can collectively innovate to fill those gaps, using low-cost, accessible social technologies. These efforts can help reshape the dominant discourse and begin to dismantle the paternalistic system that has created the ethical and obstetrical crisis women now face.

The Role of Social Media in Providing Access to Support and Information

The e-Patients White Paper provides numerous examples of the critical role “disease communities” and other online support networks play in equipping patients to access the right care and offering support for day-to-day disease management (Ferguson & e-Patients Scholars Working Group, 2007). The best evidence for the importance of such networks in pregnancy comes from a qualitative study analyzing interviews with 66 women carrying fetuses with diagnosed anomalies (Lowe, Powell, Griffiths, Thorogood, & Locock, 2009). The analysis suggested that women use the Internet to gain understanding of the experiences of others with similar diagnoses, which can provide a framework for coping and decision making that available biomedical information does not offer. One participant explained the importance of personal stories and advice from other mothers online:

The sensible [professional] Web sites would say things like, that you knew were right, and then the ones where mothers had written other things, I mean, it's like, people could be more sympathetic or they could empathize more. . . . Here were various contributions from individuals there and as, as you sort of flicked in and out of them you got a picture of, of, um you know, how credible the stories were, and often the same person was coming back on and giving advice to others. And I felt there were a number of individuals there who were giving good advice and who'd obviously had quite, you know, interesting stories that were relevant. (Lowe et al., 2009, p. 1482)


Filtered through social media, medical information for pregnant women “forms an organic, multilayered array” (Kukla, 2007, p. 28), which includes

The International Cesarean Awareness Network represents the nexus of online support and information for women considering or planning VBAC.

patient and community voices, along with more traditionally authoritative sources. In the case of VBAC, the Internet offers pregnant women with prior cesarean surgery access to information about the risks and benefits of VBAC. For many women, however, the large and close-knit community of like-minded women, many of whom have successfully navigated a hostile system to achieve a VBAC, represent an even more important resource.

The International Cesarean Awareness Network (ICAN) represents the nexus of online support and information for women considering or planning VBAC. The all-volunteer organization, founded in 1982, has provided various online venues for child-bearing women to engage in information sharing, advocacy, and support for over a decade. The organization's first consumer-driven online network began as a simple bulletin board dial-in service in the late 1990s, migrated to a Yahoo e-mail group in 2003, and now serves 788 active subscribers. In 2008, ICAN launched online discussion forums to offer a web-based alternative that allows users to engage in multiple discussions around the general themes of cesarean prevention and recovery. The forums have over 3,500 registered users, with most activity occurring in the VBAC forum. Cesarean recovery, cesarean birth planning, advocacy, birth stories, and general conversation are other popular discussion topics. In addition to online forums, ICAN offers a call-in online radio show, interactive webinars, and a blog and has an active presence on Facebook and Twitter. Many of the organization's 130 local chapters also maintain their own e-mail listservs, Facebook pages, or other social media outlets.

These overlapping social networks offer an open, safe, and trusting environment where a woman can tap into her power as a woman, mother, and consumer. Although no one has measured the impact of ICAN's social networks, the organization regularly receives unsolicited feedback indicating that ICAN is a lifeline for the women in its online community. As one mother wrote in a post on ICAN's Facebook page, “ICAN made me an advocate of birthing my way. It gave me the tools I needed to have the birth experience that I deserved and always knew was

 For more information about the International Cesarean Awareness Network, visit the organization's website (www.ican-online.org/).

possible.” Another wrote, “If it weren’t for ICAN and the *amazing* support that I have received from them over the last 6 years, I would still be feeling like I was the only one in the world that felt the way I felt about my cesarean. ICAN opened my mind to taking my own care seriously and doing the research for myself.”

Social media strategist, Deanna Zandt, writes, “In traditional power systems, those with more influence or power...are dependant on our being passive consumers of information. We’re freed significantly from that dependency when we’re given easy tools with which to share our stories” (Zandt, 2010, p. 55). Indeed, birth stories are among the most popular resources on ICAN’s website. Forty-six stories, most of which recounted VBACs sometimes under very unlikely circumstances, were posted during 2010 Cesarean Awareness Month, reaching over 10,000 readers that month.

The Role of Social Media in Enabling Innovation

Engaged consumers do not just “pay it forward” by sharing information and personal testimonials. They also innovate to fill in the gaps when existing information sources fall short. The e-Patient White Paper predated the advent of patient-centered mobile applications and health data sharing sites that now dominate the participatory medicine landscape, but even with the relatively simple social technology available several years ago, patients with chronic illness were tracking symptoms and treatments together or driving the creation of new health services, such as e-therapy for mental health conditions.

