Young-Adult Cancer Survivors Face Unique Challenges

By Mike Fillion

Sixteen years ago, while washing her hair, Anne Willis found a bump on the back of her head. She didn’t think much of it because her parents had a history of sebaceous cysts. Still, she visited her family doctor and dermatologist, who concurred: It was nothing serious.

A few months later, as she prepared to leave the same dermatologist’s office for an unrelated issue, the doctor suddenly called her back. “My hand was literally on the door to leave the office, and he said he wanted to examine the bump on the back of my head,” said Willis. “We were standing in the hallway when he examined me. He became alarmed since the growth was now the size of an egg. He told me I had to get it biopsied, and I did.”

Anne Willis, aged 15 years, was soon diagnosed with Ewing sarcoma. She unwillingly joined an understudied and largely misunderstood group: adolescents and young adults (aged 15–39 years) with cancer, also known as AYAs.

The National Cancer Institute reports that more than 72,000 AYAs are diagnosed with cancer each year in the United States. This is up to seven times more than the number diagnosed under the age of 15 years. The status and prognosis for AYAs as a group is grim at best. “The survival improvement trends for young adults today with cancer portend a worse prognosis than 25 years ago,” said Jennifer S. Ford, Ph.D., at the 2011 Connecticut Survivorship Summit in New Haven. “And this deficit actually seems to be increasing.” Ford is assistant attending psychologist in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan–Kettering Cancer Center in New York.

Cancer survivorship is a topic that clinicians, surgeons, and other medical professionals face every day. Although most hospitals and universities have survivorship symposia and outreach, most are geared toward older people, not young people facing obstacles and challenges as cancer survivors—in addition to the normal growth and maturity issues they confront. “I felt very isolated throughout my experience,” said Willis. “At the children’s hospital where I began treatment, I was the oldest patient and nobody really knew what to do with me. When I moved to the adult oncologist practice, I was the youngest patient and had little in common with the others. I felt completely out of place.”

Experts who study AYAs say that Willis’s experience is all too common. “These are patients who often slip through the cracks once they reach adulthood,” said April L. Barbour, M.D., associate professor of medicine at George Washington University. “They can no longer see their pediatric oncologists for surveillance of late and long-term effects, and adult oncologists often won’t take over their care.”

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Ford said that a growing body of literature looks at the young adult survivor and their particular biomedical and psychosocial needs. For one thing, said Ford, “cancer complicates the life of a [young] person at an age range when his or her life is already in a constant state of flux and already at a heightened vulnerability to stress.”

Part of the difficulty in addressing issues for AYAs is their wide age range. Opinions vary on whether lumping teens in with people in their 30s at time of diagnosis is reasonable. However, although survival rates have improved for older and younger populations since the 1970s—for example, survival for all pediatric cancers combined has improved from 58% in the mid-1970s to 83% today—AYAs have experienced little improvement in survival rates during the same period.

Brad J. Zebrack, Ph.D., associate professor of social work at the University of Michigan in Ann Arbor, who has published many research studies about this age group, said that few empirical studies of cancer patients and survivors have distinguished the particular psychosocial outcomes and service needs of AYAs. He said that during the critical developmental transition from childhood to adulthood, AYAs have the typical concerns of establishing their identity and developing a positive body image and sexual identity, such as independence, dating, career decisions, higher education, and starting a family. At the same time, said Zebrack, most haven’t lived long enough to develop many of the skills needed to deal with having a serious life-threatening condition such as cancer. “Most of them have never been to a funeral, haven’t had enough challenges in their lives to develop coping skills—and then boom, cancer hits.”

