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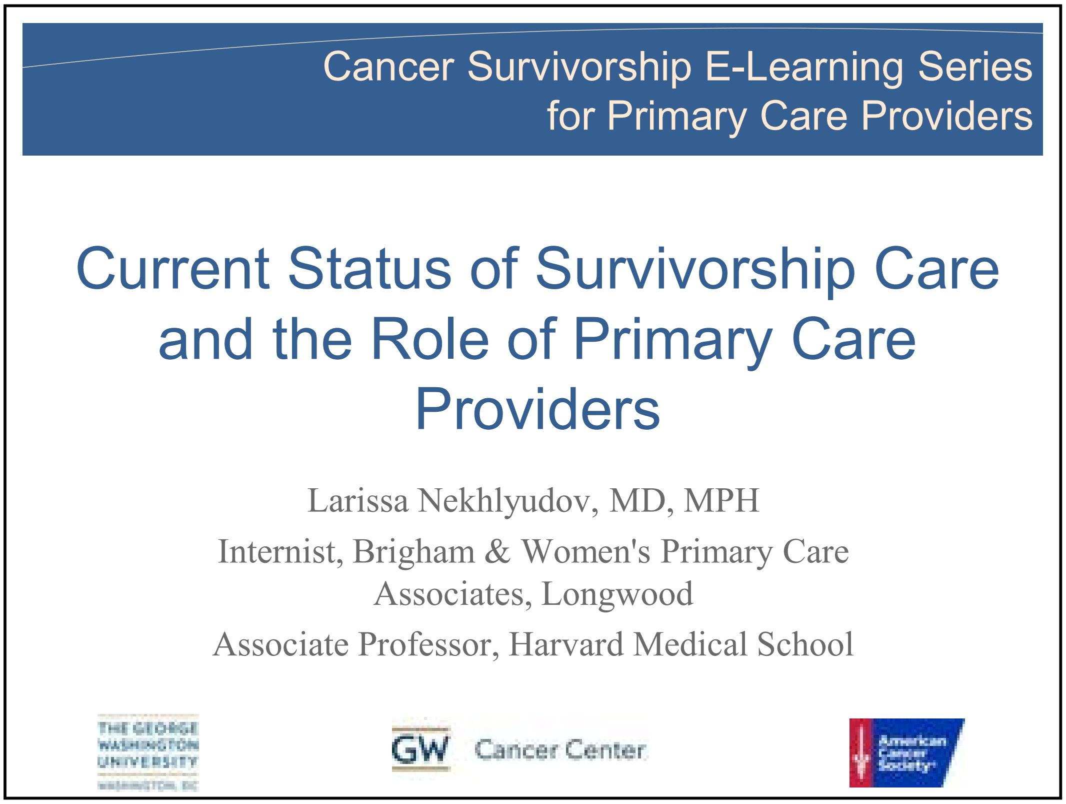

Cancer Survivorship E-Learning Series
for Primary Care Providers

Current Status of Survivorship Care and the Role of Primary Care Providers

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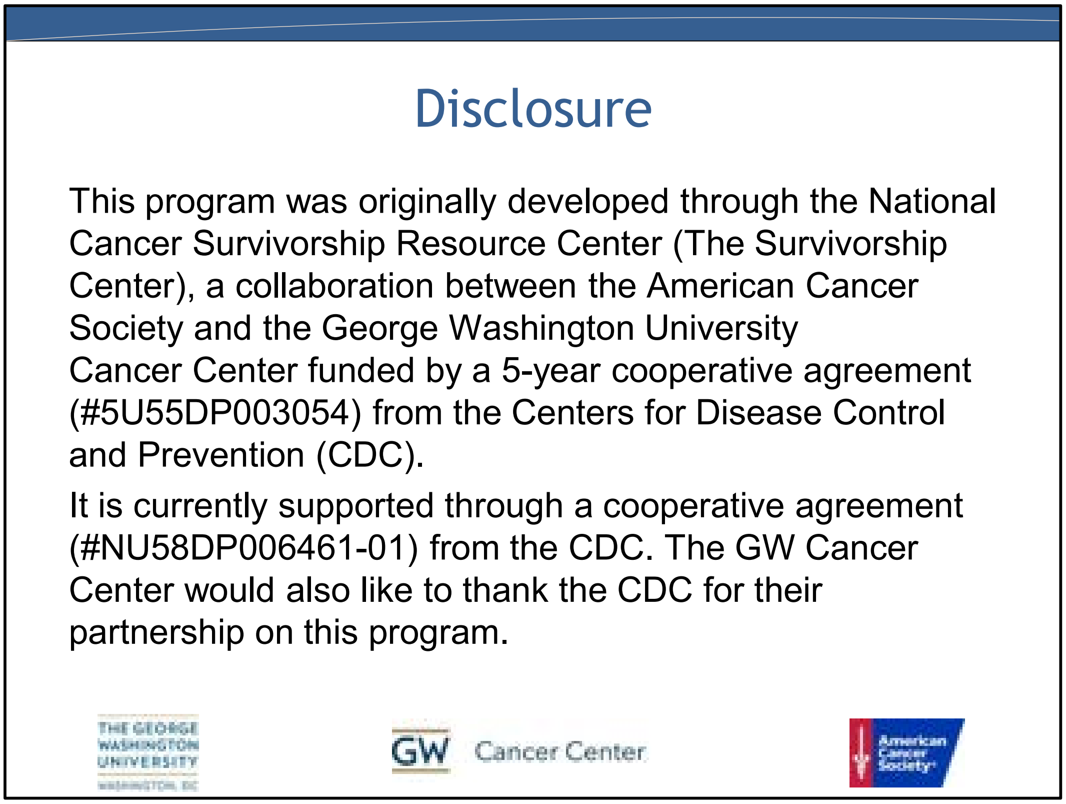
Welcome to this presentation on the Current Status of Survivorship Care and the Role of Primary Care Providers. I am Dr. Larissa Nekhlyudov, Internist at the Brigham & Women's Primary Care Associates and Associate Professor at Harvard Medical School.

We are pleased to offer this educational session through the National Cancer Survivorship Resource Center, a collaboration between the American Cancer Society and the George Washington University Cancer Center, originally funded by a five year cooperative agreement from the Centers for Disease Control and Prevention.



Disclosure

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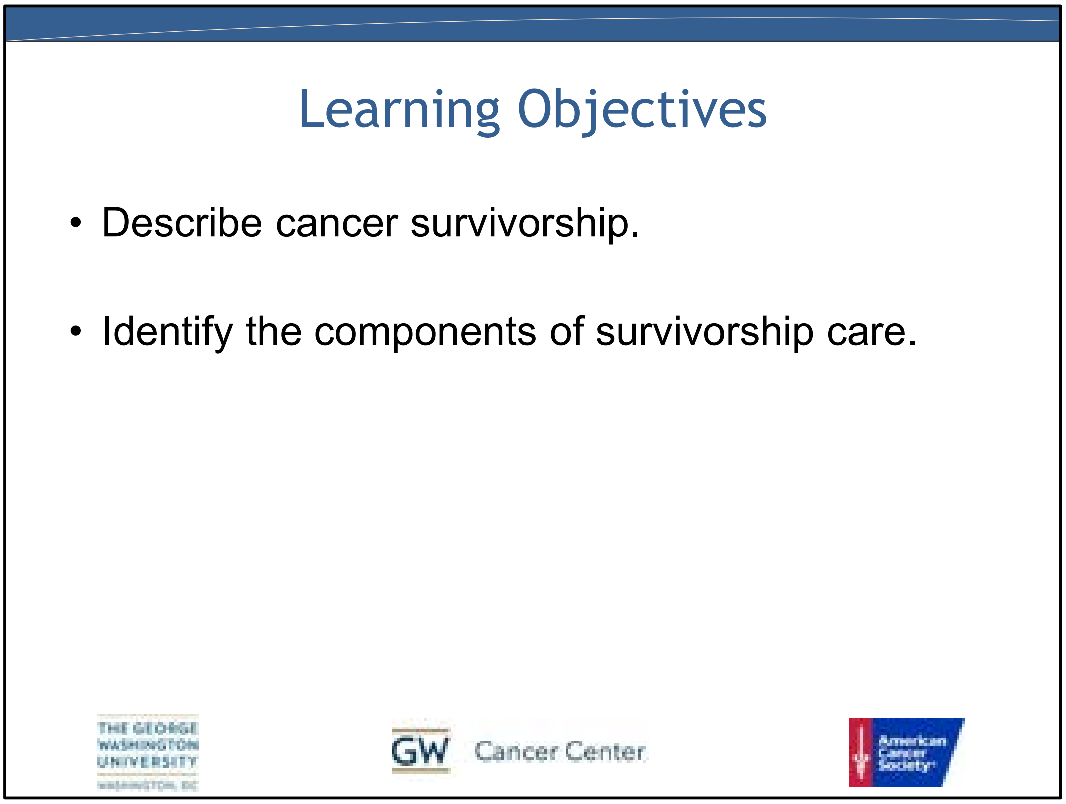

Learning Objectives

- Describe cancer survivorship.
- Identify the components of survivorship care.