In the case of VBAC, consumers often go online to get facility and provider recommendations, recognizing that the availability of VBAC in the first place and the adherence to best practices in VBAC labors varies significantly across maternity care provider facilities. Although “VBAC bans” are an acknowledged phenomenon, even the researchers preparing the evidence for the NIH Consensus Development Conference on VBAC were able only to identify a single, 3-year-old published report of the scope of VBAC bans, reporting the VBAC ban rate in 225 hospitals in California (Shihady et al., 2007). Clearly, “official” channels of information are insufficient to help women evaluate their care options.

In contrast, since 2004, ICAN has offered a continually updated online database of VBAC policy for every hospital that offers maternity care in the United States. The information from 2,979 hospitals

is collected by an all-volunteer task force of committed women who call hospitals and ask a series of questions designed to determine whether VBACs are accessible, banned outright, or permitted by hospital policy but inaccessible due to lack of credentialed care providers who will attend them (referred to as “de facto ban”).

As of May 2010, the phone survey revealed that 821 (28%) of U.S. hospitals officially ban VBACs and 612 (21%) have de facto bans, rendering nearly half of U.S. hospitals inaccessible to women who want to make an informed choice to plan a vaginal birth after prior cesarean surgery. The ongoing nature of the survey allows ICAN to identify trends on VBAC access, and indeed the volunteers documented a 175% increase in the number of VBAC inaccessible hospitals in the first 5 years of data collection (ICAN, 2009).

Although the database provides useful quantitative data on the overall availability of VBAC care, equally useful are the qualitative data gleaned from hospital representatives and the public at large, who add comments and provide quality ratings for specific hospitals and practitioners. A woman can learn about hospital procedures if she were to present for care and refuse surgery, which may range from respect for informed refusal to coercive tactics including forced or court-ordered surgery (see Table 2).

Another example of innovation by engaged consumers is a collaborative effort to translate the proceedings of the NIH Consensus Development Conference on VBAC into understandable, meaningful, actionable information for consumers. Following the NIH Consensus Development Conference, Kristen Oganowski—a doula, VBAC mom, and birth blogger—wrote a blog post suggesting the need for an “NIH VBAC Primer” for consumers (Oganowski, 2010). Recognizing that pregnant women may know that the NIH Consensus Development Conference took place and wish to use the conference proceedings and panel recommendations to negotiate safe VBAC care with their care providers, Oganowski recruited a cadre of leading birth bloggers and advocates to contribute consumer-friendly summaries of the evidence presented and controversies raised by the conference. In addition to explanations of the risks and benefits of planned VBAC and planned repeat cesarean, the primer addresses what to do when a woman is not an “ideal candidate” for VBAC, how to understand and navigate the “immediately available standard,” the significance of the gaps the NIH panel identified in the evidence, and tips for using

TABLE 2

Selected Comments Describing Various Hospitals' Refusal Procedures Regarding Vaginal Birth After Cesarean (VBAC)*

"Not allowed to refuse; they have no forms for refusal of a procedure. Even if you are crowning, they will section you because it's against hospital policy." [a regional medical center in Arkansas]

"Can't refuse; it's hospital policy. Will be sectioned unless there is absolutely no time to do it." [a county medical center in Arkansas]

"Unless the baby is just about 'hanging out,' they will send you home if you refuse the section. That's the only way." Hospital has publicly stated that they would seek a court order for a cesarean if a patient refused a repeat cesarean, even if she has already had a VBAC at that facility, previously. [a hospital in Arizona]

"Too high-risk. Too much liability. You won't find anywhere around here that does them." [a regional medical center in California]

"VBAC is very high risk of. . . hemorrhage and [uterine rupture]. Basically, since you've already had a baby, your uterus is like a birthday balloon that's been blown up, cut in half, so it's quite risky." [Interviewer asks survey participant if she has ever seen (a rupture).

Participant replies, "Oh yeah. They die in 7 minutes before they even get to the OR." Participant continues, "For the doctors that do them, you have to sign lots of papers, informed consent." [a hospital in California]

Women arriving at the hospital and refusing a c-section will be "sectioned anyway." [a hospital in Colorado]

Note. *Comments recorded by International Cesarean Awareness Network (ICAN) volunteers who surveyed hospitals by phone. (Source: ICAN's "VBAC Ban Database" at www.ican-online.org/, as of May 24, 2010.)

the NIH recommendations to challenge VBAC bans at the community level. The complete primer is available at Lamaze International's new consumer community, GivingBirthWithConfidence.org.

