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Blogging Infertility

Cheryl Miller

Infertility, once referred to as the "silent disorder," has found a voice. In recent years, the *New York Times Magazine* and *Washington Post Magazine* have featured long, ruminative articles about egg donation and fertility tourism. Books about the fertility industry, such as Debora Spar's *The Baby Business* and Liza Mundy's *Everything Conceivable*, have garnered considerable attention. And a spate of infertility memoirs, such as Peggy Orenstein's *Waiting for Daisy* and Beth Kohl's *Embryo Culture*, prompted one critic to anoint the genre "Repro Lit."

Repro Lit has established a serious presence online as well, where the message boards of websites such as Fertile Thoughts and IVF Connections teem with the comments of men and women exchanging information about treatment options and commiserating over experiences at various fertility clinics. But it is blogging that has provided the most popular and heterogeneous outlet for the infertile. There are blogs devoted to almost every aspect of and response to infertility: donor insemination, donor eggs, surrogacy, in vitro fertilization, intrauterine insemination, and adoption. There are blogs written by gay and lesbian parents, single mothers by choice, and by couples who have successfully conceived after infertility. Although many of these blogs are deeply personal, or even confessional, others function as practical networking sites where readers can find information about infertility book clubs and even film festivals. The names of the blogs reflect the hopeful, harrowing, and at times absurd experience of living with infertility: "A Little Pregnant," "And I wasted all that birth control," or "Wishing On a Star," for example.

As it has for people suffering from cancer or other illnesses, the blogosphere offers the infertile a place to chronicle their personal stories, create community, seek support, and raise awareness about their condition. "One of the great things about technology today is its democratization," blogger "Bea," of "Infertile Fantasies," says. "You don't have to be a professional writer or film school graduate to tell your story online—anyone can do it, and even if it's of interest to only a small percentage of people in the world, they can find you." (Throughout this essay, bloggers will

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be identified by their *noms de blog*—whether their real names or pseudonyms.) These blogs offer a unique perspective on the lives of infertile men and women, revealing the many ways the infertile are tackling the tricky questions reproductive technology poses: What does it mean to be infertile? If treatment succeeds, what, if anything, do you tell your family, your friends, and the children you have conceived? When, if ever, should one give up on fertility treatment? And, perhaps most importantly, how do these technologies transform our understanding of what it means to be a family?

Yet the openness and transparency encouraged by the Internet pose new challenges, particularly for something as intimate as human reproduction. Allowing the world to read about—and comment on—your political opinions is one thing. Allowing the world a front-row seat to witness your struggles to conceive is another. The blogosphere's much-heralded opportunity for connection and expression, over time and amid the cacophony of competing voices, can lead to a form of leveling that risks rendering even the most serious topics banal. And the medium's encouragement of self-exposure can transform private pain into voyeurism. Finally, it is worth asking if these online support groups, message boards, and blogs are an effective substitute for real-world support groups and professional counseling. Has the online world made the experience of being infertile easier to bear? Or has it created new and unanticipated problems?

"Sad, Desperate Women"?

As with any subculture, the world of infertility blogs can be confusing to outsiders. Infertility bloggers have their own lingo, a bewildering array of acronyms and abbreviations that can be intimidating to the uninitiated. Tertia Albertyn, a thirty-something South African and one of the stars of the infertility blog world, described herself thus on her blog in 2004:

> I am Tertia, I am 35 yrs old, dh is 30, TTC 4 yrs, dx = PCOS, stage II endo, irregular AF and I don't O on my own. 3 x injectible IUI's, all BFN. IVF #1 = cancelled due to falling E2's. IVF #2, zero fert, rescue ICSI, BFN. IVF#3 = BFP, but ectopic, 3 x FET's = BFN, IVF #4 = BFP, but MC 8w3d due to T21, IVF #5 = BFP, twins, loss of one at 21w, the other born 25w6d, died after 10 days in NICU.

