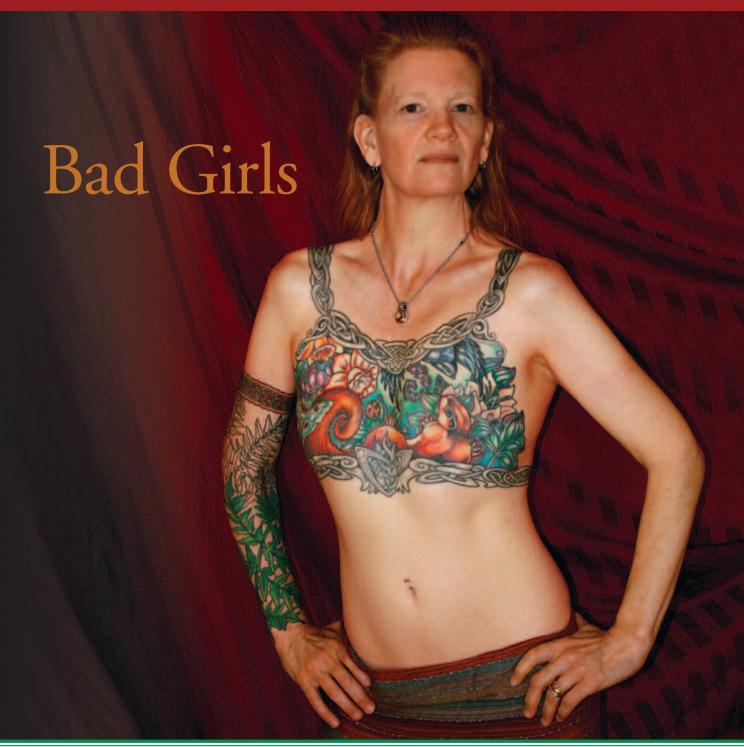


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The Report of the Northwestern Medical Humanities and Bioethics Program



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ABOUT THE COVER: Bad Girls

Rather late in the process of editing this issue of *Atrium,* I started to wonder whether the postal service might give us trouble about our front cover. It features, after all, a topless woman. This question should have occurred to me sooner, especially given that I ran into a postal problem with a journal cover for my very first academic publication. That 1995 article for *Victorian Studies* had examined the medical

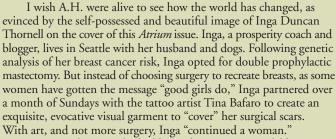
That 1995 article for *Victorian Studies* had examined the medica treatment of men and women once labeled "hermaphrodites." It reproduced a number of relevant photographs and sketches from

fin de siècle medical journal articles, and the editors of *Victorian Studies* had decided to use one as the issue's cover. The medical photograph, from 1897, was of a topless woman with small breasts (see right).

The subject, identified as A.H., a twentyfour-year-old English domestic housemaid, had come to the local surgeon to ask why she had never menstruated. Upon examining A.H., Mr. G. R. Green discovered in the maid two testicles, and no ovaries. Green decided that "the best solution of the difficulty"

—the difficulty being, simply, a housemaid with testicles—had to be a double orchiectomy, i.e., removal of both testes. With the patient's consent, Green performed the operation at the Ripon Cottage Hospital. According to Green's report, A.H. then "continued a woman."

Seeing A.H.'s grainy photo simply as a curious medical artifact, the editors of *Victorian Studies* had not thought twice about putting it on the journal's cover. But they soon discovered that, in order to comply with anti-obscenity postal regulations, when shipping the journal to Canada the volume would have to be wrapped in plain brown paper.



I contacted Inga and asked her to be our cover model because I had read that Facebook had used its anti-nudity policy to ban a photo of her mastectomy tattoo, a photo taken from the book *Bodies of Subversion: A Secret History of Women and Tattoo*, by Margaret Mifflin. Turns out Facebook had done no such thing. The rumor was born from and lived simply on the pervasive cultural myths of what happens to bad girls—women who not only are breastless, but still sexy, and tattooed, and lacking in the shame our culture readily offers strong women.

When I received Inga's positive response to my request to be our cover "bad girl," I smiled upon learning from her that she had once worked as a model patient for medical schools. As she put it in the email, her job back then was to "teach humanizing to interns." Inga has, then, a long history of raising bright questions about when medicine may decide who among us is teacher or patient, weakened or empowered, exotic or erotic, normal or pathological, feminine or masculine, bad or good.

What do women today with A.H.'s condition do, following their orchiectomies? They take one another by the hand, to have the excision scars tattooed with orchids. And then they continue women.

Alice Dreger Guest editor, Atrium 12

Photo credit for cover art: Tina Bafaro, http://www.bafaro.com/bio.html

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RenderedMute

Teresa Blankmeyer Burke

This is how to render a deaf girl mute.

Take One: I am chatting with a hard of hearing physician following a professional meeting. The conversation swerves from bioethics to personal lives, and I am asked whether I have children. Upon my affirmative answer, the doc inquires whether they are my biological children. When I reply, "Yes," his response shakes me to the core: I am incredibly selfish for bearing my biological children without knowing whether they would inherit my disability.

Take Two: I am dining with a childless-by-choice Ivy-League-trained hard of hearing educator, who tells me that deaf and hard of hearing parents who decide to bear biological children are cruel, abusive, and self-centered for not thinking of what a terrible life their children will have with a disabled parent.

I respond to these admonishments as a classic good girl: I sit there, silent, listening to their view of my decision to become a biological mother. That these professionals know what it is like to be deaf or hard of hearing is not lost on me. That we have reached different conclusions about the worth of our lives is lost on them.

A philosopher by temperament as well as by training, I consider their remarks. Was I a bad person for thinking that a deaf life was not so terrible? That, if my child happened to be deaf, then surely I might be able to manage this? That deaf ways of being in the world can be joyful and sublime? Had I committed the cardinal sin of motherhood by saddling my children with a terrible burden from birth—that of having a disabled mother?

It is only now, as I write this essay, that I wonder if the difficulty I had in finding an obstetrician willing to go unmasked during labor and delivery was a response to my disability. I



A mother signs 'mommy' to her son.

interviewed almost a dozen, but not a one was willing to let me lipread as I birthed. Was this a medical sort of shunning? If I were audacious enough to become pregnant, then I ought to shut up and comply with standard medical practice, even if it meant I would not understand what was being said.

But I knew that I would need to communicate during labor and delivery. I *wanted* to be able to understand any instruction or encouragement given to me. I *wanted* to be an active participant. After all, this was my body giving birth! All I needed was to be able to see the doctor's lips. Was this too much to ask for?

(continued on next page)

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Fast-forward six years. I am a graduate student who has brought my nine-month-old daughter for a well-baby check-up at the university teaching hospital. My university does not provide medical insurance as part of the graduate student funding package and I am one of many brown mothers in the clinic, but the only deaf one. The medical student who initially examines my daughter makes a comment. I miss it, and ask the student to repeat what she has said. Upon my informing the medical student of my hearing loss, the tone of the entire visit changes. My daughter's medical exam is interrupted as the medical student shifts her attention to me. I am given a lecture on birth control and how to avoid becoming pregnant again, since we got lucky this time, but my next child might not be so lucky.

I am not only nonplussed, but struck by the irony of "hearing" this from a dark-skinned woman of color who has undoubtedly experienced her own share of discrimination based on physical characteristics. I think about the kinds of things our children inherit from us. The ability to discriminate subtle gradations of color. Things like the family academic lineage and a people's history of persecution that my child of Jewish heritage inherited from his father. Things like a dimpled smile and a family history bound up with slavery and genocide that my child of African and Native American heritage inherited from her father. Things like compassion for people who have a different way of being in the world.

Before bearing my biological children, I thought about the prejudices they might face—discrimination deeply rooted in historical fact, but also in the experiences of their able-bodied fathers. I did not consider the cruelty of bringing a child into a world where she or he would be highly likely to experience discrimination. I was not dissuaded by the taunts I had experienced as a child myself for having a mother of Arab-American heritage.

But defying social discrimination is the province of good girls. Burdening innocent children with disability—whether their own or that of their mother—is the mark of an egregiously bad girl.

"How so?" I wonder.

Is there a threshold against which potential disabled mothers ought to measure their desire to become biological mothers against the harm their children might experience? And if there is such a threshold, are the harms of social discrimination related to disability unique? Or are these just a piece of the harm-continuum we consider when bringing any child into the world?

"But wait!" you interject. Social discrimination is different from physical disability! True, that.

To have a body that doesn't fit into a world designed for a narrow range of bodies is frustrating. Dismaying, even. To have a body that experiences physical pain offers up a different kind of calculus from the one I performed when deciding to be a biological mother. Assuming that discrimination experienced by a deaf child (or any child of a deaf mother) is sufficient to forego procreating is an act of medical prejudice. Leaping into biological motherhood, not knowing whether your child will be deaf or hearing, not believing your disability will harm your child, not knowing what the future will bring—well, this couldn't possibly be an act of love, could it?

This is how to render a deaf mother fierce.

Teresa Blankmeyer Burke, PhD, is a philosopher and bioethicist at Gallaudet University. Her research focuses on bioethical issues of concern to the signing deaf community, in particular issues of genetics and reproduction.

on bioethical issues of concern to the signing deaf community, in particular issues of genetics and reproduction. In addition to her scholarly work, Dr. Burke serves as bioethics expert to the World Federation of the Deaf and chairs the National Association of the Deaf Bioethics Task Force. She is currently writing a memoir about her experience of being a widowed mother living in the wilderness of Wyoming.

The Baddest Births in Town

Elizabeth Bogdan-Lovis and Raymond De Vries

You're pregnant. You're happy. Your partner is happy. Your parents are happy. Everybody is happy. We love babies. But wait. You will soon find out that our love for babies has a dark side. That little "+" on the pregnancy test? It was your ticket to (cue Rod Serling) the *Moral Twilight Zone of Pregnancy*. There are now countless ways a good girl like you can go bad.

You did what? You had a glass of wine? Ate soft cheese? Refused to give up sushi? Skipped childbirth yoga? What? Clearly you do not love your child.

Living in this moral twilight zone, you will discover what you only suspected before: your cervix is not just that nubby little opening to your uterus, it is also the portal of society's control of over women. From your first sexual activity, to your election of abortion, to how you behave while pregnant, to your choice of where, when, and with whom you will birth your baby, to your management of menopause, your cervix—what it lets in and what it lets out —will be the subject of intense social interest and surveillance.

And while all pregnant women walk the line between "good girls" (those who eat right, exercise, and put speakers on their bellies to let their future children listen to classical music) and "bad girls" (those smoking, drinking, soft cheese-eating ne'er-do-wells), the ultimate bad pregnant girls—the baddest of the bad—are those who decide to birth their babies at home, turning their backs on the "benefits" offered by hospital-based obstetric technology.

Reactions to a recent article about home birth in the *New York Times Magazine* gives us a glimpse of just how evil these home-birth-choosing bad girls are (Shapiro 2012). The comments section opens with advice from a paramedic who "has had to respond to some horrific incidents at birthing/midwifery centers and home births [and has] seen babies die because of the choice the parents made to have out-of-hospital births... babies who would not have died if born in hospitals." He tells home birth mothers: "If you choose to have a home birth, you better be prepared for your baby to die due to a lack of immediate neonatal advanced life support medicine."

Other commenters wonder: why would a pregnant woman reject "the safe, sanitary, and skilled support" available in the hospital and make a choice that jeopardizes the health and well-being of the baby? There can be only one reason: these women are selfish, guilty of the "self-indulgent, 'it's all about ME' solipsism unique to privileged Americans." The comments continue: "Being a (good) mom is about



putting your child's safety first, not prioritizing an idealized 'birth experience' for yourself.... The home birth movement is about moms', frankly, selfish desires to have a certain kind of 'experience,' egged on by a new industry of midwifery eager to take their money: it's certainly not about infant health." Picking up this theme, another commenter adds: "Homebirth kills babies. No homebirth midwife will tell you [this]; 100% of their income depends on pretending."

"Wait," we can hear you saying, "these comments are just random reactions of *New York Times* readers. What do professionals say?" In 2006, the American College of Obstetricians and Gynecologists (ACOG 2006) issued a policy statement on out-of-hospital births, announcing:

"ACOG strongly opposes out-of-hospital births." ACOG explains: "Ongoing surveillance of the mother and fetus is essential because serious intrapartum complications may arise with little or no warning, even in low risk pregnancies" (ACOG 2006). Five years later, ACOG offered a more nuanced "committee opinion on 'planned home birth." This opinion began by explaining that "[ACOG] respects the right of a woman to make a medically informed decision about delivery," but goes on to suggest that women who exercise that right and choose to birth at home must be, well, bad or crazy or both, because, according to ACOG, "planned home birth is associated with a twofold to threefold increased risk of neonatal death when compared with planned hospital birth" (ACOG 2011, p. 425). No sane, non-selfish, good and loving mother would subject her baby to a "threefold increased risk" of death!

