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The Cancer Survivorship Care Plan: Health Care in the Context of Cancer

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Introduction

Some people are skeptical about the value of the Cancer Survivorship Care Plan recommended by the Institute of Medicine in its 2006 report, *From Cancer Patient to Cancer Survivor: Lost in Transition.*[1] As a cancer survivor, I offer this contribution to communicate my experience with survivorship care planning. Whatever your opinion of the Cancer Survivorship Care Plan, I ask you to recall patients who transitioned from the acute stage of cancer care, but felt lost, who ignored their long-term health, or who reported difficulty in obtaining care to help them with their residual problems. That is what this is all about. Although many of your patients simply get on with their lives, there are probably as many who don't. Even those who do just move on should be attended to in follow-up as cancer survivors. I believe my case illustrates the importance of an organized approach to health care for these patients.

A Cancer Survivor's Perspective

I am a survivor of a grade 3 anaplastic astrocytoma in my right cerebellum diagnosed in 2002. After resection of a small amount of brain tissue, I received 59 Gy of fractioned radiation over 33 days and then oral temozolomide taken on a 5-day cycle once per month for 12 months. Thirty-six MRIs later, all continues to be stable with Wallerian degeneration and shrinkage of my right cerebellum. I went back to work two weeks after surgery, worked throughout my treatment, and continue to work now.

Like many people with cancer, once diagnosed, I embarked on a crash course on what I was up against and what I could do to try to stay as healthy and as functional as possible. I read insatiably and was a proactive partner in my care. During the 6 years since my diagnosis, I continued to experience progressive problems with episodic fatigue, working memory, multitasking, attention, and processing speed. I was working all the time to maintain productivity, but it was taking me a long time to get things done right. I sought out the best care and, despite my incessant problem-solving approach, found myself coming to the realization that I might just need to accept my new normal. Acupuncture visits helped me greatly in terms of symptom management for persistent fatigue, but I thought searching for a cause in Western science and curing these problems was the preferred long-term approach.

My efforts to establish my dream team[2] and continue to improve my health and life after treatment are described below. These providers, all the best in their respective fields, gave me the optimal standard of care. Despite their best efforts, I was not improving and nearly settled for the status quo. Here are the consultants I visited to address my post-treatment symptoms in my ongoing search to get back to normal, not just live with a new normal:

1. For my cognitive complaints, the neuro-oncologist who directed my brain cancer care referred me to a speech pathologist who tested me and, despite the cognitive symptoms that I reported and experienced in everyday life, told me I was "normal" and "not to worry."

2. Subsequently, I consulted a neuropsychologist at a leading cancer center where in a 30-minute evaluation she was able to document problems in memory, processing speed, and executive function. I received a summary of helpful accommodations and advice to reduce some of my commitments, which would have been helpful if I were not a workaholic.

3. Next, a psychiatrist with expertise in medication for adult cancer survivors with cognitive problems prescribed methylphenidate. This medication improved my attention, processing speed, and ability to multitask, enabling me to work longer and more efficiently.

4. My personal internist observed that my blood pressure was significantly elevated after starting the methylphenidate. Concluding there was a possible link between the stimulant and elevated blood pressure, I immediately stopped taking the drug.

5. At the suggestion of my internist, I consulted another psychiatrist who prescribed a subclinical dose of Paxil. This medication helped manage my distress, but over time contributed to weight gain and fatigue. I continued to take it because it did seem to help my mood and stress levels.

6. Approximately 3 years after my initial treatment, I saw a neurologist who diagnosed me with cerebellar cognitive-affective syndrome. I was hopeful that the answer might be found in a medication used for narcolepsy (modafinil) reported to be promising for cognitive limitations and fatigue in cancer survivors. I reduced the prescribed dose by half because I was concerned that it would keep me awake, but the half-dose resulted in my wakefulness for 2 days.

7. I saw an ophthalmologist for blurry vision that I thought might be related to my tumor or its treatment, but a careful examination revealed that my symptoms were simply related to dry eyes. The ophthalmologist recommended drops, which relieved dryness but had no effect on blurriness.