Attempts to decipher this paragraph, using Google, yielded a few hints: Tertia, I learned, is a columnist for the *Times* of South Africa and author of a recent infertility memoir, *So Close*, which chronicles her experience

undergoing nine IVF cycles. A little more sleuthing (and assistance from another blogger) reveals that Tertia and her "dh" (dear husband) have been "ttc" (trying to conceive) for four years, and have been through five in vitro fertilization (IVF) cycles, three intrauterine inseminations (IUI), and three frozen embryo transfers (FET). All her IUIs and FETs ended in a "BFN," a "big fat negative" or negative pregnancy test. Her first two IVF cycles failed; the third ended in a "BFP," a "big fat positive" or positive pregnancy test, but the pregnancy was ectopic (that is, the egg implanted outside the uterus). The fourth IVF cycle ended in a miscarriage (MC). During the last IVF cycle, she lost one twin at 21 weeks; the other, born prematurely, died after 10 days in the neonatal intensive care unit (NICU). Since she wrote that description in 2004, Tertia became the mother of twins, but she still keeps up her blog, Tertia.org, and helps run an online infertility support group, Fertilicare, with another South African blogger.

Like Tertia, most infertility bloggers are women. This is hardly surprising, given that women bear the brunt of infertility treatment and are, in general, more comfortable with the confessional, emotive style of personal blogging. "It's much more of a female medium across the board," says Melissa, whose flamboyantly named site, "Stirrup Queens and Sperm Palace Jesters," is one of the most popular infertility blogs. But the fact that the infertility blogosphere is dominated by women can also invite unwarranted criticism. Last November, the Canadian *Globe and Mail* published an article about infertility bloggers that portrayed the women as pathetic, navel-gazing exhibitionists. "I am not a type-A, career-obsessed, irrational narcissist who slept with one too many casual boyfriends," Bea protests. "The number of times the word 'desperate' headlines an article on infertility is appalling." Tertia wryly agrees: "I hate the way the media portrays infertiles as sad, desperate women. Even though we are sad and desperate. Only we are allowed to call ourselves that."

In fact, infertility bloggers are a diverse lot: There's Jenna Currier Nadeau ("The EpiBlog"), a schoolteacher who is hoping to adopt after multiple failed attempts at IVF; Gabrielle Sedor ("Fertility Notes"), a young woman whose childhood cancer left her infertile; "Zee" ("This is NOT what I ordered!") who is eager to begin treatment if only her boyfriend, a "reproductive Luddite," would agree. And there's Pamela Tsigdinos ("Coming2Terms"), a fortyish professional in the Bay Area, who has given up on treatments after eleven years of trying. These bloggers bristle at the implication that infertility is a "choice." They are not, they emphasize, unreconstructed feminists who put marriage and family

on the back burner to pursue a career and are now suffering the consequences of their choices. Instead, they compare infertility to diseases such as cancer. "You wouldn't say that someone who is treating their cancer is 'life-desperate,'" Melissa says.

They came to blogging for a variety of reasons. Most started out on infertility message boards, where they could discuss treatments and protocols, find doctors and clinics, and share tips on getting pregnant—from the efficacy of Chinese herbs to finding the best acupuncturist. The free flow of information on the Web can be empowering—an attraction, no doubt, during a time in which people feel particularly powerless. Patients can research their conditions and symptoms on "Dr. Google." They can also draw on a reservoir of common experience from more "advanced" patients, getting reassurance, for instance, that a particular symptom is completely normal while their doctor is out or otherwise unavailable. Melissa tells me that it was another patient—not her doctor—who showed her how to give herself an injection so it wouldn't bruise. In fact, an entire website, "IVF Shoot 'Em Up," features videos of real-life women injecting themselves with various fertility drugs for the instructional benefit of other patients, since clinics don't give much instruction on self-administering injections. For the stressed infertility patient, hopped up on hormone drugs, these are not small things.

Beyond medical advice and referrals, the Internet also offers support and a kind of community. Tertia calls her fellow bloggers her "friends in the computer," and many friendships that start online eventually cross into the offline world. Melissa has met a number of bloggers, and hosts a monthly support group in the Washington, D.C. area. "Serenity" (of "Serenity Now!") has become close friends with another blogger, Mary Ellen (of "Not According to Plan") and together they held a "sleepover" for bloggers in the northeast United States. She recalls giving Mary Ellen an injection that night, though they didn't yet know each other well. "You don't feel like you're strangers," she says, "but you don't really know the person."

