NCONN Wrap-Up

By Jason M. Broderick

The December 2010 edition of *OncNurse* highlighted the Second Annual National Coalition of Oncology Nurse Navigators (NCONN) Conference. The NCONN meeting took place on October 8 and 9, 2010, in Branson, Missouri. This month's NCONN Wrap-Up includes features on empowering young adults with cancer and sexual health in patients with cancer. For additional NCONN news and resources, check out their new Website at www.nconn.org.

Matthew Zachary, founder, CEO, I'm Too Young for This! Cancer Foundation

I'm Too Young for This!

Matthew Zachary, musician, brain cancer survivor, and founder of the I'm Too Young For This! Cancer Foundation (i[2]y), energized NCONN attendees with his session on empowering young adults with cancer. Zachary discussed the status of the young adult cancer movement and i[2]y's programs and advocacy efforts.

A TRAGIC LACK OF PROGRESS

The National Cancer Institute (NCI) reports that more than 70,000 adolescents and young adults aged 15-39 years (AYAs) are diagnosed with cancer each year. The cancers most frequently diagnosed in AYAs include lymphoma, leukemia, germ cell tumors (including testicular cancer), melanoma, tumors of the central nervous system, sarcoma, and breast, cervical, liver, thyroid, and colorectal cancers.

While the War on Cancer has significantly improved survival rates in pediatric and adult patients, the rates for AYAs have essentially remained stagnant since 1975. Cancer research and treatment has focused primarily on the much larger pediatric and adult cancer populations (AYAs makeup <10% of all cancer patients) and AYAs have slipped through the cracks.

The NCI has studied the causes and developed potential solutions for AYA cancer disparities. It attributes the lack of progress in AYA cancer rates to

- Limited access to care and insurance coverage
- Delayed diagnosis of primary cancers
- Inadequate treatment practices and settings
- Poor understanding of the biology and etiology distinguishing the cancers in this population
- Inadequate collection of patients and patient data
- Low numbers of clinical trials and poor participation
- Unique psychosocial and supportive care needs
- Inconsistent treatment and follow-up care guidelines
- Limited emphasis on prevention and early detection.

To address AYAs' unique cancer concerns, the NCI collaborated with the Lance Armstrong Foundation on the groundbreaking 2006 report *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer* (http://bit.ly/eoi3GR). The report, along with a 2007 follow-up, *Closing the Gap: A Strategic Plan* (http://bit.ly/ekknw0), provided recommendations for improving outcomes in AYAs across the entire cancer care spectrum, including

- Establish a strong scientific foundation to support the biological differences in tumors found in AYAs
- Leverage completed, ongoing, and new clinical trials to obtain knowledge about cancer in AYAs
- Increase healthcare provider awareness of AYA issues by working with professional societies and advocacy organizations
- Facilitate the development of AYA standards for, and availability of, patient navigators and health coaches.

Zachary faced a much different landscape when he was diagnosed with brain cancer. AYA cancer resources were essentially nonexistent, and the NCI was certainly not focusing on the young adult population.

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NO ROBOTUSSIN FOR BRAIN CANCER

In 1995, Zachary was a college senior and concert pianist. He had been accepted to graduate school and his dream of composing music for film was in reach. At the start of the fall semester, however, his left hand began to lose its dexterity and eventually it lost all fine motor coordination. When he sought help from the campus medical center, his frustrating experience mirrored that of many AYAs.

Young adults frequently endure diagnostic delays because of the population's low incidence rates of cancer. Healthcare professionals will often attribute potential cancer symptoms to fatigue, stress, or other causes. The campus medical center kept telling Zachary that he did not have a serious condition. At one point, they even gave him the cold medicine Robitussin for his symptoms. He now quips that he started i[2]y with the mission statement, "No Robitussin for Brain Cancer."

When he was finally diagnosed with brain cancer in December 1995, Zachary learned he had a congenital medulloblastoma (pediatric brain cancer). This brain tumor is classified as a primitive neuroectodermal tumor (PNET) and originates in the cerebellum, which controls balance and other complex motor functions. Most pediatric medulloblastomas are diagnosed in children aged <10 years, so Zachary's situation was extremely rare.

In January 1996, Zachary had an hour-long craniotomy to remove his tumor, which he described as "the size of a golf ball." He additionally received 33 treatments of craniospinal radiation, but refused the recommended chemotherapy.

