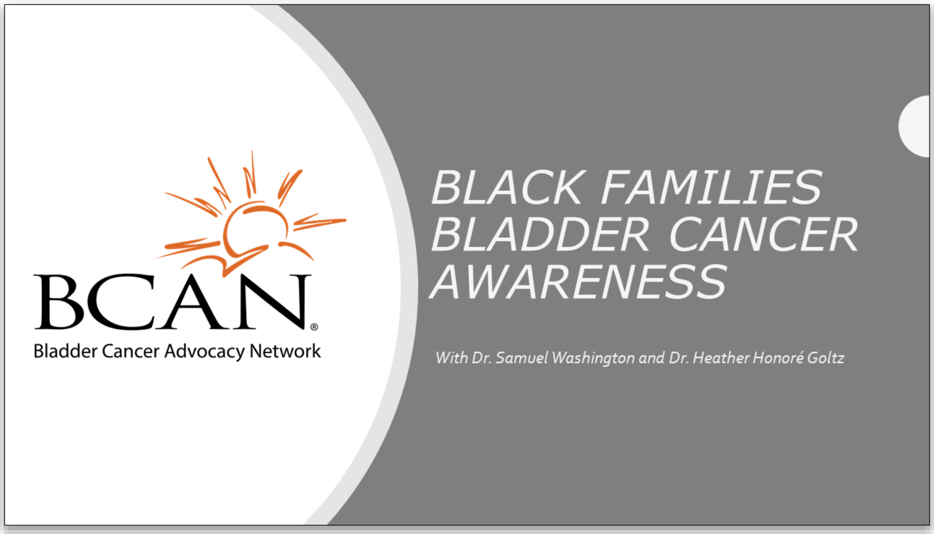

BCAN
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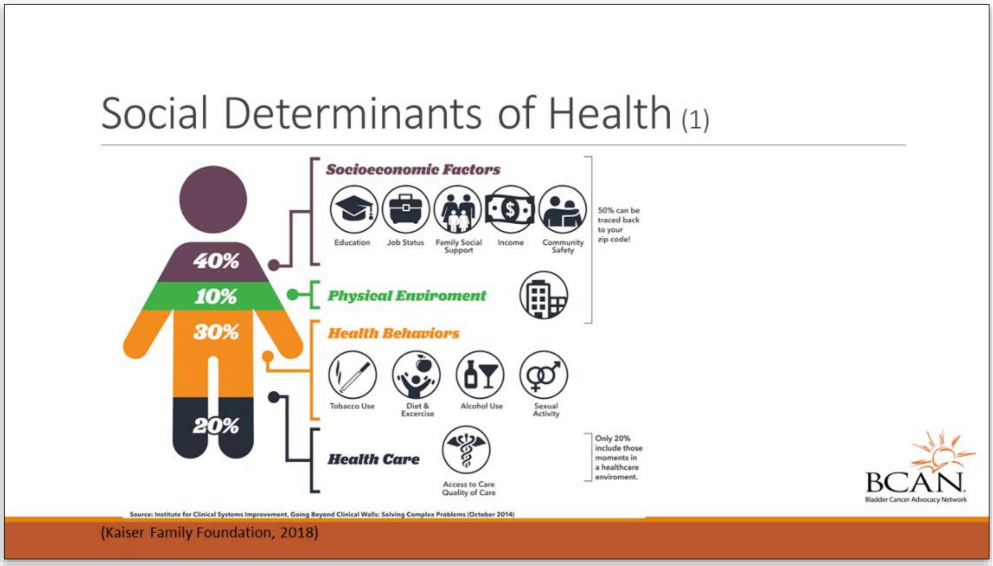
BLACK FAMILIES
BLADDER CANCER
AWARENESS

With Dr. Samuel Washington and Dr. Heather Honoré Goltz

How Environmental and Social Affect Black Bladder Cancer Patients

Dr. Heather Honoré Goltz: Okay. Thank you very much Dr. Washington for providing the background and some of the information that really lends itself well into the beginning of my portion of the talk, which is to help explain in terms of social determinants of health, how some of these disparities come about, how they may lead to differences in symptomology among bladder cancer patients and what we might be able to do about that.

I'll start with talking a bit about this concept called social determinants of health. I appreciate that. social determinants of health are really those aspects of life in our environment where we live, work, play, worship, grow, we were born, we age, we grow old and die that really determined how we age in place the quality of our health, the quality of life.



Social Determinants of Health (1)

50% can be traced back to your zip code!

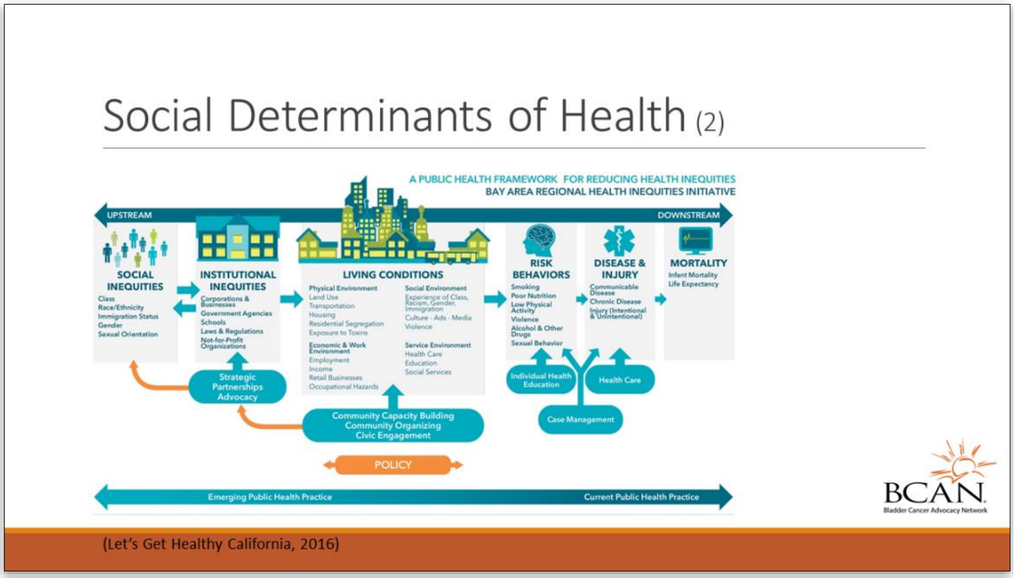
Only 20% include those moments in a healthcare enviroment.