As with any close-knit group, there can be something of an "us vs. them" mentality on infertility blogs, with the world divided between "infertiles" and "fertiles." Melissa, ever the diplomat, disagrees: "I don't think there's a great divide between fertile and infertile; I think there's a great divide between sensitive and insensitive." But it's clear that the "fertile"—to judge from some infertility blogs—make up the majority of the "insensitive." Bloggers and commenters alike swap outrageous stories about "Fertile Myrtles," the annoying co-workers, in-laws, and assorted others who flaunt their pregnancies and their baby pictures. They formulate

strategies to deal with the pitfalls of life among the "fertile": how to cope when cocktail party chatter turns to parenting, how to gracefully bow out of your sister-in-law's shower, how not to let the blissfully unaware pregnant woman ahead of you in the checkout line ruin your day. "When you're infertile," Serenity tells me, "you're sensitive to everything."

Cycle Buddies and Mean Girls

If the online infertility community can be said to have a den mother, it is Melissa of "Stirrup Queens." A self-described "sustainable-living, kosher, Jewish, mother of twins," Melissa, known as "Mel" to her blogger friends, runs not one but five blogs. A veteran of the "infertility merry-go-round," she conceived twins using IVF and is currently in treatment to conceive another child. An enthusiastic advocate for the infertile, she is working on a book about her experience with infertility.

Her blog, launched in June 2006, has evolved into "the freakin' infertile *Cheers* of the blogosphere," as she puts it. Like the bar in the popular television series, it's a welcoming place. She herself monitors as many as one hundred blogs a day, and regularly posts messages of support on friends' blogs. Her site includes an online book club, "The Barren Bitches Book Brigade," where members read books related to infertility, such as P. D. James's *Children of Men* and Margaret Atwood's *A Handmaid's Tale.* Aided by volunteers, Melissa manages "Lost and Found Connections," an infertility information clearinghouse. She even has a fleet of approximately thirty "peer infertility counselors"—fellow fertility bloggers whom she has enlisted to offer advice to her readers. The site is truly "one-stop shopping" for the infertility neophyte.

But the television camaraderie of *Cheers* relied on consistent, face-to-face interaction. In the world of infertility bloggers, by contrast, patrons use only their first names or pseudonyms, and few reveal the existence of their blogs to friends and family. Bea, for example, hosts two blogs, one password-protected for family and friends, and the other, "Infertile Fantasies," which she writes pseudonymously. Her husband, "Mr. Bea," knows about her "secret" blog, but she has asked him not to read it.

Yet though most of these bloggers keep their names and addresses off their blogs, the sheer amount of personal information they share can be disconcerting—not just the intimate and graphic details of procedures they have undergone (which is more than enough to scare off the delicate reader), but complaints about family and work, arguments with their spouses, and their darkest thoughts about infertility and life. "In some

ways I have been more intimate with these people than with people in 'the real world,'" blogger Meg B. ("Cyclesista") tells me. Melissa likens blogging to therapy; people feel freer to share their feelings and thoughts because there's no transference, she says. Another blogger, Tsigdinos, doubts that the intimacy she feels with her fellow bloggers would be possible without the anonymity of the Internet. "There's this barrier, this kind of protective quality of knowing that we can have these very personal discussions, and I wonder if we'd be as comfortable having those discussions face-to-face."

The intensity and challenges of these kinds of relationships are perhaps best illustrated in the phenomenon of "cycle buddies." These are pairs or small groups of women in the same stage of infertility treatment who connect online and track each other's progress, exchanging information and support during an IVF or IUI cycle, for example. The friendships, which often begin on message boards or online support groups, can quickly become intense, with buddies connecting daily to compare protocols and share feelings.

