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Insiders and Outsiders and Insider(s) Again in the (In)fertility World

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Co-Researchers as Insiders and Outsiders

Bethany

At 28, while studying the history of women's health in graduate school, I attended a panel examining the relationship between feminism and reproductive technology. When a panelist said, "We've been able to change so much for women, but we still can't control the age of our eggs," the entire room drew a sharp breath. After turning 30, my husband and I started trying to conceive and after 4 months I visited a reproductive endocrinology and infertility (REI) practice for testing, given my "advancing maternal age." My partner and I received the common yet maddening diagnosis "infertile, unexplained," and over the course of 4 years, we pursued corrective surgeries, fertility medicines, intravenous (IV) antibiotic courses, two intrauterine inseminations (IUI), and three in vitro fertilizations (IVF). To our deep disappointment, nothing resulted in pregnancy.

At 34, my experiences as an infertile woman and Maggie's experiences as a potentially infertile woman and fertile ally became the focus of a qualitative study. I believed that interviewing individuals undergoing familiar infertility treatments provided a therapeutic outlet; shortly after my third failed IVF I started conducting them (Birch & Miller, 2000; Drury, Francis, & Chapman, 2007). After each interview, I felt exhausted but energized, grateful to be a principal investigator (PI) in a study giving voice to the struggles of infertile women like myself. However, my body remained "leaky"—my weight fluctuated and my energy did not return after the last IVF. I feared years of treatments caused new medical problems and anxiously sought medical advice. This led to the discovery that I was pregnant with a "miracle baby" in the midst of research on infertility.

Maggie

I spent my 20s going straight from undergraduate to graduate school with little time to date and few potential partners. Due to my interest in (dis)ability and women's health from communication perspectives, I was highly aware of my "ticking biological clock." A network of friends and academic colleagues shared their infertility statuses and relayed treatment experiences that heightened concerns about my own fertility. Given the advanced risk of miscarriage and infertility for women 30–35 and above, I assumed fertility issues would be part of my story too—I often

referred to myself as "anticipatorily infertile."¹ However, at 33 and after 2 months of marriage, I became pregnant.

The qualitative study with Bethany began with me as "outsider," a fertile woman and a pregnant one at that. Passionate about our work, I interviewed up to 2 weeks before my due date. For the last few weeks, one interview a day was the only work I completed. I felt I wasn't "pulling my weight" during this period and felt self-conscious about how deeply these interviews impacted me. I remember being 35 weeks pregnant and listening to an interviewee frankly disclose the loss of her own baby at 35 weeks. At that point I really questioned whether I could or should continue collecting stories; my doctor warned me about stress during pregnancy. I wondered: Can hearing and holding these stories negatively impact my unborn fetus (e.g., preterm birth, low birth weight) (Möhler, Parzer, Brunner, Wiebel, & Resch, 2006)? Although I had a healthy, successful pregnancy, I still consider myself temporarily fertile and have anxiety about secondary infertility if I/we "decide" to conceive again.

Bethany as Outsider; Maggie as Insider

In the spring of 2014, during a 10-hour car ride home from Brooklyn, NY, where we completed research on media depictions of an obstetric intervention called Twilight Sleep,² Maggie and I finally had the time and space to discuss our fertility identities (Johnson & Quinlan, 2015, in press). In fact, Bethany's problematic communication with her REI practice during the trip prompted our discussion. As we ruminated over the historical intersections of pregnancy, infertility and identity, the discussion turned to the present-day communication structures within REI practices. Although narrative communication scholars have addressed pregnancy loss, infertility, and miscarriage (e.g., Bute, 2009; Bute, Quinlan, & Quandt, 2016; Geist, Gray, Avalos-C'deBaca & Hill, 1996; Harter, Kirby, Edwards, & McClanahan, 2005; High & Steuber, 2014; Ross & Geist, 1997; Silverman & Baglia, 2014), we were surprised to find relatively few research studies specifically addressing communication within REI practices and the impact of that communication on patients and treatment outcomes (Willer, 2014).