Source: Institute for Clinical Systems Improvement, Going Beyond Clinical Walls: Solving Complex Problems (October 2014)

(Kaiser Family Foundation, 2018)

You can see from this slide that contrary to popular belief, personal behavior is only one component of health outcomes and quality of those outcomes. You see that roughly 20% of these social determinants of health are related to health care, access to health quality of care, but socioeconomic status and the physical environment in which we live, work, learn, play, et cetera, those combined with the physical environment take up 50%. They are responsible for 50% roughly of our health outcomes. This is really an important thing to note in contrast with what we think of as personal or individual health behaviors.

Now, I love this graph because this takes that previous slide and really helps us understand more so than ever before in our history, what it means to be healthy and what influences our health in general. You notice that social inequities, racism, class, all of these pieces really feed into institutional inequities and institutional inequities, sometimes you may hear them called structural racism, actually influence health as well and our living conditions.



Social Determinants of Health (2)

A PUBLIC HEALTH FRAMEWORK FOR REDUCING HEALTH INEQUITIES
BAY AREA REGIONAL HEALTH INEQUITIES INITIATIVE

UPSTREAM
DOWNSTREAM

SOCIAL INEQUITIES
Class
Race/Ethnicity
Immigration Status
Gender
Sexual Orientation

INSTITUTIONAL INEQUITIES
Corporations & Businesses
Government Agencies
Schools
Laws & Regulations
Not-for-Profit Organizations

LIVING CONDITIONS
Physical Environment
Land Use
Transportation
Housing
Residential Segregation
Exposure to Toxins
Economic & Work Environment
Employment
Income
Retail Businesses
Occupational Hazards
Social Environment
Experience of Class, Racism, Gender, Immigration
Culture - Ads - Media
Violence
Service Environment
Health Care
Education
Social Services

RISK BEHAVIORS
Smoking
Poor Nutrition
Low Physical Activity
Violence
Alcohol & Other Drugs
Sexual Behavior

DISEASE & INJURY
Communicable Disease
Chronic Disease
Injury (Intentional & Unintentional)

MORTALITY
Infant Mortality
Life Expectancy

Strategic Partnerships Advocacy
Community Capacity Building
Community Organizing
Civic Engagement
Individual Health Education
Health Care
Case Management
POLICY
Emerging Public Health Practice
Current Public Health Practice

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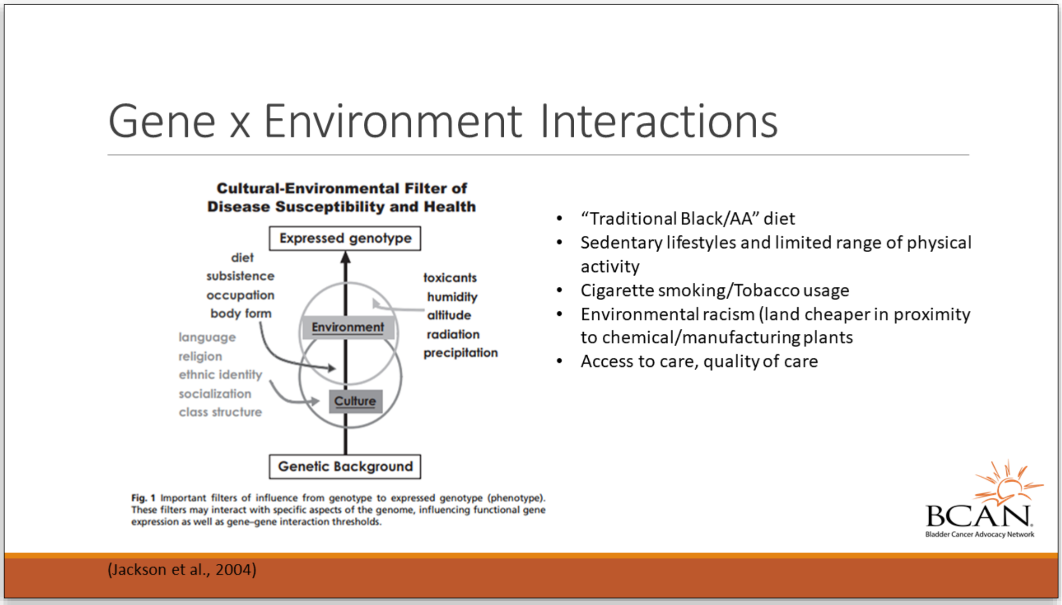
(Let's Get Healthy California, 2016)

So when you take a child, a young Black child, where they live, their socioeconomic status of their family, their access to education, all of these things influence eventually what kinds of work opportunities they may have. Work influences what kinds of insurances we may be eligible for or access or not, and how that then can play into what kinds of health care and the quality thereof that we can access.

Our personal behaviors then are influenced by where we live both as a child and as we grow and mature and age. And that then has an impact, especially when we're diagnosed with bladder cancer. Well, let me back up and say, it has a very impact on when and how we're diagnosed with bladder cancer, and then how we access quality guidelines-based treatments that then can really impact our morbidity, which is our changes in physical status and potential injuries and side effects, and then our mortality, which is our length of time that we made live post-diagnosis.



Gene x Environment Interactions

Cultural-Environmental Filter of Disease Susceptibility and Health

Expressed genotype
diet
subsistence
occupation
body form
language
religion
ethnic identity
socialization
class structure
toxicants
humidity
altitude
radiation
precipitation
Environment
Culture
Genetic Background

Fig. 1 Important filters of influence from genotype to expressed genotype (phenotype). These filters may interact with specific aspects of the genome, influencing functional gene expression as well as gene–gene interaction thresholds.

- "Traditional Black/AA" diet
- Sedentary lifestyles and limited range of physical activity
- Cigarette smoking/Tobacco usage
- Environmental racism (land cheaper in proximity to chemical/manufacturing plants
- Access to care, quality of care

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(Jackson et al., 2004)

I want to take a moment just to talk about gene by environment interactions. We did pre-webinar have a question about genetics. Broadly considered, bladder cancer is not considered a hereditary disease. Only less than 10% of bladder cancers that we are aware of are linked to some type of familial genetic link. However, going back to those social determinants of health, we begin to see how our genetic background or genotype can interact with the environment that we're born into, that we're raised and live our lives and age in.