So what drives an otherwise good woman to the dark side? What are homebirthing women choosing and, more importantly, what are they refusing? Rejecting the idea that all births are fraught with risk, these women see no need to surround themselves with the full armament of obstetrics, "just in case." Even worse, these women have the audacity to tell obstetric specialists that the many tools doctors use to reduce risk—electronic fetal monitoring, induction, cesarean surgery, to name a few—actually increase risk.

Somehow, these "bad girls" missed the boat that carries other pregnant women down the river of medicalization. This boat set sail somewhere around the middle of the twentieth century. Before then, there was a society-wide "acquiescence to the inevitable"; fate was recognizably fickle, and there was little or nothing one could do to reliably forestall all bad things. As the horrors of the World Wars faded, we were slowly seduced by the idea that we are not the slaves of fate. Innovative technologies to visualize, test, and measure previously unknown biopsychosocial minutia would deliver information to steer us around the nasty bits of life and lead us to a safe and healthy future. By analyzing this information, we could "manage" risk and banish the frightening uncertainties of life. Only the foolhardy, the Luddite, or the hippie living off the grid would reject the promise of safe living afforded by the science of probabilities.

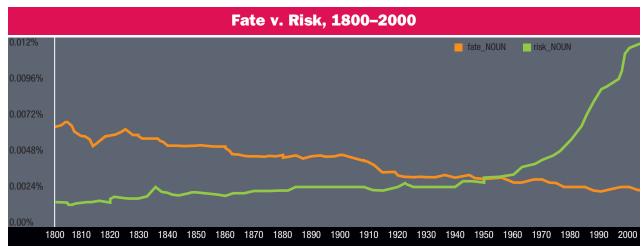
The cultural change in attitudes about life's uncertainties is shown in this "Ngram." We plotted uses of the noun forms of the words "fate" and "risk" in all English language books published in the United States in the Google library between 1800 and 2008. Notice how we now talk far less about "fate," something uncontrollable, and much more about "risk," a phenomenon we think we can "manage.'

In obstetrics, risk is supposedly managed via new technologies. If listening to the baby's heartbeat every 15 minutes with an old-fashioned stethoscope pressed to a mother's belly was good, continuous electronic monitoring must be better. If Nature sometimes refused to get labor started "on time," no problem; we can induce. Heck, we could now get a jump on Nature and get your labor going on a day that suits your work schedule (and ours)! The pain of labor? Who needs that? Gone, with the help of an epidural.

How could this be bad? Why not get on that boat? The majority of pregnant women in America, those perceived as the good girls, are on board. Fewer than one percent of births in the U.S. happen at home. Hospital birthers trust the technologies of obstetrics. A recent national survey of women who birthed in the twelve-month period extending from July, 2011, through June, 2012, found that "mothers agreed that getting more rather than fewer maternity tests and treatments is generally better quality care (63% versus 22%)" (Declercq et al. 2013, p. 71). Bring it on!

So why do some women let that boatload of medicalization sail without them? We think it is less about their selfish desires or the wily ways of greedy midwives than it is about science. Ironically (given our science-obsessed society), these women are "bad" because they based their birthing decisions on the best scientific evidence available. Skeptical about the data touted by ACOG, these women are inclined to believe the more objective findings found in a review of the research on the safety and place of birth done by the Cochrane Collaboration: "Increasingly better observational studies suggest that planned hospital birth is not any safer than planned home birth assisted by an experienced midwife with collaborative medical back up, but may lead to more interventions and more complications." (Olsen and Clausen 2012; emphasis added).

Huh? Hospital birth might cause complications? The authors of the review explain: "impatience and easy access to many medical procedures at hospital may lead to increased levels of intervention which in turn may lead to new interventions and finally to unnecessary



Use of the words "fate" and "risk" (as nouns) as a percentage of all words in the Google library, by year, 1800-2000. For more information on this technology, see http://books.google.com/ngrams.

complications." The script usually goes like this: "That epidural has slowed your labor so we need to augment with Pitocin. Oops, now your contractions are too strong, so we need to give you just a little sedative. Gee, your labor has stalled. Time to do a cesarean section."

Because they are floating with the cultural current, the women on the good ship S.S. Medicalized Pregnancy are given a pass if something bad happens at their hospital birth, even if it was the result of this cascade of unnecessary obstetric interventions intended to manage risk. "How unfortunate," they are told, "but thank goodness you were in the hospital! They did everything they could."

They sure did.

But when something untoward occurs in an out-of-hospital setting? Bad girl! Heaven help the few women who begin labor at home and then seek obstetric help because of an unexpected complication. Unlike women who went to the hospital in early labor and then need to be taken to the operating room for an unforeseen problem, women who transfer from home to hospital are punished. The most infamous case involves a home birth mother whose child was born severely mentally and physically impaired as a consequence of the mother being forced to wait two hours for an "emergency" cesarean section by the obstetric staff at Johns Hopkins University Hospital (Wenger and Rector 2012).

Our social covenant with medicine reflects faith and trust that we are getting the best that medicine has to offer. Those who challenge that covenant by suggesting that the newest and the latest medical intervention might not be the best medicine are begging to be vilified. And if that challenge comes from women who are known to be carrying the future of society in their wombs? Lord, have mercy.

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The authors are guest editors, along with Charlotte De Vries, of a special issue of the Journal of Clinical Ethics on the place of birth (volume 24, number 3, Fall 2013).

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Forgiveness in the Abortion Clinic

Lori Freedman

During her abortion procedure, the patient turned to Claudia*, a fifty-year-old Latina licensed vocational nurse who sat beside her, holding her hand, and whispered, "Can you lean this way?" Claudia perched forward on her stool to get closer to the patient and suddenly the patient grasped the crucifix that dangled from Claudia's necklace. The patient implored her not to move. Claudia recalled her surprise: "I had everything done to me, but I never had this." The patient was very focused on the crucifix and seemed to stop paying attention to what was going on in the room. Claudia asked the head nurse to take the patient's vital signs; the patient was medically high-risk and Claudia couldn't take vitals from her position. Claudia stayed fixed in place, back aching slightly, throughout the rest of the fifteen-minute procedure while the patient held the crucifix close to her own heart. At the end, Claudia recalled, "I said to her, 'Mi hija, it's over.' And she said, 'It is?'" And then the patient took Claudia's hand, kissed it, and said, "You're an Angel." Claudia was shocked and moved by the gesture. No patient had said that to her before. When she went to check on the patient later in the recovery room, the patient thanked her repeatedly. With visible emotion, Claudia finished the story: "I almost keeled over when she told me this—she goes, 'Now I know I've been forgiven.' And that was it. I think I've had that in my head—you know how you think about stuff like that—that thing lasted me for the whole month."

Claudia told me this story thirteen years ago, while I was conducting ethnographic research as a participant-observer in a hospital-based abortion service. I spent considerable time there helping, observing, and intermittently conducting as many interviews as I could with counselors, doctors, and nurses, in order to gain a rich view of abortion clinic life. This study became my master's thesis, but nothing else. I feared publication might amount to a gratuitous exposé of people I respected dearly. I couldn't think of any policy or academic imperative that necessitated revealing the intimate dynamics of this particular social world—certainly nothing that could make the potential feelings of betrayal worthwhile. Ultimately, I just tucked it away.

But recently, I heard the Rev. Rebecca Turner speak about how some abortion patients have unmet spiritual needs, and my ethnographic memories came flooding back. Her organization, Faith Aloud, like another organization called the Clergy for Choice Network, connects pro-choice clergy with religiously diverse women to help address their spiritual concerns about their abortions in ways that counselors, nurses, and doctors often cannot. The Faith Aloud website tells potential clergy volunteers, "Many women have felt shame and stigma forced on them by their religious groups, their families, and the society. We want to provide women with the spiritual comfort of knowing that God is with them through all things."

Listening to Rebecca Turner talk about the work clergy members do to spiritually meet women where they are, I remembered how surprised I had been during my ethnographic work to find that the counselors, nurses, and physicians often informally addressed women's spiritual needs. They ministered, in a sense, to their patients, some from a spiritual place of their own, and some from a gut feeling about what women needed to hear.

The counseling and nursing staff in the abortion clinic where Claudia worked were mostly middle-aged and vocationally trained. They were predominately Latina, like their patients, but some were Filipina, African-American, or white non-Hispanic. One particularly intriguing aspect of this abortion service was how these staff members were largely recruited from other parts of the hospital rather than from the ranks of the college feminists who staff many outpatient abortion clinics. In many ways the hospital clinic felt and looked much like any other ward, but for the simultaneously unsettling and reassuring lack of clinic-naming signage and the visible emotionality of some patients.

^{*} Names of clinic personnel are pseudonyms.

Clinic workers told me that they addressed patients' emotions as they arose in all their forms, including sadness, fear, relief, guilt, and shame. Notably, some patients expressed this shame in religious terms and were not easily consoled by responses based on concepts of reproductive freedom and rights. Beatriz, a Latina recovery room nurse, herself very religious, shared how she approached patients who were experiencing spiritual angst.

[I] do a lot of spiritual counseling with them because of their guilt. They cry and they think that they will never have forgiveness from God. Sometimes they say, "I hope God forgives me for this," or "My mother thinks that I'm really a sinful person," or they cry and say, "I feel so bad about what I did and what happened to me." So I say, "Well, many times we have to do things in this life, some kinds of decisions that are very painful, and that sometimes we have no choice or sometimes it seems like there's no way out. But God understands and he knows what's happening...and you can ask forgiveness to God and he forgives you immediately. It doesn't take years for that."

Beatriz and Claudia starkly challenged my own unexamined assumptions that religion and abortion mixed like oil and water. I marveled at their easy confidence that they could help these women spiritually. There is no script for such moments, certainly no mainstream religious scripts that so readily grant women who get abortions forgiveness in such reassuring ways. In fact,

data show that women who get abortions are likely to keep it a secret precisely because they fear they will receive harsh disapproval. They fear they will be judged and that the people that they care about will see them as less than what they were.

Ironically, for these patients, the abortion clinic may be one of the few safe spaces to seek spiritual counsel. Leticia, a Latina counselor, observed to me that patients who are socially or emotionally isolated are more likely to divulge their spiritual concerns: "They talk a little more with me when there's not a relative that can understand the situation... when there's nobody, no support system, that's when the women will approach me and tell me about their feelings at that moment." These nurses and counselors may have had such candid conversations about forgiveness not only because patients lacked alternate sources of support, but also because the staff and patients shared ethnic and religious identities. Along these lines, a white nurse named Anne contended, "I think sometimes you can say the right thing for people who are religious, particularly if you come from the same background."

Today, research and teaching about abortion regularly address stigma, ambivalence, regret, and complexity.^{3,4} We are exiting a political moment (that lasted decades) during which women's spiritual

and emotional pain around their own abortions was often poorly understood or even perceived as threatening to women's rights by giving voice to moral questions, thereby presumably ceding ground to abortion's opponents. Such women were often met with impassioned pleas to keep silent and with rhetoric that repeatedly asserted that most women feel relief (subtext: "So, what's wrong with you?"). Influenced by the work of leaders and members of the Abortion Care Network to address this problem, new literature on the topic wades into nuance, acknowledging the effects religious teachings against abortion have had on the women who both share those beliefs and, because of the circumstances of their lives, decide to have an abortion. 5.6

"Many women have felt shame and stigma forced on them by their religious groups, their families, and the society. We want to provide women with the spiritual comfort of knowing that God is with them through all things."

Faith Aloud website

I am taken back to these decade-old observations as I currently conduct research on the effects of religious doctrine on obstetrics and gynecology practice in Catholic hospitals. One in six patients in the United States receives care in a Catholic hospital where abortion, sterilization, birth

...data show that women who get abortions are likely to keep it a secret precisely because they fear they will receive harsh disapproval. They fear they will be judged and that the people that they care about will see them as less than what they were.

control, and infertility services are prohibited. In my interviews with doctors who have worked in Catholic hospitals, I have learned that treatment options for women facing some of the most difficult pregnancy complications and losses, such as incomplete miscarriage in the second trimester, are restricted as well. These physicians tell me that, as they tried to offer their patients the best care they could, they felt their hands were tied by doctrine.

Stories from my earlier research of nurses and counselors ministering to the need for forgiveness in the abortion clinic provide a useful reminder of the value and importance of religious beliefs for some patients, but they also illustrate how religious practice in ob-gyn care is best directed by the patient, not the institution. I am learning in my current project that, in the context of Catholic hospitals, hospital ownership dictates the role of religion in women's reproductive lives by using doctrine to restrict access to care in ways that neither those working there nor patients necessarily want. Whereas women like Claudia, Beatriz, and Leticia met individual women's needs and concerns in the moment, with faith in a forgiving and understanding God, the Catholic health doctrine governing hospitals prescribes a one-size-fits-all religious approach.