Zachary's doctors wanted to give him chemotherapy, but in his view the treatment offered a limited benefit for an unacceptable risk. His physicians told him the chemotherapy would increase his 5-year survival chance by 5% (50% to 55%), but would also increase his risk of developing peripheral neuropathy, a nerve condition that would effectively end his piano playing. Unwilling to give up on his passion, Zachary rejected the chemotherapy and never looked back.

The radiation treatment, however, left Zachary physically and emotionally devastated. At one point, he was taking 17 medications. "I had every [side effect] you could possibly imagine," Zachary said. With the dearth of resources and support groups available to AYA survivors, Zachary was lost and unsure how to move on with his life. "I looked different in the mirror; I was impotent for 2 years; I didn't understand how to talk to people," Zachary said.

Zachary was eventually able to rediscover and redefine himself through his music. He rehabilitated his left hand and performed a concert only 1.5 years after his cancer diagnosis. Starting with that performance, he renamed himself Matthew Zachary (Zachary is his given middle name, not his last name), saying, "I couldn't deal with being myself."

Renaming himself and restarting the piano allowed Zachary to regain control over his life. "I was able to take back what cancer took away. I could own what happened to me because I finally had a legacy—I was able to play piano again." Zachary eventually performed a series of concerts and released several albums. He played 2 songs at NCONN 2010, both of which earned standing ovations.

Now married with twin children, Zachary shares his story to raise awareness of disparities in AYAs with cancer. He started i[2]y to help AYAs avoid the isolation and helplessness of his cancer experience.

I[2]Y

During his treatment, Zachary realized the cancer care system was ill-equipped to address AYAs' unique needs. His pediatric oncologists were used to treating children, so they would speak to his parents instead of him. Additionally, the atmosphere and lack of peer support in the pediatric facility left Zachary feeling extremely isolated. "I [was] in a room with squeaky toys [and] cows on the ceiling—not okay!" Zachary told NCONN attendees.

Zachary founded i[2]y in 2007 to help create a new reality for AYAs with cancer. i[2]y ensures young adults affected by cancer can access the resources and support they need. The progressive enterprise tailors its message, content, and events to the social and cultural values of young adults. Often infusing Zachary's irreverent humor and love of music, i[2]y's catchphrase is "stupid cancer," which Zachary devised by wondering, "What would Homer Simpson say if he were diagnosed with cancer?" To support AYAs, i[2]y provides both offline and online resources.

Offline

Community Organizing

i[2]y hosts community outreach events called "Stupid Cancer Happy Hours" to allow AYAs to have fun with their peers. Past events include film screenings, book signings, tweetups, bowling nights, scavenger hunts, golf outings, bar crawls, weekend retreats, roofdeck parties, wine and cheese events, BBQ fundraisers, and Halloween costume balls.

Stupid Cancer Boot Camps

"Stupid Cancer Boot Camps" are educational workshops that focus on specific issues relevant to AYAs with cancer. The events are often conducted in collaboration with local cancer centers or franchises of national cancer organizations. Previous Boot Camps include Progress/Gaps in Young Adult Biology; Clinical Trials in Young Adults; Social Media and Health Technology Advocacy; Employment, Legal and Disability Rights; Navigating Health Insurance; Fertility, Relationships and Sexuality; and Grassroots Activism and Legislation.

The OMG! Cancer Summit For Young Adults

This international conference brings together AYAs affected by all cancers. The gathering unites >20 advocacy, research, and support groups, and fosters an AYA global support network. NCONN will be speaking at the 4th Annual OMG! Summit (www.omgsummit.org/2011), which will take place in New York City on April 16 and 17, 2011.

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Online

The Stupid Cancer Show

The Stupid Cancer Show is a live talk radio Webcast that gives a voice to the young adult cancer movement. Zachary co-hosts the program with young adult cancer survivor Lisa Bernhard, i[2]y's vice president of Marketing and Media Development, and formerly an Entertainment Correspondent for FOX News and Deputy Editor of *TV Guide*. New episodes air live on Mondays at 8 pm Eastern Standard Time.

The show covers cancer issues related to multiple topics, including politics, healthcare, the environment, social media, entertainment, and education. Some of the previous episode titles were "Breast Cancer and the Environment," "Stupid Lung Cancer," "Advocacy Innovation," and "Showtime's *The Big C*." NCONN's president, Sharon Francz, and vice president, Rebecca Trupp, were guests on *The Stupid Cancer Show*'s November 1, 2010, episode, entitled, "Insurance and Navigation." This broadcast and all other previous shows can be downloaded on the program's Website (www.stupidcancershow.com).

