

Notes on Survivor Forum: *Addressing Long-Term Side Effects After Treatment for Anal Cancer*
Held on October 9, 2013

On October 9, the HPV and Anal Cancer Foundation partnered with Memorial Sloan Kettering Cancer Center (MSKCC) to hold the first forum for survivors on long-term effects of anal cancer treatment, called Addressing Long-Term Side Effects After Treatment for Anal Cancer.

Many survivors traveled great distances to attend – a true testament to the power and resilience of this community! For the majority of survivors, it was the first time they had ever met a fellow anal cancer survivor! It was wonderful to meet so many anal cancer survivors and hear their stories.

The evening started with an opening talk by Dr. Karyn Goodman, Associate Attending in the Radiation Oncology Department at MSKCC, who gave an overview of the long-term effects of anal cancer treatment.

Dr. Goodman was followed by Dr. Jeanne Carter, Head of Female Sexual Medicine and Women's Health programs at MSKCC, who discussed strategies for managing changes in sexual function after pelvic radiation.

Justine Almada, Co-Founder and Executive Director of the Foundation, spoke about the stigma, the courage of the attendees and tools to bring the anal cancer community together.

Survivor panelists also spoke and gave impassioned accounts of their experiences with the challenges of life after treatment for anal cancer. The panel was followed by a Question and Answer Session.

We've posted documents and notes from the evening for the benefit of all survivors who could not attend in the October 16, 2013 blog post available at www.analcancerfoundation.org. Dr. Goodman and Dr. Carter were generous enough to share the slides they presented that evening. These are the notes taken during the event to accompany the doctors' slides.

Please note these are documents to inform the community about what occurred at the forum, and are not recommendations by the Foundation or Memorial Sloan Kettering Cancer Center. Always consult your medical team before making any medical decisions.

Dr. Karyn Goodman
Associate Attending in the Radiation Oncology Department
Memorial Sloan Kettering Cancer Center

Download accompanying powerpoint slides presented by Dr. Goodman, available in the blog post dated October 16, 2013 at www.analcancerfoundation.org.

Slides 2-4: The different treatment approaches to anal cancer diagnosis, including surgery and the chemoradiation Nigro Protocol first used in 1973.

Slide 5: Anal cancer incidence is rising.

Slide 6: TN category of disease impact on anal cancer patients.

Slide 7: The name and groups of patients in a study that evaluated patterns and predictors of locoregional failure after conventional radiation to better define the clinical target volume for Intensity-Modulated Radiation Therapy (IMRT), a type of radiation that is also used to treat anal cancer patients.

Slide 8-9: The results of a study that compared outcomes for conventional radiation therapy with IMRT in anal cancer patients.

Slide 10: The results of a study that assessed 5-fluorouracil and mitomycin-C and dose-painted IMRT vs. 5-fluorouracil and mitomycin-C conventional radiation in reducing grade 2+ combined acute gastrointestinal and genitourinary adverse events.

Slide 11: Two studies of chemoradiation regimens that are different from the 5FU/Mitomycin-C/Radiation Therapy combination. Each study combined radiation therapy with chemotherapy and evaluated the results. One study included chemotherapies capecitabine and mitomycin-C. The second study included chemotherapies capecitabine and oxaliplatin.

Slide 12: MSKCC approach to chemoradiation for anal cancer. Goodman: IMRT is able to reduce side effects. 5FU is now in pill form.

Slide 13-14: General radiation therapy toxicity and side effects, which include diarrhea, rectal pain, urgency, pain with urination, inflammation of small bowel, which affect the patient's quality of life long-term.

Slide 15-18: Focus on one long-term effect of radiation, enteropathy, which is indirect injury to the intestines after radiation, and its symptoms, risk factors, and recommendations to help alleviate it.

Slide 19-20: Focus on one long-term side effect of radiation, bone density, and recommendations to help.

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Slide 21: One long-term effect of radiation, sexual dysfunction, affects both men and women.

Slide 22-23: Focus on one long-term side effect of radiation, vaginal stenosis. There is a need for more research. Dilators have been recommended to reduce stenosis, however, dilators generally have low compliance rates.

Slide 24- 26: A study's objectives and methods to determine the effectiveness of vaginal dilators. The results showed that younger age, higher educational level, sexual activity at baseline, use of vaginal moisturizers, and higher compliance with vaginal dilator use were associated with returning to pre-radiation-therapy vaginal size after a year.

Slide 27: New Directions

Slide 28-31: A discussion of the factors, including proteins and immune system, that play a role in HPV becoming cancer. Proteins in human papillomavirus called E6 and E7 are a factor in our normal, healthy cells becoming cancerous. Prophylactic vaccines, vaccines that prevent infection with HPV like Gardasil and [Cervarix], have successfully prevented infection that could lead to cancer. However, there are no approved therapeutic vaccines that would treat the cancer once it exists. There are currently potential therapeutic vaccines in the early stages of study.

Slide 32: Conclusions.

Dr. Jeanne Carter
Head of Female Sexual Medicine and Women's Health Programs
Memorial Sloan Kettering Cancer Center

Download accompanying powerpoint slides presented by Dr. Carter, available in the blog post dated October 16, 2013 at www.analcancerfoundation.org.

Slides 1-3: Discussion of the increasing number of cancer survivors and those diagnosed with anal cancer. Because the population of survivors is expanding, it is becoming more important than ever to address quality of life (QOL) concerns. More specifically, with the growing number of people diagnosed with anal cancer, clinicians and professionals need to consider the specific changes in QOL to this segment of the survivor population. Also, noted is the change in treatment trends for anal cancer from 1960 to today.