As such, the individual suffering of spiritually diverse women goes unaddressed in the name of God—a problem made worse when the

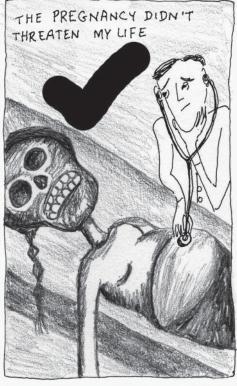
Catholic hospital is the only game in town. Religion and abortion can and sometimes do mix well at the individual level when patients speak their concerns and are ministered to by compassionate people, be they abortion clinic staff or supportive clergy, who meet them where they are.

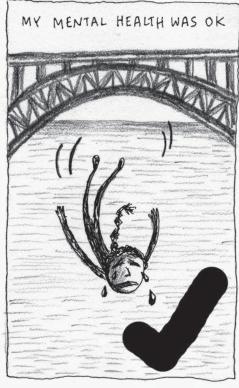
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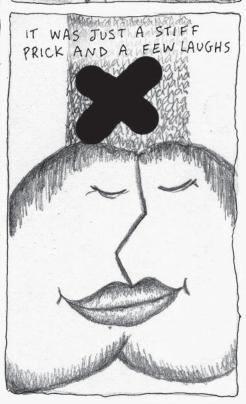
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Choices









Nicola Streeten has worked as an illustrator since 1996. In 2011, Myriad Editions issued Streeten's Billy, Me & You, the first published graphic memoir by a British woman. About the artist's own experience of bereavement following the death of her child, Billy, Me & You was recognized by the British Medical Association (BMA) with the citation of "Highly Commended" in the Popular Medicine category of the 2012 BMA book awards. Streeten is currently completing Hymn, a fictional graphic novel exploring the ethical issues surrounding abortion, scheduled for publication in 2015 by Myriad Editions. Streeten received an Arts Council England award for the research and development of Hymn.

In the Manner of a Bad Girl

Paul Vasey

Trisha is waiting by the bustling food market in downtown Apia, the capital of Samoa, as I arrive to pick her up one minute past our designated meeting time. Samoans will never be confused with Germans in the punctuality department, but Trisha decides to milk the situation for all it's worth.

"You're late!" she proclaims in an exasperated tone. This draws the attention of people in the market. "Do you know how long I've been waiting?" she asks with a dramatic flourish.

"About 30 seconds?" I retort, rolling my eyes. This sends Trisha diving forward to swat me, but I dodge her, jumping backwards. The onlookers are clearly entertained by this impromptu street performance involving a *palagi* (white man).

Motioning at Trisha, I address the crowd. "Mai i le ulu" ("sick in the head"). This gets laughs all around. The palagi has a sense of humor and he can speak some Samoan.

Trisha decides to switch gears. Pursing her lips and batting her eyes she asks, "Darling, don't you love me anymore?" Confident that my answer will be in the affirmative, she doesn't wait for my response, but instead instructs me to "run over to that shop and get me a cool drink." I do her bidding and arrive back to hear a woman in the market telling Trisha how lucky she to have a *palagi* of her very own, as if I'm some sort of exotic pet, like an ocelot.

Trisha Tuiloma is my Samoan research assistant and for the past seven years we have been conducting research together on sexuality in Samoa. Trisha is not a woman in the conventional sense, but she is not a man either. She is a fa'afafine—a member of a large Samoan community of transgendered males. In Samoa, young boys who exhibit girlish behaviors and interests (like helping with housework and playing with girls) are placed into this special gender category and are treated differently from typical boys or girls. Most fa'afafine grow up to be androphilic, i.e., sexually attracted to adult men. Unlike the way transgender has typically been dealt with in the modern West, fa'afafine don't change their bodies. So they have male bodies, to some extent they live like women, and they take men as lovers. I know that can be hard for you to wrap your head around. It took me a while to get it. Basically, how you perform gender trumps what you do with your genitals.

As Trisha and I are on our way to our first set of interviews for the day, Nancy Sinatra's "These Boots Are Made for Walking" blares from the radio. Trisha sings along, stomping her feet and waving her hands. She keeps up a running commentary about people on the side of the road. Pointing to one young man she exclaims, "Oh, he's got a BIG one!" and tosses me a knowing glance.

"Bad girl," I say, and she laughs.

In the Samoan language, *fa'afafine* means "in the manner of a woman," a reference to how the *fa'afafine* behave and live. I've come to think of Trisha as behaving in the manner of a bad girl. She transforms mundane workdays into irreverent spectacle. But as we've grown closer, I've learned that,

while Trisha puts on a good show, she's not *really* a bad girl. In reality, Trisha is the sole breadwinner for her large family and she works like crazy to support them. She's also the best research assistant in the world.

If Trisha lived in just about any Western country she'd be diagnosed with "gender dysphoria," a mental disorder which is thought to cause big-time distress. What a bizarre concept that would be to apply to Trisha. When I ask her if she is upset by her femininity, she looks at me like I've gone nuts. Why would the most beautiful *fa'afafine* in the world be distressed by her obvious fabulousness?

Because pandemonium doesn't break out when Samoans see a "guy" walking down the street in a dress, *fa'afafine* don't grow up being constantly bombarded with the message that they're sick. My team's research has documented how the accommodating Samoan approach to gender-atypical boys means that "distress" about their femininity never comes into play. Samoans simply acknowledge that feminine males are part of the cosmos and they move on. They don't throw the transgendered away like garbage, nor do they try to "fix" them medically, and as a consequence, the society benefits as a whole.

My team's research has also shown that, like many androphilic males in the West, children who are *fa'afafine* stick close to their relatives. In North America, this gets labeled "separation anxiety," another supposed disorder, but not so in Samoa. We've found that this anxiety is mostly about concern for the wellbeing of one's family. So it actually reflects prosocial empathy, not pathology. What a lesson the West has to learn from these tiny islands.

Because some of our previous research in Samoa has shown that women with *fa'afafine* relatives have more babies than those without, we are trying to figure out whether this might help explain why male androphilia persists from one generation to the next, even though *fa'afafine* themselves don't reproduce. In our current research, we are trying to pin down the mechanism underlying these relative differences in offspring production. The cause(s) could be anything from social to physiological to psychological.

Trisha and I eventually arrive at our destination and prepare to interview a group of women who are the sisters of *fa'afafine*. Some of the questions we will ask are of a delicate nature. For example, we'll want to know at what age the women had their first periods. We know that, in order for us to get this data, the women need to feel comfortable and relaxed. Trisha springs into action, explaining that she herself had her period three times last month and is pregnant with her fifth child. The women roar with laughter.

"Yeah," I add, "so far she's had two dogs, a pig, and a frog." More guffaws. Mission accomplished. Trisha and I settle in for some serious data collection, and I count my lucky stars that we're a team.

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Bad Girls Cant Win



Billie Jean King and Bobby Riggs in an obviously-staged photograph circa 1973, when the two engaged in the so-called "Battle of the Sexes" tournament. AP Images/Anthony Camerano

Pam R. Sailors, Sarah Teetzel, and Charlene Weaving

Since the beginning of women's participation in modern athletics, sports have been used as an excuse to medicalize women's bodies, to enforce heterosexual norms, and to define strictly who will count as a "real" woman. Yet for their part, athletic girls and women have (intentionally and unintentionally) used sport to subvert and even defy gender-based discrimination.

The late 1800s saw a significant increase in women's participation in modern sport, especially in cycling. In order to cycle with efficiency and comfort, women moved away from traditional long and heavy skirts that could easily get caught in wheels or spokes. Instead, they wore tight fitting knee-length hose called "bloomers." Naming this innovative clothing after American women's rights advocate Amelia Bloomer made sense, as the bicycle had a significant impact on

allowing women new independence. Besides allowing women to physically distance themselves from home, the bicycle provided women with the opportunity to distance themselves from the early Victorian ideal of weak and passive females and to gain empowerment through outdoor sport.

Even though it became more acceptable over time for women to participate in cycling, they were still expected to display restraint and refinement in order to conform to socially prescribed notions of 'ladylike' behavior. If they did not subscribe to this ideal, they were considered 'bad' or 'deviant'. Some men (both physicians and laymen) were so opposed to women's involvement in sporting bicycling clubs that they invented pseudo-medical and moral reasons why women

should not cycle. Writing about the American cultural history of women in sports, Mariah Burton Nelson has noted that:

Cyclists' saddles [...] were said to induce menstruation and cause contracted vaginas and collapsed uteri. While appearing to enjoy an innocent, healthful ride, female cyclists might use the upward tilt of the saddle to engage in the 'solitary vice' of masturbation. And, skirts hiked provocatively above the ankle, female cyclists might contribute to immorality by inciting lewd comments from male pedestrians.¹

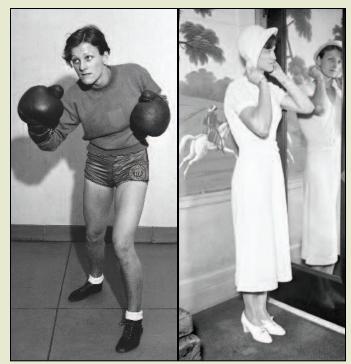
Women could not simply enjoy the act of cycling for its own sake. Unable to tolerate women's participation in physical activity, some nineteenth-century physicians linked athletics to childbirth complications, stating that strong developed arms and legs would be detrimental to child birthing. Writing in the *British Medical Journal* in 1867, one physician stated

bluntly the extent of control physicians expected to have over women's bodies, and indeed over their entire beings:

As a body who practice among women, we have constituted ourselves, as it were[,] the guardians of their interests, and in many cases[,] the custodians of their honor. We are[,] in fact, the stronger and they the weaker. They are obliged to believe all that we tell them[;] we[,] therefore, may be said to have them at our mercy.²

Even today, outdated claims about sport participation damaging women's bodies continue to surface. For example, in 2009, female ski jumpers attempted to be included in the Vancouver 2010 Winter Olympic Games program, and in response, Gian-Franco Kasper, President of the International Ski Federation, indicated that the reason women should not participate in ski jumping is because it could result in damage to their uteri or lead to infertility. These ideas were presented without any actual supporting medical evidence, and neither Kasper nor others of his ilk expressed any concern that male ski jumpers might damage their reproductive organs or risk infertility. It is not difficult to find other examples of "protection" of women athletes' bodies: rules prohibit women's ice hockey players from body checking, and in speed skating and cross country skiing, women are restricted from competing in the longer distances allowed in the men's competitions. What these double standards show is that women's bodies continue to be viewed as frail and incompatible with "men's" sports. Women who challenge these double standards are often regarded as bad athletes and bad women.

Women athletes have also suffered discrimination when they have been seen as exhibiting 'mannish' characteristics in body or behavior. Writing about the historical intertwining of gender, sexuality, and sport, Susan Cahn has examined medical studies on women and physical exertion in the late nineteenth and early twentieth centuries. Some medical experts of that period argued that physical activity would unleash wild sexual desire in women, while others claimed it would provide a healthy outlet for sexual desire. However, there was no disagreement among the experts when it came to their belief that supposed female masculinity or "mannishness" equated to sexual unattractiveness and deviance. Initially "mannishness" implied being unable to capture male attention, but later it also came to connote the absence of desire for men. Cahn labels both conditions "heterosexual failure," meaning a failure to adhere to cultural heterosexual norms for body and behavior. Cahn argues further that the medical field's preoccupation with sexual deviance contributed to the twentieth-century medicalization of homosexuality and the marking of lesbianism as pathological. Given this, and the accompanying connection of mannishness and athleticism, it is unsurprising that a general stereotype of all female athletes as lesbians was firmly in place shortly after World War II.3



Babe Didrikson, American boxer, shown (left) warming up at Art McGovern's Gym in New York City, 1933, and (right) dressing up according to feminine expectations, 1932. AP Images

Women athletes could counter this stereotyping and backlash only by changing "heterosexual failure" to "success" through demonstrated allegiance to mainstream heterosexuality. Cahn presents the story of Babe Didrikson as a perfect role model of "conversion" from ugly athlete to happy heterosexual homemaker:

In the early 1930s the press had ridiculed the tomboyish track star for her "hatchet face," "door-stop jaw," and "button-breasted" chest. After quitting track, Didrikson dropped out of the national limelight, married professional wrestler George Zaharias in 1938, and then staged a spectacular athletic comeback as a golfer in the late 1940s and 1950s. Fascinated by her personal transformation and then, in the 1950s, moved by her battle with cancer, journalists gave Didrikson's comeback extensive coverage and helped make her a much-loved popular figure. In reflecting on her success, however, sportswriters spent at least as much time on Didrikson's love life as her golf stroke. Headlines blared, "Babe Is a Lady Now: The world's most amazing athlete has learned to wear nylons and cook for her huge husband," and reporters gleefully described how "along came a great big he-man wrestler and the Babe forgot all her man-hating chatter."4

Even though Didrikson was said to be "the world's most amazing athlete," society's focus fell on her "greater" accomplishment—escaping her mannishness by leaving sport behind for the world of heterosexual subservience.

The unjust and connected stigmatization of lesbians and of women athletes continues to plague women's sport in our own time, as evinced by lack of media coverage and pressure on women athletes to project a heterosexual image.