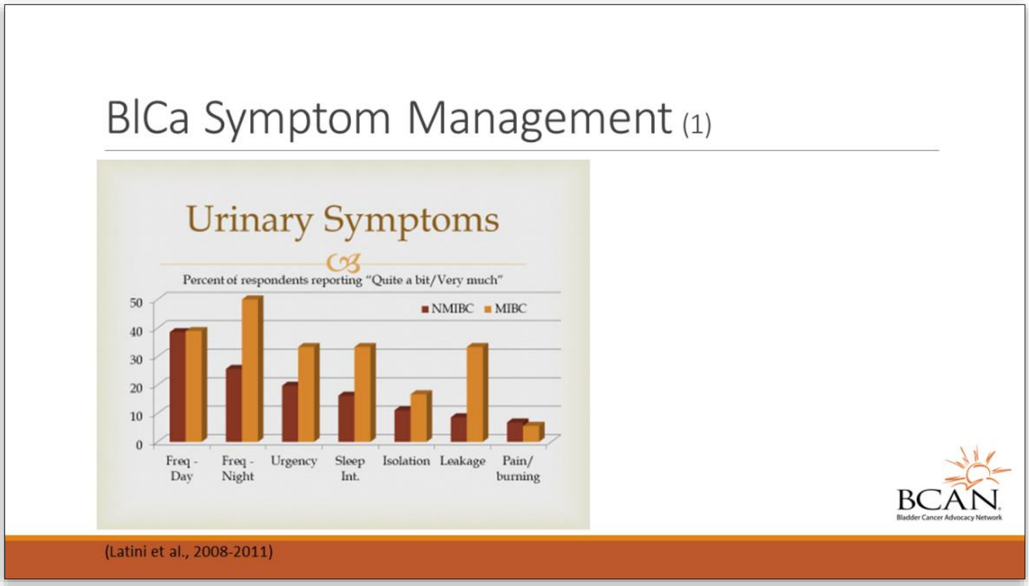
And that can also influence how our genetics, our genotype are expressed, which we also refer to as phenotype. We can see how things like radiation precipitation in the case of bladder cancer, exposure to arsenic or agent orange, agent orange recently being acknowledged. Our diet, our physical activity, our proximity to toxic waste or Superfund sites can influence our genetics and whether we will express the type of genotype that might lead to an eventual bladder cancer diagnosis.

So while not genetic, as in hereditary from our family line, we can accumulate mutations from our environment that may lead to a bladder cancer diagnosis. This is why things such as our diet, and diets that may be higher in fat or carbs, diets that make us overweight or perhaps obese, sedentary lifestyles that on one level may seem like personal choices and behaviors. But if you live in an environment where there are no sidewalks or there's heavy environmental pollution that might make it difficult to breathe, are you going to go outside? Are you going to exercise? Perhaps not.

Cigarette smoking, tobacco usage also can play into manifestations of bladder cancer. Environmental racism, the land that is closer to Superfund sites and manufacturing and chemical and petroleum manufacturing plants is very cheap. And so these plants are often placed in closer proximity to areas where low and limited income families live. Often these families are Black families. I see this a lot back home in Southern Louisiana.

So all of these things feed into whether we are exposed from cradle to grave with potential pollutants and other factors that may lead to individual cancer diagnosis, and specifically, perhaps a bladder cancer diagnosis. Other social determinants, with our socioeconomic status, again, what can we access from work? Do we have jobs that are eligible for benefits? These can influence whether we have access to quality health care guidelines-based treatments, et cetera.

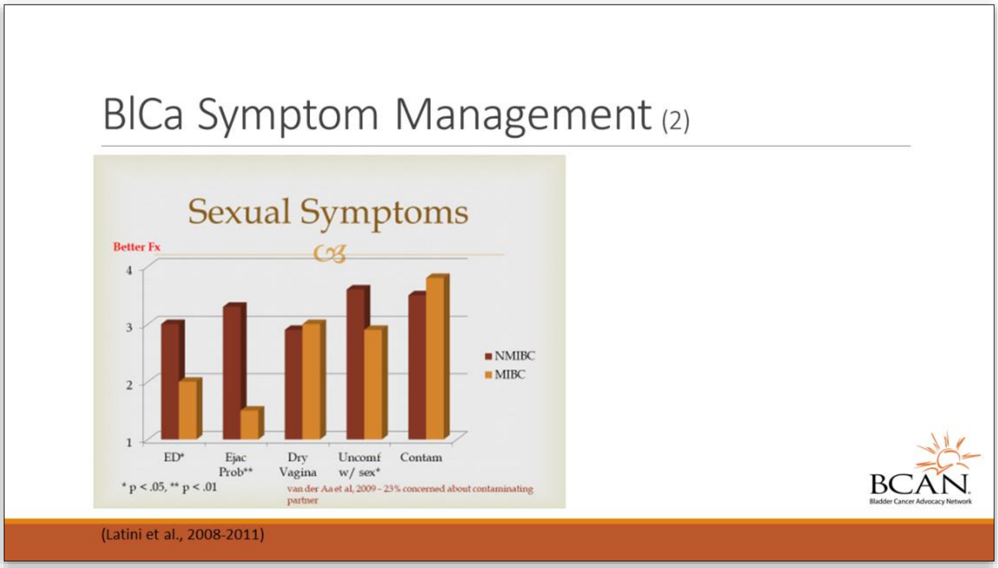
I want to talk a little bit about some things we found over time in terms of once people are diagnosed with bladder cancer. And we've done some studies with non-muscle invasive bladder cancer and also muscle-invasive bladder cancer related to symptom management quality of life. And what we found is that often what one would expect in urology settings and with urology patients, which is those patients who are diagnosed with muscle-invasive bladder cancer in terms of urinary symptoms often report at a higher level that they are quite a bit or very much impacted by especially frequency of your



BlCa Symptom Management (1)

(Latini et al., 2008-2011)

urination at night, the feelings of urgency, sleep interruptions, feelings of isolation, because of need to frequently urinate or empty pouches or et cetera. Leakage from pouches or even perhaps neobladder.



BlCa Symptom Management (2)

Sexual Symptoms

* p < .05, ** p < .01

van der Aa et al, 2009 - 23% concerned about contaminating partner

(Latini et al., 2008-2011)

What we'll see in terms of sexual functioning from some of our participants in the past, however, is that non-muscle invasive bladder cancer patients, at least in the studies that we've performed are actually reporting better functioning, those who have muscle-invasive bladder cancer reporting worse functioning. So again, while we think of non-muscle invasive bladder cancer often as something where folks may have fewer symptoms and fewer symptoms to manage, they're still being impacted.

