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 to put out a call for volunteers to tell their stories. And what amazing e-mails from survivors wanting to tell 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 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.

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