For example, media representations of women's beach volleyball sexualize players while simultaneously emphasizing their required adherence to stereotypical heterosexual female roles. Within just a couple of years of winning a second gold medal at the 2008 Olympics and becoming a mother, beach volleyball player Kerri Walsh signed a sponsorship agreement with Procter & Gamble to promote Pampers diapers as part of their "Thank you, Mom" campaign. In her public work, she carefully portrayed herself as both sexualized athlete and mother—a classic whore/Madonna dual expectation for women—proclaiming that her young sons would be wearing their Team USA diapers while she sported her bikinis. Similarly, track athlete Alysia Montano always wears a flower in her hair when she competes, dispelling hints of mannishness while competing fiercely, all in an effort to exhibit femininity while simultaneously showing strength.

Athletes who refuse to engage in this kind of heterosexualized "good girl" performance are consistently penalized and labeled "bad." In 1981, when tennis star Billie Jean King was forced to reveal that she had engaged in a lesbian relationship, she appeared before the media with her husband by her side to denounce her lesbian relationship as a mistake. Still, King lost almost all of her commercial sponsorships, and the Women's Tennis Association issued a warning that revelations of lesbianism by other players would not be tolerated. More than thirty years later, women's sports' leaders and institutions remain generally averse to any perception of lesbianism, as shown by women's college basketball standout Britney Griner's decision not to acknowledge publicly her lesbianism until after graduation. According to Griner, her coach had warned against speaking out earlier because she thought it would make it more difficult to recruit players to the school.

Women athletes have also had their sexual anatomy subject to extreme surveillance. This has been done in the name of protecting women's sports for "true" women, but has often, in practice, meant harm to individual women athletes. When the International Olympic Committee (IOC) formed a Medical Commission in 1966, one of its first tasks involved investigating how to best classify athletes as women and men without subjecting them to the nude parades and genital inspections that had been occurring in some major competitions. The Medical Commission decided that all female competitors at the Olympics would require a "Certificate of Femininity" that would be issued after undergoing a Barr body test, which involved the analysis of an athlete's chromosomal patterns as obtained from a mouth swab of the inner cheek. Athletes whose results indicated the XX chromosome pattern typically associated with women were awarded a certificate. Competitors whose test results showed chromosomal patterns other than XX were considered to have "failed" the test and were barred from competing in the women's events. The language used by one IOC Medical Commission member in describing the consequences of a failed test demonstrates the patronizing and negative attitude



Certificate of Femininity for María José Martínez-Patiño, 1983



María José Martínez-Patiño is now a Professor of Education and Sports Science at the University of Vigo in Spain, and has been working with the IOC's Medical Commission to revise their gender-testing policy. Photos are used with permission from Prof. Martínez-Patiño.

toward competitors whose chromosomal patterns differed from XX: "I consider that our duty as doctors comes before everything, even Olympics, and that if we find such hybrid beings, we must if possible treat them and at the very least, help them to accept their fate as we ourselves do when we discover a shortcoming of some kind in ourselves." 5

Women who possessed a Y chromosome would henceforth be considered unwelcome in sport, as they were not "real" women. Women with masculine physical appearances, like women who were found to carry a Y chromosome, were ridiculed, had their past accomplishments negated, or simply disappeared from the international sport scene. The 100meter sprint Olympic champion from the 1964 Games, Eva Klobukowska from Poland, was barred from participating in the 1968 Olympics after a Barr body test identified the presence of XX/XXY mosaicism in her sample. Her medals and records were also revoked. Former USSR track and field stars Irina and Tamara Press, who together broke world records in their events more than 25 times, failed to appear at the 1968 Olympics or ever again in international sport competitions. Their absence after the introduction of sex verification procedures, as well as their masculine physical

appearances, fueled speculation that they were "really" men and did not deserve their medals. These "bad girls" were no longer welcome in sport.

Those few women who refused to back down and withdraw from sport following the identification of a "chromosomal abnormality" faced a huge battle to eliminate the XX requirement for women's competition. Hurdler María José Martínez-Patiño fought to address the discriminatory policies after she was informed in 1986 that more sensitive medical equipment had identified she had XY chromosomes, despite having "passed" the test two years prior. Martínez-Patiño has explained:

As I was about to enter the January, 1986, national championship, I was told to feign an injury and to withdraw from racing quietly, graciously, and permanently. I refused. When I crossed the line first in the 60 m[eter] hurdles, my story was leaked to the press. I was expelled from our athletes' residence, my sports scholarship was revoked, and my running times were erased from my country's athletic records. I felt ashamed and embarrassed. I lost friends, my fiancé, hope, and energy.⁶

Martínez-Patiño was eventually reinstated to compete in 1988 after she had established that she gained no athletic benefit from her XY chromosomes, because she has androgen insensitivity, which actually puts her at a competitive disadvantage hormonally compared to typical XX females.

Through the efforts of Martínez-Patiño and others advocating for elimination of the XX requirement, the IOC agreed to stop conducting the Barr body test as a condition of eligibility prior to the 2000 Olympics in Sydney.

But the removal of the chromosomal sex testing policy in the late 1990s did not mark the end of debates over who should be permitted to compete in the women's category. The worldwide media attention focused on Caster Semenya after she won the women's 800 meter race at the 2009 World Athletics Championships in Berlin demonstrates the continued interest in classifying, labeling, and policing women's bodies. In response to massive public speculation about whether Semenya was female, male, or intersex, the International Association of Athletics Federations (IAAF) released a new policy on hyperandrogenism in sport, which was adopted by the IOC prior to the London 2012 Olympic Games. This policy explains that athletes whose sex is under suspicion will be examined and classified by a team of experts from the fields of endocrinology, gynecology, genetics, and psychology, among others, that will render a decision about the athlete's eligibility as a woman.

In addition, since 2004, the IOC Medical Commission has enforced the "Stockholm Consensus," a policy that specifies the conditions under which transgender women (and men) are eligible to compete at the Olympics. Yet even transgender women who meet the criteria and compete in the women's category continue to face ample discrimination

and even protests regarding their right to participate. Rather than celebrating these women's achievements in sport, media attention tends to focus on questions about the fairness of their participation and whether they are "cheating." The recent media coverage of mixed martial arts fighter Fallon Fox's male-to-female transgender history, which highlighted some of her competitors' views that it is selfish and unfair for her to compete in the women's division, demonstrates the anti-inclusive attitudes that remain in sport.

Through the heterosexism, sexism, and transphobia that continue to pervade sports, women athletes are still being constructed—over 150 years since the introduction of the bicycle—as 'bad girls,' lacking in bodily agency and subjectivity. Still today, women are having to push for inclusion in Olympic events like ski jumping, to fight for uniforms that represent and respect them as true athletes, and to suffer the tendency of the media to focus mainly on their appearance. Women who push for fairer policies and women who fail to adhere to heteronormative expectations are presented as 'bad girls' in sport. So it is that, still today, women athletes who fall outside of cultural criteria for 'femininity' are treated as cheaters, frauds, and poor sports: 'bad girls' all.

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Jane Addams: A Bad Girl Good for Training Doctors?

Aron Sousa

If we had the opportunity to ask Jane Addams (1860-1935), founder of Hull House and recipient of the Nobel Peace Prize, what it means to be a good or bad person, I have the sense she would have much to say about character—in the nineteenth-century sense of character as something to be consciously sought, built, and expanded. Louise Knight's tender biography, *Jane Addams: Spirit in Action*, draws a convincing portrait of Addams' genuine struggle to create for herself a good character, one constructed of self-sacrifice without self-absorption. For Addams, being good or bad seems to have been as much about attitude and orientation as behavior.

Indeed, Addams appears to have been convinced by the physician Silas Weir Mitchell that her period of significant depression, while she was in medical school at the University of Pennsylvania, was the result of self-absorption. For Mitchell, and then also for the depressed Addams, to be a woman working to achieve her long-held dream of being a doctor was to be self-centered in a way dangerous specifically to women. That her dream was to be a doctor working among the poor did not mitigate the medical opinion of Dr. Mitchell nor her subsequent negative self-assessment.* For Miss Addams in her early twenties, to be a woman medical student meant being selfish, too little engaged with family—lacking in good character. She was bad, and therefore sick, and likely to remain so if she stuck to her plan of becoming a physician. So she did not.

Fortunately for the world, bad medicine and bad health did not stop Addams, as she took on the goal of being good in deed and attitude. I don't get the sense that goodness was a simple thing for Jane Addams. In her books on the sex trade (*A New Consciousness and an Ancient Evil*, 1912) and youth (*The Spirit of Youth and the City Streets*, 1909) she is generous and understanding of the dilemmas and decisions of the downtrodden. But she also argued against the self-regard of philanthropists, and thought that beneficence and the self-satisfaction that comes with being a benefactor were the wrong motivation for work with the poor or dispossessed. She positioned Hull House, the first Settlement House in the United States, to work with the people of Chicago's 19th Ward as a part of their neighborhood, rather than as a social service agency providing succor. Where traditional philanthropy might have focused on direct aid, the residents of Hull House designed their own programs to be useful to neighbors, putting effort into improving their lots in life. Through Hull House, the neighborhood enjoyed adult education in cooking, sewing, trades, and language, a kindergarten, a lecture series, performances, and community meeting rooms. No one builds an institution like Hull House without significant self-regard and ego, but by intentionally "working with" her disadvantaged neighbors, Adams created good in her community without the bad character traits that she believed had derailed her previously.

^{*} There is another history to be written on the bad doctor, bad girls, and bad medicine as they played out in story of Dr. Mitchell; one could begin by reading the work of another of his patients, Charlotte Perkins Gilman, author of "The Yellow Wallpaper."

By all accounts Jane Addams was an honest person, a good collaborator and neighbor, and a devoted partner to Mary Rozet Smith. By 1912, she had been a part of nearly every major progressive effort in the country, and had become a very successful author and highly sought-after speaker. Some describe the ovation she received at the 1912 Progressive Party Convention as rivaling that received by Teddy Roosevelt himself.

And then the trouble started to really accumulate. People like the president of Harvard started criticizing her for brazenly entering politics by seconding the nomination of Roosevelt at the party convention. Her status as a mature, single woman was now scorned and derided, as it challenged the place of women married and rooted in family life. (Curiously, her relationship with Smith was either not noticed or not to be publically commented on.) Then, as nations began to prepare for war, and finally war came to Europe in 1914, the U.S. forces favoring militarism lined up in opposition to those strongly advocating peace, including Addams. Before the U.S. entered the war, Addams stood as an important voice in an

organized and active international peace movement. But after the sinking of the *Lusitania* in 1915, the political climate changed. Roosevelt began attacking Addams, *The New York Times* joined in, and then newspapers across the country piled on.

When the U.S. officially entered the fray in 1917, the war declaration was accompanied by the Espionage Act, which made speaking against the war or the government an arrestable offense. When speaking publicly, Addams was limited to speaking of the futility of war in general terms, for instance, opining that only good could overcome evil, or making reference to Tolstoy's concept of non-resistance. Soon her speaking invitations dried up, and those speeches she did give were met with stony silence or even boos. Many of her oldest friends and collaborators

Maybe medical schools would produce more badass physicians and fewer bad physicians if there was more focus on usefulness rather than self-regard, on courage rather than beneficence.

decided to support the war and abandoned her. Funding for Hull House dried up, and detractors befouled the house door. Some called Addams a danger to the nation. Others spoke of lynching her.

Jane Addams had to know she had become bad in the eyes of many, but even as the political tides turned against her, she remained a badass renegade, a voice to be reckoned with. When Illinois allowed women to vote in the election of 1916, the Republicans and Democrats were both anxious to claim Addams' first presidential vote. (She went with Wilson.) Despite the challenges of the time, she kept Hull House afloat and served as president of three international peace committees. Her work informed Wilson's plan for the peace, and yet after the war she argued, presciently, that the peace agreement and reparations forced on the Central Powers by the Allies were unjust and would not lead to a lasting peace. Then the Depression descended and brought a new progressive energy to the country, allowing her again to be recognized as a true American leader. Finally in 1931, for her more than twenty years of work on behalf of peace, she was awarded the Nobel Peace Prize—perhaps the ultimate sign of an individual being understood not to be self-absorbed.

I became interested in Jane Addams because her philosophical and educational work at Hull House had a strong influence on John Dewey, whose educational work seems ripe for use in contemporary medical schools. I spend a good deal of my time thinking about how best to educate medical students, and I looked to Addams because I hoped to use her ideas about adult education and about uniting the practical and the theoretical in education. Her ideas and those of Dewey still drive my thoughts on medical education, but I have come to realize that Addams gives us more to think about than educational practice; she helps us think about character.

Most medical schools have some chunks of curriculum that attempt to inculcate altruism and beneficence into medical students. Whether curriculum can do that is an important empirical question, but nowadays I think maybe we should not even try. Maybe medical schools would produce more badass physicians and fewer bad physicians if there was more focus on usefulness rather than self-regard, on courage rather than beneficence. What if we somehow helped our medical students become what Addams became by virtue of leaving medical school?