The tenuousness of these relationships is revealed, however, when one cycle buddy receives a positive pregnancy test and the other does not. Suddenly, one woman is busy furnishing her nursery and paging through books of baby names, while another is left disappointed, and, perhaps, not a little envious. Almost all of the infertility bloggers I spoke to had a story about a disappearing cycle buddy. Serenity, for example, met her buddy on a message board and connected when they realized that they would both be transferring embryos on the same day of their IVF cycles. They contacted each other almost every day until they received their pregnancy test results. Serenity's buddy received a positive pregnancy test; Serenity did not. Not long thereafter, they lost touch. Serenity was philosophical: "Friends wax and wane depending on where you are in your life together," she said, but one can't help but wonder if the anonymity and physical separation fostered by the Internet enables these connections to wither more quickly—and what kind of emotional toll is exacted for both as a result.

For the buddy still in treatment, these desertions can be heartbreaking. Infertility blogger Zee has watched as the links on her blogroll have moved one by one from the "Still Trying" category to the "Two Pink Lines"—that is, positively pregnant—category. "A huge proportion of them have gotten pregnant, and moved on," she says, admitting, "That is really hard for me. You get into this group of people…and then one by one everyone gets on the train and leaves." She likens the experience to high school, where the girls without boyfriends band together. "And then

little by little, people get boyfriends and get new crowds…as opposed to just being rejects."

But it isn't only the "rejects" who feel betrayed. Many cycle buddies who become pregnant discover that they are no longer welcome once they have left the community of the infertile. Meg B. watched her readership drop off as her pregnancy progressed; a fellow blogger went to so far as to put her on an "outlawed list." "At the time it was incredibly upsetting," she recalls. "There is a sense of 'foul-weather friendship' in the infertile blogosphere sometimes. People are there for the hard times, but not necessarily there to help others celebrate success."

The question of just who counts—and who doesn't—as a member of the infertile community recently ignited a controversy on "Infertility Diaries," a blog associated with the women's magazine *Redbook*. When one of its bloggers, Lili, returned from maternity leave after giving birth to twins, many readers were unhappy at the news—especially since Lili's co-blogger, Julia, had also become pregnant. "Well, welcome back. I think I'll be leaving," one commenter posted. Another upbraided the *Redbook* editors on their infertility etiquette: "I really think having TWO mothers blogging about infertility is akin to bringing a baby to an RE's [reproductive endocrinologist's] office—it's just not the courteous or sensitive thing." Another agreed, but lamented: "Infertility at its worst truly does turn us into people we never wanted to be."

Redbook's editor-in-chief, Stacey Morrison, defended the magazine's bloggers, posting a note to readers: "If our biggest challenge in maintaining an infertility blog is that our writers keep turning up pregnant, it's a problem we'll be delighted to have." Readers were not placated. "I feel like we just got called to the principal's office—we are wrong, *Redbook* is right, there will be no more discussion," complained one commenter. *Redbook* soon caved, moving Julia to a new "mommy blog," and hiring another infertile blogger to take her place.

Even failure can prompt a disconcerting degree of competitiveness. Infertility bloggers note the prevalence of "comparative grieving," or what Tertia dubs "the Pain Olympics of infertility"—a kind of one-upmanship in the effort to disclose the most painful personal story about fertility treatment. These disputes can appear absurd to an outsider, yet the situation has gotten so bad that one blogger, only half-jokingly, devised a system of "Pain Points" by which aggrieved bloggers could measure their suffering.

The blogosphere's relentless demand for disclosure often leads to condemnation for those who refuse to reveal. Infertility bloggers are

unanimously scathing about celebrities and public figures—such as actress Geena Davis, model Cheryl Tiegs, and former U.S. Senator John Edwards's wife Elizabeth—who refuse to reveal if they underwent infertility treatments. They praise those, such as *Desperate Housewives* stars Marcia Cross and Brenda Strong, who do. Infertility, the bloggers insist, is not shameful or something to hide. Yet many never tell their family or friends that they're undergoing treatment, or only tell them after treatment is over. "It really is a double-edged sword," Tsigdinos says. And, perversely, it's a dilemma made more complicated by modern technology. "I often wonder," she says, "Was it harder to be infertile in the Fifties [than today]? Because in the Fifties, at my age, people would say, 'Gee, they couldn't have children' because birth control, the Pill, didn't exist.... Today, there's more ambiguity. People don't know if you *elected* not to have children, if you *couldn't* have children, if we made the 'mistake' of waiting too long."

