Chapter 37

The Role of a Patient Navigator in Fertility Preservation

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As the patient navigator for the Department of Fertility Preservation at Northwestern University, my main concern is the overall emotional well-being of the patient. I have spoken with over 300 patients who have had a recent cancer or autoimmune disease diagnosis. Finding out that you have a life-threatening illness is horrifying, and patients have told me of the emotional rollercoaster that they experience when they are first diagnosed. Many patients will not even think how their treatments may affect their fertility. Likewise, it is not necessarily the first thought on their surgeon's or oncologist's mind either. This is not surprising when the first priority is to save the patient's life. When facing a life-threatening illness with unknown costs, trying to make a decision about their fertility may not be a priority for some patients. However, preserving fertility is important for many patients and should always be discussed regardless of prognosis or income.

When talking with patients, I try to give them the full spectrum of options, including the option of not doing anything to preserve their fertility. Although not all treatments will affect fertility, the type of chemotherapy, dosage, and age of the patient are all things that need to be taken into account on an individual basis. It is hard to know with absolute certainty whether the treatment patients receive will eliminate their fertility, as each individual responds different to the impact of cancer treatment. Sometimes the initial course of treatment may not cause any risk to a patient's fertility but if the patient does not respond to this treatment, a more aggressive regimen may begin immediately. This is why it is critical to discuss fertility preservation when the patient is first diagnosed. In many cases, patients view fertility preservation as an insurance policy, a preventative health measures to protect the potential to parent.

My role as the patient navigator is to serve as the patient advocate, explaining the impact of cancer treatment on fertility, outlining the options available to each patient, helping the patient schedule appointments and navigate the health care system, and offering supportive counseling if the patient is in need. In my experience, the typical patient is female, recently diagnosed with breast cancer, in her late twenties to early thirties, newly married or in a committed relationship, and knows that she wants to preserve her fertility. When discussing her options, I break down the conversation into three categories: having biological children, using an egg donor, and adopting. Patients who are given the time can undergo an egg harvest that takes about 2 weeks (timed with her menstrual cycle) and

freeze either embryos (if the patient has a partner) or unfertilized eggs (experimental research protocol). If the patient does not have the time to undergo an egg harvest, I discuss ovarian tissue freezing, an experimental research protocol where one ovary is removed and the resulting ovarian tissue frozen for later use. If the patient has the time and the resources to have an egg harvest, this is her best option to have a biological child in the future, as ovarian tissue freezing is still considered an experimental procedure. Aside from time, cost can be another factor that influences patient's decision making, and in my role as patient navigator I outline the expenses for each procedure and help patients understand insurance coverage and out-of-pocket expenses for each option.

Men have a number of advantages when it comes to fertility preservation. They can bank sperm (which can be scheduled quickly) by making an appointment with a sperm bank. Fertility preservation costs are lower for men, although cryopreservation and storage fees are generally not covered by insurance. Although fertility preservation for men may be more straightforward, these cancer patients still require counseling and support in the decision-making process. As the patient navigator, I also assist male cancer patients, addressing their fertility preservation concerns and guiding them through the medical system.

Two key points that need to be considered when counseling fertility preservation patients are time and money. How much time is the oncology team willing to give the patient to preserve his or her fertility? Can the patient afford any of the possible options? For the patients that I have consulted, cost is almost always the deciding factor. Fertility preservation can be very expensive, especially when the patient is already burdened with large medical bills for their cancer treatments. Many patients, male and female alike, do not have any coverage for fertility preservation so it becomes an out of pocket expense that can run up to $15,000 (one IVF cycle plus the cost of medication). Some centers have discounted prices and are willing to arrange payment plans with patients. It is unfortunate that cost keeps many patients from preserving their fertility, but this is the reality, and my job is to make sure patients understand their options and the costs associated with their medical decisions.

My goal is to give patients information on fertility preservation as soon as possible, thereby allowing them to make an informed decision about their future fertility.

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