The Role of Social Media in Shaping the Dominant Discourse of VBAC

While social media have enabled consumers to connect with one another to share information and support, the same tools have played an important role in breaching the walls among researchers, professional organizations, clinicians, activists, and patients in the greater debate surrounding VBAC access.

The official announcements and posted agenda for the NIH Consensus Development Conference provided no indication that stakeholders outside of the traditional levels of the medical establishment would have a presence in the conference. Except for one medical reporter from *USA Today* whose contribution was called "Mothers' Stories," a panel was slated to discuss decision-making surrounding VBAC but was missing the most important stakeholder, women themselves.

However, the very first conference presentation was emblazoned with the mastheads of two patient advocacy websites: VBAC.com, run by a childbirth educator and author, and *The Unnecesarean*, a consumer-run site that garners tens of thousands of visits per month and has over 5,000 Facebook fans. VBAC advocates, many from the thriving online community, dominated the open discussion periods during which the panel considered public testimony. Bloggers snapped digital photos of graphs and charts and uploaded them directly to the

web. The speakers were webcast simultaneously, and interested parties at the conference and all over the world were able to react and interact in real time on Twitter. A coordinated blogging effort ran simultaneously with the conference, offering various contributions addressing the question, "Why is VBAC a Vital Option?" (ICAN, 2010). In summary, for the first time in the history of birth advocacy, consumers played a central role in both shaping and disseminating the proceedings of a scientific meeting with major national and even international significance.

In another remarkable example of collaboration among doctors and engaged consumers online, an anonymous obstetrician reader of *The Unnecesarean* solicited the assistance of the blog's readers to edit a VBAC consent form (Jill-Unnecesarean, 2010). The form was required by his liability insurance carrier and, although he could not delete required language, he was allowed to add content to the form. Over 60 suggestions, nearly all from consumers, were provided on two different iterations of the consent form, with the obstetrician actively engaged in discussion and clarification with the participants.

At the NIH Consensus Development Conference, a coordinated, consumer-driven social media effort, coupled with the NIH's commitment to broadcast the proceedings and solicit public testimony, enabled consumer advocates to interact with and influence bioethicists, epidemiologists, and clinicians involved in the NIH conference. At *The Unnecesarean* blog site, the spontaneous, iterative contributions of engaged consumers and a clinician who valued these contributions created



Be sure to visit the website [Giving Birth With Confidence](http://GivingBirthWithConfidence.org), powered by Lamaze (www.GivingBirthWithConfidence.org).

a “crowd-sourced” informed consent form that incorporated the clinical knowledge of the obstetrician, the risk-management priorities of the liability insurer, and the informational needs of women. These types of interactions would not have been possible without the advent of an organized consumer movement enabled by social technology. However, they remain impossible in the contexts of more conventional venues for the dissemination of clinical and scientific knowledge: closed professional meetings and peer-reviewed journals.

CAN SOCIAL MEDIA FIX THE BIG PICTURE?

Kukla and colleagues (2009) contend that “autonomy is a relational feature of decisions and actions that are planted in the right way within a network of social relationships and narratives” (p. 7). Tapping into online social networks may enhance women’s opportunities to achieve autonomy, empowerment, and self-efficacy and may help them make health-care decisions that align with their personal and family priorities and individual concepts of risks and reward.

The willingness and effectiveness of women empowering other women requires openness (willingness to share) and altruism (willingness to help for the sake of helping), both of which are well-recognized features of online social networks (Zandt, 2010). Researchers are just beginning to document the mechanisms by which these qualities enable online patient networks to empower the patients who use them (Schroeder & Burroughs, 2010), although the “organic authority” (Zandt, 2010, p. 57) that underpins consumer-to-consumer empowerment is by nature idiosyncratic and ever changing, rendering it difficult to study with the traditional research toolbox.

Social networks that are effective at empowering women may still fail to make meaningful changes to the system at large, however. Major barriers still stand in the way to true informed choice and unhindered access to safe, satisfying VBAC care and support. Moreover, women need to rely on the health-care system for care in pregnancy and birth, and interactions with care providers and institu-

tions cannot (and should not) be replaced entirely by social networks, no matter how robust and innovative. Social networks have played a role in driving a small but apparently growing movement of women opting for unassisted home VBAC (Freeze, 2008). This movement reflects the lack of choice women face in conventional health-care settings and the distrust of hospitals and health-care providers that has been fueled by stories of trauma and abuse. While social networks play a critical role in shining a light on these abuses and helping women heal trauma, it is unlikely that the optimal outcome of the empowerment of health-care consumers is that they opt out of the health-care system entirely.