Accordingly, cancer-related issues such as facing death so early, changes in physical appearance, increased dependence on parents, treatment schedules, and health-related concerns about the future may frighten them.
To investigate many issues confronting AYAs, the George Washington University Cancer Institute (GWCI) recently held a symposium for researchers, clinicians, caregivers, other health care professionals, and survivors to consider optimal interventions for improving care and support. “We had just launched our multidisciplinary clinic for the transition of adult survivors of pediatric cancer, and we thought it was a good time to investigate gaps in the survivorship field,” said Mandi Pratt-Chapman, M.A., associate director of community programs at GWCI. “The symposium was an opportunity for us to investigate the topics we believed would most benefit the research community and the patient community by bringing members of both communities together.” The study appeared in the February 2013 Journal of Oncology Navigation and Survivorship.

At the end of the symposium, participants listed five key areas to address:

1. Health care delivery system challenges
2. Psychosocial impacts
3. Health maintenance needs
4. Employment issues
5. Community-level barriers

For psychosocial impacts, one important issue Ford hears repeatedly in her own research and clinical practice is the importance of meeting and talking with other AYAs. “We know that peer support among young cancer survivors can improve psychological well-being, decrease distress, decrease anxiety, and improve coping. In fact, in a recent study 96% of young adults ranked opportunities to meet other young adult survivors as a top-five need.”

One person committed to the success of the GWCI initiative is Anne Willis, M.A., coauthor of the paper and director of the Division of Cancer Survivorship program. Overcoming many of the same obstacles that her peers face, she has been cancer free for more than 15 years.

© Oxford University Press 2013. DOI:10.1093/jnci/djt294

TCE, Designated a Known Carcinogen, Now the Focus of Ongoing Research

By Caroline McNeil

Late last year, the International Agency for Research on Cancer (IARC) determined that trichloroethylene (TCE) was carcinogenic to humans, upgrading it from a probable to a known carcinogen.

The U.S. Environmental Protection Agency recently came to the same conclusion. Its evaluation of TCE in 2011 concluded for the first time that TCE was “carcinogenic to humans by all routes of exposure.”

And a third key organization, the National Institutes of Health National Toxicology Program, is evaluating whether TCE should be upgraded from its 2000 designation, reasonably expected to be a human carcinogen, to known human carcinogen.

Coming after decades of study, the three actions could seem a collective milestone for the field. But viewing them as part of a process far from over may be more realistic.

“They are important steps, but steps on a continuum,” said Aaron Blair, Ph.D., a scientist emeritus at the National Cancer Institute, who chaired the IARC committee on TCE. They represent decades of research that established strong links between occupational exposures and kidney cancer and possible links to non-Hodgkin lymphoma (NHL) and liver and other cancers. But much more is left to learn.

Some questions that remain, Blair said, include its links to other cancers, its effects at lower exposures, and the role of gene—environment interactions.

TCE, now used mainly as metal degreaser, was once common in the dry-cleaning industry. TCE use has declined over the past two decades in Europe and the U.S. and has stopped in cosmetics, drugs, food processing, and pesticides. Nonetheless, it is “ubiquitous in atmosphere, soil, ground, surface and drinking water, and food,” according to the National Toxicology Program’s concept paper for TCE, released last August as part of the evaluation process. And its use may be rising in developing countries, according to a 2013 United Nations Environment Programme report.

Other Cancers?

So far, studies have conclusively linked only kidney cancer to TCE via occupational exposures. Other studies have suggested that workplace exposures increase the risk of liver cancer and NHL and, to a lesser extent, cervical and other cancers. But results for these studies have been inconsistent.

One approach to gain more data on other cancers is to pool results of smaller studies. In the June 30 issue of JNCI (June 1 online), Johnni Hansen, Ph.D., of the Danish Cancer Society Research Center in Copenhagen, and colleagues established a pooled cohort—participants from earlier, smaller studies—that included more than 5,500 workers with documented exposure to TCE. After 154,778 person-years of follow-up, the authors found statistically significantly higher rates of liver and cervical cancer, but not of kidney cancer or NHL.

The strong association with liver and cervical cancers and the weaker finding for kidney cancer is the reverse of what many other studies found. Coming so soon after...