Bethany

At 7:38 a.m. I received the first voicemail from my embryologist. This was the first morning of my research trip with Maggie and

we were preparing for a day in the archives. The embryologist said our (mine and my partner's) embryos would likely not continue dividing ("fizzle out" was her term), which meant the expensive, exhausting, 6-week round of drugs and surgery I had just completed was completely futile. The recorded voice chided me: "I really hate to leave this kind of information on a voicemail, so please call me back as soon as possible at the office." Apparently the embryologist didn't know that all calls were routed through a call center until 9:00 a.m. and there was no direct line to reach her. The voicemail ended with, "okay thank you—have a good day!" A *good day*? I was devastated; I was furious. I hurriedly informed Maggie that the news was bad and called my partner, who was hundreds of miles away. Standing in the hotel hallway, he and I cried together. We would know the final results in 48 hours. I walked back into our hotel room, looked at Maggie and said, "We just have to come to terms with the fact that we probably won't have biological children." The only way I continued to function on our trip was to wholeheartedly immerse myself in our research. I didn't openly entertain my anxiety until two mornings later when the next voicemail—to my shock—was very different. The embryologist chirped, "I have very good news! Although it's rare, your embryos turned around and I froze two good embryos for you this morning." While relieved, I remained angered by the embryologist's poor communication, and the emotional rollercoaster I endured while conducting research in a city far from home.

During the years of my infertility treatment the future felt entirely out of my hands. However, our qualitative research ensured that even if I could not have a biological child, I could help others diagnosed with infertility. The interviews we conducted helped me move within and through my infertility experience (Johnson, 2016). To date, we have collected the stories of 24 women around the country.

Maggie

As we shared a hotel room that first night I lay in a separate bed, holding my belly and grieving the news that Bethany received. I felt some of the first fetal movements of my pregnancy on that trip. I was in awe of her—she had just heard what to me would be the most devastating news imaginable and she still was able to work on our Twilight Sleep research. I sat in the archives and watched her collect historical data and remain so focused at our task at hand—it was above and beyond having a strong work ethic. However, I was very distracted. I would have canceled the trip to grieve alone. Reflexively, I did my best to cover my belly—just showing—in maternity clothes and a sweater and tried not to make too much eye contact because I didn't want to be asked about my pregnancy or even have strangers smile at me knowingly in front of Bethany. The entire trip, I remained keenly aware of how lucky I was to easily conceive.

The ensuing miscommunication with the embryologist at the REI clinic and the difficulty of getting much-needed information angered and saddened me. My heart ached for Bethany and I wholeheartedly engaged our discussion. By the time we pulled into my driveway, we had our interview protocol and the rough outlines of an institutional review board application written. I acknowledged my obligation to use my

academic background and resources available to me to launch this qualitative project with Bethany—a trained historian. The research also allowed me to be a more informed and supportive friend; I couldn't get that voicemail or Bethany's reaction to it out of my mind. Certainly other patients had experienced something similar—was anyone investigating this?

Bethany as Insider and Outsider; Maggie as Insider(?) and Outsider

At the start of the study, we each held particular assumptions about what an "insider" or "outsider" would likely be aware of, and at times, those expectations failed us. Throughout the study, we experienced a "feast or famine" cycle with potential interviewees. Initially, this was baffling and so we reviewed our recruitment materials and consent forms. In a follow-up discussion between Ms. A³ and Bethany, Ms. A mentioned that interviewees who viewed our call for participants were often on similar treatment cycles. Bethany confided her shock that this had not occurred to her as an "insider." She wondered how she had overlooked the cyclical response mimicking her own treatments and results. After receiving negative results, candidates once excited about participating during an IVF cycle might not be at all eager to participate.

While we initially believed that one of us having an infertility diagnosis and the other lacking an infertility diagnosis would be beneficial to our research, we found the reality to be more complicated.

Bethany

The line between "insider" and "outsider" initially felt quite firm, as I had never been pregnant and underwent fertility treatment for 3½ years before we started our work together. However, the boundary between "insider" and "outsider" blurred and then collapsed once I discovered I was pregnant. Prior to conceiving, there were instances in which I shared my status with interviewees, including that my most recent IVF had failed. Reflecting on my claims that "I've never been pregnant and I've gone through two IUI and three full IVF cycles," I am left with a kind of shame. On at least one occasion, without my knowledge, I conducted an interview while pregnant. Yet I depicted my body as truthfully as I knew it throughout the study.