8. I then consulted a neuro-ophthalmologist who, after a comprehensive evaluation, concluded the blurriness was not related to brain tumor or treatment.

9. An audiology consultation for what I perceived to be a progressively worsening hearing loss was completed. There had been a few studies on sensory loss in brain tumor patients after treatment with radiation and chemotherapy, and I feared that because my radiation was aimed at my cerebellum and my right ear was in the treatment field, the cause could be treatment-related.

10. Continuous surveillance of my brain tumor revealed a stable MRI. However, I continued to experience persistent symptoms.

I had many consultations, with no single provider coordinating care. Coordination was left to me. I was fortunate, however, as I sought out highly knowledgeable and clinically skilled experts in their fields. They were responsive and provided first-rate quality care in their specialties. However, my overall care was fragmented, which is illustrative of how the health care system currently responds to the needs of cancer survivors.

The Pursuit of Happiness

I read about the idea of a comprehensive survivorship care plan that summarizes treatment exposures, current health, health behaviors, psychological conditions, and other long-term and late effects of cancer and its treatment. Thinking that this approach would be helpful, I searched for physicians in the Washington, DC, area who could provide a cancer survivorship care plan, but most were unfamiliar with it. I was aware that it was only recently proposed,[1] but I didn't realize that only a few places were providing such a clinical service.

As a cancer survivor, I was invited to provide a survivor's perspective on the challenges of survivorship at a conference where Patricia Ganz, MD, was also speaking. I spoke to her about my desire to find a group that provided such a plan. She graciously offered to see me at her survivorship center, and I followed up with an appointment. For the first time since leaving the comprehensive care of my oncologist and neuro-oncologist, I felt that my health and well-being were viewed within the context of a cancer patient. I felt that the problems I was experiencing, though not life threatening, were affecting my life and putting me at risk for other health problems.

What Was the Upshot?

The survivorship care consultation team carefully reviewed my medical records, family history of cancer and other diseases, general health, potential late effects, mood, activity level, nutritional habits, and other health-promoting behaviors. I also saw an endocrinologist to rule out any late effects of endocrine changes after brain radiation. I was prescribed different medications that have greatly helped my fatigue and mood. I have lost 15 pounds during the past 6 months since attending the consultation, increased my activity level, and corrected the vitamin D deficiency that was identified. I have also reduced my risk of metabolic syndrome. After the complete review of my endocrine function, I have been given a clean bill of health for now. Even though I have a more uncertain future than if I didn't have brain cancer, I now have the perspective and energy to keep moving forward. My family has seen a difference in terms of more interest and energy to get out of the house and do something other than work. Of course, I continue to experience the cognitive limitations, the blurred vision, and hearing loss. As recommended at the visit, I had an updated audiology examination and am now shopping for "cool" hearing aids.

Another aspect of this evaluation that proved to be an eye opener was the comment that I may never be able to find the cause and return to normal. However, there is another option to simply living with problems. I can take an active role in accepting my symptoms and palliating them as best I can. This is different than accepting a new normal; it is working to change the new normal through palliative efforts such as hearing aids.

As a clinical psychologist who has helped many learn to live with untreatable health conditions, I am now faced with the same dilemma. Call it denial, hope, or realistic optimism,[2] but we need to help cancer survivors move beyond their new normal with many approaches, and palliation is one. This consultation helped me place the information provided about my current concerns and, more important, their management (medical and nonmedical) in the context of a cancer survivor. An evidence base on the efficacy of such an approach to improving the management of cancer survivors is essential.[3]

Looking to the Future

Participating in the development of my comprehensive survivorship care plan was a catalyst for me to move forward and view my problems from the broader perspective of my experience with this illness. Despite my past efforts and new found knowledge, I still cannot shake some of my problems. I continue to be evaluated as a 6-year survivor of a malignant brain tumor. I realize it must not stop with the initial Cancer Survivorship Care Plan. It will need to be tweaked as with any living document, and I intend to be one of the leaders in this movement. I now understand how such a simple and logical dimension of care can be so profound. Just think what it will do for the millions of cancer survivors out there for whom this is not an option … yet.

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Author's Disclosures of Potential Conflicts of Interest

The author indicated no potential conflicts of interest.

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