

Oncology Unplugged Podcast Interview: *Science of Survivorship: A Discussion of Optimizing Quality of Life for Cancer Survivors*

An Interview With Kenneth Miller, MD, and Richard Boyajian, NP, a Cancer Survivor

Introduction

Currently, there are more than 11 million cancer survivors in the United States, and this community is expected to grow as a result of the aging population and improved methods for cancer detection and treatment.¹ The posttreatment period poses some unique challenges to cancer survivors, including gradual recovery from treatment, late effects of therapy (some of which can be chronic), and emotional and psychological problems surrounding the diagnosis of cancer.² A lack of information about posttherapy care, not knowing what to expect regarding symptoms from therapy, and fears about recurrence all contribute to a reduction in quality of life following cancer treatment.^{3,4} In this interview, Kenneth Miller, MD, and Richard Boyajian, NP, discuss critical issues for cancer survivors, including survivorship care planning and symptom recognition and management.

Kenneth Miller, MD: I am Dr Ken Miller, the Director of the Adult Cancer Survivorship Program at the Dana-Farber Cancer Institute. I am very pleased to be joined today by colleague and friend, Richard Boyajian, who is a nurse practitioner and cancer survivor. Rich, thanks for joining me today.

Richard Boyajian, NP: Thanks for asking me Dr Miller.

Kenneth Miller, MD: Would you share your experience with us? You are a healthcare professional and also a cancer survivor.

Richard Boyajian, NP: In 1995, I started having some symptoms of fatigue, but I just brushed it off as working too much. Unfortunately, my symptoms increased, and I started to have night sweats. I went to my primary care physician, and he drew some blood. I found out that I had chronic myeloid leukemia (CML). At first, they told me that they thought I was in an advanced stage, in blast crisis, and there wasn't much they could do; but then, after a bone marrow biopsy, they told me that I was lucky and could have an allogeneic stem cell transplant. I had the transplant Friday, December 13, 1996.

Kenneth Miller, MD: What was your season of acute survivorship (right after the diagnosis) like?

Richard Boyajian, NP: It was overwhelming from the information perspective. I needed to learn what CML is, what an allogeneic transplant is, etc. I was somewhat familiar with [allogeneic transplants], but I still needed to be educated by all of my providers to determine my best option. Physically, I actually felt pretty good, but it was emotionally draining not knowing if I was making the right decision and knowing that there was a fair chance that I could die just from complications of the transplant alone.

In December of 1996, I received total body radiation and high-dose cyclophosphamide prior to my transplant. I developed mucositis. My hair fell out. I slept for about a week and a half because my blood counts were very low, and I needed blood transfusions and platelet transfusions. I spent a total of 5 weeks in the hospital. I had minimal complications secondary to cyclosporin toxicity. My mucositis was very severe, requiring a fentanyl drip to control the pain. The fatigue was overwhelming. The most notable thing to me was the cognitive impairment. It was very difficult for me to concentrate on anything. I thought I would have books I could read, or I'd watch TV, but my attention span was next to nothing.

Kenneth Miller, MD: What was it like, transitioning from being in the midst of acute survivorship and treatment to all of a sudden starting to go back to life?

Richard Boyajian, NP: The day I stepped out of the hospital I was overwhelmed. It was actually comforting to me emotionally that I was sitting in this specialized room with expert care around the clock with all the nurses knowing exactly what they needed to do and the physicians always supervising everything. I felt protected in that transplant room because I knew that there were experts taking care of me. But when I was discharged from the hospital, it was actually kind of scary. I actually felt like I'd rather just stay in the hospital because it was overwhelming for me as a patient to go home and figure out what I was supposed to do to manage my symptoms and also what symptoms I should report. Even though the providers did a good job of verbally educating me about things, my cognitive impairment was pretty significant; so it was difficult for me to remember everything that they had said.

It was tough because on the outside I looked very good, but inside I was just exhausted; I was emotionally drained. The mental health professionals that I saw during and after treatment made the transition easier.

The emotional aspects of cancer treatment and survivorship are as difficult, if not more so, than the physical aspects. It is as important for survivors to take care of their emotional health as it is for them to take care of their physical health, and mental health providers can help you with this.

Kenneth Miller, MD: When did you start finding that your life started refocusing on just life? You know, your work, your family, just the day to day, and the cancer was not as much of a minute-by-minute, hour-by-hour thought? Or has that happened?

Richard Boyajian, NP: It has happened, but exactly when that kind of switch went on is hard to pinpoint. I think it was probably when I was healthy enough that I could become more active in doing other things. For me, it was when I found a sense of purpose; I wanted to do something. I went back to school to get my nurse practitioner's license and masters degree. I think when I was able to focus on something in a positive aspect and feel like a valuable member of society again, that was when I think my focus was less on my day-to-day aches and pains, and I was more focused on a goal that I wanted to achieve and taking actions to do that.

Kenneth Miller, MD: What are some of the major symptoms or concerns for people who join the cancer survivorship program?

