

Telling the Tales of Young Adult Survivors

Have you ever noticed how sometimes things just work out perfectly? I love it when that happens. . . . I am hard at work on another book for Hygeia Media, the consumer imprint of the Oncology Nursing Society, and the book focuses on young adults with cancer. Although many memoirs are available that describe personal experiences with cancer, few take an evidence-based approach to the advice provided for the reader.

The idea for the book came to me last November when I presented the keynote address at the Young Adult Cancer Canada conference. Standing at the podium, I looked out at an audience of young people and their partners and, although I have given many presentations to audiences of survivors, seeing so many young faces was very moving. I also presented two workshops the next day and heard stories and questions about their unmet needs and challenges. In addition, I met a young woman survivor who is an editor, writer, and blogger, and we talked about doing a book as a joint project. I was so enthused that I worked on an outline of the chapters on the airplane ride home and started writing in early January.

It has been an interesting journey, to say the least. Little research exists specifically for this age group (18–39 years); however, they have some very real challenges that are unique to their stage of life.

Earlier this year I was invited to speak at the Living Beyond Breast Cancer conference for young women with breast cancer. I have presented at the annual conference previously; they are the parent organization of the Young Survival Coalition (www.c4yw.org). The conference was attended by more than 650 young women and, needless to say, a whole lot was going on. All of these

women were in one hotel, and many of them were away from their families for the first time since their diagnosis and treatment. There was much laughter in the hallways and more than a few tears. The exhibit hall was filled with vendors selling all sorts of breast cancer merchandise, from lymphedema sleeves to t-shirts with funny slogans. My favorite was the one printed with the following message on the front: “Yes they’re fake. My real boobs tried to kill me!”

And here is the serendipity part. When I got back from the conference, I needed to do some interviews with young adult survivors to highlight the concepts in the book in progress. Fortunately, I had the contact information for some support groups and, after a couple of clicks, I had agreement from three organizations that were prepared to put out a call for volunteers to tell their stories. What a response!

Soon I was literally swamped with e-mails from survivors wanting to tell me their stories. And what amazing stories they are. What was remarkable was the consistency with which these young people were told that they were too young to have cancer by healthcare providers who ignored their symptoms and looked for other causes of their complaints. I know the old saying, “When you hear hoof beats, look for the horses and not the zebras,” but in retrospect, some of these people would have been diagnosed much earlier if only cancer had been part of the differential diagnosis. Young women with

breast lumps found while breast feeding were told that they had mastitis; others ignored their symptoms until they literally fell over at work. Not



Young women with breast lumps found while breast feeding were told that they had mastitis; others ignored their symptoms until they literally fell over at work.

all the stories have happy endings. A number of the people I interviewed have metastatic disease and I wonder if they will be here to read the book when it is published.

I have finished the interviews and they are now being transcribed. By the time this issue of the journal reaches your mailbox, I will be putting the finishing touches to the book and submitting it.

In addition to a number of life lessons that I have learned from the interviews and the process of writing a book with a coauthor, I also have recognized that, despite the relative rarity of cancer in young adults, this is a population that needs research and interventions that address their needs.

Anne Katz, RN, PhD, is a clinical nurse specialist at the Manitoba Prostate Centre, an adjunct professor in the Faculty of Nursing at the University of Manitoba, and a sexuality counselor for the Department of Psychosocial Oncology at CancerCare Manitoba, all in Winnipeg, Manitoba, Canada. Katz can be reached at ONFEditor@ons.org.

Digital Object Identifier: 10.1188/13.ONE203