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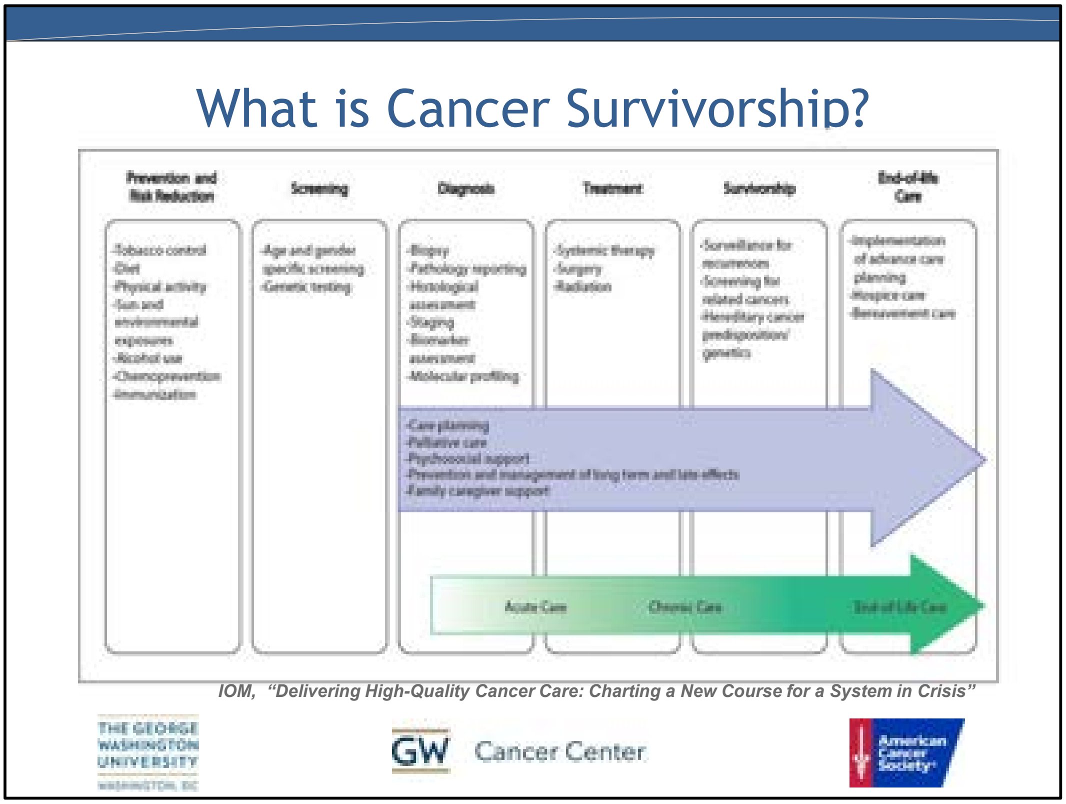
After completing this lesson, you will be able to:

Describe cancer survivorship and what we mean when we use this term, as well as who are cancer survivors; and

Identify the components of survivorship care.



What is Cancer Survivorship?

Prevention and Risk Reduction
- Tobacco control
- Diet
- Physical activity
- Sun and environmental exposures
- Alcohol use
- Chemoprevention
- Immunization

Screening
- Age and gender specific screening
- Genetic testing

Diagnosis
- Biopsy
- Pathology reporting
- Histological assessment
- Staging
- Biomarker assessment
- Molecular profiling

Treatment
- Systemic therapy
- Surgery
- Radiation

Survivorship
- Surveillance for recurrences
- Screening for related cancers
- Hereditary cancer predisposition/ genetics

End-of-life Care
- Implementation of advance care planning
- Hospice care
- Bereavement care

- Care planning
- Palliative care
- Psychosocial support
- Prevention and management of long term and late effects
- Family caregiver support

Acute Care
Chronic Care
End-of-Life Care

IOM, "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis"

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What is cancer survivorship?

This term has been around for several decades and has recently received greater attention as more and more individuals are living with and beyond cancer.

It is really a phase of the cancer continuum that begins with prevention and risk reduction, through cancer screening, diagnosis, treatment, and then carries on to end of life care.

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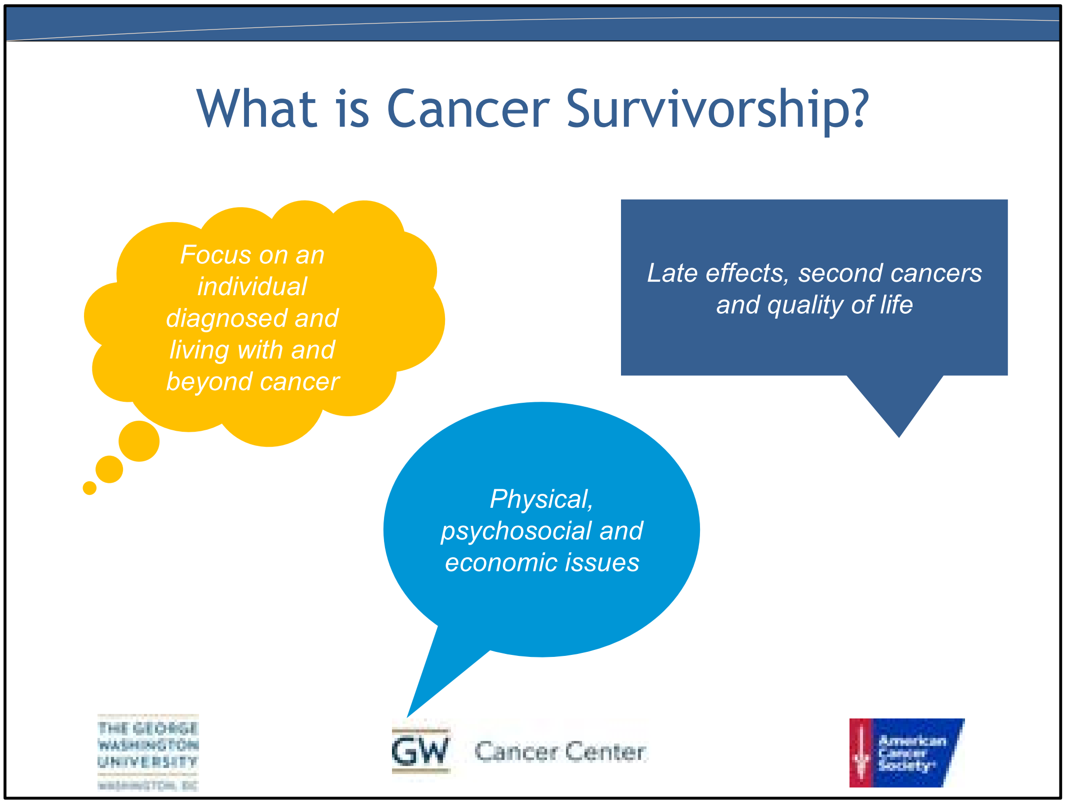

What is Cancer Survivorship?

Focus on an individual diagnosed and living with and beyond cancer

Late effects, second cancers and quality of life

Physical, psychosocial and economic issues

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Cancer survivorship focuses on the health and life of an individual living with and beyond cancer, through the end of life.

As defined by the National Cancer Institute, it covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases.

Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancer and quality of life.

Who are Cancer Survivors?

An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life

There are many types of survivors, including those living with cancer and those free of cancer

American Cancer Society, 2019; Roy, Vallepu, Barrios & Hunter, 2018; DeSantis et al., 2019; Hunt, Silva, Lock & Hurlbert, 2019.

The term "cancer survivor" has been used in a variety of ways and sometimes causes confusion. While the focus is often on those who have completed active treatment, an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. There are many types of survivors, including those living with cancer and those free of cancer. This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.

For example –

Someone may be living cancer-free after treatment for the remainder of their life

Someone may also be living cancer-free after treatment for many years, but experience one or more serious, late complications of treatment

Someone may be living cancer-free after treatment for many years, and then develop a late recurrence

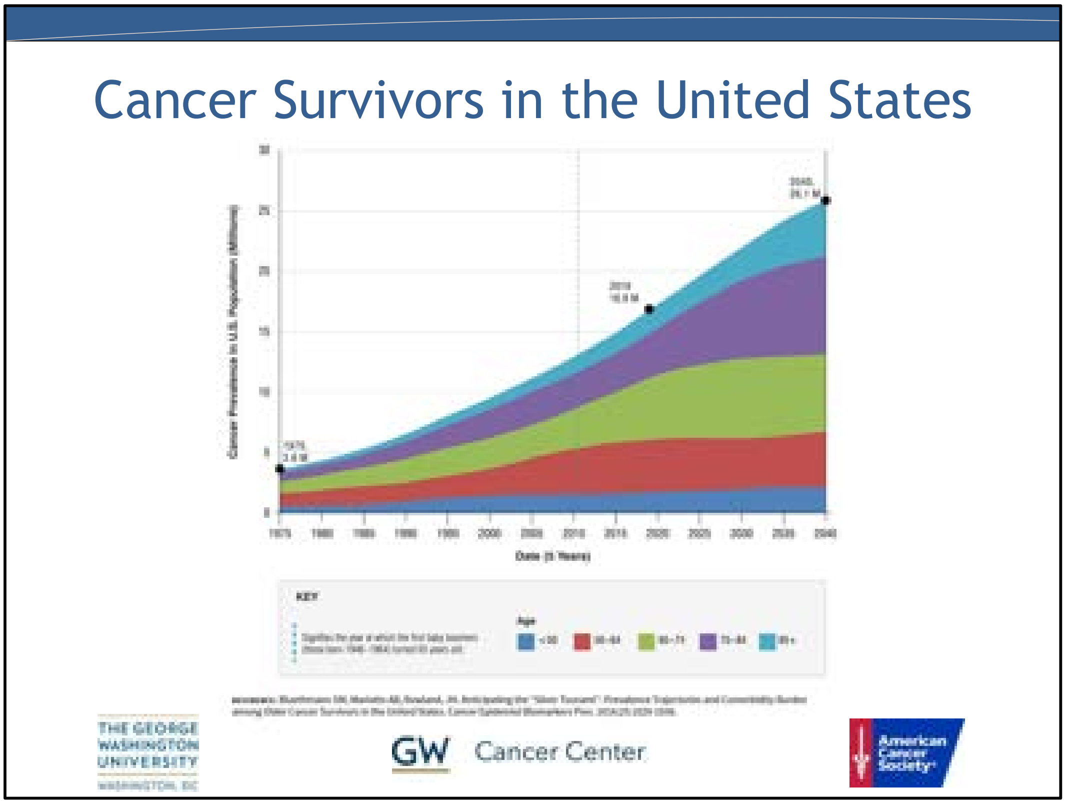
Someone may be living cancer-free after their first cancer is treated, but then develop a second or third or fourth cancer

Someone may be living with intermittent periods of active disease requiring treatment

And someone may be living with cancer continuously, with or without treatment, without ever having a disease-free period.

