PRACTICE

WHAT YOUR PATIENT IS THINKING

It felt like I was living in a fog

Elizabeth Lerner Papautsky shares the impact that “chemo brain” had on her life and how this unexpected side effect of chemotherapy was the most challenging for her to manage

Elizabeth Lerner Papautsky *patient and human factors psychologist*

After I started chemotherapy, I spent several days feeling like a zombie. As I received more treatments, I was in an ever present haze. Sometimes I couldn't concentrate enough to read or watch television, let alone work. I became over-stimulated in noisy and crowded places. I had difficulty carrying on a conversation with several people at the same time. I tried to manage by doing the more complex tasks in the morning, then focusing on simpler tasks in the afternoon. I also started to avoid public places, including not taking my children to activities and birthday parties. I might have been more prepared for making these sacrifices had I known about “chemo brain” before starting chemotherapy.

Fighting the unknown

Chemo brain, also known as brain fog or chemo related cognitive impairment, was a devastating and debilitating side effect of chemotherapy for me. Before starting treatment for breast cancer, I received chemotherapy education in a face-to-face appointment. At that time I was also given a thick packet of information on what to expect. The side effects covered were primarily physical. They included nausea, fatigue, and hair loss. Cognitive side effects, such as chemo brain, were not mentioned.

Without this information, the fog associated with chemo brain was unexpected. I couldn't manage my expectations of how I was going to function while undergoing treatment; how I would deal with treatment within the context of my life—family, job, goals. And because I wasn't prepared for chemo brain, I fought it. I mourned the loss of having a clear mind. I thought that if I tried harder or drank more coffee maybe it would get better. I even thought that I was imagining it.

Managing realistic expectations

I started to look for information about brain fog by googling my symptoms and the side effects of chemotherapy. I looked at websites for people with cancer, and at the latest research in the area regarding side effects of chemo. Finally, I connected with a community of other women who were undergoing or had undergone chemotherapy for breast cancer. I learnt that, although

people might experience chemotherapy in different ways, many will be affected by chemo brain.

I wish my health professionals had created opportunities to discuss the impact of chemotherapy before treatment began, as well as during and after. Just acknowledging chemo brain as a common side effect during and after treatment would have helped. Being able to manage expectations of what I could or could not do while receiving treatment would have allowed me to more effectively plan the life adjustments needed, including taking leave from work and arranging lifts to my treatments. It would have helped me feel more in control of my life and empowered about my care.

What you need to know

- Eliciting and considering the life context, goals, and preferences of patients can help ensure they get information tailored to their needs during chemotherapy
- Discussing chemo brain with patients before treatment can help them to prepare and plan logistically and psychologically, and this should be ongoing throughout treatment
- Suggesting strategies, such as doing more challenging tasks in the morning, can help patients navigate their lives more effectively during treatment

Education in practice

- How can you ensure that you inform patients of the cognitive and psychological aspects of treatment, as well as the physical ones?
- How can you create opportunities for patients to discuss their challenges and concerns before, during, and after treatment?
- How could you support a continued conversation with patients throughout treatment on how they are coping and any challenges they are facing?

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