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All Due Weight to Sympathy



Indrany Datta-Barua

Though her older sister Elizabeth had already paved the way as the first woman to graduate from an American medical school in 1849, Emily Blackwell found the medical profession far from accepting when she began her own career. Emily had applied to eleven schools before being accepted by Rush Medical College, but then was expelled after a year due to pressure from the Medical Society of Illinois. Tenacious, she finally earned her degree in 1854 from Western Reserve University's School of Medicine in Cleveland, Ohio.

Like many women before her, Emily Blackwell often entertained the idea of disguising herself as a man when she met with opposition to her success. But she also longed to "establish great principles, to found great institutions, to be one of the foremost rank through whom the great ideas of the age are developed" (quoted in Faderman, 1999), ambitions incompatible with anonymity. In 1857, Emily and Elizabeth founded the New York Infirmary for Women and Children and, a decade later, the Women's Medical College of the New York Infirmary, the 18 first institution of its kind. After Elizabeth's departure, Emily continued as the primary administrator of the Infirmary and College for nearly thirty years. Her alma mater, Case Western Reserve University School of Medicine (CWRU), has honored her legacy as a physician and educator through the Blackwell Society, one of four academic societies that guide current medical students from matriculation to graduation, and the only society named for a woman.

Dr. Emily Blackwell attributed much of her success to her eschewing traditional femininity. She described herself as "very persevering and very resolute—and very ambitious," with "a something sprawling in my character and way of doing things" (quoted in Faderman, 1999). If to be a "true woman" in the nineteenth century was to be "the teacher of children, the genial companion of man, the loving mother of sons" (Susan B. Anthony quoted in Faderman, 1999), then, according to her life partner Dr. Elizabeth Cushier, Emily Blackwell was more than happy, proud in fact, to have "stepped out from her place in creation" (quoted in Faderman, 1999).

As an educator, Dr. Blackwell hoped to foment the same spirit in her students: "If I might but see that I was doing something to raise them not in position only but in nature—to inspire them with higher objects—loftier aspirations to teach them that there is a strength of woman as well as of man." In letters to her sister, she often fretted about interns with "womanly airs" and disdained traditional femininity as diametrically opposed to her own character (quoted in Faderman, 1999). In their "Address on the Medical Education of Women" (1864), the Blackwell sisters acknowledged societal contributions to what they saw as feminine flaws: "[The education of women] is desultory in its character: girls are seldom drilled thoroughly in any thing; they are not trained to use their minds any more than their muscles; they seldom apply themselves with a will and a grip to master any subject." Thus, Dr. Emily Blackwell despaired of an essential

weakness of woman's nature while also seeking to change that nature.

Today we live in a different world, where women make up half of medical school classes, thanks to to the pioneering work of women like the Blackwells. We are now fortunate to no longer be limited by low expectations or educational barriers. Nor are we seen as less womanly by virtue of pursuing medicine.

However, I worry that medicine today entails an overvaluation of "lofty aspirations" and "sprawling characters" and a remnant of disdain for "womanly airs." In my own medical training, I have seen a friend laughed away from study tables for exposing a lilting voice and bubbly laugh, and I have had to comfort a soft-spoken classmate ignored repeatedly by (often female) faculty for being seen as too passive. I worry that we women have devalued and even lost sight of that part of our nature, whether acculturated or essential, that makes us particularly suited for doctoring.

I was fortunate while a student at CWRU to be placed in the Blackwell Society, where I was mentored by Dr. Elizabeth McKinley, the only female society dean. There is no doubt that Dr. McKinley was the right leader for a society named after Emily Blackwell. Indeed, upon her recent retirement, the society was appropriately renamed "Blackwell-McKinley."

In my first meeting in 2009 with Dr. McKinley, I happened to mention that I liked hockey and so learned that she had been a field hockey player. (In fact, she had been invited to try out for the Olympic team [McKinley, 2013].)

Needless to say, I was thrilled to learn that my mentor was something of a "bad girl"—that is, not entirely "girly" and formidable to boot. Being quite tall, she had the potential to be physically imposing, but she always spoke softly and politely (like many other hockey players I'd met). She was a welcome foil for the other society deans who, at least in public settings, had the boyish tendency to play to the crowd. Without being dry or serious, she took care of business, was active in course development, and mentored many, even adopting students not in her society.

All this and more she accomplished while battling breast cancer. Diagnosed in 1996, following treatment she enjoyed ten years apparently cancer-free. Then one day she rolled over in bed and broke a rib, signifying metastasis. By the time my class sat in our first lecture three years later, she was receiving chemo, hormone therapy having failed her. Her battle was no secret to us students. She organized a class every semester called "Cancer Survivorship" and necessarily made announcements when she would be unavailable due to treatment. Eventually, the progression of the illness required her to retire from her duties as dean, but by that time, she had persevered well beyond expectations.

I have one particularly striking memory of meeting with Dr. McKinley early in my fourth year. At this point, I had heard that the severity of her disease was profound. As she shuffled through stacks of books and files, looking for my portfolio and the draft of my personal statement, I found myself thinking she looked and sounded quite like herself. Then she suddenly placed her hands flat on her desk, looked right at me and laughed, "They have me on steroids now, and I'm so loopy. I am always misplacing things." Thus, she subtly but clearly spelled out for me just how serious the situation was, the use of steroids indicating that the disease was now impacting her central nervous system.

There is no question that Dr. McKinley shares a similar strength with the early women pioneers in medicine, pursuing her goals in the face of great obstacles. Given her perseverance, I doubt that Dr. Emily Blackwell could have chided her for "womanly airs." Indeed, the "bad girl" qualities that she shared with Emily Blackwell—ambition, resolution, a "sprawling character"—made a striking first impression on me. But it

was her sensitivity—a femininity that the Blackwells might have thought "bad" for women entering the medical profession—that made a lasting one.

As today's "bad girls" of medicine, we should accept the "good girls" in ourselves and others, embracing the traditionally feminine qualities of sympathy and sensitivity in order to make ourselves the best healers and teachers that we can be.

In the beginning of my association with Dr. McKinley, I was a bit reserved with her, wondering just how much of my life outside of school to share, worried that it would shade her judgment of my fitness for this profession. Already I had gotten negative feedback from other faculty about where I was applying my energies. Perhaps it was her "bad girl" nature that allowed her to relate, but it was Dr. McKinley's warmth that supported me. She endorsed my plan to spend the summer between first and second year touring in a band. She smiled from earto-ear when she saw me perform at an outdoor festival, hugging me and asking if she could keep the pictures she had taken. Meanwhile, through her Cancer Survivorship elective, she exposed my classmates and me to integrative and complementary therapies, enabled other cancer survivors to share the stories that they wanted to tell (as opposed to the medical histories that we were trained to elicit), and provided a space for reflection when one of my closest childhood friends was diagnosed with cancer.

Dr. McKinley attributes the focus of her teaching, particularly the values and skills that she emphasizes, to her experience, calling cancer itself a "teacher" for her. Perhaps it is poetic that it is breast cancer, that most overtly feminine of diseases, that imbued her teaching with the prioritization of empathy and sensitivity. As one local reporter wrote of Dr. McKinley, "Now she teaches students to listen to their patients' fears, their struggles, their stories—not just treat their diseases" (Brett, 2010). Having lived with cancer for over ten years, she has experienced

firsthand the psychological toll that illness takes on the patient and family. She shares that journey through her writing, and, as when she told me about the steroids, she has also intimately shared her body for the benefit of others. If that is not common to being a woman, I don't know what is.

The Blackwells lived in a time when women faced immense cultural hurdles. Therefore, it was reasonable that Dr. Emily Blackwell's priority be to train women to be single-mindedly resolute and ambitious. However, we also have it in us to be teachers and companions, loving and sympathetic, as Dr. McKinley has taught me.

"Let us give all due weight to sympathy, and never dispense with it in the true physician... Warm sympathetic natures, with knowledge, would make the best of all physicians," acknowledged the Blackwells in their "Address" (1864). However, the task before them was to obtain the right to education for women. Now our task is to achieve our fullest potential. As today's "bad girls" of medicine, we should accept the "good girls" in ourselves and others, embracing the traditionally feminine qualities of sympathy and sensitivity in order to make ourselves the best healers and teachers that we can be.

Editor's note: While this issue was in press, Dr. McKinley died at home, surrounded by her family.

Indrany Datta-Barua, MD, is a 2013 graduate of Case Western Reserve University School of Medicine and now a Psychiatry resident at Tufts Medical Center. In 2013, she designed and led the "Art+Medicine" elective at CWRU, where medical students examined illness-related themes in art of different media and workshopped their own creative pieces together. She would like to acknowledge the new dean of the Blackwell-McKinley Society, Lynda G. Montgomery, MD, M.Ed., for her guidance during that course as well as for the idea for and critical feedback on this essay. Dr. Datta-Barua has interests in Palliative Medicine and Psycho-oncology, and she currently blogs for Cleveland Clinic Wellness. idattabarua@tuftsmedicalcenter.org

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19

"Head Nurses"



Graphic: Sexability

William Peace

After a decade of increasingly severe neurological deficits, I was paralyzed in 1978 at the age of 18. Prior to the widespread development and use of antibiotics, people who had experienced a traumatic spinal cord injury (SCI) usually died. But by the time I was paralyzed, thanks to broad-based advances in medical care, men and women with SCI were not merely surviving, but thriving. All of a sudden, healthcare professionals were confronted with a population of paralyzed people such as myself who expected to live a long life post injury.

The job of "rehabilitating" a person fell to physiatrists and other rehabilitation professionals such as physical, occupational, and speech therapists. Even as a young man, I quickly learned that these professionals had no clue what to do. My generation of paralyzed people was essentially a pod of guinea pigs. On the forefront of the creation of modern-day rehabilitation, we all embraced experimentation. A Wild West mentality prevailed: no idea was too crazy, nothing dismissed. The focus was on getting paralyzed people ready for the real world.

At the time, I had few thoughts about the social structure of rehabilitation. A single emotion drove me and most of my peers: fear. What was I going to do with the rest of my life? I had just graduated from high school and all my friends were heading to college. I expected to do the same. I would like to say that my primary reason for going to college was to get a great education. Education *was* a priority, but as a newly paralyzed man, I had something far more basic in mind. No, not walking—my bulky Everest & Jennings wheelchair was more than enough for me. In fact, I considered that piece of junk a modern marvel. I had something more important in mind: I wanted to have sex. But did my dick still work? Could I still fuck?

Prior to leaving rehabilitation, I was a good patient. I worked hard to learn my "ADLs" —activities of daily living. I accepted without thought that I had to be able to do everything myself. Asking another person to help me was never a consideration—it was a sign of weakness, an anathema. I was brainwashed into an extreme sort of self-sufficiency and independence. Then, the week before I left rehabilitation, I asked the attending neurologist, "Can I have sex?" His reply unnerved me: "I don't know." These words reinforced something I could not articulate at the time: I had, in fact, learned virtually nothing from the health care professionals charged with teaching me how to really live with a SCI. The real lessons and practical information—and all of my SCI sexual education—had come from my paralyzed peers.

Part of that included an education about the "bad girls" of rehabilitation. Bad girls were broken up into two distinct and indeed opposite groups: one set formed the "dick police"; the other, the "head nurses." The dick police had no redeeming value. Early mornings and late afternoons were when they roamed the hallways. When you hear the cart, I was told, *hide.* The cart was filled with catheters and was pushed by a nurse who was on the lowest rung of nursing seniority. These "bad girls" were young woman and inevitably pretty. Fresh out of nursing school, they had to spend their days teaching people like me how to get a catheter in and out. The first time I held a catheter with a very pretty bad girl deputized as a member of the dick police, I was shocked. You want me to shove that tube up and into my dick? You have got to be kidding me. This was bad enough but my "teacher" was barely older than me. She wanted to demonstrate the correct technique and I was supposed to replicate her efforts. The word humiliating does not begin to cover what I felt.

When the bad girl from the dick police wrapped her hand around the shaft of my penis, my descent into entropy seemed complete. I may have thought I was still the same person I was before I was paralyzed, but when the dick police came around, there was no doubt my life had taken on an Alice in Wonderland type of existence. Pretty young women were searching me out in a way I never dreamed possible. So, like those who had warned me, I learned to avoid the dick police.

But late at night, my roommates told me about the other group of bad girls—the ones I desperately wanted to meet. These bad girls were called "the head nurses." Initially I thought this was an urban legend if not a bad practical joke. Yet I was told again and again that, at some point during my rehabilitation, a nurse I knew or had never seen would answer the call bell late at night and give me a blowjob. There was no privacy in rehabilitation centers at the time. Rooms usually held four to six men. All that separated me from the other paralyzed guys was a flimsy curtain. We did not even have a television in the room. Just the physical set-up alone made the stories seem like impossible fantasy.

But sure enough, late one night I was awoken by the guttural sounds of deep moaning. I turned to see the silhouette of a young shapely woman giving my roommate a world-class blowjob. I remember this night with crystal clarity because it was the first time since being paralyzed I got an erection. My dick was alive! Who needs a doctor when you have a head nurse!