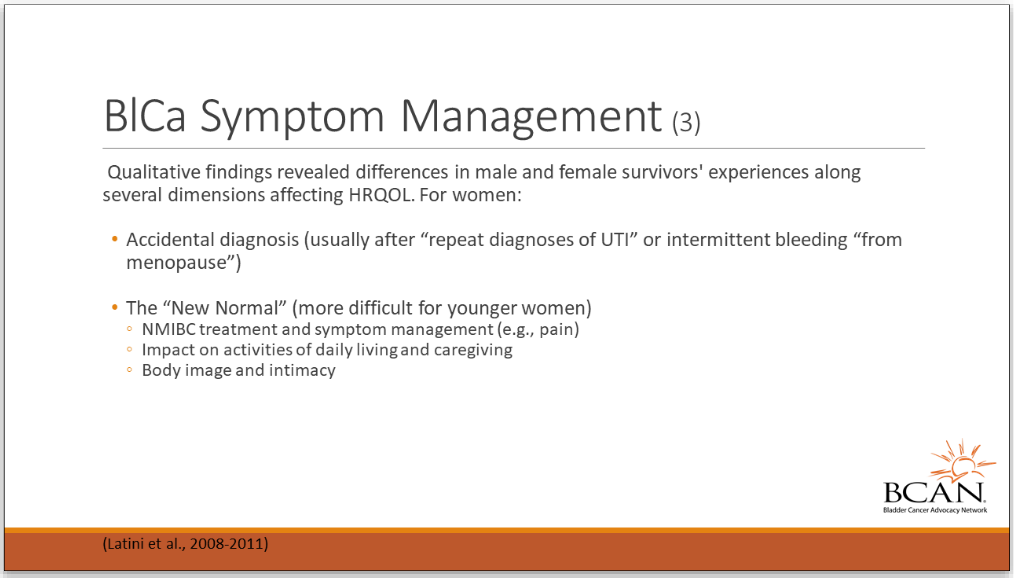
Our muscle-invasive bladder cancer patients however, folks we typically would expect to have issues with symptomology, symptom management are very much showing through our studies that yes, they are very much struggling with managing those symptoms. Sexual functioning being right up there with negative changes in urinary functioning.

As you can see here, erectile dysfunction, folks with muscle-invasive bladder cancer reporting worse functioning in terms of ejaculation, women whether non-muscle invasive or muscle-invasive type are reporting some issues in terms of vaginal dryness, issues with lubrication. Folks are reporting discomfort during sex. This contamination component to the right is very interesting, and I say that in a scientific way. I think my grandmother would have said, "No, this is not a good thing," and I agree with her.

But we are having folks who have had BCG and other treatments who are reporting issues of concern with potential contamination of the modified TB bacterium from the BCG. These are reported concerns about contaminating their partners via sex, which then inhibits their desire to have sex. And I certainly can speak more to that during the Q&A if folks have questions. But this is definitely something that is a barrier or a deterrent to folks after they complete BCG treatment, reengaging in sexual behavior, sexual activity.

When we interviewed folks on studies and asked men and women about their various symptoms, how they manage those symptoms, we did begin to see differences in how women responded versus men in interviews. This wasn't quantitative or survey-based, these were based on just talking through questions in a qualitative study. But women really talked about the impact of accidental diagnosis.

This is what we determined or at least what we got from them, where they spoke heavily about sometimes years, sometimes many rounds of being diagnosed with a urinary tract infection or when they reported hematuria, bleeding. They were told that that intermittent bleeding was linked to menopause or sometimes even advanced urinary tract infections and treated under the treatment of a gynecologist or a primary care physician without a referral to a urologist, which delayed their treatment and delayed... Excuse me, delayed their diagnosis and thus their treatment. And so they reported really suffering.



BlCa Symptom Management (3)

Qualitative findings revealed differences in male and female survivors' experiences along several dimensions affecting HRQOL. For women:

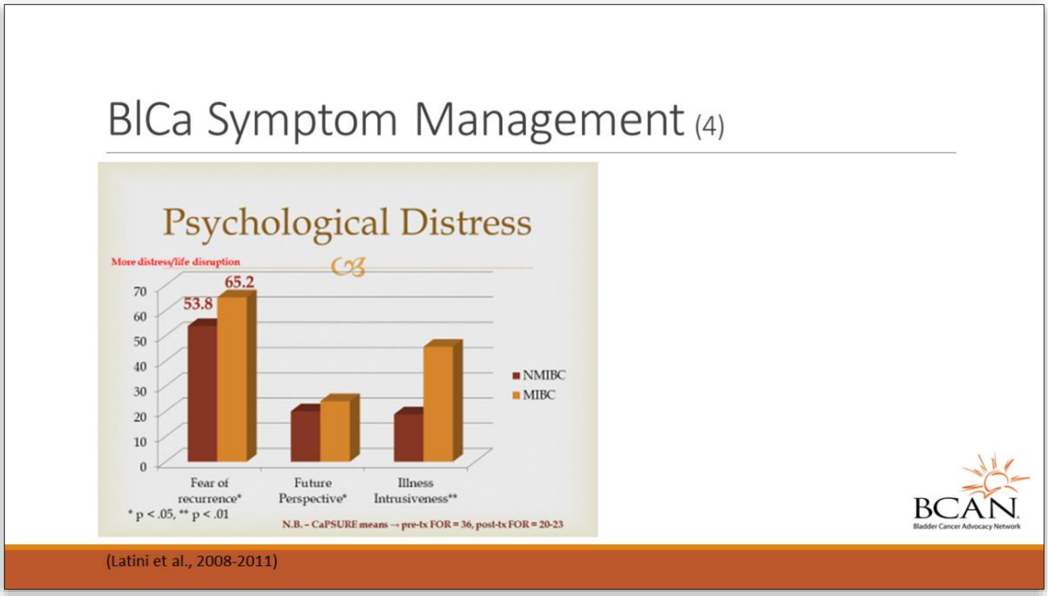
- Accidental diagnosis (usually after “repeat diagnoses of UTI” or intermittent bleeding “from menopause”)
- The “New Normal” (more difficult for younger women)
  - NMIBC treatment and symptom management (e.g., pain)
  - Impact on activities of daily living and caregiving
  - Body image and intimacy

(Latini et al., 2008-2011)

And when they were treated, this new normal that they've reported in terms of their bodies, in terms of their lives, this new normal was very difficult for younger women in particular as opposed to older women who might have gone through menopause fully at the time that they may have had surgical treatment, for instance.

So they talked at length about the impact, differences in their activities of daily living, the struggles they had with caregiving, especially with pain, especially with changes in how they perceive their bodies in terms of body image, their willingness to engage in intimate or sexual activities. So there really was at least a sense among the women with the types of treatments, particularly with surgeries they had post-diagnosis that there was a change in their physical functioning. Some mentioned changes in their mobility and certainly that other symptoms such as pain, changes in sexual functioning, urinary function, et cetera.

And all of these changes, whether we're talking males or females really resulted in what we call psychological distress. The coping, the pivoting, however you'd like to call it in the new normal was very difficult for a lot of people, and particularly among those who had muscle-invasive bladder cancer. But I'd like to emphasize that just because someone was diagnosed with non-muscle invasive bladder cancer, that didn't mean that they felt they were home free.