It is important to emphasize that some individuals do not wish to use “cancer survivor” as a term to describe themselves or their experiences.

https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship
https://www.cancer.org/cancer/glossary.html#alpha-s
https://www.canceradvocacy.org/news/defining-cancer-survivorship/



Cancer Survivors in the United States

According to the American Cancer Society, there are currently 16.9 million cancer survivors living in the United States. This number is projected to grow to 26 million by 2040 due to a number of factors including improved cancer treatment and outcomes as well as the aging of the population (ACS, 2019).

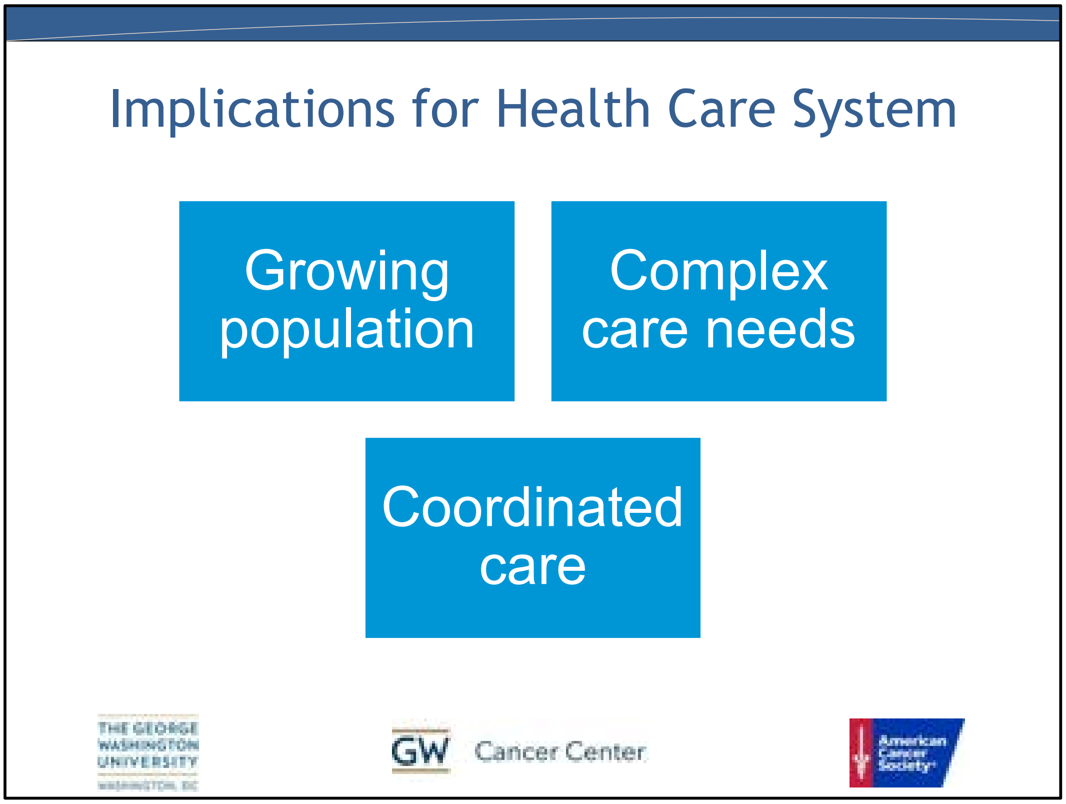
Cancer survivors are mostly 65 years of age or older, with about 64% of the cancer survivor population, but younger survivors, those below age 50, account for 10% of the population (ACS, 2019).

Older survivors are more likely to have comorbid medical conditions like heart disease and diabetes, and thus require additional consideration when planning for long-term survivorship care, including the need for care coordination.

Disparities in cancer survivorship care do exist and this will be addressed in the next lesson.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4933329/figure/F1/ - **see updated citation in the slide**

https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-treatment-and-survivorship-facts-and-figures/cancer-treatment-and-survivorship-facts-and-figures-2019-2021.pdf



Implications for Health Care System

Growing population

Complex care needs

Coordinated care

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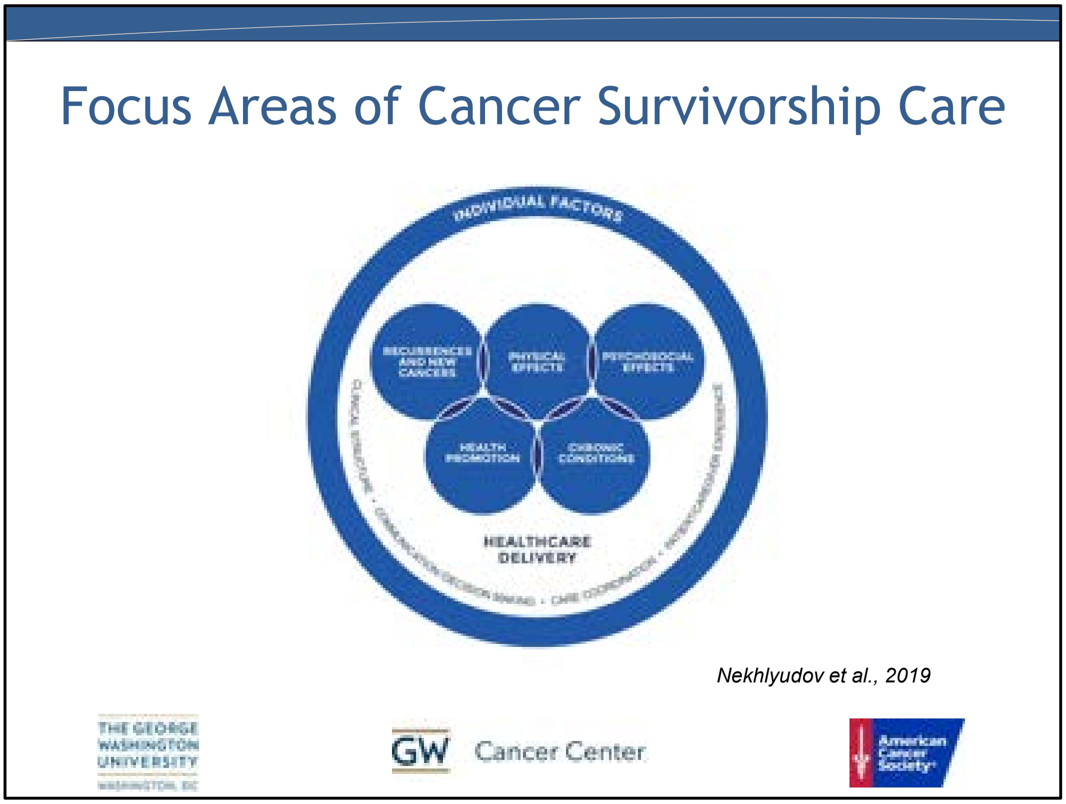
The growing survivor population has widespread implications for the health care system.

It is a growing population, too large for oncology providers to care for them alone.

It is an older population, with complex medical needs.

And as such, it is a population that requires coordinated care from oncology providers and primary care providers, as well as specialists.

Because of these and other factors, primary care providers need to be prepared to directly care for cancer survivors as well as share and coordinate care with other health care providers.