Writing about pregnancy and data collection, Kannen (2013) said, "Our bodies are never not involved in what we do, where we are, and how we interact with others" (p. 184). I found Kannen's words especially poignant after my final failed IVF, my (then) barren body sitting next to Maggie's pregnant body during research meetings. Emotionally incapable of engaging Maggie's pregnancy despite her sensitivity to my needs, the respect with which she shared her pregnancy, and the support she had provided me in my own journey, I kept a laser-like focus on research when we met for work. I even avoided looking at her abdomen and I still feel embarrassed about that. At the time, it was much easier for me to discuss pregnancy and fertility with our interviewees than with my close friend and co-PI. Honestly, I was unable to move beyond my silence until Maggie was 6 months pregnant.

Eventually, Maggie shared how hard my avoidance was for her. Once I acknowledged and celebrated her pregnancy, I realized we had to discuss our experiences as infertile and fertile women to truly engage our own research. A few months into our study, I revealed my own pregnancy. I'll never forget Maggie squealing through the phone, "I'm more excited for you than I was for myself!" Still guarded, I found myself consumed by statistics and risks. My identity as a pregnant woman remained tenuous long after I embodied it and miscarriage loomed large. Like many of our interviewees, I could not be certain of the baby until it was in my arms. Despite my "new" ability to conceive, I identified as an infertile woman who inexplicably carried a baby—an outlier. I still do. Must I identify as an insider now? Despite a "babe in arms," I remain both an insider and an outsider.

Maggie

Throughout the study, the line between "insider" and "outsider" blurred in the face of my own anxieties regarding conception and then potential (dis)ability and/or miscarriage after I became pregnant. I found most interviewees perceived me as an "outsider" with a unique perspective, but I was pleasantly surprised when many interviewees thanked me for being an ally.

When we sent out gift cards to participants a couple months after the interviews were conducted there was no obligation for participants to "stay in touch," but I admitted to Bethany that I hoped more participants responded to our follow-up with news. It was a relief when two interviewees shared stories of successful pregnancies after they received their gift card. However, the rest of our candidates remained silent. While expected, this still took me by surprise—Bethany and I both predicted some acknowledgment of receipt, as so many of our candidates expressed a desire to receive project updates (e.g., publications). So the silence from more than 90% of our participants made us both nervous—was this a sign of bad news? Had treatments failed? We will likely never know.

I also wondered whether the material I gathered as an "outsider" differed from that of Bethany, who often shared her infertility status with interviewees, particularly when asked. It is impossible to know when or how my status impacted the research process, especially since candidates did not elucidate this. Hence, I assumed interviewees might be annoyed by the need to explain a medical treatment or spell unfamiliar drug names.

In my second trimester, Bethany was still going through an IVF cycle, and the gap between our "infertile" and "fertile" statuses caused me anxiety during research meetings. In a phone conversation, I choked out, "It is a real loss for me that we cannot share in this [pregnancy] together." Bethany is more than "just a co-PI" but a friend, and it was difficult not to process my pregnancy excitement and trepidation. It was harder still that she virtually never asked—the interviews constantly reminded me why, but I still had to grieve my inability to share with her.

Maggie and Bethany as Outsider(s)

We struggled with our identities as pregnant women during and after these interviews, though our embodied (in)fertility

experiences differed. Nevertheless, in public, our pregnant bodies eventually marked us both as "outsiders" to infertile women, despite our perspectives and divergent experiences. At the end of our interview cycle, we consulted for a local REI practice designing new technology (a smartphone app) aimed at empowering patients and improving communication between practitioners and patients. From a crystallization standpoint (Ellingson, 2009), we conducted the research striving to "give back" to the women in our study. Thus, our invitation to be consulted, based on that research, was a powerful reminder that our work can directly impact those still in treatment. We had a very fruitful series of meetings with a local REI doctor, a nurse, and an individual tasked with branding and building the app. The practice is already utilizing some of our suggestions, culled from our interviewees' stories, so we are already witnessing practical implications.

Bethany

On the day of our first consultation with the REI practice, I reflected on my experiences in fertility clinics. I worried that infertile women would view my body (now 7 months pregnant) and be emotionally triggered by it if I entered through the front door. Before the meeting, I asked to use the emergency exit to enter (and leave) the REI clinic unseen, which was the easiest way to respect the women in the waiting room.

Once inside, I was starkly aware of the blurred boundaries between fertile and infertile—the environment was so familiar—though I never thought I would enter an REI practice as a fertility researcher, much less a woman pregnant without infertility treatment.

