Chapter 39

Reading Between the Lines of Cancer and Fertility: A Provider's Story

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As oncologists with experience in the growing area of oncofertility, there are some standard elements we think of with new patients in regards to oncofertility, such as sperm donation, egg harvesting, ovarian cryopreservation, cost of the procedures now and in the future, and cost of storage. We try to think of everything to tell our patients – all their options, the benefits and risks, and the odds of various outcomes. And while we know the issue is monumental for our patients, we can sometimes lose sight of the lifelong impact of their cancer and oncofertility decisions, and the myriad of ways these decisions will shape their lives and manifest themselves in surprising ways unique to each patient. We can also forget that the discussion of oncofertility itself may create an issue for a patient with which he or she might not otherwise have struggled.

A good example is a former patient of mine. When I met Samantha[1] in mid- 2002, she was 26, had just started a new job, and was engaged to marry that fall. The circumstances that led her to me began as it does for many of our young adult patients. Nearly 2 months earlier, she went to a walk-in medical clinic complaining of a nagging sore throat and tiredness. There, she had some blood work done that looked a bit unusual, so she was sent to an internist. The internist did more blood tests, which showed a high white blood cell count and low red blood cell and platelet levels. He ordered a bone marrow test and told Samantha that while waiting for the results, she should schedule an appointment with an oncologist, just in case. The day before her scheduled oncology appointment and 10 days after the bone marrow test, the internist called her at work to tell her that the test had revealed that she had acute myeloid leukemia (AML). At her appointment the next day, the oncologist told her that he primarily worked with breast cancer patients and since her diagnosis was AML, he advised her to see a hematologist/oncologist instead. He told her that he just happened to know someone across the street at a different medical center he thought she should see. He then called my staff and Samantha came over shortly after.

When Samantha arrived in my clinic that June day, she was already so sick that I told her she would have to be admitted immediately and that I wanted to conduct my own bone marrow test, under conscious sedation, to confirm the diagnosis and evaluate more extensive prognostic indicators. There was no time to delay or, as she asked, go home first to pack her favorite pajamas and other personal items. A few hours after the test, the

[1] The patient's name and other identifying details have been changed to protect her privacy.

diagnosis was confirmed (a drastic comparison to the 10 days it took the internist to tell her the results). She required 4 units of packed red blood cells when she was first admitted, and later that night she had a central line put in and began chemotherapy.

Thus began Samantha's initial 6-week hospitalization and two rounds of chemotherapy to force her leukemia into remission. During this time, she celebrated her 27th birthday. We talked a bit about her having children in the future. I told her that it was unlikely she could carry a child of her own because of the chemotherapy and that there were not really any fertility preservation options for leukemia patients. At the time she seemed rather untroubled by the loss of her fertility, having told me that even before her diagnosis she and her fiancée had been undecided about having a family and now she was simply happy to be alive. In the midst of various hospitalizations and chemotherapy, Samantha got married. At the suggestion of one of my staff members, she chose to get legally married that fall on the originally planned day and to postpone the ceremony until the following year, on what would be her 1-year wedding anniversary.

Samantha had her bone marrow transplant at the beginning of 2003. By the end of February, she was recovering at home and starting to feel better, and over the summer we took out her central line. That fall, I was honored when she asked me to be her first dance at her wedding. Shortly after returning from her honeymoon, she began working part time, slowly building up her strength, and working to reassemble the pieces of her life left strewn by the cancer. We talked about family planning more and I advised her to wait until she passed the 5-year mark, when her odds of recurrence would drop dramatically. As she and her husband had always been fairly ambivalent about children, she seemed content to delay thinking about it.

As Samantha later would say, she figuratively held her breath for those 5 years. In addition to delaying dealing with fertility issues, she put off processing most of the other emotions and events related to the cancer as best she could. Some issues, however, she could not ignore. The chemotherapy induced the onset of menopause with the hot flashes and other side effects that come with it. Her desire for sex had all but vanished, not only a trying situation for a newlywed but also devastating to her personally.