A week or two later, I received my own visit. It started out badly. It was late at night and I had pissed all over myself and the bed. I hit the call button, upset. I thought I had had a handle on bladder management at that point. The nurse that came to help was one with whom I was very close. She changed my sheets and came back as I was washing myself. I was playing with myself without much luck. She explained I had to be a bit more vigorous and try non-traditional approaches.

Then she rubbed my leg and pulled the skin on my inner groin, and sure enough I grew hard. I started to cry in relief. She wiped away my tears and then went down on me. She brought me to orgasm, and I was taken aback when I realized no ejaculate had emerged. She explained to me that this is common for paralyzed men and that it involves a retrograde ejaculation. She assured me it would not affect my fertility or my sex life in a major way. My son is living proof she was correct.

That night forged a lifelong friendship with this woman, one that lasted until her death two years ago. Once in a blue moon, she or I made reference to that night, the night she reaffirmed my manhood and masculinity in a way I will forever appreciate.

Newly minted crippled men inform me that "head nurses" no longer exist. In fact, when I tell this story about two sorts of "bad girls" I encountered in rehabilitation circa 1978, most people do not believe me. I am accused of telling fish tales.

Obviously my experiences constitute a lost part of medical history—lost perhaps because people are too uncomfortable with it. The fact was that rehabilitation stays at the time were long and intense, physically and emotionally. The medical professionals that did the hard work were almost all young attractive women, not much older than myself; the patients were almost exclusively young men. The occupational and physical therapists and the nurses touched our bodies in intimate ways on a daily basis. They held us when we cried. To relieve the pressure we felt, much sexual innuendo and many sexually provocative jokes were exchanged. Drugs, prescribed and recreational, were shared and consumed. Sexual relations happened between patients and staff. Some married.

Truth be told, I could tell many stories that would be far more objectionable to most people than my "head nurse" experience. But what is etched in my mind some thirty-five years later is the compassion that woman showed me—the compassion so many of these women showed us young men. This woman was able to provide me a level of care and a connection that no longer exists. I should note that not all men received such a visit; this was not a standard part of nursing care. Married, older men, and those who did not work exceptionally hard to become independent never got a visit from a "head nurse." Such visits were reserved for men such as

myself. I was young, naïve, sexually inexperienced, polite, driven to succeed, and was in need of basic knowledge that was not forthcoming. Into this void the nurse injected a compassionate eroticism that made me a better man, one capable and prepared to function in a hostile post-SCI world. This was, after all, a time when there was no such thing as disability rights or disability studies. The ADA did not yet exist.

Part of me longs for the old days for newly crippled men. It's true that rehabilitation thirty years ago was primitive. Many people who failed to progress or displayed too much anger or clinical depression were quietly sent to another facility. I now shudder and wonder what happened to these lost souls. But it was more typical to spend months in a rehabilitation facility where life-long friendships were forged. I knew a few quadriplegics that spent over a year at a rehabilitation facility. Today—forget extended rehabilitation experiences. Newly paralyzed people are shipped out within weeks and so are in my estimation set up to fail. Rehabilitation facilities are often quite nice and located in rural areas. But they now serve as short-term bubbles of social understanding. Worse yet, much time is

wasted discussing a cure to SCI and less time is spent on practical matters for a post-injury life. Obviously a cure is an admirable hope, but a desire for cure is much less important than the sort of kindness a "bad girl" such as a "head nurse" can offer a paralyzed man who is wondering about the present and future of his sexuality.

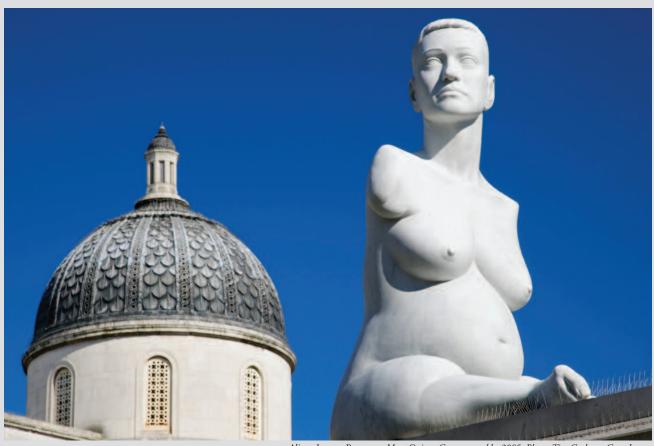
I am not suggesting we return to our primitive past. Advances in rehabilitation and social progress have revolutionized the lives of many persons who suddenly find themselves paralyzed. But I will never forget the "bad girls" who gave me quite an educational experience—who gave me myself.

William J. Peace, PhD, is the 2014 Jeannette K. Watson Distinguished Visiting Professor in the Humanities at Syracuse University. His book Evolution and Revolution is the definitive biography of Leslie A. White. Peace has also published in a host of peer-reviewed journals such as The American Anthropologist, Journal of Anthropological Research, and The Hastings Center Report. Peace is also on the Board of Directors of the grass roots disability rights organization Not Dead Yet. His research interests include bioethics, disability studies, body art and modification, and the history of anthropology.

... what is etched in my mind some thirty-five years later is the compassion that woman showed me—the compassion so many of these women showed us young men.

"BAD GIRLS"

from the World of Disability



Alison Lapper Pregnant, Marc Quinn, Carrara marble, 2005, Photo: Tim Graham, Getty Images

Kristi Kirschner

Two decades ago, early in my career as a rehab doctor, I helped to found a reproductive health care center for women with disabilities. 1 The smartest thing my colleagues and I did in creating that center was to engage a community board of about twenty women with a variety of physical disabilities to guide us. And what dynamos these women were! We had women of all ages, disabilities, socioeconomic classes, races, and ethnicities—some proudly self-identifying as disability activists and feminists, others not so sure. What was clear from these early meetings was that disabled women were coming into their own. They were tired of being treated as asexual, second-class patients, excluded from gynecological exams and mammograms by inaccessible clinics and hospitals. From the seeds of the feminist movement and the disability civil rights movement, and with the recent passage of the ADA in 1990, a new focus on the needs and rights of disabled women had begun to take root.

Most of what I learned about life with disability came not from medical training but from my engaging with these women, many of whom have also become dear friends. How I loved hearing their conversations. They talked about all the things women often talk about when they get together: relationships, dating, sexuality, birth control, the challenges of exercise, diet and managing their weight, their views on genetic counseling, pregnancy, abortion, parenting, and how to dress. Only it was different. Why did people assume that "crips" should date only other "crips"? What types of clothes worked best if one used a wheelchair or had a catheter? When should you talk to a potential partner about having a catheter, or that you could become dysreflexic during intercourse? Did a woman's right to choose abortion trump concerns that selective abortion of a fetus with a disability (such as Down syndrome) is a form of genocide?

I remember in particular their heated debates about two brave, high profile, and controversial women who blazed new paths by defying cultural stereotypes about the disabled female body. These two women weren't "bad" in the simple sense of being disobedient or naughty—though there was a bit of that. 23

from the World of Disability (continued from previous page)

They were confident, mischievous, sexy, and good-looking. These women challenged us to look at their naked, feminine and, yes, atypical bodies. They were unashamed, uncloaked, with nothing to hide.

The first of these two women, Ellen Stohl, shocked feminists and disability activists alike by posing nude for *Playboy* in 1987. From the waist up, Stohl was indistinguishable from other "playmates." From the waist down, she was atypical because she had paraplegia. The difference wasn't immediately obvious to the casual observer. Indeed, as feminist disability studies scholar Rosemarie Garland-Thomson subsequently noted, Stohl could have "passed" as non-disabled, as the accompanying accourtements of her disability (such as her wheelchair) were downplayed. But it was clear in the *Playboy* narrative, and several accompanying photos of a clothed Stohl using a wheelchair, that she was, indeed, a disabled woman.

The disabled body is intensely beautiful—memorable, unexpected, and lived in with great self-awareness. -RIVA LEHRER

Prior to the motor vehicle crash which caused Stohl's paraplegia (three years before her Playboy feature), Stohl had been a model and actress. She had been accustomed to the positive attention young attractive women receive. With the onset of her disability, though, she was thrust into a new reality—one involving covert social and cultural norms. On the inside she knew she was the same woman, albeit now with a physical difference. On the outside, she knew her sexuality and physical attractiveness had become suspect. Feeling invalidated, frustrated, and even angry she reached out to Hugh Hefner in a letter, writing:

The reason I choose *Playboy* for this endeavor is that sexuality is the hardest thing for disabled persons to hold onto.Well, I believe it is time to show society the real story. Anyone can be sexy; it is a matter of how a person feels about himself or herself..."³

The women of our community board aligned with Stohl's sentiments, but not necessarily with her choices. They agreed that health care and society often viewed them as asexual, unattractive, and diminished. But was posing for *Playboy* really an act of empowerment, or was it co-optation by a dominant male-culture magazine that objectified women? Was it playing to a form of voyeurism? In the end, was it a really a step forward for disabled women, or was it a step backward? I simply loved the fact that we could be having this conversation, that these women could agree to disagree but ultimately desire the same options and access as other women.

The group also introduced me to Alison Lapper. Born in 1965 with phocomelia (absent arms, and foreshortened legs), institutionalized at birth by a rejecting mother who also refused to allow her adoption by a loving foster family, Lapper had to fight for every step of her independence and self-esteem. Though she was eventually fitted with prostheses, she rejected them and developed her own way of doing things, including cultivating a career as an artist in the media of photography, digital imaging, and painting. She often focused her work on the subjects of physical normality and beauty, playing with images of her own body, tapping into its ironic similarity to the iconic Venus de Milo. When, as a single woman, she found herself unexpectedly pregnant, Lapper rejoiced in the normality of her reproductive organs. Lapper even chose to pose nude for sculptor Marc Quinn in 1999, when she was eight-and-a-half months pregnant. 4

The resultant startling massive white marble sculpture (3.55 meters high), *Alison Lapper Pregnant*, occupied the fourth plinth in Trafalgar Square from September 2005 to October 2007 and stimulated much buzz. Quinn had been looking for a design that would bring needed femininity to the square, and his choice of Lapper for subject certainly raised the theme of gender and power while also opening questions about disability, power, sexuality, and motherhood.⁵ He noted that, while most public sculpture amounts to "triumphant male statuary" and almost never features people with disabilities, Trafalgar Square was one of the few public spaces where disability was represented, namely in the form of the statue of Lord Nelson with his apparent missing arm. In preparing his work for the Square, Quinn noted that:

Nelson's Column is the epitome of a phallic male monument ... In the past, heroes such as Nelson conquered the outside world. Now it seems to me they conquer their own circumstances and prejudices of others, and I believe that Alison's portrait will symbolize this From working with disabled sitters I realized how hidden different bodies are in public life and media. Her pregnancy also makes this monument to the possibilities of the future.⁶

As expected, the sculpture provoked much public debate about beauty and difference and was again in the public eye at the 2012 summer Paralympics when a giant replica (43 feet high!) was displayed in the opening ceremony.

This then brings me to the last of the three "bad" girls I want to profile in this piece: the artist Riva Lehrer. Riva and I met about ten years ago through a disability arts festival planning committee in Chicago. The was then in the midst of creating her Circle Stories—collaborative portraits of disabled artists in which the artist is portrayed in a setting of their choosing (either real or fantastical). Riva's sense of exquisite detail, brilliant use of color, and explorations of themes of atypical beauty permeate each of her works. She has written:

The disabled body is intensely beautiful—memorable, unexpected, and lived in with great self-awareness. These are not bodies that are taken for granted or left unexplored. This beauty has often stayed unseen despite the constant, invasive public stare. Disability is complex; it demands images that combine hard facts with unexpected gifts.

24



Cauda Equina, Riva Lehrer

I remember when I first saw Riva's painting of a nude full figure standing against the startling cerulean backdrop. The figure initially appears young, twenties perhaps, her red hair pulled back into a jaunty ponytail grazing her left shoulder blade, her bangs casually brushed to the side. We see her mostly from behind, her body with a quarter-turn toward the right, her arms raised and externally rotated behind her neck. As with a Mary Cassatt painting, one can easily imagine the subject captured unaware, perhaps in the midst of performing her morning toilette.

Upon further study, the eye is drawn to the exquisite details—the woman's large sinuous, hands, the collapsing scaffolding of her chest wall. Her low back is lordotic, pelvis tilted with her left hip rising higher than right. Her pink flesh is firm, her upper arms muscular, her buttocks pert and slightly rounded.

And then we see it—a ghostly mammalian skeleton hovering in the background. The spine of the skeleton is massively elongated, its right posterior acetabulum merging with the woman's left hip, drawing the eye to her grainy

grey- scale ischial tuberosities, femurs, and sacrum. The animal's long shadowy skull is tilted back looking toward the woman. Her sensual nakedness feels invaded by the radiographically-exposed anatomical details.