Website

i[2]y's Website aggregates the available resources for AYAs and provides an online support network. The "How Can We Help You" directory on the home page provides links to resources offering social, financial, legal, and employment support. The ongoing conversations in "The Stupid Cancer Forums" allow AYAs to communicate and support each other. "The Stupid Cancer Blog" provides continuous updates of the young adult cancer movement. The site's "Get Involved" section allows AYAs to start participating in i[2]y through a mailing list, Facebook, Twitter, iTunes podcasts, wristbands, local i[2]y chapters, and more.

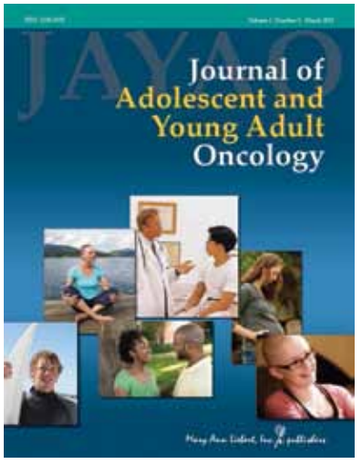
STUPID SUCCESS

Despite its brief existence, i[2]y already boasts an impressive list of achievements:

- Shortly after its 2007 launch, *Time* magazine named i[2]y's site one of the "50 Best Websites"
- i[2]y will soon have >10,000 Facebook friends
- *The Stupid Cancer Show* has >500,000 listeners
- Fox News named i[2]y's The Stupid Cancer Blog one of the "Best Health Blogs of 2010"
- Actor Zac Effron has become a spokesperson for i[2]y.

Beyond its own success story, i[2]y's advocacy has contributed to tremendous advances for young adults with cancer:

- *The Journal of Adolescent and Young Adult Oncology* (*JAYAO*) (www.liebertpub.com/jayao) is launching this spring. This groundbreaking publication will foster interdisciplinary collaboration on research and education in AYA oncology. *JAYAO*'s editor-in-chief, Leonard S. Sender, MD, is also the chairman of the board of directors of i[2]y. The journal's content will include original peer-reviewed articles, review articles, highlights of clinical trials relevant to AYAs, case studies with AYA-impact enhancement, advocacy group spotlights, pharmacology highlights, editorials and perspectives, provocative roundtable discussions, and news bites.



- i[2]y is working to create a continuing medical education program in AYA oncology that would be institutionalized through the NCI
- Support is growing for the young adult cancer clinic model, whereby in addition to pediatric and adult cancer hospitals, there would also be AYA hospitals
- The International Charter of Rights for Young People With Cancer (www.cancercharter.org) is a patients' bill of rights for young adults with cancer. The Charter hopes to establish an international standard of cancer care for AYAs. You can sign the charter on the organization's Website.
- The Leukemia and Lymphoma Society (www.leukemia-lymphoma.org) now offers a non–disease specific young adult support platform
- Advances in genomics and stem cell research are exploring the contribution of biological factors to the outcome differentials in the AYA versus the pediatric and adult populations. The young adult cancer movement supports increased tumor banking to support research in these fields.

HOW CAN NAVIGATORS HELP?

Zachary's discussion on epowering AYAs with cancer illustrated a clear role for nurse navigators. "Navigation is the cure for Robotussin for brain cancer," Zachary joked. He meant that navigators are on the frontlines and can increase education and awareness of cancer in young adults. They can help ensure that cancer is never overlooked as a possible diagnosis.

Beyond strictly medical care, navigators can also address the tremendous psychosocial issues that plague the AYA cancer population. "Young adults have issues that suck when you don't have cancer—dating, fertility, sexuality, intimacy, relationships, insurance, [and] careers…Slap cancer [onto] that and you've got a real nightmare," said Zachary. Either through direct aid or referrals, navigators can connect AYA patients to the support and services they need.

NO YOUNG ADULT LEFT BEHIND

As Matthew Zachary might say, the situation for AYAs with cancer is still, "Not OK." Despite some improvements, AYAs still face disparities in survival rates and cancer treatment. Eliminating these disparities will require a comprehensive effort from the oncology community. For its part, i[2]y will continue to ensure no young adult is left behind to fight "stupid cancer" alone.