Moreover, infertility is not just the hopeful parents' story, but also their future child's. "Do I go and tell the world...only to have that be an issue that my potential child has to deal with later on?" Gabrielle Sedor asks. That question is further complicated when you add donors, surrogates, or a birth mother into the mix. And not everyone is certain they want to belong to a movement in the first place. When I spoke with Zee, she immediately corrected me when I referred to the "infertility community." "I hate the term 'infertility bloggers,'" she explained, "I don't refer to myself as an 'infertile.'" On her blog, she refers to infertiles as "people who are struggling to have a child" or "people who are having a hard time getting pregnant." Evidently, even those who participate in this active subculture are not always eager to define themselves by it.

While modern reproductive technology might answer the prayers of some, it can make life even more difficult for those—no small number—who do not achieve pregnancy. (Only a third of IVF cycles are successful.) "While failing to conceive naturally is devastating," Tsigdinos says, "it's compounded by living in a culture that believes (erroneously) that with enough time and money infertility treatments will produce a baby." Infertility can be isolating, leaving one feeling alienated from the wider fertile community. But failing to conceive even after years of medical intervention can leave one feeling alienated from the infertile world as well. Moreover, those bloggers unwilling to do whatever it takes to have a child—for example, using donor gametes—can find themselves and their desire to have a child being second-guessed by others, especially by those who used those technologies and feel defensive about their own decisions.

Not the Typical Man

It's not just women who are trying to create new roles for the infertile. A few men have joined the online infertility community, hoping to provide what Melissa calls on her blogroll "the elusive male point of view." On blogs like "Maybe Baby" and "The Adventures of (In)Fertile Frank," male bloggers are challenging the notion that infertility is just a women's issue.

That this notion is so persistent is puzzling given that one-third of infertility cases are male-factor, and another third have more than one cause or factor. (It's not just women who have biological clocks; men over 35 are twice as likely to be infertile as those under 25.) Yet male infertility is felt to be somehow more shameful or damaging than female infertility. Indeed, even many infertile women feel "relieved" to find out that the difficulty does not lie with their partners.

It's a double standard that angers Matthew Miller of "Maybe Baby." Miller, a journalist based in Chicago, is one of the few bloggers to write under his own name, and he is completely open about his "ttc" troubles. Starting the blog, he says, was a way of making good on his promise to "never feel ashamed or embarrassed" about his infertility, and to avoid being like other men, who "hide behind their wives," allowing others to assume that their childlessness was a result of female infertility. Miller is currently finishing an infertility memoir (due out in 2008), and he sees his mission—both online and off—as educating the public about men's experience of infertility, and fighting the stigma surrounding it.

Blogging, too, allows men to be more "active participants" in their infertility struggles. Miller felt helpless as he watched his wife, Constance, go through treatments, and the blog helped give him a role. "So much of what we deal with falls on her—ultrasound, medicines," he says. "I get to write about this and digest this for the both of us." Likewise, "Frank" of "The Adventures of (In)Fertile Frank" began reading infertility blogs as a way to better understand what his wife was going through. A lifelong "planner," he used the blogs for medical research, gathering information about treatment protocols and side effects. Now that he and his wife are expecting twins, he picks up parenting tips as well. Blogging, he says, has also helped him better communicate with his wife; when he had trouble voicing his feelings about his infertility, he wrote about them in a post for his wife to read later.

Male bloggers want to challenge the idea that infertility is not painful for men. They discuss how unromantic baby-making can be and how their partners seem to view them as "walking sperm donors." They describe

the guilt they feel about their wives carrying more of the burden, about feeling helpless in the face of their partners' anguish as another cycle fails or another pregnancy is lost. They tell of the awkward and humiliating experience of visiting the "deposit room," sharing horror stories tinged with a kind of gallows humor.

Just as they read women's blogs to better understand their partners' experiences, male bloggers hope that their blogs can also serve as guides for women. "I want women to know that the men in their lives are feeling something, and they are interested" in what the couple is going through, Miller says, "and if they're not, they sure as hell should be." Frank says he sometimes gets comments from his female readers, thanking him for giving them insight into their own husbands' situations. Some even direct their partners to particular entries in hopes of starting up conversations.