Slides 4-6: A European study that looked directly at QOL of anal cancer survivors identified the long-term side effects that result from treatment. The findings highlight the importance of diminishing the negative effects of these changes.

Slides 7: Outlines resources available at Memorial Sloan Kettering Cancer Center (MSKCC).

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Slides 8-9: There are side effects from anal cancer treatments that directly impact male sexual function. These challenges can be mitigated through interventions such as physical therapies available at MSKCC. MSKCC Male Sexual and Reproductive Medicine Program staff list.

Slide 10: MSKCC Center for Rehabilitation Information.

Slide 11: Female Sexual Medicine and Women's Health Program staff list.

Slides 12-13: Referral trends surveyed pertaining to female sexual side effects after treatment for cancer. Some women experience more than one of these side effects. Slide 13 points out that the majority of women treated for cancer experience negative or worsened changes to sexual function after treatment for cancer.

Slide 14: Women were surveyed and the majority of women treated for cancer were "somewhat to very concerned" about sexual/vaginal health regardless of cancer type and whether or not they were seeking treatment at the Female Sexual Medicine and Women's Health department at MSKCC.

Slide 15: All women with a history of anal cancer that were seen at the Female Sexual Medicine and Women's Health Program reported being "somewhat to very concerned" about their vagina/sexual health. More than half of women indicated that they were not confident about future sexual activity.

Slides 16-17: Presents demographic characteristics and referral reasons for anal cancer patients seen in the Female Sexual Medicine Program. Only 16% of women were engaging in sexual activity at the time of seeking treatment at the Female Sexual Medicine and Women's Health Program. Dr. Carter articulated that this is problematic as humans have a desire to be physically close and strategies need to be developed to reduce barriers to intimacy.

Slides 18-22: Strategies for increasing vaginal and sexual health after treatment for cancer. It is important to understand the difference between vaginal moisturizers and lubricants. Moisturizers provide a longer-lasting benefit by hydrating the vaginal tissue over time, while lubricants are used to supplement the lubrication response and make sexual activity more comfortable. She addressed the significance of pelvic floor exercises and compliance with the use of dilators. Dr. Carter noted that dilators that are solid are preferable for uniformity in stretching the tissues and targeted strategies. She also spoke of "the sacred plane" (perianal area) for anal cancer patients/survivors and that this region also requires attention with moisturizers.

Slides 23-24: Review of goals and key strategies for sexual rehabilitation.

Slides 25-28: Communication is important in establishing a greater understanding of one's sexual functioning and goals after treatment for cancer. Lack of communication between survivors/partners and survivors/practitioners can create more obstacles in the rehabilitation process. Important to enhance communication in the medical setting and with partners.

Slides 29-32: Points to remember and resources for managing sexual health changes after treatment for cancer. Resources are available nationwide.

Justine Almada
Co-Founder and Executive Director
The HPV and Anal Cancer Foundation

Justine addressed the stigma and misinformation associated with anal cancer. She spoke about her mother's experience with anal cancer, and how her family learned how few resources were available to anal cancer patients. Justine, her brother Tristan, and sister Camille committed to changing that dynamic by starting the HPV and Anal Cancer Foundation in 2010 after their mom passed away.

When Justine asked how many people were meeting an anal cancer patient for the first time that night, the majority of people raised their hands. She spoke about ways to connect – in the winter the organization is launching a Peer Support Program to match survivors with each other. The Foundation is looking for people to participate in the program as either mentors (to the newly diagnosed or people in or post-treatment) or peers (survivors who could use the support of a mentor). To sign up, email info@analcancerfoundation.org. Justine also noted the green and purple colors for anal cancer that many people were wearing.

Justine discussed an important step for improving diagnosis and treatment in the anal cancer community – connecting the doctors with each other. The Foundation is working to achieve this through the medical society the Foundation co-founded and the upcoming first ever scientific conference on anal cancer in November 2013. Please send doctors that should be informed about this network to the Foundation.

Justine and her siblings see a better scientific and medical infrastructure in the future that will develop less painful treatments, diagnose the disease in its precancerous stages and prevent it altogether. By working with each other and the doctors that support the anal cancer community, the co-founders believe we can end anal cancer for future generations and mitigate the emotional and physical side effects for current patients.

Survivors Panel

Survivors Dr. Judy Logue and others described their personal experiences with anal cancer and treatment. They discussed their fears during treatment, coping strategies, pain management and desire to live every day post-treatment to its fullest!

Q&A

During the Q&A, members from the audience asked questions of the panelists. The answers below are from the doctors and survivors on the panel.

Q: I did not know that they made vaginal dilators. Could this work for the anus?

A: Yes, there are anal dilators. Use the same moisturizers in the anal area as suggested for the vagina.

Q: Am I susceptible to other HPV cancers?

A: Your cells have changed because of one HPV. (HPV can also cause cervical cancer, head and neck cancer, vulvar cancer, vaginal cancer and penile cancer.) Recommend getting screened regularly.

Q: If we have HPV, can we transmit it to other areas, like from the vagina to the anus?

A: HPV travels along the mucosa even if no anal sex.

Q: What should I tell my partner if I have anal cancer caused by HPV?

A: HPV is very prevalent. Protect yourself in future interactions.

Q: Is there a connection between herpes & HPV?

A: No connection between herpes and HPV except that they are sexually transmitted viruses.

Q: How did patients get over PTSD and anger?

A: Survivors:

- Put emotions in internal box
- Psychological stress with waiting

Q: I'm still coming to terms with what's happening? My primary relationships want me to get over it?

A: - Hears from patients: "I didn't know survivorship could be this tough"

- Cancer diagnosis brings uncertainty
- Let people know what you're thinking
- Connect with others that understand