Richard Boyajian, NP: Fear of relapse is one of the most common concerns.^{1,5,6} The more recent a patient's treatment, the more likely this will be a primary worry. Cognitive impairment is also common. It can be very worrisome for people, especially when they're trying to return to their "normal life," when they can't do what they did before.

Kenneth Miller, MD: If someone doesn't use the terms "chemo-brain" or "chemo-fog," what are their actual complaints?

Richard Boyajian, NP: Many people will talk about short-term memory. They don't remember as well; they need to write things down more now, or they'll show up at places on the wrong day. Survivors really feel like it impacts their day and their ability to function. They're very concerned that this could be getting worse.

Kenneth Miller, MD: When you ask about sexual health, what do people tell you?

Richard Boyajian, NP: People might feel more comfortable identifying sexual problems (eg, erectile dysfunction, low libido, or reduced sex drive) on a checklist, which can facilitate the discussion. If they don't check it off, then I ask anyways; but I think most people will check it off because they feel uncomfortable bringing it up. People often think that part of their identity is their sexual being. Survivors can be conflicted because they think they should be grateful to be alive and not worry too much about it, but it does distress them because it affects their relationships with their partners. And for women as well, it's a difficult subject. Bringing the subject up with a paper intake form or just asking, "how is your sex life?" helps. Don't beat around the bush, just ask about those issues.

Kenneth Miller, MD: The majority of patients really will benefit from appropriate medical or psychosocial interventions.

Richard Boyajian, NP: In males, sexual dysfunction can be caused by hypogonadism from alkylating agents or radiation fields, and survivors can benefit from testosterone supplementation.⁷ A low testosterone level can play a role in fatigue, depression, and sexual dysfunction, so addressing these issues can have a big benefit. Women that had pelvic radiation or might have vaginal graft-versus-host disease from a transplant, can benefit from an early discussion about whether certain medications or vaginal dilators can help them.

Kenneth Miller, MD: What are some of the pain problems that patients come to you with in the survivorship program, and what are some of the approaches in terms of trying to help people?

Richard Boyajian, NP: I think pain varies greatly depending on the patient's previous treatment and the medications they're currently receiving. Avascular necrosis from radiation or high-dose steroids causes tremendous pain.⁸ We often send patients for imaging to confirm exactly the cause of the pain, to actually address the etiology of the pain. One of the issues for survivors is that this can be a chronic problem; so it is often more beneficial to refer survivors to experts, eg, a pain clinic, because they may need long-term management and more monitoring than the survivorship clinic might be equipped to do.

Kenneth Miller, MD: What's so important about having a survivorship end-of-treatment summary and a care plan?

Richard Boyajian, NP: It is very scary to have to rely on your knowledge to care for yourself. You are not in frequent contact with a team of experts. I think one of the most valuable things that a treatment summary and a care plan can do is to educate the patient about this unknown time period, because patients are often overwhelmed and worried about recurrence. They need to know what follow-up care they need, when/how often they will have appointments, what blood work they need, how frequently they need scans, and the symptoms they should report.⁹ Often, healthcare providers are relaying this information verbally, and that is not enough. Healthcare professionals need to take the time to put down on paper the pertinent information we think you should know about your cancer and what your follow-up care will be, whether it's a grid like the National Comprehensive Cancer Network (NCCN) or whether you list how often they need to be seen for the first year and beyond. Just put it down on paper so that the patient has a reference guide.

Kenneth Miller, MD: What's special about a survivorship care plan?

Richard Boyajian, NP: Often, providers will explain things to the patient, but there is no systematic way that it is being done. Verbally is not enough; patients need something to refer to. Also, the care plan can be useful for the primary care provider.

Kenneth Miller, MD: Rich, we have a few minutes left, so let me ask you about the whole topic of wellness. We have a growing group of cancer survivors. What are the things we need to help teach our cancer survivors?

Richard Boyajian, NP: Cancer survivors need to know whether they are at risk for anything because of the treatment they received. I think by giving the patient a health and wellness focus it can help them to feel like they are doing something to help keep themselves healthy. Talking to them about normal, healthy screenings is very important. Just because you had breast cancer doesn't mean you can't get colon cancer and vice versa. So normal screenings are very important as well as the need to eat healthier and exercise.¹⁰

Kenneth Miller, MD: Healthy diet and exercise do, in fact, have an impact on survival.¹⁰ I loved what you said about that.

Richard Boyajian, NP: I think it is very important that we figure out a way to develop some standardized material; there are many great organizations, including the American Society of Clinical Oncology, NCCN, the National Cancer Institute, the Lance Armstrong Foundation, and the National Coalition for Cancer Survivorship, that have developed material that can be used in the community and academic medical centers.^{5,6,9,11,12} These plans can help educate patients on risks and health behaviors that can go a long way toward improving their overall health and quality of life.

Kenneth Miller, MD: I think our time is coming to an end. In conclusion, cancer survivorship is a distinct phase of cancer care and a growing part of the field of oncology. Rich, thank you.

Richard Boyajian, NP: Thank you Dr Miller; it was a pleasure.

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