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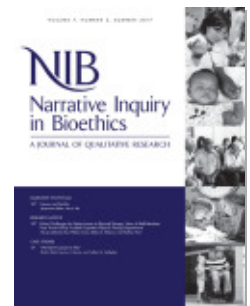
What We Didn't Know

Maggie Rogers

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Dreams for the Future

Erin and Robert

With familial support, we thankfully found our way to pay for the second round. As it turned out, precisely 58% of our embryos inherited the BRCA2 mutation. Of those embryos remaining without the mutation, less than a handful were free from chromosomal abnormalities. These results, which were exactly in line with the expectations Dr. B set forth for a 32 year old woman, were no less jarring to comprehend and accept. We remain grateful for these chances we will have to expand our family in the years to come. If these chances do not manifest into our original dreams coming true, we will work with the wonderful doctors, nurses and counselors we have met to make new dreams come true.

“I never truly researched one thing during our cancer journey. I never looked up a word I didn’t understand at the time. I told myself from the very beginning that we are fortunate to be surrounded by angels (some people just call them doctors) to lean on throughout the process, and as decisions had to be made. In my opinion, my job wasn’t to know the ‘ins & outs’ of the diagnosis, but simply do everything humanly possible to support Erin—my Superwoman during the fight. I feel we conquered the first round and now it is onto the next: Parenthood.”—Rob

Editor’s Note. One of Erin and Rob’s embryos was successfully implanted and they are expecting their first baby in early 2018.



What We Didn’t Know

Maggie Rogers

In 1994, I was just a little kid growing up in Northern New Jersey. I was lucky; I had just graduated to sharing the upstairs bedroom with my older sister—a huge room even to this day—but monstrous to small child. One of my favorite things to do was to play with my dad; I would run across

the huge expanse of pink carpet, launch, and land on him giggling. My bright blonde hair in pigtails would fly in the air as I ran and jumped.

I was diagnosed with stage III Wilm’s tumor, a type of pediatric kidney cancer, at the age of 4 and a half years old. It came in the shape of a large softball-sized tumor that caused my right kidney to rupture while I was playing with my dad in my bedroom. At the time of my diagnosis, my parents had to make lightning fast decisions that neither was expecting to ever have to make about their child. They had only hours to sign pages upon pages of documentation about surgical procedures and treatment protocols. Words, phrases, and medical terminology that was as foreign to them as another language. My parents signed off on the doctor’s suggested treatment plan, the most promising protocol at the time: nephrectomy, followed by radiation to the entire abdomen, and nearly a year and a half of Vincristine, Actinomycin D, and Adriamycin chemotherapies. While there might have been something in the fine print of the pages upon pages thrust into my parents’ hands, the focus in the hospital that March in 1994 was not about fertility: it was about keeping me alive. And it did. I was declared “cancer free” by the summer of 1995.

It wasn’t until years after my treatment ended that the topic of infertility was brought up in a routine discussion about my care. I don’t remember this conversation but during a regular follow-up appointment, my oncologist said to my parents that, “*there could be long-term fertility issues.*” This news came as a complete shock to my parents. They thought back to the mountains of paperwork and the conversations with my medical team and didn’t remember fertility ever being mentioned as a possible long-term effect. Their devastation was so obvious that hours after delivering the news of possible infertility, my oncologist called my mom at home at 9:00pm that night to make sure she was okay.

Year after year, I went loyally to my annual oncology clinic appointment. There were a lot of things that we didn’t know. Infertility, like another cancer recurrence or sudden heart problems, was discussed as “*maybes.*” It was a possibility—not a

probability. But, while I've been followed by my oncologist and a cardiologist for decades, it has only been within the last five years that I've been followed by a reproductive endocrinologist. Infertility was never weighed the same as other late term effects—and perhaps rightfully so. Infertility, if it happened, wasn't going to kill me.

Fast forward through adolescence and I got my period when I was 12—nothing out of the ordinary. I don't remember talking about infertility explicitly, but I do remember that getting my period at a normal age was a “*good sign*.” I remember thinking this was confirmation that I was developing normally.

At 16, in what I believe was the first time addressing me directly about it, my oncologist tried to broach the subject of my fertility. The outcome of the conversation, or lack thereof, was that I didn't want to talk about it. My care team respected my choice—we didn't talk about it.

The funny, or not so funny thing, is that I don't remember the infertility aspect of the conversation at all. I remember a brief conversation about premature menopause—that it might happen, especially since the women in my family experienced menopause at an earlier age as it was. My doctor informed me that if I wanted to have a family I might want to start earlier rather than later, but not being able to have children at all? I don't remember that part of the conversation. I don't know how it was approached; I don't know what was said; and I don't know who was in the room when it happened. At 16, I was a teenager worried about tomorrow's geometry test. I sat in high school health class day after day, learning all the ways to actively avoid pregnancy. At 16, talking about sex was embarrassing and uncomfortable. At 16, and even now, I shied away from having painful conversations because I didn't like to get upset in front of other people. So when I was 16, and my doctor tried to broach the topic of infertility explicitly for the first time to me directly—most likely in front of other members of my care team and in front of my parents—I apparently shut it down. And no one pushed me.