NCONN Wrap-Up

Sexual Health & Cancer

Michael Krychman, MD, FACOG, executive director, Southern California Center for Sexual Health and Survivorship Medicine

The National Cancer Institute (NCI) estimates that sexual dysfunction rates among cancer survivors range anywhere between 40% and 100%. Survivors of both sexes often experience a loss of desire and the inability to reach orgasm. Females also report dyspareunia (pain with intercourse) and a loss or change in genital sensation, while men suffer from erectile dysfunction, anejaculation (absence of ejaculation), and retrograde ejaculation (ejaculation going backward into the bladder).

Sexual dysfunction stems from both physiological and psychological causes, so treatment requires a comprehensive approach. Additionally, sexual problems often last much longer than other side effects of cancer treatment, so sexual health remains an issue well into survivorship.

Michael Krychman, MD, medical director of Sexual Medicine at Hoag Memorial Presbyterian Hospital, and executive director, Southern California Center for Sexual Health and Survivorship Medicine, discussed sexual dysfunction at NCONN 2010. Although Krychman's information pertained to breast cancer, he said his message applied to all patients with cancer.

BREAST CANCER AND SEXUAL DYSFUNCTION

The NCI estimates that 50% to 90% of breast cancer survivors have some form of sexual issue. Some of the more upsetting comments Krychman has heard from his patients include, "Yes, I'm thankful to be alive, but I am dead down there," and "They never told me I would feel like this." In his presentation, Krychman addressed some of the causes and treatments of sexual dysfunction in breast cancer survivors.

Breast Cancer Treatments and Sexual Health

Surgery

Krychman said that despite treatment advances that preserve more of the breast, surgical intervention still affects sexual functioning. Evidence from several reviews suggests that breast conservation or reconstruction does not greatly impact preservation of sexual function versus mastectomy. "We would assume that those having breast conservation [surgery] do better sexually than those that have a mastectomy, but that is not necessarily the case," said Krychman. Although those receiving conservative operations are more likely to enjoy breast caressing, the two groups do not differ on issues such as coital frequency, ease of orgasm, and overall sexual satisfaction.

Radiation

Side effects of radiation treatment that can cause sexual dysfunction include volume loss, retraction, fatigue, dryness of skin and erythema, loss of normal sensation, discoloration, skin thickening and fibrosis, lymphedema exacerbation, range of motion difficulties, and alopecia. Krychman also mentioned that some patients and their partners still mistakenly believe the patient becomes radioactive and that intimacy could cause radiation poisoning.

Chemotherapy

Krychman listed several side effects of chemotherapy that can disrupt sexual functioning, including premature ovarian failure, amenorrhea, menopausal syndrome, bone marrow suppression, mucus membrane irritation, neurological changes, vaginal muscosal erythrodysesthesia, alopecia (public and private), weight changes, nausea/vomiting, diarrhea/stomatitis, and fatigue. Chemotherapy can also induce a flare-up in patients with genital herpes or genital warts.

Hormone Therapy

According to the NCI's Website, research suggests the antiestrogen tamoxifen may reduce sexual desire and the ability to reach orgasm. Also, treatment with aromatase inhibitors may cause vaginal dryness and dyspareunia.

Treating Sexual Dysfunction

Comprehensive Wellness Centers

Comprehensive wellness facilities such as Dr Krychman's Southern California Center for Sexual Health and Survivorship Medicine (thesexualhealthcenter.com) offer sexual medicine and counseling to cover both physiological and psychological concerns. Patients with cancer often struggle to find an outlet for their sexual issues, and these centers provide access to the proper treatments while maintaining complete discretion.

Hormone Therapy

Due to the uncertainties and disagreements surrounding hormone therapy, Krychman discussed hormonal treatment for sexual dysfunction within the context of individual risk assessment. Personalized cancer treatment has been the longtime goal in oncology, and Krychman stressed that sexual dysfunction issues require the same approach. Manipulating hormone levels may be too risky in one individual but exactly the right treatment in another.

Krychman cited data demonstrating that several common therapies are used to treat other medical issues despite presenting their own set of risks. For example, beta-carotene therapy, calcium CHD supplements, and aspirin, can increase the risk of lung cancer, stroke, and GI bleeding, respectively. Likewise, the risk of using a hormonal treatment for sexual dysfunction may be worthwhile for specific patients.

Low Dose Vaginal Estrogen Treatment

Minimally absorbed local vaginal estrogen products such as Estring (estradiol vaginal ring), Vagifem (a vaginal estradiol tablet), and Premarin Vaginal Cream (an estrogen mixture) raise estrogen levels, which could enhance sexual function and desire in patients with breast cancer, said Krychman. He sited a small, 7-patient study of Vagifem by Kendall et al to suggest treatments can increase estrogen levels. The study concluded Vagifem, at least in the short term, "reverses the estradiol suppression achieved by aromatase inhibitors in women with breast cancer and is contraindicated."