In June of 2007, Samantha passed the 5-year mark and celebrated with a trip to Hawaii with her husband. Upon her return however, with the wall of the 5-year mark now removed, all of the grieving, emotions, issues, and questions that she had put off the past 5 years came over her like a tidal wave. She told me how she mourned the loss of the second half of her 20s to the cancer, lamented that she would never feel as secure in her health again, and grieved for the effect the cancer and its aftermath had wrought on her marriage and sex life. She also began to question why she had lived when so many of her friends from chemotherapy had not – was there some purpose to her surviving? Was it to have a family and be a mother?

I referred her to a fertility specialist, who explained to Samantha that her options were either to use donor eggs or to adopt. Her sister offered to donate eggs, but Samantha struggled with what it would be like to bear a child that she knew was genetically her

sister's – what if the child looked more like her sister than herself? How would her sister really feel toward the child? How would her husband feel? As it was, the fertility specialist was reluctant about this option as her sister was 35, saying he would prefer Samantha to use a donor in her 20s, a possibility that raised a host of other doubts and questions for her. While she was initially reluctant about adoption, Samantha knew another patient who had adopted two children internationally and seeing her friend's experience had warmed her to the idea somewhat. During this critical decision point in 2007, Samantha and her husband determined that the only way they could afford the more than $20,000 it would cost to use a donor's eggs or adopt was to use the equity from their home (with the recent downturn in the housing market, that financial option is no longer available to them today).

Samantha came to see me, distraught and overwhelmed. She told me that she felt an inexplicable and overwhelming internal pressure to make a decision – to create some meaning out of her cancer because her sister was at the upper age limit to donate eggs, because her husband was 10 years older than she was, because she felt as though it was what everyone expected her to do, because everyone kept asking her about it. Unlike some survivors, she felt she did not struggle much with the long-term consequences and health implications of having a child, as she was too consumed with the more basic question of whether she even wanted to have children at all. In the midst of this, she was nagged by the question of whether she was focusing on this decision because of the cancer and the 5-year mark. Since she and her husband had been indecisive about having a family before her diagnosis, was she questioning her feelings about having children because they had now been married for a few years? Or, would they not even be thinking about having a family if she had not developed and then survived cancer?

I encouraged her to see a therapist and to begin to confront and process all these experiences, losses, and emotions she had put off for the past 5 years. While working with the therapist, she agreed to delay thinking any more about her fertility options for 4 months while she worked through her other emotions. Two years later, she still has not revisited the issue. Her wide social circle now includes a number of women, both married and unmarried, who are choosing not to have children, which has increasingly made her question if she really ever wanted children or if it was cancer that made children such an issue in her life. She has sought out other women who went through experiences similar to hers and talked with them about what decisions they made about family planning, how they arrived at those decisions, and how they felt about their decisions over time. Today, Samantha will not go so far as to say she has definitively decided against having children, but will say she does not plan to revisit the issue any time soon. She also still questions whether the compulsion she felt to have children after she passed the 5-year mark was truly how she would have felt regardless of the cancer, or whether it was driven by her perception of expectations from others or a need to make some sense of her survival.

Samantha's life was undeniably altered by her leukemia – her career is likely not what it would have been, their financial situation was negatively impacted by the extended time that both she and her husband did not work while she was sick and he cared for her, and, in what is perhaps the most persistent issue for her still today, she has expressed concern

to me that her sexual drive is only beginning to approach what it once was. Samantha will also tell you that the cancer brought some wonderful things and people into her life and led to some experiences she feels certain she would not have otherwise had, including running a marathon.

Samantha's journey illustrates the complexity of being a young adult with cancer today. While fertility preservation is an amazing option we can now offer some cancer patients, having children is no longer a default expectation of becoming an adult, or even of getting married. Samantha's story is a cautionary reminder to all of us that every aspect of a cancer diagnosis and treatment influences the lives of our patients and when discussing all of the options a patient has, we must be careful not to assume the importance of fertility preservation and having children.

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