Focus Areas of Cancer Survivorship Care

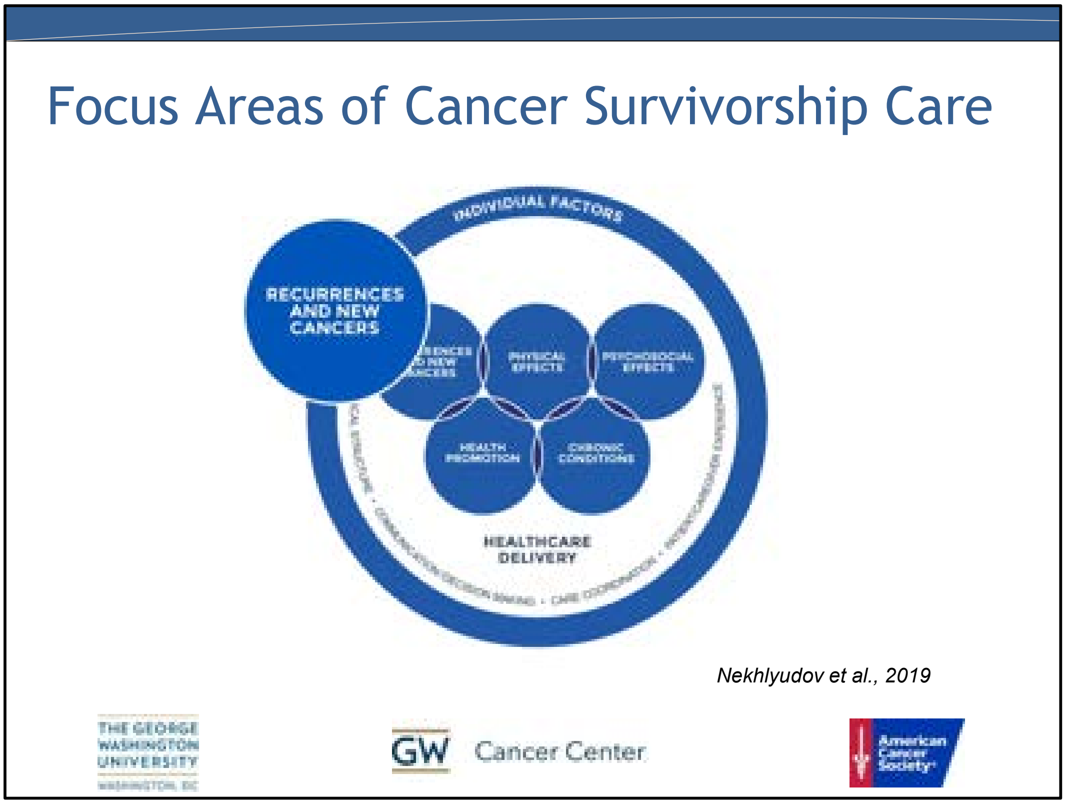
Nekhlyudov et al., 2019

So lets review the areas of focus in cancer survivorship care.

This graphic represents the areas that should be considered when caring for any cancer survivor.

We will go through these in more detail over the next slides.

https://academic.oup.com/jnci/advance-article-abstract/doi/10.1093/jnci/djz089/5490202



Focus Areas of Cancer Survivorship Care

Nekhlyudov et al., 2019

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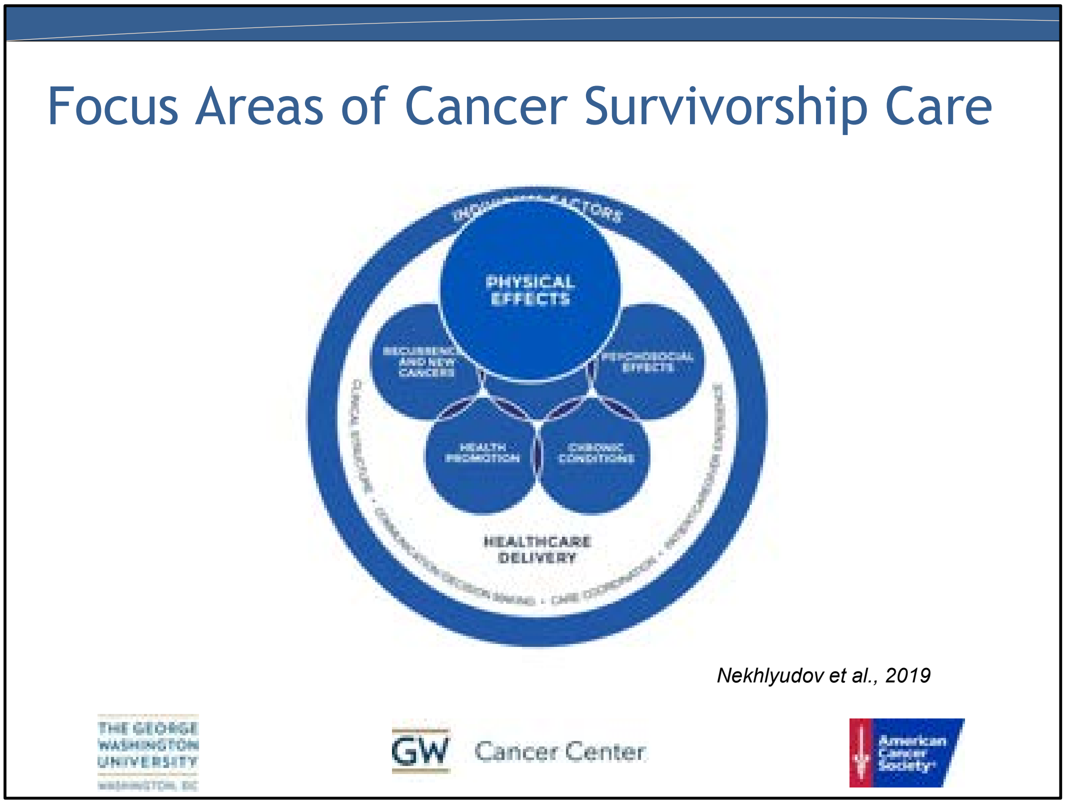
We begin with focusing our attention on preventing and detecting recurrences and new cancers.

This is often the main focus of cancer follow-up done by oncology physicians.

This may include clinical visits with taking history of symptoms, physical examination, laboratory testing and as needed imaging.



Focus Areas of Cancer Survivorship Care

INDIVIDUAL FACTORS

PHYSICAL EFFECTS

RECURRENCE AND NEW CANCERS

PSYCHOSOCIAL EFFECTS

HEALTH PROMOTION

CHRONIC CONDITIONS

HEALTHCARE DELIVERY

CLINICAL STRUCTURE • COMMUNICATION/DECISION MAKING • CARE COORDINATION • PATIENT/CAREGIVER EXPERIENCE

Nekhlyudov et al., 2019

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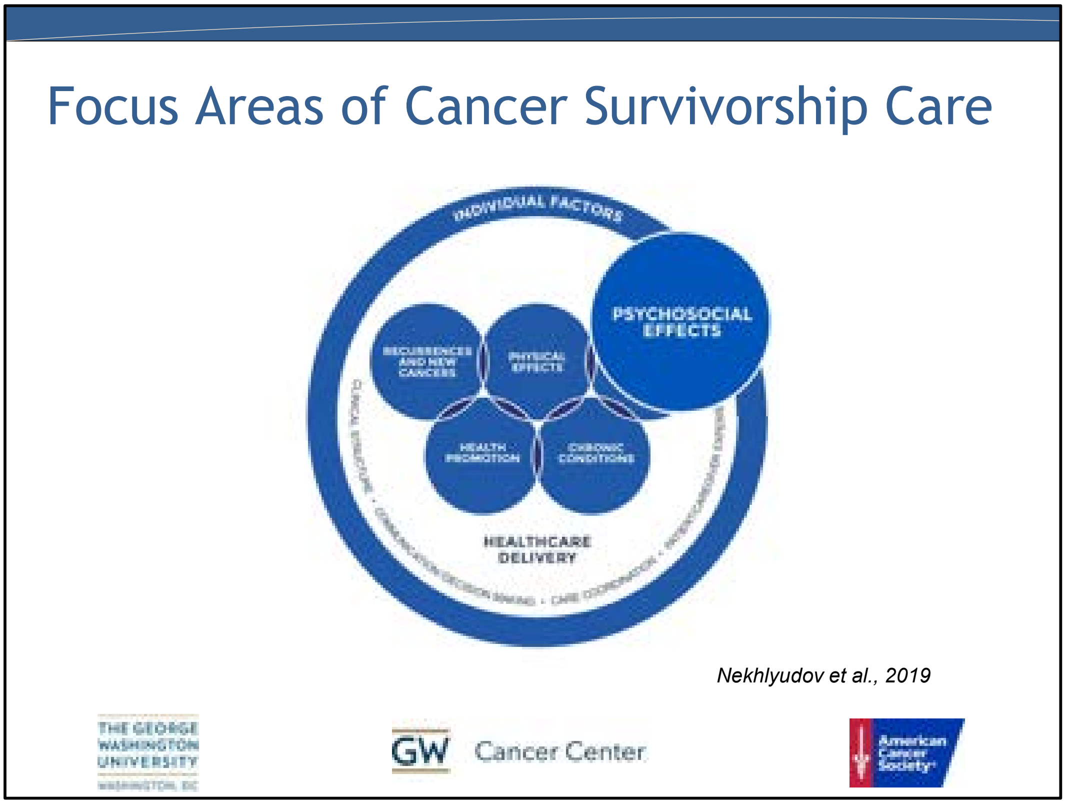
Next we must focus on the evaluation and treatment of physical effects of cancer and its treatment. These effects may include those due to surgery, chemotherapy and radiation therapy. Future lessons will expand on such physical effects.

It is important that health care providers ask survivors about physical symptoms that they are experiencing, be on the look out for specific symptoms and problems that may occur as a result of treatment and be sure to evaluate and treat these when they are diagnosed. This may require referral to specialists who are best equipped to provide such care.