The expert panelists who participated in the NIH Consensus Development Conference on VBAC concluded that it is a priority to identify and modify nonmedical factors such as “workforce availability and training, professional association guidelines, type of maternity care providers, liability concerns, health insurance, and institutional policy” (NIH, 2010, p. 16) that unnecessarily hinder access to safe planned VBAC. These barriers will only be overcome with the collaboration and input of multiple stakeholders, and it may seem unlikely that consumers could play a meaningful role. However, recent history provides numerous examples of patients contributing to system improvement, whose journeys began with their own, sometimes desperate and too often unsuccessful, efforts to access safe, effective, patient-centered care for themselves or their families.

The most visible and vocal spokesperson for the patient engagement movement, Dave deBronkart, survived Stage IV kidney cancer and now testifies at federal hearings on patient-centered adoption of electronic health records (deBronkart, 2010) and is a sought-after keynote speaker at major health-care conferences in the United States and abroad. Donna Cryer, a liver transplant recipient, now sits as a voting member on advisory committees for the U.S. Food and Drug Administration and provides direct input into the drug approval process (Cryer, 2010). Jamie Heywood, whose brother was diagnosed with and eventually died from ALS, developed a tool that allows patients to track and share their health data online, an award-winning initiative that has generated new knowledge about diseases and treatments using only a tiny fraction of the time and money typically spent in formal clinical trials (C. Brownstein, J. Brownstein, Williams, Wicks, & Heywood, 2009).

Tapping into online social networks may enhance women's opportunities to achieve autonomy, empowerment, and self-efficacy and may help them make health-care decisions that align with their personal and family priorities.

Each of these people started their remarkable journeys as individuals navigating a fragmented and complex system, making keen and critical observations about what works and what does not work in U.S. health care and contemplating how the system could serve its beneficiaries better.

In the online community of VBAC mothers, some women will get empowered, give birth, and move on, some will leverage their communication skills and social media tools to help other women, and some will build on those same skills and tools to transform into leaders—equipped, enabled, and empowered to contribute meaningfully in areas of research, policy-making, institutional quality improvement, and national advocacy.