BlCa Symptom Management (4)

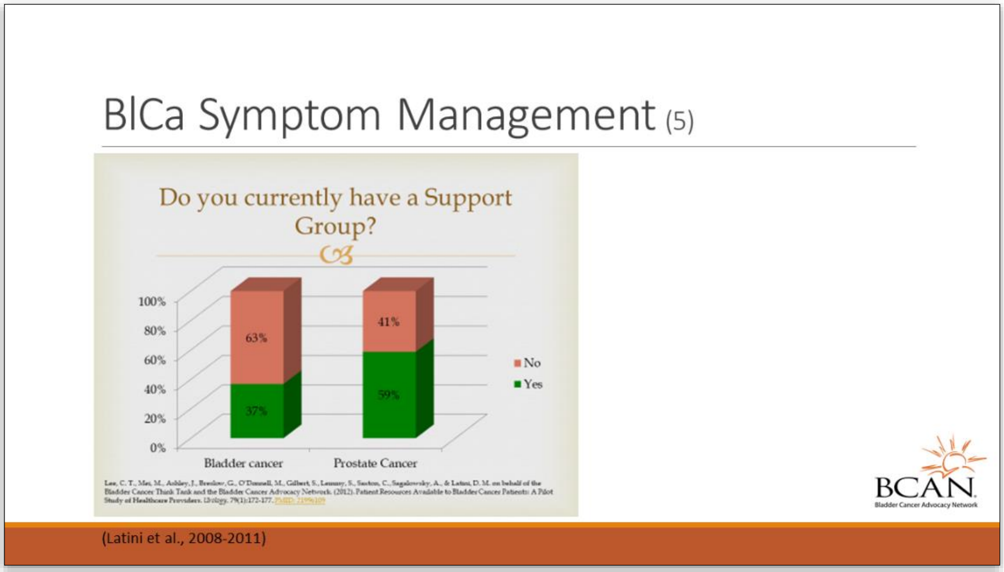
(Latini et al., 2008-2011)

A lot of folks, particularly those with muscle-invasive, but quite a number who were diagnosed with non-muscle invasive bladder cancer had fears of recurrence. And we know with bladder cancer in particular, it is a highly recurrent disease. I've heard estimates of anywhere from 50 to 90%. And so this is a valid fear that is causing distress among folks who've been diagnosed and even been treated.

This idea of a future perspective, there were impacts on people's ability to imagine or envision a future post-diagnosis and treatment that really impacted them in terms of their feelings, of emotional, psychological wellbeing. That was whether you had muscle-invasive or non-muscle invasive. You can see that while it wasn't as disruptive or distressful as say the fear of recurrence, it was still there for a pretty large subset of folks.

And then this illness intrusiveness is really when you're distressed, when you're concerned, when you're psychologically ruminating and you're struggling with coping with having been diagnosed and perhaps treated, the way that the illness really intrudes in your life and disrupts your habits and your hobbies and your interactions with coworkers or relatives or friends, you can see again with muscle-invasive bladder cancer, it is an incredibly distressful disruptive disease.

But non-muscle invasive folks are also reporting intrusiveness and distress from the disease. Now, that is quite significant.



BlCa Symptom Management (5)

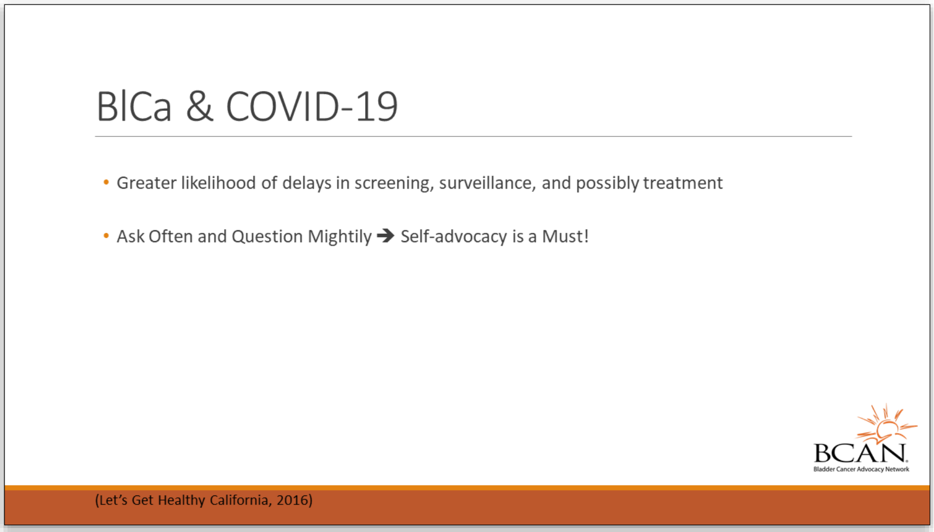
Lee, C. T., Mei, M., Ashley, J., Breslow, G., O'Donnell, M., Gilbert, S., Lerner, S., Sexton, C., Sagalowsky, A., & Latini, D. M. on behalf of the Bladder Cancer Think Tank and the Bladder Cancer Advocacy Network. (2012). Patient Resources Available to Bladder Cancer Patients: A Pilot Study of Healthcare Providers. Urology. 79(1):172-177. PMID: [illegible]

(Latini et al., 2008-2011)

I put this slide here because I think this is interesting and it points, I think, more so to a failure on the part of practitioners, and I'm a practitioner too, so I don't hold myself exempt from that. But a failing on our part to offer what we call psychosocial or supportive care services for bladder cancer patients. When we've queried a study done several years ago by Cheryl Lee who's on BCAN board show that we offered support groups at a higher level for prostate cancer patients than we did for bladder cancer patients.

Luckily, we have BCAN and BCAN helps connect folks with groups. But in terms of practitioners and organizations, it shows that we need to do a better job of offering this supportive care services, this psychosocial oncology care, so that as people experience distress and issues with coping and quality of life, we have something to offer them. If you build it, I really believe people will come. Next slide.

I would be remiss in having this presentation with talking just a little bit about COVID. There have been studies broadly with cancer. We just published a paper not too long ago broadly about cancer, but we're certainly noticing this with bladder cancer too, where due to changes in clinic and hospital operating procedures, due to public health efforts related to distancing and limiting the number of people in spaces, the ways we have to clean equipment and so on, we are seeing a greater likelihood of delays in people's screening, undergoing surveillance and possibly treatment.



