

## The Trouble With Teen and Young Adult Cancer Care

For the past two years, I have been immersed in the writing of two books—*This Should Not Be Happening: Young Adults With Cancer* and *Meeting the Need for Psychosocial Care in Young Adults With Cancer* (Katz, 2014, 2015). In the preparation of these two manuscripts, I read everything ever written about cancer in these populations. The experience proved to be a somewhat frustrating endeavor, with more information and evidence missing than available.

Adolescence is a time of great physical and psychological growth and spans the time from puberty until age 18 years. Young adulthood is defined as occurring between the ages of 19 and 35 years; however, some regard the upper limit as age 39 years. Development continues in this age group, with multiple significant milestones to be accomplished. A number of challenges exist with these definitions, including lack of consensus on the upper and lower limits and the broad age range encompassing many developmental milestones and psychosocial issues.

In reading the literature on these two life stages, how individuals with cancer negotiate the cancer system, and how oncology care providers treat adolescents and young adults with cancer, it became abundantly clear to me that a paucity of research exists, including descriptive studies and very few intervention studies. The challenges related to sexuality and body image changes are barely described, and essentially no interventions have been proposed or evaluated in this domain. Some information exists about fertility preservation, but it mostly describes how we are not doing a good job of informing our young patients about the risks to fertility from treatment or referring them for fertility preservation services. We also have some preliminary descriptive

data on how these young people parent their children during and after cancer. Some early studies exist on the return to school and work. These are just four of the developmental milestones that should be achieved during adolescence and young adulthood—defining one's sexual identity, starting a family, going to school, and creating a career—and they are all potentially and significantly interrupted by cancer.

I was honored to present a 90-minute plenary session at the 2015 Oncology Nursing Society Congress on the topic of meeting the psychosocial needs of adolescents and young adults with cancer, and I received excellent feedback from some members of the audience. Afterward, one nurse said to me, "I've been working in this area for more than 10 years, and your presentation made me realize how much I don't know." This is concerning. How can you work with adolescents and young adults and not understand the unique needs of this population and act to fill the gaps? Many nurses end up caring for adolescents and young adults with cancer in pediatric or adult settings by default, not because they had a specific interest in caring for this population. If you do not understand the unique needs of adolescents and young adults, you risk alienating your patient through ignorance—and alienation is the enemy of trust and communication.

In North America, we are behind our colleagues in the United Kingdom and Australia when it comes to caring for adolescents and young adults with cancer—far behind. The first hospital units specifically designed for teens were opened more than 20 years ago in

the United Kingdom, and it is only now that we are seeing similar units in the United States. Adolescents and young adults with cancer have specific and unique needs that are often not met by pediatric or adult units. Think about a typical adolescent or young adult and his or her internal clock—awake for the first time at 10:30 am and still awake and active at 1 am. How well does that fit with the pediatric patients or older adults? When their friends are able to come to visit, it is usually not during



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the day, but after hours when we expect patients to be asleep. Although we can plan units with flat screen TVs, video games, and communal "hang out" areas, it is not until the staff adopt a culture and attitudes that are appropriate to the unique needs of the adolescent and young adult population that we will truly be providing comprehensive and holistic care.

I have been invited to speak at the 2015 Critical Mass conference later this year ([www.criticalmass.org](http://www.criticalmass.org)). Critical Mass: The Young Adult Cancer Alliance has a mandate to bring together patient advocates, clinicians, researchers, non-profit organizations, medical institutions, and others who are interested in

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improving the lives of adolescents and young adults with cancer. The theme of the conference is “Addressing the Elephants in the Room,” and it will deal with those issues that are often difficult to talk about and particularly difficult with adolescents and young adults. There are sessions planned on sexuality (guess who’s giving that one?); decision making and choices; death, dying, and the role of palliative care; and family building. I have plans of my own at this conference—aside from giving my very best in my presentations—and that is to meet face-to-face with expert nurse

clinicians and administrators who will be there from the United Kingdom and Australia, to learn from them, to ask their advice about improving the care I provide to adolescents and young adults as a sexuality and fertility preservation counselor, and then to share that information with my oncology colleagues here in North America. I cannot wait.

## References

Katz, A. (2014). *This should not be happening: Young adults with cancer*. Pittsburgh, PA: Oncology Nursing Society.

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