Focus Areas of Cancer Survivorship Care

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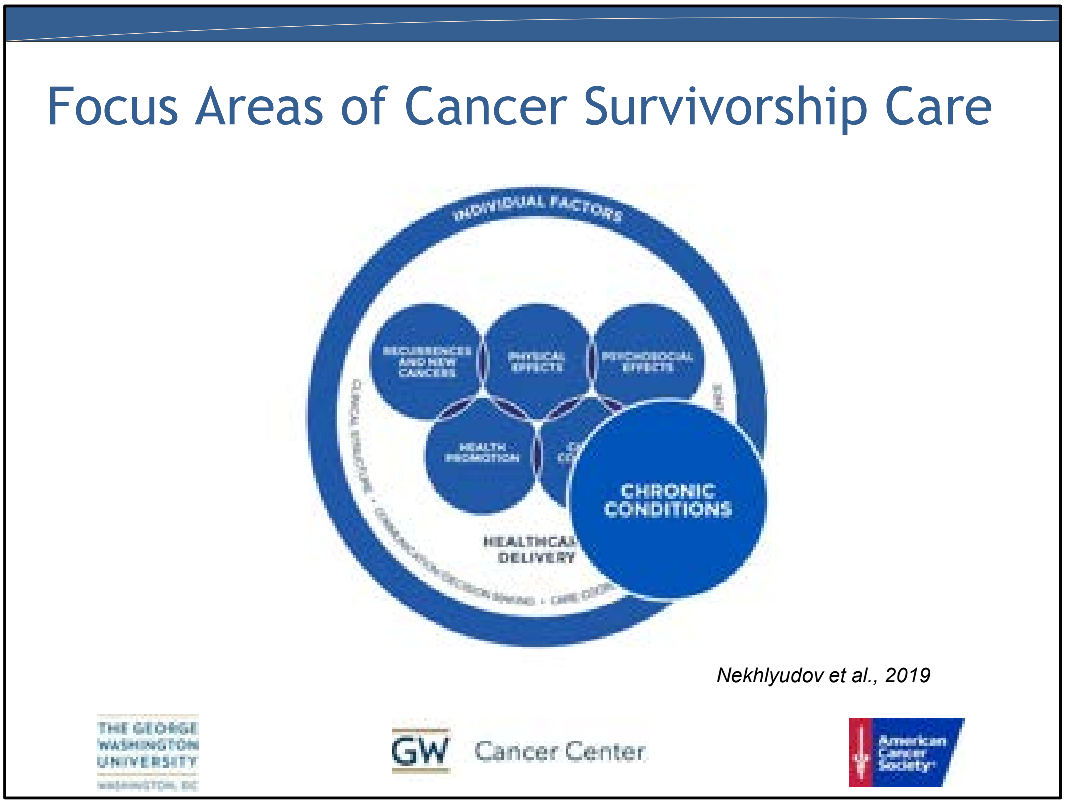
Similarly, health care providers must focus on psychosocial effects of cancer and its treatment. This may include psychological issues such as depression, anxiety and fear of recurrence. Also issues pertaining to finances, employment and school. And also interpersonal issues such as relationship with loved ones, sexuality and intimacy.

Again, it is important that health care providers ask survivors about symptoms that they may be experiencing, and find ways to treat them. This may be with medications, therapy or by other means. Referral to specialists may be needed.

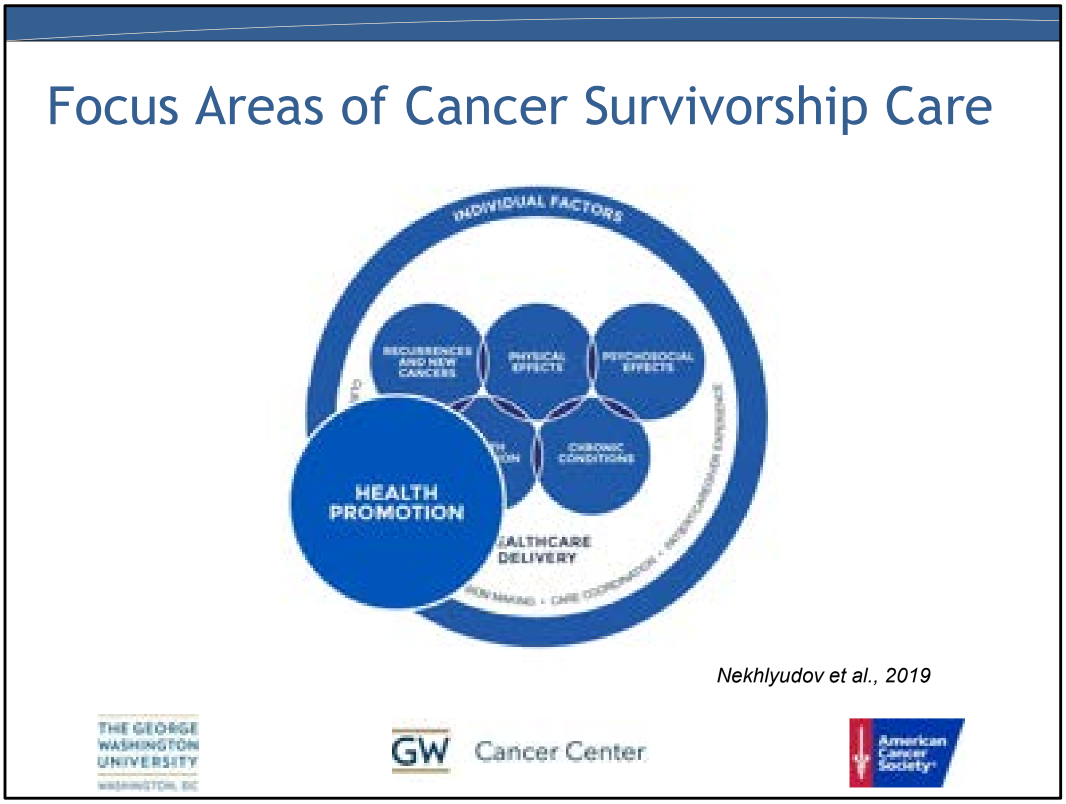


Focus Areas of Cancer Survivorship Care

Nekhlyudov et al., 2019

As mentioned earlier in the talk, most cancer survivors are older and therefore may have chronic medical conditions that were present prior to diagnosis. It is important that these are not ignored and are given the appropriate attention.

This may mean making sure that survivors continue to see their primary care provider, and/or specialists, and that attention in placed on making sure that they are adherent to treatment recommendations for these medical conditions. Taking stock of medications being taken is important.



Focus Areas of Cancer Survivorship Care

Nekhlyudov et al., 2019

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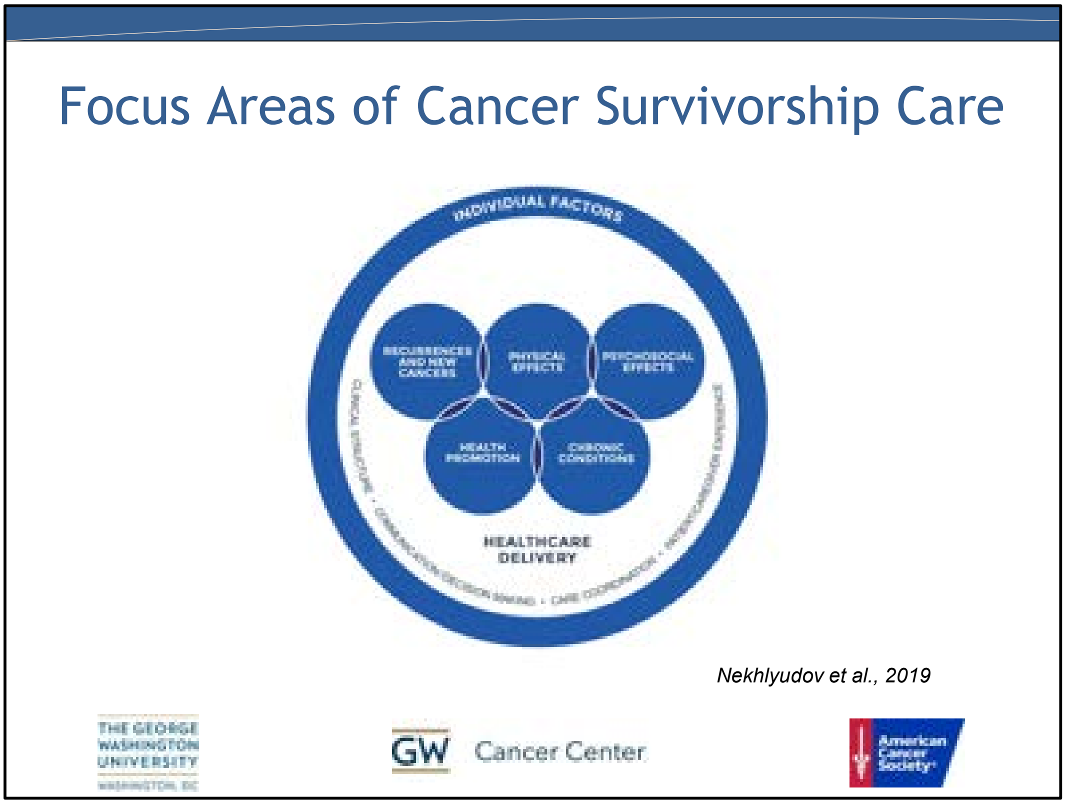
Focus on health promotion and disease prevention is necessary in cancer survivorship.

This includes exercise, healthy diet, reducing alcohol use, quitting smoking and getting the appropriate preventive care, including vaccinations.