BlCa & COVID-19

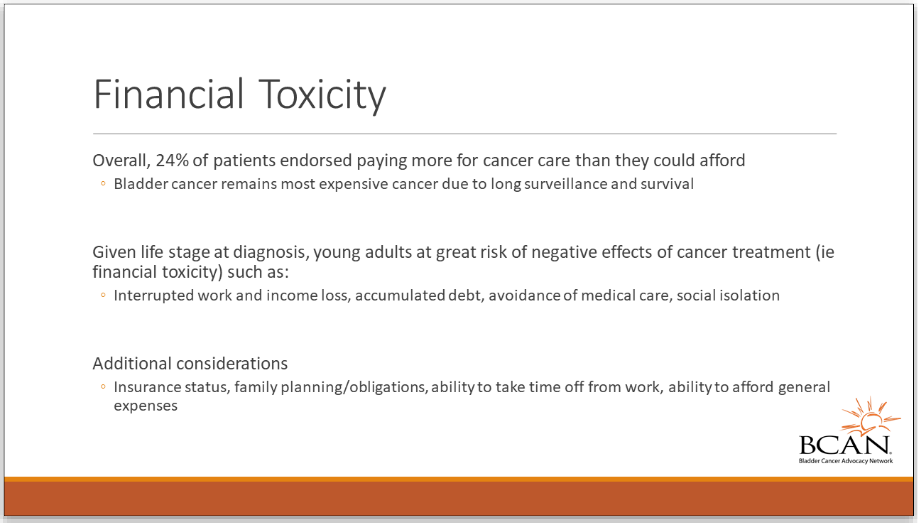
- Greater likelihood of delays in screening, surveillance, and possibly treatment
- Ask Often and Question Mightly ➔ Self-advocacy is a Must!

(Let's Get Healthy California, 2016)

So I want to echo something that my colleague, Dr. Washington said earlier in this webinar, which is self-advocacy is a must, especially now. The pandemic's not over, certainly vaccination rates are going up. And I will say that the latest figures in terms of Black people in America, we started the year with at least with surveys showing as little as 42% of Black people saying that they might either vaccinate immediately when it became available to them or vaccinate at some point. Those figures have gone much higher over the last few months, several months, really, as vaccine has become more widely available, people are having fewer issues accessing.

But we still are working through as a country, as a people through this pandemic, clinics and hospitals are still taking a lot of precautions, necessarily so. So if you or a loved one is really needing surveillance, you're seeing perhaps delays in getting scheduling. If there are treatments that you're experiencing delays, ask often, question mightily. This is the very space where you must advocate for yourself, caregivers, you must advocate for your loved ones, it's a must right now. And that was pre pandemic too, but especially right now, self-advocacy is essential to getting the care that you and your loved ones need.

We know from research for many years that bladder cancer treatment and surveillance is incredibly expensive. It's the most expensive cancer per patient. In one study, over 24% of patients endorsed paying more for cancer care than they can afford. I'm a social worker, I know down here in Texas that people routinely take out mortgages or loans to get their cancer care. And so, bladder cancer can be very toxic in terms of one's finances, one's prospects of retiring, one's financial future and that of the family.



Financial Toxicity

Overall, 24% of patients endorsed paying more for cancer care than they could afford

- Bladder cancer remains most expensive cancer due to long surveillance and survival

Given life stage at diagnosis, young adults at great risk of negative effects of cancer treatment (ie financial toxicity) such as:

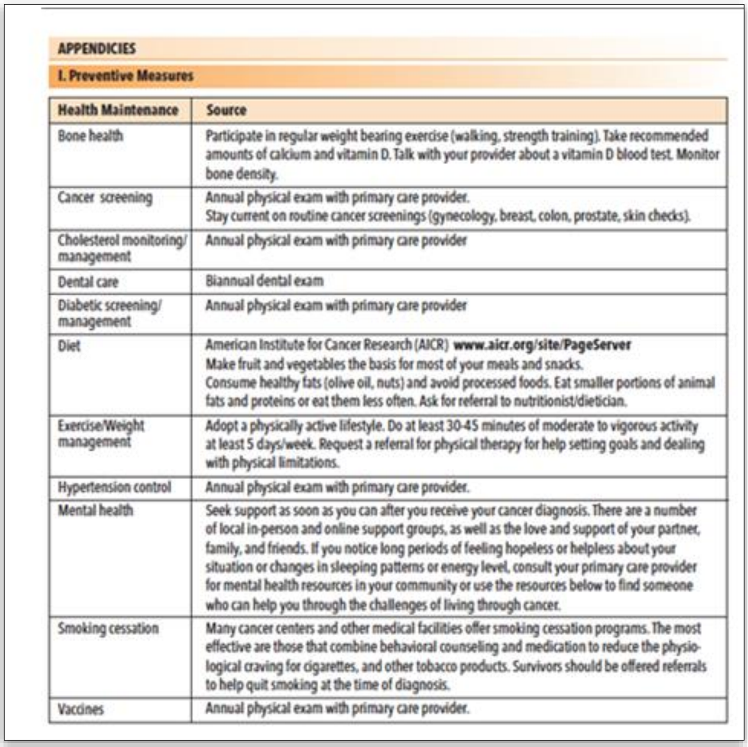
- Interrupted work and income loss, accumulated debt, avoidance of medical care, social isolation

Additional considerations

- Insurance status, family planning/obligations, ability to take time off from work, ability to afford general expenses

And really that brings up issues of, well, if you have insurance, do you have high deductibles? Do you have copays? Can you afford the copays? Financially, that can really impact family planning, your obligations, surveillance and treatment. If you're still in the workforce and people are working longer, especially since 2007, 2008, the Great Recession that happened about a decade ago, people are still trending to working longer.

So in terms of treatment and surveillance, the impact on ability to take time off from work, paid time, is it available? Can you telecommute to work or do you have to work in-person? All of these things come into play, particularly with bladder cancer.