Krychman said, "Surgical oncologists, medical oncologists, gynecologists, and patients will often

Chris Schmelke

disagree about [the] safety [of estrogen therapy]." When he discussed Kendall et al's study at ASCO shortly after its release, about half the medical oncologists in the audience strongly objected to any estrogen use.

Again, Krychman stressed the importance of individual risk assessment. While some women's estrogen levels may skyrocket, others could experience increased sexual function with manageable estrogen levels. When using estrogen treatment, Krychman recommends implementing a management plan that includes closely monitoring estradiol levels and any abnormal bleeding.

Testosterone

Although some studies such as Barton and colleagues 2007 research suggest testosterone therapy has no impact on sexual dysfunction, others suggest the treatment may help some patients. The long-term safety effects of testosterone treatment are unknown, so personalized risk assessment, as with all hormonal treatments, is Krychman's recommended approach. He currently sees 50 mostly late-stage patients with breast cancer who are taking testosterone. Thus far, their hormone levels have remained at acceptable levels.

Hormones Are Not the 'Be-All and End-All'

At the end of his segment on hormone therapies, Krychman concluded, "Women are not ruled sexually by hormones." He sees women who have no estrogen or testosterone and they have functioning, satisfying sex lives, while others with normal hormone levels experience sexual dysfunction. Sexual issues often stem from emotional or social issues unrelated to hormones, and resolving these issues is the key to treating some patients.

Psychological Issues and Behavior Modification

The effects of cancer treatment can greatly damage a woman's sexual self-esteem—her image of herself as a sexy, desirable woman. The process can also induce depression, anxiety, and stress that reduce the desire for intimacy. Treatment and counseling can help patients manage the psychological issues affecting their sexual health.

Sexual issues can also arise from simply not making sex a big enough priority. "Often the patient will say, 'I'm consumed with cancer. I'm consumed with appointments—I'm going from one appointment to the next,'" Krychman said. Reprioritizing and modifying behavior patterns will help patients make time for intimacy.

Buproprion Therapy

Depression and low sexual function often overlap, and Krychman said buproprion (Wellbutrin) may address both symptoms. Buproprion is a norepinephrine and dopamine uptake inhibitor that is not associated with the sexual side effects of other antidepressants, such as selective serotonin reuptake inhibitors (SSRIs). In addition to boosting a patient's mood, buproprion may improve libido. Krychman noted that treating sexual dysfunction with buproprion is an off-label use.

Complementary Therapy

Complementary therapies such as acupuncture and yoga are often prescribed to individuals with sexual dysfunction. Patients with cancer may find them useful in alleviating the pain, stress, depression, and/or anxiety that is affecting their sexual health.

Self-Stimulation

Krychman discussed mechanical products (dilators, vibrators) and fluids that women can use to help rehabilitate their sexual desire and functioning. The self-help tools are highly individualized, both in comfort level and effectiveness. Insurance may cover some of the items. Comprehensive Wellness Centers can help patients obtain these products with maximum discretion, Krychman said.

HOW CAN NURSE NAVIGATORS HELP?

Although cancer treatment has come a long way, patient and physician discomfort and misinformation still lead to a suppression of sexual problems. A survey by Marwick published in the *Journal of the American Medical Association* (1999;281:2173-2174) found that while 85% of adults want to discuss sexual functioning with their physician, 71% believe their physician lacks the desire and time to discuss sexual issues, 68% worry they would embarrass their physician, and 76% feel treatments do not exist for their sexual dysfunction.

Krychman sees a tremendous opportunity for oncology nurse navigators (ONNs) to bridge this communication gap and help patients overcome these obstacles. "As frontline providers, [you] have to start the dialogue because a majority of physicians will not talk about it," Krychman told NCONN attendees.

When broaching the topic with patients, ONNs should remain sensitive to the various factors that contribute to a patient's sexuality, including age, gender, sexual orientation, personal attitudes, and religious and cultural values. Krychman also said ONNs can be direct when initiating the conversation, saying something to the effect of, "It's important to take care of you as a complete person, I'm going to ask you some questions about sexual function."

The bottom line is that sexual health is a major quality of life component in patients with cancer. Through mindfulness, screening, education, and follow-up, ONNs can ensure their patients receive the comprehensive treatment they need. **Onc**