Focus Areas of Cancer Survivorship Care

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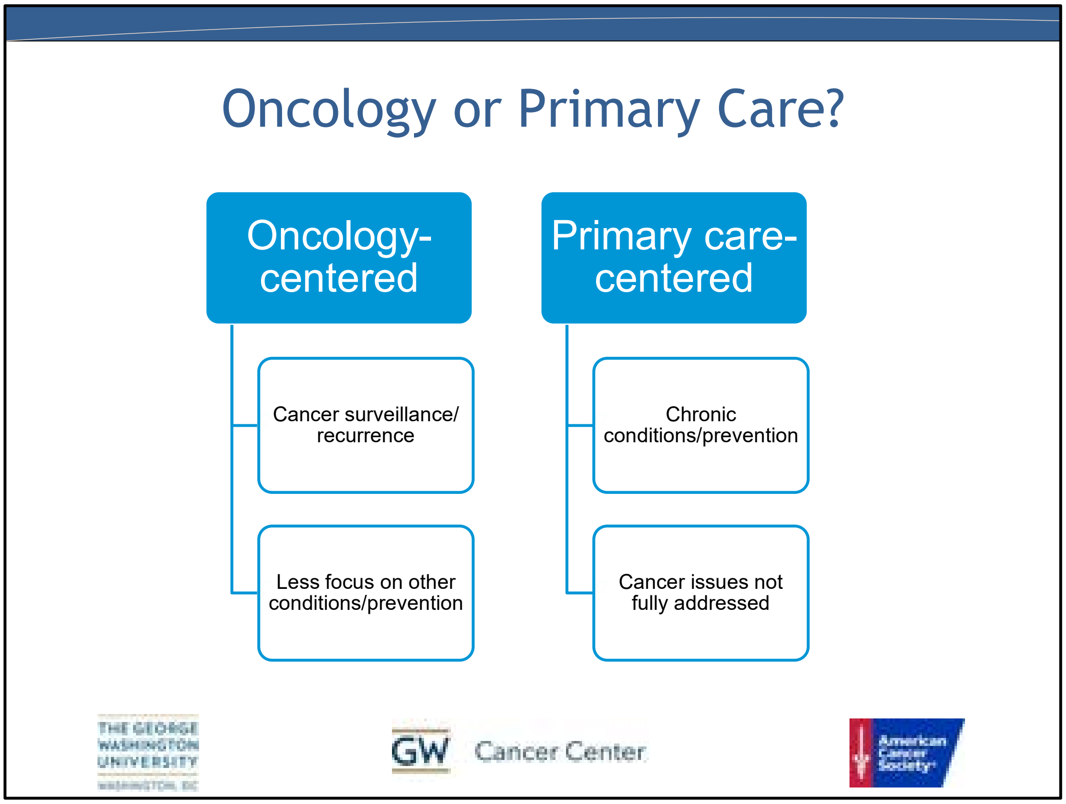
With focus on these areas, it is important to pay attention to the overall health care environment in which the patients are receiving their care and be sure that communication, decision making, coordination of care takes place and that the needs of patients are being taken into account.

And of clear importance is that the patient or individual factors are clearly emphasized. Attention may not need to be equally placed on all of these areas that I have described, but it is important that for each individual, these are considered and addressed if needed.



Oncology or Primary Care?

Oncology-centered

- Cancer surveillance/ recurrence
- Less focus on other conditions/prevention

Primary care-centered

- Chronic conditions/prevention
- Cancer issues not fully addressed

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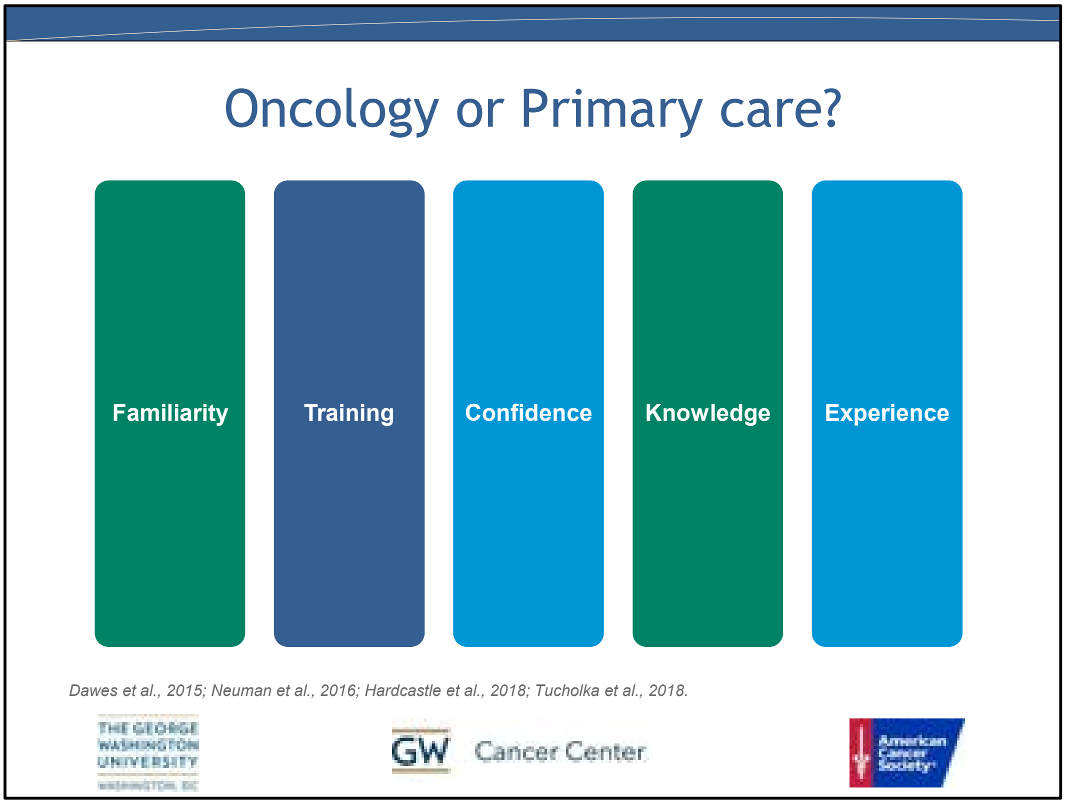
So who should provide cancer survivorship care? Oncology care and primary care constitute different things.

Oncology-centered care is cancer-focused. It includes much attention on cancer surveillance and recurrence. Other conditions or comorbidities are often not the focus of oncology-centered care.

On the other hand, primary centered-care is focused on general wellbeing including care for chronic conditions and disease prevention.

Consideration of long-term and late effects of cancer and its treatment, and psychosocial care directed towards the effects of cancer – may or may not be adequately addressed by either oncologists or primary care providers.

For primary care providers in particular, it may depend on how much knowledge, training, and confidence they have in providing cancer survivorship care.



Oncology or Primary care?

- Familiarity
- Training
- Confidence
- Knowledge
- Experience

Dawes et al., 2015; Neuman et al., 2016; Hardcastle et al., 2018; Tucholka et al., 2018.

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There are benefits and challenges to oncology-centered and primary centered-care.

Providers have different familiarity and training. Oncology providers are clearly more experienced than primary care providers in offering cancer-related care. (Dawes et al., 2015).

Cancer survivors often have more confidence in their oncology providers when it comes to survivorship care, especially after building a relationship during their cancer treatment. This can create a loop where survivors seek out oncology providers first rather than their primary care providers. This also creates fewer chances for primary care providers to gain survivorship care experience (Neuman et al., 2016).

On the other hand, primary care providers have more experience caring for conditions such as heart disease or diabetes. Oncology providers are not equipped to provide such general care, including regular screenings and tests for comorbidities.

This can create a gap where patients continue to see their oncology provider for all care, but do not receive the necessary screening, tests, or treatment for these medical conditions (Hardcastle et al., 2018).

But, for most cancer survivors, it is important for them to return to primary care, even though they may be reluctant to do so due to trust that has been established with their oncology provider, concerns that primary care providers may not be able to provide survivorship care and lack of clear communication about the plan for survivorship care (Tucholka et al., 2018).

One important strategy is to communicate clearly with survivors about expectations for post-treatment survivorship care.

It is also important that even during cancer treatment that the PCP remain involved. As treatment winds down, survivors can then work with their providers to develop their post-treatment care plan.

What happens when treatment ends?

Alfano et al., 2019

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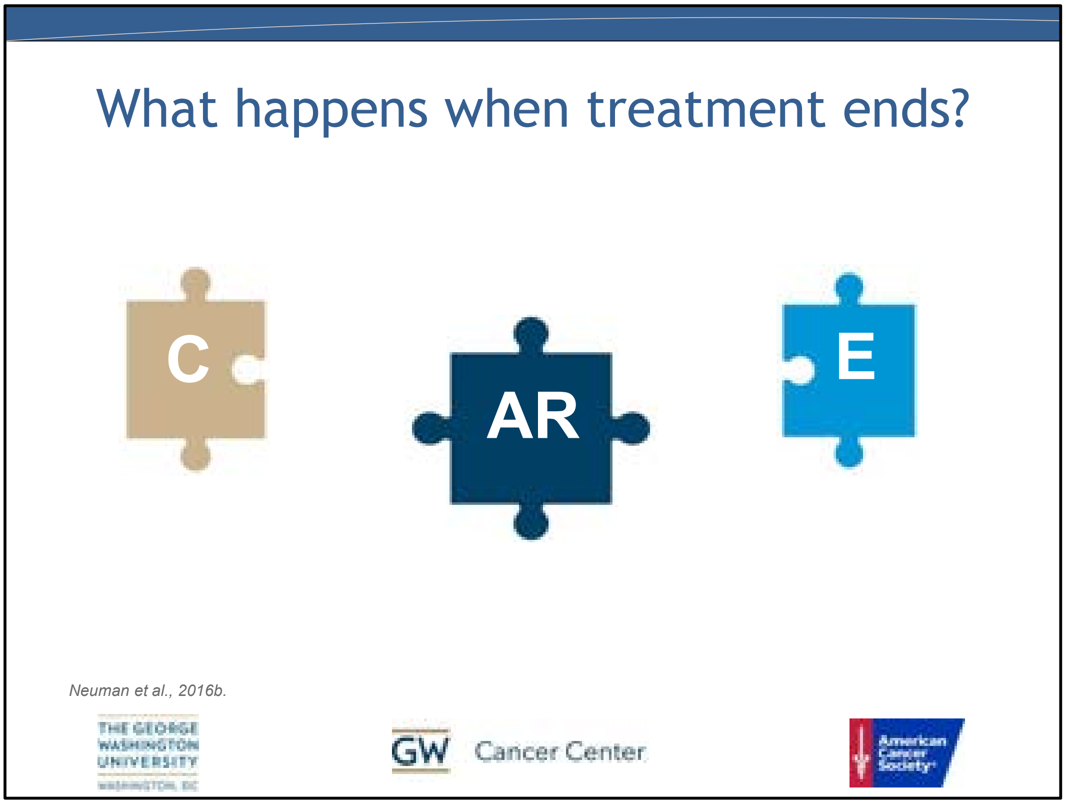
What happens when treatment ends? Survivorship care consists of many moving parts across multiple providers. There are several recommended models for survivorship care that have been recently proposed including shared care, risk stratified or personalized care.