REFERENCES

- American College of Obstetricians and Gynecologists. (2009, August). *Florida liability lowdown*. Retrieved from <http://www.acog.org/departments/professionalLiability/2009PLSurveyDistrictFlorida.pdf>
- Angood, P. B., Armstrong, E. M., Ashton, D., Burstin, H., Corry, M. P., Delbanco, S. F., et al. (2010). Blueprint for action: Steps toward a high-quality, high-value maternity care system. *Women's Health Issues, 20*(Suppl. 1), S18–S49.
- Brownstein, C. A., Brownstein, J. S., Williams, D. S., III, Wicks, P., & Heywood, J. A. (2009). The power of social networking in medicine. *Nature Biotechnology, 27*(10), 888–890.
- Cohen, E. (2009, December). *Mom fights, gets the delivery she wants*. Retrieved from <http://www.cnn.com/2009/HEALTH/12/17/birth.plan.tips/index.html>
- Cryer, D. (2010, May 22). *Donna Cryer's "I am an e-patient" story: E-patient advocate to the FDA*. Retrieved from <http://e-patients.net/archives/2010/05/donna-cryer-i-am-an-e-patient-story-e-patient-advocate-to-the-fda.html>
- deBronkart, D. (2010). *Let patients help. We are the ultimate motivated stakeholders. Testimony before the Meaningful Use Workgroup, HIT Policy Committee, April 25, 2010, Washington, D.C.* Retrieved from <http://e-patients.net/u/2010/04/2f-deBronkart-MU-WG-testimony-4-20-10.pdf>
- Declercq, E., Sakala, C., Corry, M. P., & Applebaum, S. (2006). *Listening to Mothers II: Report of the second national survey of women's childbearing experiences*. New York: Childbirth Connection.
- Ferguson, T., & e-Patients Scholars Working Group. (2007). *e-Patients: How they can help us heal health care*. Retrieved from http://e-patients.net/e-Patients_White_Paper.pdf
- Fox, S. (2008, August 26). *The engaged e-patient population*. Washington, D.C.: Pew Internet & American Life Project. Retrieved from <http://www.pewinternet.org/Reports/2008/The-Engaged-Epatient-Population.aspx>
- Freeze, R. A. (2008). *Born free: Unassisted childbirth in North America* (Unpublished dissertation). University of Iowa, Iowa City, IA. Retrieved from <http://dl.dropbox.com/u/238755/Born%20Free%20UC%20in%20NA.pdf>
- Gibson, P. G., Powell, H., Coughlan, J., Wilson, A. J., Hensley, M. J., Abramson, M., et al. (2002). Limited (information only) patient education programs for adults with asthma. *Cochrane Database of Systematic Reviews, 2*, CD001005.
- Godolphin, W. (2009). Shared decision-making. *Health-care Quarterly (Toronto, Ont.), 12*(Special issue), e186–e190.
- Goodall, K. E., McVittie, C., & Magill, M. (2009). Birth choice following primary caesarean section: Mothers' perceptions of the influence of health professionals on decision-making. *Journal of Reproductive and Infant Psychology, 27*(1), 4–14.
- Grossman, L. (2006, December 13). *Time's person of the year: You*. Retrieved from <http://www.time.com/time/magazine/article/0,9171,1569514,00.html>
- Guise, J.-M., Eden, K., Emeis, C., Denman, M. A., Marshall, N., Fu, R., et al. (2010). *Vaginal birth after cesarean: New insights (Rep. No. 191)*. Rockville, MD: Agency for Healthcare Research and Quality.
- International Cesarean Awareness Network. (2009, February 20). *New survey shows shrinking options for women with prior cesarean* [Press release]. Retrieved from <http://www.ican-online.org/ican-in-the-news/trouble-repeat-cesareans>
- International Cesarean Awareness Network. (2010, March 8). *VBAC blog carnival: Why is VBAC a vital option?* [Web log]. Retrieved from <http://blog.ican-online.org/2010/03/08/vbac-blog-carnival-why-is-vbac-a-vital-option/>
- Jill-Unnecesarean. (2010, May 19). *VBAC consent form revision revisited: Your feedback requested* [Web log]. Retrieved <http://www.theunnecesarean.com/blog/2010/5/19/vbac-consent-form-revision-revisited-your-feedback-requested.html>
- Kukla, R. (2007). How do patients know? *The Hastings Center Report, 37*(5), 27–35.
- Kukla, R., Kuppermann, M., Little, M., Lyerly, A. D., Mitchell, L. M., Armstrong, E. M., et al. [The Obstetrics and Gynecology Risk Research Group] (2009). Finding autonomy in birth. *Bioethics, 23*(1), 1–8.
- Lagan, B., Sinclair, M., & Kernohan, W. G. (2010). Internet use in pregnancy informs women's decision making: A Web-based survey. *Birth (Berkeley, Calif.), 37*(2), 106–115.
- Lowe, P., Powell, J., Griffiths, F., Thorogood, M., & Locock, L. (2009). Making it all normal: The role of the Internet in problematic pregnancy. *Qualitative Health Research, 19*(10), 1476–1484.
- Lyerly, A. D., Mitchell, L. M., Armstrong, E. M., Harris, L. H., Kukla, R., Kuppermann, M., et al. (2007). Risks, values, and decision making surrounding pregnancy. *Obstetrics and Gynecology, 109*, 979–984.
- Murray, E., Burns, J., See Tai, S., & Rai, R. (2004). Interactive Health Communication Applications: The story of a Cochrane review. *Cochrane Consumers and Communication Review Group Newsletter, 11*, 6–7.
- National Institutes of Health. (2010). *Final statement: National Institutes of Health Consensus Development*

- Conference Statement – *Vaginal birth after cesarean: New insights*. Retrieved from http://consensus.nih.gov/2010/images/vbac/vbac_statement.pdf
- Oganowski, K. (2010, March 14). *I went to the NIH Consensus Development Conference on VBAC and all I got were these lofty goals* [Web log]. Retrieved from <http://birthingbeautifulideas.com/?p=1470>
- Roberts, R. G., Deutchman, M., King, V. J., Fryer, G. E., & Miyoshi, T. J. (2007). Changing policies on vaginal birth after cesarean: Impact on access. *Birth (Berkeley, Calif.)*, 34(4), 316–322.
- Schroeder, C., & Burroughs, J. (2010). *What motivates the empowered patient*. DTC Conference, Washington, D.C., April 8, 2010.
- Shihady, I. R., Broussard, P., Bolton, L. B., Fink, A., Fridman, M., Fridman, R., et al. (2007). Vaginal birth after cesarean: Do California hospital policies follow national guidelines? *The Journal of Reproductive Medicine*, 52(5), 349–358.
- Transforming Maternity Care Consumers and Their Advocates Stakeholders Workgroup. (2010). *Priorities for moving to a high-quality, high-value maternity care system from the perspective of consumers and their advocates*. New York: Childbirth Connection.
- Wikipedia. (2010). *Social media*. Retrieved from http://en.wikipedia.org/wiki/Social_media
- Zandt, D. (2010). *Share this!* San Francisco: Berrett-Kohler.

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