APPENDICIES

I. Preventive Measures

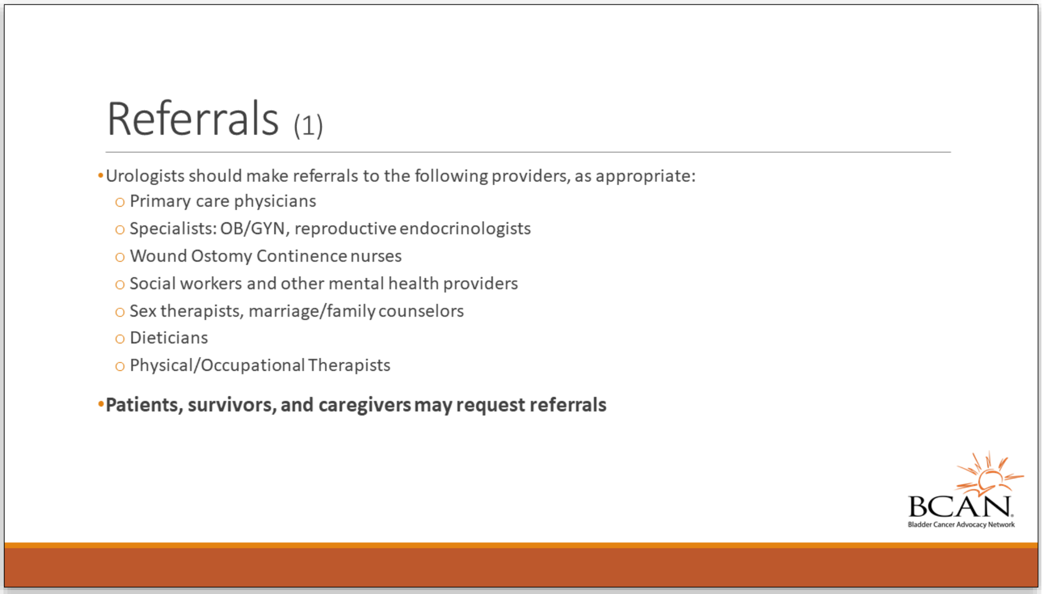
Health Maintenance	**Source**
Bone health	Participate in regular weight bearing exercise (walking, strength training). Take recommended amounts of calcium and vitamin D. Talk with your provider about a vitamin D blood test. Monitor bone density.
Cancer screening	Annual physical exam with primary care provider. Stay current on routine cancer screenings (gynecology, breast, colon, prostate, skin checks).
Cholesterol monitoring/ management	Annual physical exam with primary care provider
Dental care	Biannual dental exam
Diabetic screening/ management	Annual physical exam with primary care provider
Diet	American Institute for Cancer Research (AICR) **www.aicr.org/site/PageServer** Make fruit and vegetables the basis for most of your meals and snacks. Consume healthy fats (olive oil, nuts) and avoid processed foods. Eat smaller portions of animal fats and proteins or eat them less often. Ask for referral to nutritionist/dietician.
Exercise/Weight management	Adopt a physically active lifestyle. Do at least 30-45 minutes of moderate to vigorous activity at least 5 days/week. Request a referral for physical therapy for help setting goals and dealing with physical limitations.
Hypertension control	Annual physical exam with primary care provider.
Mental health	Seek support as soon as you can after you receive your cancer diagnosis. There are a number of local in-person and online support groups, as well as the love and support of your partner, family, and friends. If you notice long periods of feeling hopeless or helpless about your situation or changes in sleeping patterns or energy level, consult your primary care provider for mental health resources in your community or use the resources below to find someone who can help you through the challenges of living through cancer.
Smoking cessation	Many cancer centers and other medical facilities offer smoking cessation programs. The most effective are those that combine behavioral counseling and medication to reduce the physiological craving for cigarettes, and other tobacco products. Survivors should be offered referrals to help quit smoking at the time of diagnosis.
Vaccines	Annual physical exam with primary care provider.

I'm going to switch tacks for just a moment and talk about general health and wellness. BCAN sponsored a study that generated a survivorship care plan several years ago. This is actually a slide that talks about general health and wellness strategies that as folks who've been diagnosed or who are actively undergoing treatment or in the survivorship period really need to think about, talk with physicians about, and perhaps look at ways to incorporate this into your health care or your general personal care. Looking at your diet, reducing fat intake, reducing carb intake, unless it's introducing fresh fruits and vegetables, things like that into the diet.

Looking at your bone density and making sure that you have care that can help with a proper bone density, not forgetting your routine vaccinations like flu shots and MMR and tetanus, people still get tetanus. Still having your breast cancer screenings, your mammography, or if you're eligible and it's warranted, still having your pap smears. Interacting in terms of physical activity, getting up, getting mobile, working and keeping your heart healthy and your lungs healthy.

All of these things, even having regular routine dental care once or twice a year. These are all ways that can keep you healthy through bladder cancer, but also can help with early detection of potential other cancers or other potentially preventable diseases.

Right here, I'll just speed through the rest of the content. These slides should be available to everyone, so I wanted to add extras so that people could have resources and referrals, points to ponder. Again, self-advocate, your urologists can make referrals to a number of other specialties, such as wound, ostomy, continence nurses, oncology workers, sex therapists, dieticians. You may request those referrals as well and should.



Referrals (1)

- Urologists should make referrals to the following providers, as appropriate:
  - Primary care physicians
  - Specialists: OB/GYN, reproductive endocrinologists
  - Wound Ostomy Continence nurses
  - Social workers and other mental health providers
  - Sex therapists, marriage/family counselors
  - Dieticians
  - Physical/Occupational Therapists
- **Patients, survivors, and caregivers may request referrals**

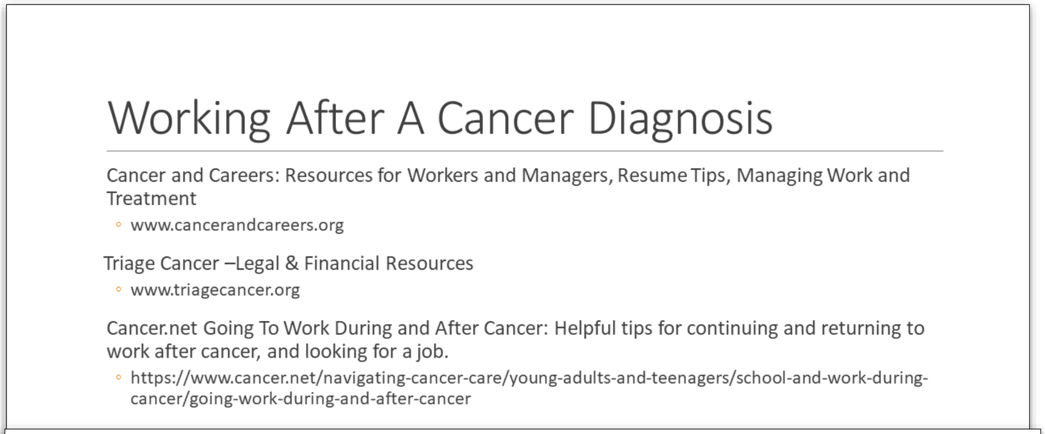
Don't forget that there are community providers where you might be able to get housing or utility assistance, wigs, prosthetics, even pet care and supplies. I was very happy when our local Meals on Wheels program did a pet Meals on Wheels program. Because we have a lot of older adults on fixed incomes who have pets, and that program can help with pet care, so you have companionship and limiting isolation.

Referrals (2)

- Insurance/Employee Benefits
  - Medicare/Medicaid, Health exchanges, SS, SSDI
  - Short/long-term disability policies, FMLA, ADA accommodations
- Community providers (churches/synagogues/mosques, non-profits)
  - Housing, utilities, food, and transportation
  - Support groups, counselors, respite services
  - Wigs, prostheses, and other supplies
  - Pet care, supplies
- Prescription Assistance Programs
- Special cases: Veterans, Individuals of childbearing years

There are prescription assistance programs, oncology social workers are throughout the country and I have a resource where you can meet perhaps with oncology social workers and get some of these referrals or information on some of these resources.