Regardless of the model, it is important that providers communicate across specialties, that survivors feel empowered and be included as members of their care team in order to ask questions, make suggestions, and communicate freely with their providers, that survivors receive regular screening and surveillance for both for cancer and for late effects, and that they also receive disease management for chronic conditions and counselling and support for healthy lifestyle behaviors like smoking cessation, diet and nutrition and physical activity (Alfano et al., 2019).



What happens when treatment ends?

Neuman et al., 2016b.

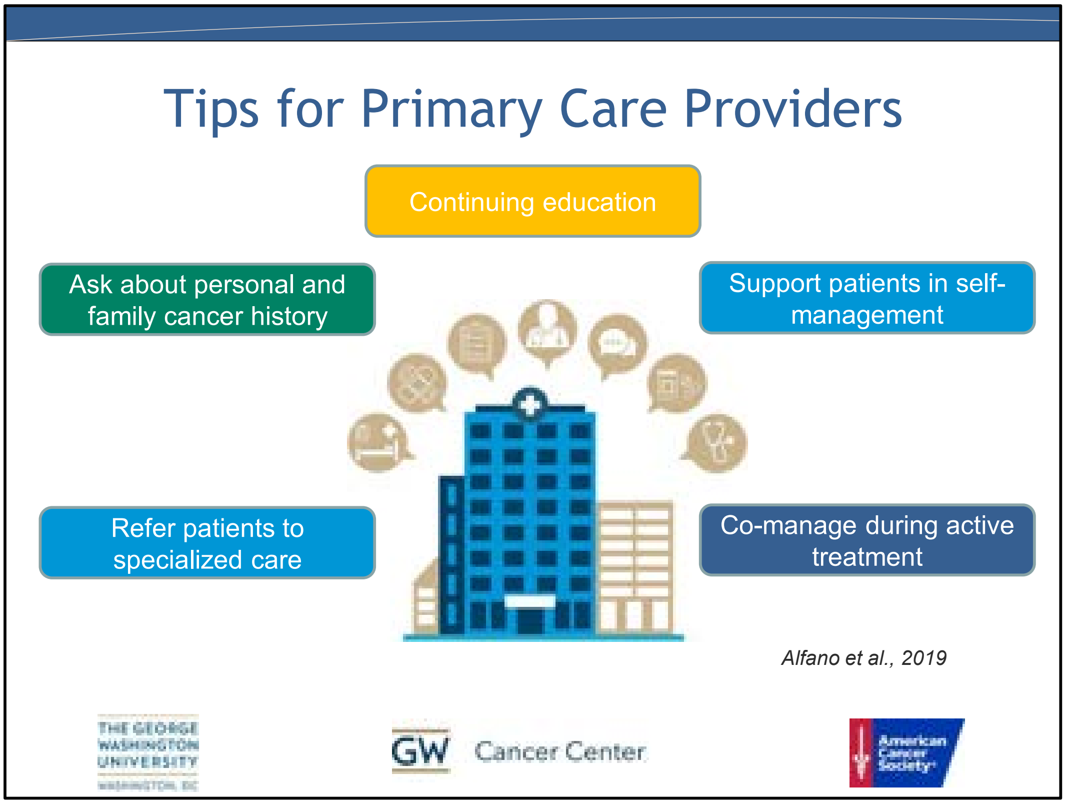
Unfortunately, the reality is typically a fragmented survivorship care.

Providers don’t usually communicate across settings through electronic health records or written communication. It can be difficult for providers to navigate the relationships formed between survivors and their oncology providers. Additionally, oncology providers lack training and education for general care while primary care providers lack training and education for cancer-specific care. This mismatch in confidence and skills can impact the quality of care provided.

It can also be confusing for survivors because it isn’t clear who has responsibility for what care (Neuman, 2016b). For example, who is supposed to do cancer screenings for other cancers?

Expectations for cancer survivorship care is changing and the cancer survivor population continues to grow.

These are all factors to consider when caring for survivors and working towards less fragmented care.



Tips for Primary Care Providers

Continuing education

Ask about personal and family cancer history

Support patients in self-management

Refer patients to specialized care

Co-manage during active treatment

Alfano et al., 2019

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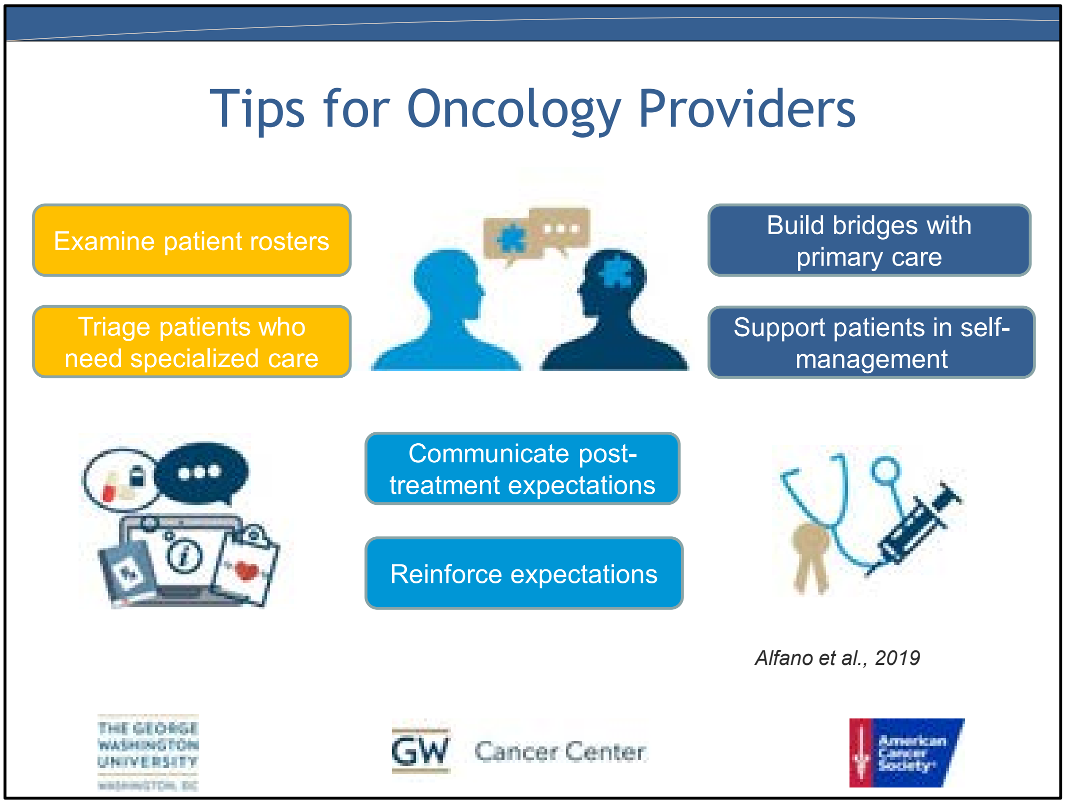
Here are some tips and strategies for primary care providers to improve survivorship care in their settings.

- Ask patients about their cancer history, including their personal history and family members' history; request oncology treatment records and survivorship care plans, and document treatment and care needs in the electronic health record
- Participate in formal (for example, continuing medical education) and informal training to increase understanding of cancer-related chronic and late effects
- Learn how to co-manage patients during active treatment and ongoing oncology-based follow-up care
- Participate in educational activities to increase comfort and skills in providing follow-up care for patients with cancer who are transitioned from oncology care
- Refer patients who previously received extensive cancer treatment and/or those experiencing chronic and late effects of treatment for specialized survivorship care
- Work toward supporting patients who are doing well in self-managing their health outside of surveillance visits
- And lastly, build bridges with oncology to understand survivors' risks and ongoing health care needs, better coordinate care, and facilitate referrals back to oncology if needs arise

https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21558



Tips for Oncology Providers

Examine patient rosters

Triage patients who need specialized care

Build bridges with primary care

Support patients in self-management

Communicate post-treatment expectations

Reinforce expectations

Alfano et al., 2019

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As survivors transition back to primary care, here are some tips and strategies for oncology providers to such transitions.