The portrait's initially puzzling title, *Cauda Equina* ("Horse's Tail"), becomes jarringly clear. The woman has spina bifida. The anatomical difference in her neural tube (at a point where the filamentous tail of the spinal cord is in fact known in medicine as the "cauda equina") gives rise to her small stature, her curved spine, her thin limbs.

Unashamed by her physical difference, the woman's carriage is proud, sensual, defiant even. How delightful to learn that the woman is none other than the artist, Riva Lehrer. I was mesmerized by the portrait at the time I purchased it years ago, and still am.

I asked Riva to engage with me in a conversation about her work, and the evolution of her work over the years as she has explored themes of beauty and disability by painting bodies. What follows are lightly edited excerpts from that conversation:

from the World of Disability (continued from previous page)

KLK: When I showed my colleague and guest editor of this issue of Atrium, Alice Dreger, your Cauda Equina self portrait, she immediately saw a connection with the work of seventeenth-century German-born Dutch anatomist, Bernhard Seigfried Albinus. Are you familiar with his Clara Rhinoceros piece? I'm wondering whether he consciously influenced your approach to own piece?

RL: Yes, I know that series of engravings quite well. I teach anatomy at the School of the Art Institute, and drawing for medical students at Northwestern. I've used Albinus

engravings in class off and on for years, and find the incongruous pairing pretty darn amusing. That said, I'm not consciously aware of being influenced by that image in particular. Every portrait I make is a layering of ideas and desires. Part of this one came from thinking about imaginary anatomies, such as those that might belong to centaurs and mermaids. It seemed to me that I became both animal and mythic from the waist down because of the mutation in my spinal column. The cauda equina was a perfect way to meld myself toward a bestiary.

KLK: Some of your portraits are naked, some not. How do you choose how much of the body to show?

RL: I rarely ask others to pose nude for me, because of the toxic history of medical imagery around the disabled body. (And,

for that matter, the problematic history of the female nude.) When a viewer sees a naked, variant body, I believe that his or her tendency is to reduce that person to a specimen, that is, to become unseeing of nuance and attributes that would give you a deeper, more complex entrée into that person's life. Disabled people (if they are visibly disabled) often live with constant observation and painful judgment. I never want to replicate that in either the making of, or final product of, a portrait.

When I have portrayed someone nude, it's almost always because it fits with what we're trying to say about who this is. Sexuality within disability is an intricate and essential subject, and I always welcome the places we can go when a collaborator wants to explore that in their portrait. I NEVER try to persuade a person to pose unclothed unless it arises naturally and importantly during our process.

I should say something about that process. I've developed a collaborative method that begins with a long series of interviews. I ask my portrait subjects about the effect that their bodies have had on their lives, and vice versa. My subjects are given quite a bit of control of the visual narrative. Their opinions and ideas are crucial to the final image. These are not commissions. I usually choose subjects because of

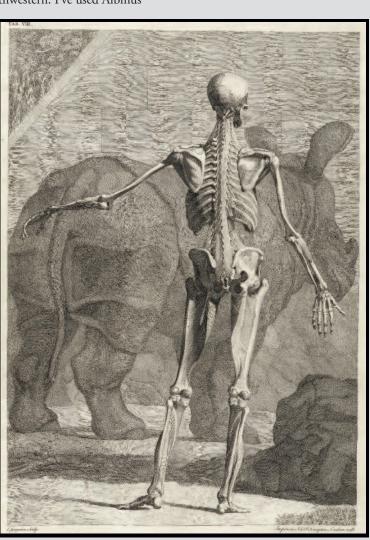
> the work they do, and out of a fascination with how they inhabit their bodies.

The majority of my subjects are disabled, though not all of them are visibly different. An increasing number are not disabled at all. It surprises people to learn that some of the most fraught egos I've worked with have belonged to non-disabled people. Perhaps this is because those with variant bodies are forced to try to reach levels of peace with their appearance. The experience of being looked at is a familiar daily struggle. For some, being observed in the studio is a way to engage that struggle directly and fruitfully.

Most of the nudes I've done have actually been self-portraits, as with Cauda Equina. Self-portraiture lets me explore ideas that might be too painful for others. I can work with my own

body in extreme ways that might be too scary for someone else, and I don't have to worry about hurting another human being. I know what I can tolerate. Still, I'm trying to push that line with my newest collaborative works. I've been asking those who work with me to go to edgier places than ever before.

Another important part of the process is that I work in thematic series. This allows me to explore the similarities and variances between individuals, and between disabled and able-bodied lives. I ask a central question and see how it plays out in divergent ways. This series approach has included Totems and Familiars, which looked at personal symbols as sources of strength; Mirror Shards, which places collaborators in animal costumes to consider loss and metamorphosis; and



Clara Rhinoceros, Bernhard Seigfried Albinus, 1749

If Body and Ghost Parade, which both document the invisible bodies (those which we used to have, wanted to have, or expect to have) that haunt our experience of embodiment.

KLK: Your subjects are almost always staring directly at the viewer. Tell me about that.

RL: That comes from two sources.

One, I want to begin from a position of power. I want the person I'm drawing or painting to not be a passive subject, but fully, actively engaged in the act of looking at me while I look at her or him. Looking away immediately puts someone in a much more objectified state. When I agree to be stared at while staring, it makes things significantly more equal than a one-way exchange. I do on occasion have my subject look elsewhere, if we're going for an intentional feeling of privacy or distance.

I make portraits so that I can let people exist in the world in a way they generally can't do for themselves. Often this has had a transformative effect. I want this to be a mutual transformation. I've been changed through portrait relationships every bit as much as anyone who has sat for me—or more. Having subjects look at me, at the viewer, and at themselves in the mirror of a portrait is to begin that change.

KLK: I imagine your paintings are somewhat like your children. I'm sure it's hard to pick a favorite, but do you have one or two that would rise to the top of your list? Why?

RL: Oh, boy. I don't really like looking at my work after I do it. It takes about ten years before I stop seeing the problems, mistakes, and failures. I only have one of my works hung in my house, which is *Zora: How I Understand*. It's a portrait of my dog that I completed just before she died. My portraits of Zora tend to be the pieces I want to look at most and that I regret having sold. Other works represent major transitions or milestones, as with *Corner (Terra Incognita)*, the first full nude self-portrait I ever did. I think of it as the wall I had to break through before I could do my real work.

KLK: Where do you hope to go next with your work?

RL: I'm working on the *Ghost Parade* series now. I'm asking people about the bodies they thought they'd have as children; bodies that they wanted to have; bodies they lost due to physical history (illness, surgery, weight change, gender change, pregnancy, etc); and their fantasy bodies (not in the "I want to look like Audrey Hepburn" sense, but asking whether they'd ever wanted wings, or horns, or tiger stripes).



Sheri/Dragon (portrait of Sheri Rush), Riva Lehrer

I feel that we're haunted by invisible bodies, and that they disrupt our ability to live in the ones we have. I'm depicting these ghost selves using medical imagery and devices. Right now I'm doing a portrait of a South African curator, using maps and acupuncture meridians to explore issues of racial dislocation.

I'm also writing a book about being

a member of a transitional generation, the first one to live with significant disabilities that the previous generation did not, for the most part, survive. We lack elders or precedents. Everything had to be invented as we grew up. It's also about my family, about art, and sex, and my haunted elementary school. The title is *Golem Girl Gets Lucky*.

For more on Riva Lehrer's extraordinary work, see her website: rivalehrerart.com.

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- At the time, I was on staff at the Rehabilitation Institute of Chicago; the program was originally known as the RIC Health Resource Center for Women with Disabilities and later as the RIC Women with Disabilities Center. The program closed in 2010. For a description of the program see www.hhs.gov/od/summit/whitepaper.doc.
- ² Rosemarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory," in *The Disability Studies Reader*, L.J. Davis, ed., second edition (New York: Routledge, 2006): chapter 21; quotation on p. 267.
- ³ Ellen Stohl to Hugh Hefner, as quoted in an interview with Chet Cooper for ABILITY magazine, at http://www.abilitymagazine.com/charleshugh\$20Hefner-stohl.html (accessed June 19, 1013).
- ⁴ Alison Lapper, with Guy Feldman, "Beauty Unseen, Unsung" (excerpts from My Life In My Hands [New York: Simon & Schuster, 2005]), The Guardian, September 2, 2005, at http://www.guardian.co.uk/artanddesign/2005/sep/03/art1 (accessed July 24, 2013).
- 5 Anonymous, "Fourth Plinth: Marc Quinn, Alison Lapper Pregnant," at http://www.london.gov.uk/fourthplinth/commissions/marc-quinn (accessed June 19, 2013).
- ⁶ Quinn, quoted in *ibid*.
- 7 See http://bodiesofworkchicago.org.
- From Riva Lehrer's website: http://www.rivalehrerart.com/#!circle-stories/ c68x (accessed October 29, 2013).

Sayantani DasGupta

Reproductive public health campaigns may harness not only beliefs about what constitutes a good family or proper sexuality, but also deep-seated social concerns and even hostility about poverty and race. Several recent anti-teen pregnancy campaigns can be examined as examples of moral panic, manifesting a broad public concern over "bad girls" making "bad babies." In the words of sociologist Stanley Cohen, moral panics are "condensed political struggles to control the means of cultural reproduction." Cohen explains, "successful moral panics owe their appeal to their ability to find points of resonance with wider social anxieties."1 It is clearfrom restrictive abortion laws in Texas and Ohio to shaming and blaming anti-teen pregnancy campaigns in New York and Chicago—pregnant bodies, particularly teen, of color, or impoverished pregnant bodies, are the site of widespread anxieties about social welfare, economic deterioration, and unregulated female sexuality.

As someone working in the interstices of narrative, health, and social justice, the question of interest to me here is not whether teenage pregnancy is bad for young women, or even if shame is an effective motivator for behavior change (which I would argue it is not). The question is what *other work* such campaigns are doing. In other words, what *additional* cultural stories are anti-teen pregnancy campaigns telling? And are those narratives socially just or unjust?

Three types of visual tropes seem to recur in teen pregnancy campaigns in the U.S.: bad girls, bad babies, and bad bumps. "Bad girl" stories are those that chastise (potential) teen mothers for not being able to engage in socially sanctioned teen girl activities. One poster in Milwaukee's "Baby Can Wait" campaign, for instance, features a cheerleading-uniform -clad African-American teen carrying an infant in a baby carrier. The anxious appearing young woman is tossed in the air by other cheerleaders, her baby strapped in front of her, while the headline scolds, Think your teen life won't change with a baby? 2

Bad Girls, Bad Babi€s, Bad Bumps





YOU'RE SUPPOSED TO BE CHANGING THE WORLD... **NOT CHANGING DIAPERS.**



thecandiesfoundation.org

Similarly, a 2013 Candie's shoe company public service campaign features celebrities such as Fergie and Carly Rae Jepsen on hot pink posters with slogans such as You're supposed to be changing the world, not changing diapers, and (next to the image of a baby crib) Not how you pictured your first crib, huh? Get pregnant and you won't be moving out of your house anytime soon.3 Such campaigns position teen pregnancy against an idealized, aspirational story about American teenage life: from cheerleading to moving out of one's parents' house to perhaps even musical superstardom.

Some campaigns try to stop the "bad girl" by portraying the potential "bad baby." In 2013, the New York City Mayor's Office and Human Resources Administration launched a new campaign called "The True Cost of Teen Pregnancy." The ubiquitous bus and subway posters feature wailing toddlers and babies (mostly of color) alongside a variety of fear-mongering captions: Honestly, Mom, chances are he won't stay with you; I'm twice as likely not to graduate high school because you had me as a teen; and, Got a good job? I cost thousands of

dollars each year. The campaign has drawn harsh criticism for its sexist, racist, and classist undertones. Haydee Morales, vice president for education and training of Planned Parenthood of New York, has suggested that the "True Cost" campaign gets it backward. In her words, "It's not teen pregnancies that cause poverty, but poverty that causes teen pregnancy."4

Like racist fantasies about "welfare queens," the (not so) hidden narrative beneath the "True Cost" campaign speaks to a racialized panic about bad girls producing bad babies who will strain the social system. Interestingly, the 2013 "True Cost" ad series shares much visually with an earlier New York-based campaign, one that features a photo of an elementary school-age girl of color under the slogan: The most dangerous place for an African American is in the womb. Although this privately-funded 2011 anti-abortion campaign clearly intends to tap into historical concerns about eugenics and reproductive health, it simultaneously plays into the same moral panic about unfettered female sexuality among teens of color as does the 2013 "True Cost" campaign. In the 2011 image, a banner bearing the campaign's contact site,

thatsabortion.com, spans the young girl's abdomen, making it unclear if the girl in the image is the (not) aborted child or the (eventually) sexually active teen of concern.