Maggie

One potential interviewee noted our work might be too embodied—that the boundaries between "insider" and "outsider" were simply not stable enough (Reich, 2003). During the recruitment stage, this potential interviewee and qualitative researcher emailed me with concerns that Bethany might not be emotionally ready and/or maintain objectivity given that she was in treatment herself. She said:

When you said that your co-PI has had infertility issues, I had some concerns about whether she was going to be "distant" enough to be "objective" ... To hear that she is undergoing IVF right now and it wasn't good news makes me very concerned for her well-being in this research project. Sorry to be such a pain in the patootie.

Although I appreciated the concern for Bethany, I was aggravated that this potential interviewee questioned my ethics of care for my co-researcher. I approached research from the perspective that Bethany's experiences with infertility build reciprocity with interviewees. Also, we both believe that the body serves as a site of knowledge production (Ellingson, 2006).

Post(Partum) Script

We could not and would not remove our bodies from a research project touching on the (dis)functionality of female

reproduction (Martin, 2001). As researchers with shifting fertility identities, we sought to account for the ways in which we assisted or obstructed the process of co-constructing meanings (Geist & Gates, 1996; Reich, 2003). Again, this study emerged as we embodied qualitative research—visible, “leaky” bodies (Ellingson, 2012). Acknowledging how identity can both help and hinder interpretations of our narrative data, we asked ourselves: How do we honestly engage identity shifts—moving from “insider” to “outsider” and back again? Our epiphany was that we struggled to define our own positions as insiders and/or outsiders because our identities are always in flux. When is the moment Bethany “became” fertile? How and when do women “lose” fertility? Is Maggie still “anticipatorily infertile” if she never attempts to conceive again? Thus, understanding identity requires an ongoing investigation of our own embodied experiences (Ellingson, 2006, 2012; Johnson, 2016). In our research, we argue that reflexivity is vital given the physical and emotional consequences of fertility treatments. Considering the nature of personal and professional boundaries highlighted the tenuous identity of our interviewees and clarified the conflicts many experienced when they considered their status as “infertile,” with or without a successful pregnancy. Some interviewees did not consider themselves “infertile” even after multiple failed treatments and in some cases multiple miscarriages.

In a pronatalist society that (by and large) pays tribute to mothers without supporting them in meaningful ways (i.e., lack of universal maternity and paternity leave) and shames those that chose childlessness while pitying those who cannot have biological children,⁴ investigating the complexity of personal fertility status is a feminist act. As ever, the experience of individuals who identify as female remains layered and complex and eludes simple categorizations. What if one is (in)fertile and transgender, gender-queer, or lesbian? What if one is (in)fertile and belongs to a minority group? (In)fertile and undocumented? (In)fertile and unemployed and/or uninsured, impoverished or without a home? As of now, our research does not include all of these voices; we desire dialogic spaces for all patients diagnosed with infertility to share previously unspoken and unheard stories of their treatment(s). As patients in REI form their own identities as insiders and/or outsiders, we believe their voices can alter the landscape of infertility care.

At this stage of our work, Maggie is 8 months postpartum, while Bethany is almost 6 weeks postpartum. We both have daughters, who may be (in)fertile. The boundary between “insider” and “outsider” is fragile, and we remain conflicted about our fertility identities, never certain when and how those identities may pivot again.

Notes

1. There is disagreement about age-related fertility statistics. Twenge (2013) argued that some studies inflate the risk. In contrast, the American Society for Reproductive Medicine (2012) reported that age is a major factor in infertility over the age of 30 and then a more significant factor after 35.
2. Twilight Sleep is an obstetric intervention during which a laboring woman enters a semiconscious state via injection of scopolamine

and a narcotic such as morphine. This drug cocktail, if successful, erases the mother’s memory of labor and birth. Our research focuses on the ways the women’s movement in Manhattan articulated the need for the procedure in the technical sphere of medicine, as well as how media outlets in Brooklyn framed the issue for upper-class individuals (Johnson & Quinlan, 2015, in press).

3. We recruited through an acupuncturist’s office that specializes in fertility treatment.
4. The stigma is complex here as well—while infertile women are stigmatized, so are those choosing donated egg and sperm, those who choose to adopt (or those that choose a donated egg and/or sperm over adoption, etc.), and those who seek surrogacy. Whichever path a couple takes toward expanding their family seems open for public debate and unsolicited advice and comment. Even fertile couples must navigate a host of expectations and opinions on the “right” time to choose to have children.

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