Here are a few resources if you find yourself working after a cancer diagnosis, Triage Cancer, Cancer and Careers, Cancer.net. These are wonderful resources, and some of them have financial assistance. So if you find that you may need copay assistance or so on, great resources.



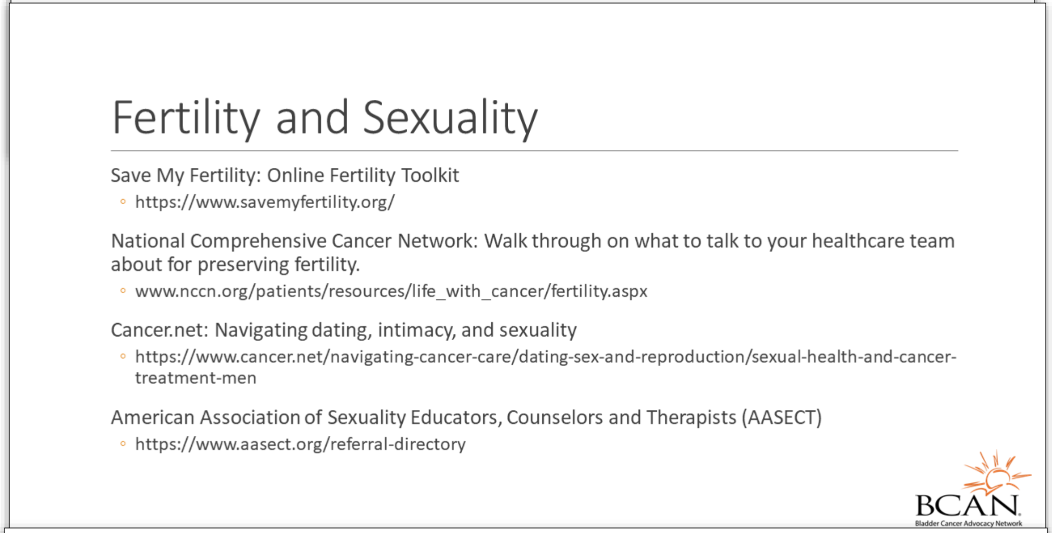
Working After A Cancer Diagnosis

Cancer and Careers: Resources for Workers and Managers, Resume Tips, Managing Work and Treatment
- www.cancerandcareers.org

Triage Cancer –Legal & Financial Resources
- www.triagecancer.org

Cancer.net Going To Work During and After Cancer: Helpful tips for continuing and returning to work after cancer, and looking for a job.
- https://www.cancer.net/navigating-cancer-care/young-adults-and-teenagers/school-and-work-during-cancer/going-work-during-and-after-cancer

Here's some resources related to fertility and sexuality, a little plug for AASECT in terms of finding certified sex therapist or sexuality counselors who can help you in terms of helping with sexual recovery.



Fertility and Sexuality

Save My Fertility: Online Fertility Toolkit
- https://www.savemyfertility.org/

National Comprehensive Cancer Network: Walk through on what to talk to your healthcare team about for preserving fertility.
- www.nccn.org/patients/resources/life_with_cancer/fertility.aspx

Cancer.net: Navigating dating, intimacy, and sexuality
- https://www.cancer.net/navigating-cancer-care/dating-sex-and-reproduction/sexual-health-and-cancer-treatment-men

American Association of Sexuality Educators, Counselors and Therapists (AASECT)
- https://www.aasect.org/referral-directory

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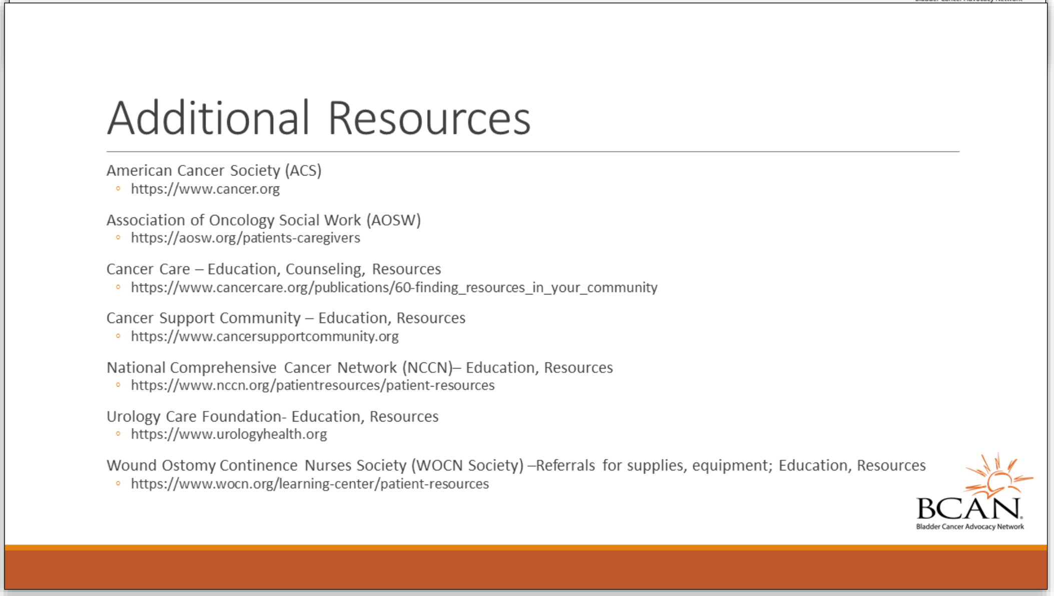
And then I put some additional resources here, particularly the WOCN Society, the Oncology Social Work Association. These are all various professional societies or foundations that may have educational or even sometimes financial resources that may come in handy.



Additional Resources

American Cancer Society (ACS)
- https://www.cancer.org

Association of Oncology Social Work (AOSW)
- https://aosw.org/patients-caregivers

Cancer Care – Education, Counseling, Resources
- https://www.cancercare.org/publications/60-finding_resources_in_your_community

Cancer Support Community – Education, Resources
- https://www.cancersupportcommunity.org

National Comprehensive Cancer Network (NCCN)– Education, Resources
- https://www.nccn.org/patientresources/patient-resources

Urology Care Foundation- Education, Resources
- https://www.urologyhealth.org

Wound Ostomy Continence Nurses Society (WOCN Society) –Referrals for supplies, equipment; Education, Resources
- https://www.wocn.org/learning-center/patient-resources

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