Yet male infertility bloggers may not exactly be "typical" men. Both Frank and Miller, for example, consider themselves feminists, and are committed to being equal partners to their wives. Other men, at least judging from the women's blogs, are not so supportive. "What don't guys get about the whole infertility thing?" Zee asks on her blog. "I know quite a few women who are dealing with fertility issues, and almost without exception, they have watched their cool, sensitive, modern men morph into thickskulled, foot-dragging oafs." Women complain about men withdrawing, refusing to go to the clinic or participate in decisions about treatment. (Indeed, Miller recalls that their doctor was "amazed" that he always accompanied his wife to their appointments.) Many fear that their partners might leave them, especially if they are the ones to "blame" for the infertility. And marriages do sometimes break up, as the sarcastic announcement on the blog "Life With Infertility" (now defunct) amply demonstrates: "This blog was originally about my infertility, now I write about the upcoming split from my husband…JOY!"

Part of this male-female divide might be because men are simply more reticent, less willing to open up about their feelings. They might feel the need to be "strong" for their partners. But they might also simply be less depressed by infertility than women. A 1985 study of infertile couples found that while half of the women described infertility as the worst experience of their lives, only 15 percent of the men did. The conversations on blogs seem to confirm this finding. "For me each miscarriage has been a soul searing catastrophe," former *Redbook* infertility blogger Julia writes. "For Steve they are… disappointing. Her co-blogger Lili agrees: "Infertility can drive a huge, splintery wedge between a couple. I felt completely in love with my husband, yet I felt we just weren't experiencing this battle in the same way."

The divide between men and women occasionally plays out in the online infertility community. Some female bloggers are not happy with what they see as male bloggers "trespassing" on their territory. Miller says that he has been criticized when he has commented on others' blogs about subjects seen as being in the domain of women. Such attitudes, male infertility bloggers say, are self-defeating. Women may find the men in their lives uncommunicative or uninterested, but change can only come about if men start taking part in the larger community—sharing, as women do, their particular thoughts and concerns. "We have to put who we really are out there for the idea of the 'typical man' to start changing," Miller says. Frank, too, asks what is gained when men's feelings are derided or dismissed: "When the role of the male in the reproduction process is diminished, are we simply stating a biological fact, or might we be contributing to the reinforcement of social norms that are damaging to women?"

Ageless Longings, Modern Tools

Until recently, infertility has been a profoundly private experience, discussed only with doctors and perhaps a few close family members. Many suffered silently, alone. The Internet has changed that, bringing together infertile men and women the world over. For many—especially those in areas without a nearby clinic or support group—infertility blogs have been a godsend, a place to find emotional support and information about their condition.

The greater awareness the Internet brings can also help men and women make more informed decisions regarding their reproductive lives. While many infertiles may not appreciate all the press attention lavished on stereotypical forty-something feminist types, knowing that fertility declines with age can help both men and women better prioritize and understand their choices. (Indeed, for all the media attention, this particular public awareness campaign hasn't been all that successful. A 2007 survey by the makers of Fertell, a home pregnancy test, found that 44 percent of men were unaware that their fertility also declines with age, and that none of the women knew that female fertility begins to decline at age 26.)

Yet no technology comes without tradeoffs. While the Internet can bring people together, it can also make them feel even more alone. It may be hard to watch friends and family members get pregnant and build families, but—as the "Pain Olympics" attest—it can be much harder to watch your "cycle buddies" of months or even years leave you behind. Having "friends in the computer," to use Tertia's phrase, can be much trickier than

in the offline world, missing, as these virtual relationships so often are, other ties and commonalities. And while blogging can serve as an outlet for some, it can trap others in the despair and anger of their condition. Still, for the infertility bloggers and their readers, the benefits of an online support network clearly outweigh the costs. And for the rest of us, their experience offers another fascinating glimpse into the new kind of community made possible by the Web: altogether virtual, yet powerfully and profoundly real.