In contrast to bad girl and bad baby campaigns, bad bump advertisements intentionally make suspect pregnancy itself by superimposing pregnant bellies on "wrong" bodies. Consider, for example, Chicago's 2013 "Unexpected?" campaign, which features young men with protuberant, pregnant bellies. Intending to shock viewers into recognizing the unplanned nature of most pregnancies and to emphasize the responsibility of teen fathers, these ads simultaneously transmit a deeply transgender-phobic narrative. The truth is, in 2013, bodies which do not look traditionally female gendered can and do get pregnant (while bodies which look 29 traditionally female gendered sometimes do not). But as with the broadly comic absurdness of male pregnancy in films like Arnold Schwarzenegger's Junior, this anachronistic campaign reinforces a traditional gender binary while essentializing pregnancy as a function of only non-transgendered (i.e., cis-gendered) female bodies.

(continued on next page)



Interestingly, older white female bodies also appear in bad bump campaigns. In the U.K., a 2013 campaign called "Get Britain Fertile"—designed to shock "good" women into having babies earlier—featured a well-known white female TV presenter, 46-year old Kate Garraway, made up to look "like a heavily pregnant 70 year old."5 This image is undoubtedly intended for a different socioeconomic demographic from most of the teen pregnancy campaigns, and has xenophobic, antiimmigrant implications that are beyond 30 the scope of this discussion. (Whose Britain does the campaign want to "get fertile"? Doubtfully an immigrant Britain.). Yet it is interesting to consider such an anti-infertility campaign against anti-teen pregnancy campaigns. These ads taken together suggest that, when pregnancy is socially desired, as it might be

for middle class or wealthy white women

in their late 20's and early 30's, infertility is a disease for which pregnancy is a cure. But when pregnancy is socially undesire*able*, as for teens of color, then pregnancy is a disease socially spread by sexually active young women themselves. Indeed, as with obesity, the language of epidemic is often used to refer to teen pregnancy, suggesting that it represents a pathology.

Even while we see evidence of a notable panic about women's reproductive health sweeping the nation, the Centers for Disease Control and Prevention report that teen pregnancy is on the decline across ethnic groups in the U.S. Yet the political right and left seem to be aligned in their burgeoning moral panic regarding teen pregnancy. Public health campaigns including bad girl, bad baby, and bad bump narratives shame and blame girls who are already teenage mothers while reinforcing broad social anxieties about these young mothers and their children.

The roots of these anxieties stem from race and class panic; in the popular imagination, wealthy, white women are delaying and perhaps avoiding pregnancy altogether, while the "wrong" kinds of babies are being born to teen mothers with alarming frequency. In practice, these campaigns shift the locus of concern from a systems-based analysis-from looking, for instance, toward more funding for parenting education, reproductive health care, or anti-poverty campaigns—to an individual-level responsibility, placing the burden of any number of social ills on the shoulders of sexually active young women. In doing so, these anti-teen pregnancy campaigns based on moral panic are themselves a bad, socially unjust business.

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"HORRID" at Life's End

Marsha Hurst

I first considered writing this piece in the early spring of 2013. The *Atrium* call for "Bad Girls" flashed at me from my computer screen, resonating, reverberating, just as my monthly weekend of caring for my ninety-three-year-old mother approached. I dreaded this caregiving weekend: traveling across state lines to witness my mother's isolation in the house she had refused to leave and in which she was now virtually imprisoned; the emotional strain of futile efforts to engage her mentally; the physical strain of transferring her dead weight from bed to wheelchair to toilet to bed; and my self-flagellation for this resentment.

"Are you my mother?" I would ask, like the baby bird in the 1960 P.D. Eastman book I read to my grandchildren.

And a voice would respond: *A good daughter would never have to ask that question.*Must we, as adult women, still be marked as "bad girls" when refusing the call to play the role of loving caregiver?

Years ago, I read Julie Hilden's book, *The Bad Daughter* (1998), and, even though I could never have imagined my own mother as the alcoholic and then demented

woman Hilden describes, I felt—if not admiration for Hilden's rejection of the dominant caregiving narrative trope—some thrill, some secret tantalizing horror at her deviance, her defiance. For Hilden, the call to take care of her mother was a test she had "failed." And when she failed that test, she had become "bad" (p. 106).

Hilden was marked, "punished," in her own life for being a bad daughter, and perhaps this is to be expected when we believe we are "bad girls." After all, as Carol Levine notes, society assumes women are "hardwired" for caregiving (2007, p. 242). We do not cross wires without consequences. Virginia Woolf famously asserted in 1931 that she had to "kill" that "angel in the house"—the ideal of Victorian womanhood embodied by her own mother, Julia Stephens, that still hovers, haunts, and whispers to women—before Woolf could write as she wanted (Hussey, 2013, p. 37).

We women still grow up with the gendered narrative of the ethics of familial care. Our parents diaper and feed us when we are babies and we, as daughters, diaper and feed them when they are dependent elders. Indeed, "the daughter track" is what Jane Gross called this narrative trope in her *New York Times* "New Old Age" blog in 2005. I resent the call to daughterly duty suggested by "the daughter track," but at the same time, when I consider my own all-male offspring, I fear my daughterless future. Often as I would toilet or dress or help

my mother to bed, I was struck by the physicality of care, the intimacy of my woman to woman touching, undesired on my part, undesirable on my mother's. Repeatedly I moved the brush through limp, gray, lifeless hair; my washcloth over folds of flesh; my hands under toneless limbs. I viscerally connect with the images of Joyce Farmer in the

There was a little girl,
who had a little curl,
right in the middle
of her forehead.
When she was good,
she was very, very good,
and when she was bad,
she was horrid.

graphic novel *Special Exits* (2010): sponge bathing her stepmother, changing the wet bed linens for her father, bear hugging the dead weight of immobile parents as she strains to lift. In my "Illness/Disability Narratives" class, a student creates her own graphic, a comic strip



Wellcome Library, London, Colour Lithograph c. 1850, by James Morison

of her thirteen-year-old self grossed out by having to apply deodorant to the underarms of her father, debilitated by stroke. Surely though, I, a grown woman, should not feel this way about my own mother.

In the hours it took me each month to get to my mother's house, I worked on myself, promising that this time I would embrace my caregiving role—and my mother. Writer Helen Shulman's vow (2007) would become my own: "[M]y father had always stood by me, he'd loved me and cared for me my whole life, and in turn, I loved him without reservation. So I made a pledge. 'I will help him as long as he needs it.'" I knew my mother had been a good mother. I believed I loved her without reservation. But her last year of decline made a mockery of my vow. Did I honestly love, without reservation, this old woman, even though she had been my mother? Not surprisingly to me, Schulman lived to regret her pledge.

In her recent memoir (2013), Jo Maeder recounts giving up her career, friends, and her life in New York to care for her aging and failing mother in the South. In this version of the returning daughter narrative, though, Maeder's daughter track leads her back to a mother who had been so uncaring, so inadequate, that Jo and her brother had chosen to move to another state with their father when their parents had divorced. I know others who have had a complete conversion to become

the dutiful caring middle-aged child of a formerly abusive or neglectful parent. Perhaps there is a sense of completeness, a striving for wholeness in the mother-daughter relationship that never before existed. The "martyr daughter" sacrifices herself on the altar of that relationship. Maeder's version of the martyr daughter narrative, though, has an upbeat moral to the story: By giving up her own life, Maeder gains a surrogate "spouse," a new cultural home in the South, and, yes, even religion.

In the ideal good girl caregiving story, the caregiver receives nothing in return. It is, to borrow a concept, the purest *mitzvah*, or good deed: one that cannot be reciprocated. The goodness comes from caring. At the end of the film "Marvin's Room" (1996), Diane Keaton's character says that her twenty years of caregiving for her father "gave her so much love." Not that those she cared for gave her so much love, but that caregiving *itself* expanded the love in her life.

Yet this loving, selfless fulfillment of the good-girl caregiver role gives us so many ways to be bad. We can do everything right and still be the "reluctant caregiver" (Span, 2013), caring *for*, but not *about*, parents or in-laws or older relatives: looking like the good girl to the outside world, and feeling like the bad girl internally. Our badness is hammered home to us each time we are praised for our goodness. Can I really—at my age—still feel guilty for doing the right thing with the wrong attitude? We all know the answer.

Caregiving, for me, coincided with the loss of the mother who had mothered me, the woman I had loved and admired. As she faded mentally, I imagined the photoshopping of her mind, the brushing out of complex colors with whiteness, until her mind was just another part of the physical body that needed care. I had nightmares of her body living on for years, a lump of needy flesh—the promise she had extracted of being allowed to stay in her own house now irreversible by incapacity, her carefully executed advance directives muted by her body's persistence.

"I lost my mother years ago, when she developed dementia," said my friend to me, as she dutifully boarded the train for her own monthly maternal visit. Psychologists have called this "ambiguous loss" (Boss & Kaplan, 2004). Those of us who experience "ambiguous loss"—mental but not physical loss of a parent—"both accept and reject the caregiving role." But badness and goodness are not supposed to be ambiguous attributes.

Until late in my mother's life, I had managed to be the proverbial good girl. I fulfilled all of my mother's expectations: I got the education she never had, I achieved the career that was so important to her, I built the family that completed a woman's life. My occasional "bad girl" performances amounted merely to episodes in a life, not the way my mother saw me as a person. But tap gently, I later discovered, and every good daughter with elderly parents seems to have a "bad girl" caregiving story. Don't you remember, says a childhood friend whose mother I adored, how I went to Bermuda four days before my mother died of cancer? You should hear me talk behind my mother's back, said another friend, cracking jokes about her mother that her mother can no longer hear. We act out like the two-year-olds we once were.

My mother loved white blouses, crisp and tailored. All of the pictures of her at the peak of her career, in the prime of her life, featured a white blouse. Whenever I wore a white blouse around her in those last years, she would recall how much she loved that look. In advance of what would turn out to be her last Mother's Day, I bought the largest crisp white tailored blouse in the store. (My mother was now formless, sagging, her breasts dragged down to meet her bulging stomach, her body slouching in the wheelchair.) I set the shirt aside to bring.

Then in mid-March, I had heart surgery and didn't tell my mother. I felt sorry for myself, having a mother and not being able to tell her I was having heart surgery. I said to myself there was no need to make her anxious. But what I meant was that she was no longer my mother. She could no longer be there for me—so what was the point? In early May, I brought the blouse with me on my caregiving weekend. But I couldn't give it to her. She was not my mother. It would have been like dressing a manikin. No, worse: I would have to look at her in the crisp white blouse and think about what she was not.

I returned the blouse and spent the credit on some t-shirts to cover my heart's scar. As I began this piece, my mother died. Going through old photos, I found one of my mother with her own then aging and ailing mother. I recalled, seeing this, that my mother placed her own mother in a nursing home—and never forgave herself for being, at the end, a bad girl. A nursery rhyme my mother used to recite to me goes like this:

There was a little girl, who had a little curl, right in the middle of her forehead. When she was good, she was very, very good, and when she was bad, she was horrid.

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Women's Work

Lisa H. Harris

I carefully balance the tray of metal instruments, bloody gauze, and the sterile bowl full of tissue, and make my way out of the procedure room to the sink. I set down the tray, and pour the bowl's contents into a hand-held kitchen strainer. It is an ordinary kitchen strainer that I purchased at the bed-and-bath store down the street, even remembering the 20%-off coupon my father had saved for me. I run water through the strainer to clear away the blood, and empty the strained contents onto another tray. The patient whose abortion I have just done was early in her pregnancy.

No fetal parts are visible yet, and it is hard to distinguish the gestational sac, which would only be the size of a cotton ball, from the uterine lining and blood clots that emerged with it. So I move the tissue into a square Pyrex baking dish and turn on the light box to illuminate the dish from below. (The light box came from the craft shop next door to the bed-and-bath store). Transillumination helps me identify fluffy white tissue, and reassures me I've removed the pregnancy. And only now, as I use ordinary kitchen tools and craft supplies, do I feel transgressive.

I do society's "dirty work," as sociologists would say. So I transgress all day long, physically and socially. I drive past picket lines. I use ultrasound to see inside bodies. I enter body cavities with metal instruments. I erase evidence of sexual transgressions. I turn women into non-mothers

(well, not really; I know full well that most women seeking abortions are mothers, or will be later). And fetuses die at my hands. Oddly, though, it is not with these recognitions that I feel transgressive. Instead I am overtaken with this feeling when I use ordinary kitchenware in the course of an abortion procedure.

Maybe kitchenware reminds me of my own defiance of gender-role stereotypes: I am a woman working as a doctor, rather than baking and doing arts and crafts at homealthough I enjoy those things, too. I certainly find irony in the fact that abortion—this most contested part of U.S. social life, which paralyzes legislators and holds federal budgets hostage—uses everyday objects. No doubt I get a hint of delight imagining the shock to conservative sensibilities that comes with realizing that kitchen tools, objects of domesticity, are simultaneously tools of reproductive agency. And I feel relief using domestic objects for safe abortion care, so women don't need to rely on other domestic objects (knitting needles, coat hangers) to end their pregnancies. But mostly these objects are reminders that "women's work" includes abortion. Anti-abortion politics and rhetoric rely on the lie that abortion is not a legitimate part of women's everyday lives and experiences. But, in fact, it is.

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