I don't remember a real conversation about fertility until I was in my early twenties and a senior in college. Back again at my annual appointment and

my doctor strongly suggested that I get my fertility tested. He thought that there could still be options on the table if my fertility was compromised. By that point, I had already gone through three basal cell carcinomas, skin cancer caused by my radiation, and already endured an embarrassing hematuria from a confused ureter while studying abroad. I was being followed by my oncologist, cardiologist, dermatologist, and gynecologist. While this wasn't my first time to the rodeo with late term effects from my childhood cancer treatments, I felt very scared. Infertility had always been just a possibility, but these other things had just been possibilities once too.

We made an appointment with a reproductive endocrinologist and I went with my mom. The waiting room was full of pregnant women (or women trying to get pregnant) and they looked at me with utter bafflement. I was nervous before even going into the room; I felt like I didn't belong there. I had blood tests done to check my hormone levels, a transvaginal ultrasound to look at my ovaries, and a gynecological and pelvic exam. The appointment was extremely uncomfortable for me. The doctor was an older man, while my gynecologists had always been younger women. I felt like my fate was being determined by a complete stranger.

Eighteen years after my initial cancer diagnosis, I finally had an answer: I would never get pregnant and I would never be able to carry a child. In that moment, infertility went from a possibility to a definite. I was told that I had less than a 2% chance of conceiving naturally. If my ovaries beat the 98% odds against them—or I was able to afford a donor egg—I wouldn't be able to carry a child to full term. Radiation left my uterus without the ability to stretch. Add on the possibility of sudden-onset heart problems, which can be caused by one of my chemotherapies, and that was it. Somewhere between the age of 4 and 22 I lost the ability to have children—all the cards were off the table. Here was this stranger delivering a loss that he could never feel. I never saw that doctor again.

Quickly after that appointment, my mom and I met with my oncologist and nurse practitioner again to debrief, for lack of a better word. I didn't

want to talk about my appointment because there was nothing to talk about. I wasn't given any options; there weren't any actions to take or decisions to make. There was no discussion of freezing my 2% chance for later, there weren't any magical medications. During our visit, I felt like they were all pushing me to express myself, like they wanted me to feel something, like they wanted me to show them I was upset, to cry. So I did. They asked how I felt. I told them I was devastated—absolutely devastated. We've never talked about it again.

A few years later at 26, I went into premature menopause—decades too early.

As a young adult, cancer was a great conversation piece: it was something that made me different and it probably even helped me get into college. Since I had been so young, many of my memories of the experience were second-hand, borrowed from someone else's telling. Conveniently that made speaking about my experience really easy. It also meant that the majority of my cancer memories were limited to those of post-cancer survivorship.

It wasn't until late effects like infertility that I truly realized how difficult the space of survivorship is to navigate. Being a cancer survivor comes with a lot of pressure: pressure to be perfect, pressure to be healthy, pressure to be in a constant state of appreciation for the gift of life. For me, infertility caused a lot of shame and guilt. Not only was it something as extremely personal as the inability to have children, but infertility also ripped the mask off my survivorship experience. I was failing at survivorship and all of a sudden I felt like everything was a big sham. Infertility even made connecting with other cancer survivors more difficult. I was no longer the embodiment of the inspirational survivor—I now had a stack of dirty cancer secrets with infertility right at the top.

Sometimes I feel like I'm stuck in an endless internal struggle, going around and around the stages of grief from anger to depression to acceptance and back again. Sometimes I wonder if I have any right to grieve my fertility at all. At the end of the day, my infertility was caused by the very cancer treatment that saved my life.

My cancer diagnosis came at time when the medical world was still learning about the late effects of childhood cancer chemo and radiation. I don't think anything about my treatment could have been done differently. There weren't options. There wasn't time. I'm lucky that my cells responded to treatment and that I'm alive and healthy. And I'm lucky to have a pediatric oncologist and care team that has followed me through everything and continues to follow me throughout the course of my survivorship. Perhaps they could have done something earlier or even pushed me harder, but they didn't know either. None of us knew.

More than anything, I'm lucky that I don't have to navigate the intricacies of today's dating world as an infertile, menopausal, 27 year old who is missing a kidney. I'm lucky that my extremely supportive boyfriend happens to be adopted and is open to building a family in one of the many other ways there are to do so.

I know that there are always other options if I want to become a parent and I know that in the grand scheme of life, I'm lucky—I just wish we had known what we didn't know.



Mitigating Surprises: How Conversations with Caregivers Could Empower Young Cancer Patients to Determine their own Fertile Futures

Bailey Hoffner

I shouldn't have been surprised when my OBGYN called in the summer of 2013 to let me know that I was "*hormonally menopausal*." Sitting in a cubicle, facing a desk littered with the day's tasks, my ears filled with blank noise and my eyes wavered. I raced to the bathroom downstairs, locked myself inside, and cried quietly with the phone to my ear, listening but not hearing anything after those two words.