- Examine current patient rosters, clinic utilization patterns, and new patient visit slots and consider how shifting care of low-risk/low-need survivors to primary care would affect these factors
- Begin to triage patients who need specialized follow-up care to survivorship clinics
- Clearly communicate to patients from the time of diagnosis that they will be expected to continue to be followed by their primary care provider and likely will transition back to their primary care or a follow-up cancer survivorship clinic after treatments ends
- Reinforce expectations about follow-up by ongoing communication throughout cancer treatment
- Work toward supporting patients who are doing well in self-managing their health outside of clinic visits
- And again, build bridges with primary care to better equip primary care providers with information that they need to care for their patients who are cancer survivors, coordinate care and facilitate referrals back to oncology if needs arise

Resources

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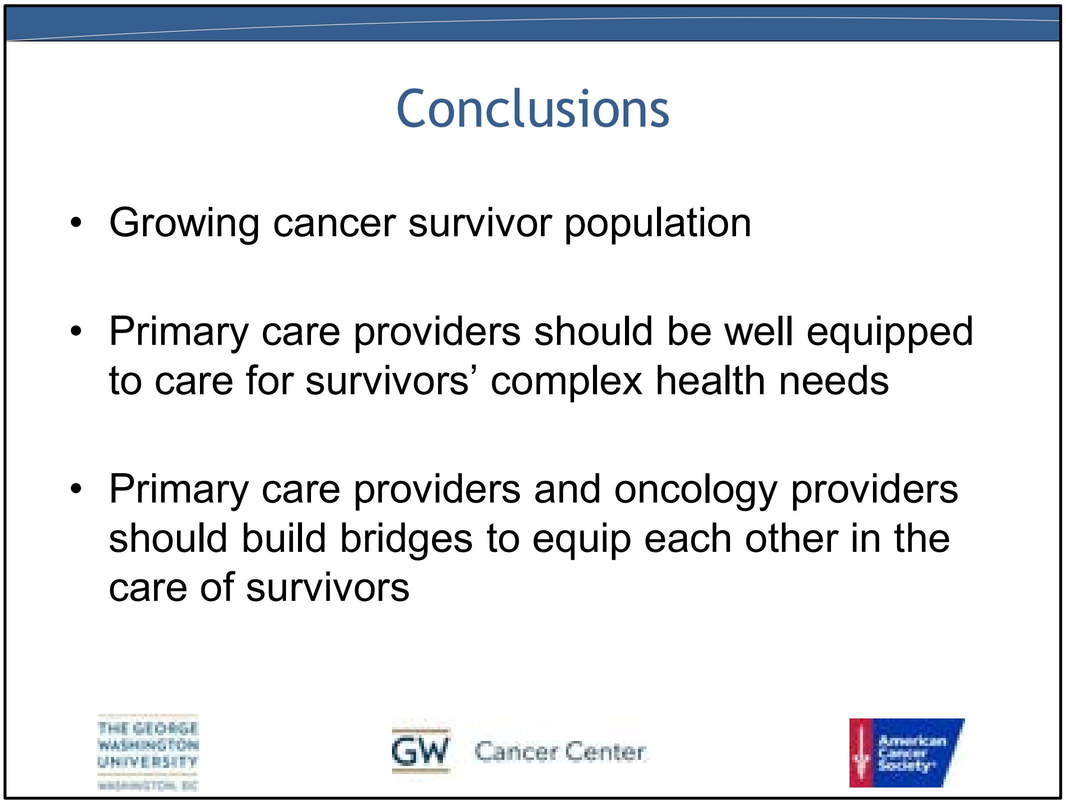
Resources for patients and providers are available in the learning management system. Please take time to browse and download resources relevant to your practice.



Conclusions

- Growing cancer survivor population
- Primary care providers should be well equipped to care for survivors' complex health needs
- Primary care providers and oncology providers should build bridges to equip each other in the care of survivors

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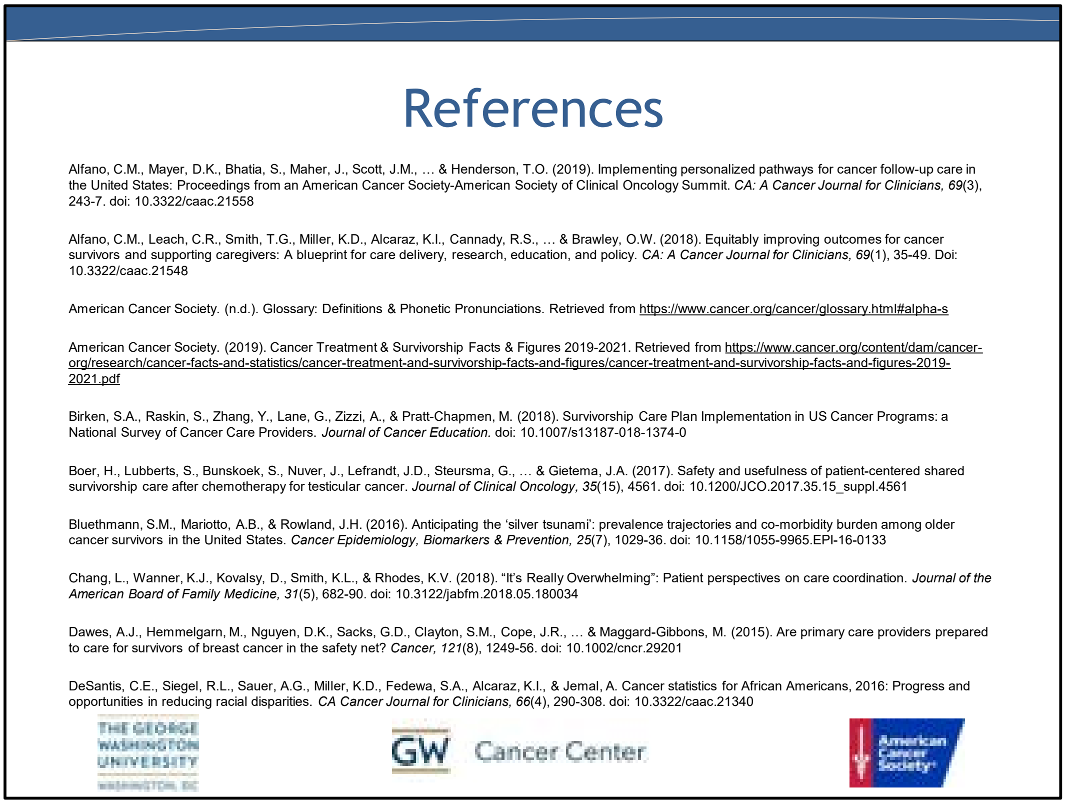
In conclusion, as the cancer survivor population grows, primary care providers will need to be well equipped to care for their complex health needs. This includes long-term and late effects, psychosocial needs, and healthy lifestyle behaviors. Primary care providers and oncology providers need to build bridges to equip each other so that their patients receive the care that they need.

In future modules, we will explore in more depth the long and late effects of cancer treatment, team approach to care and spotlight specific types of cancer.



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This concludes the presentation, please continue to explore the remaining sections of the cancer survivorship e-learning series.

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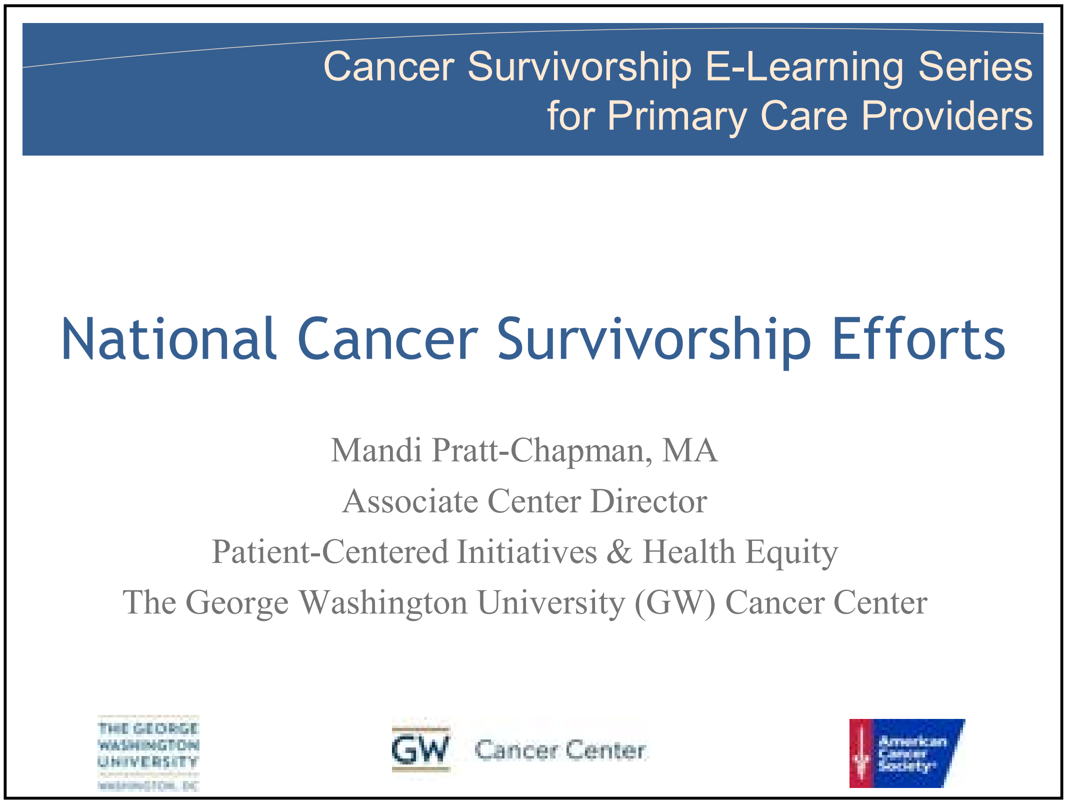

Cancer Survivorship E-Learning Series
for Primary Care Providers

National Cancer Survivorship Efforts

Mandi Pratt-Chapman, MA
Associate Center Director
Patient-Centered Initiatives & Health Equity
The George Washington University (GW) Cancer Center

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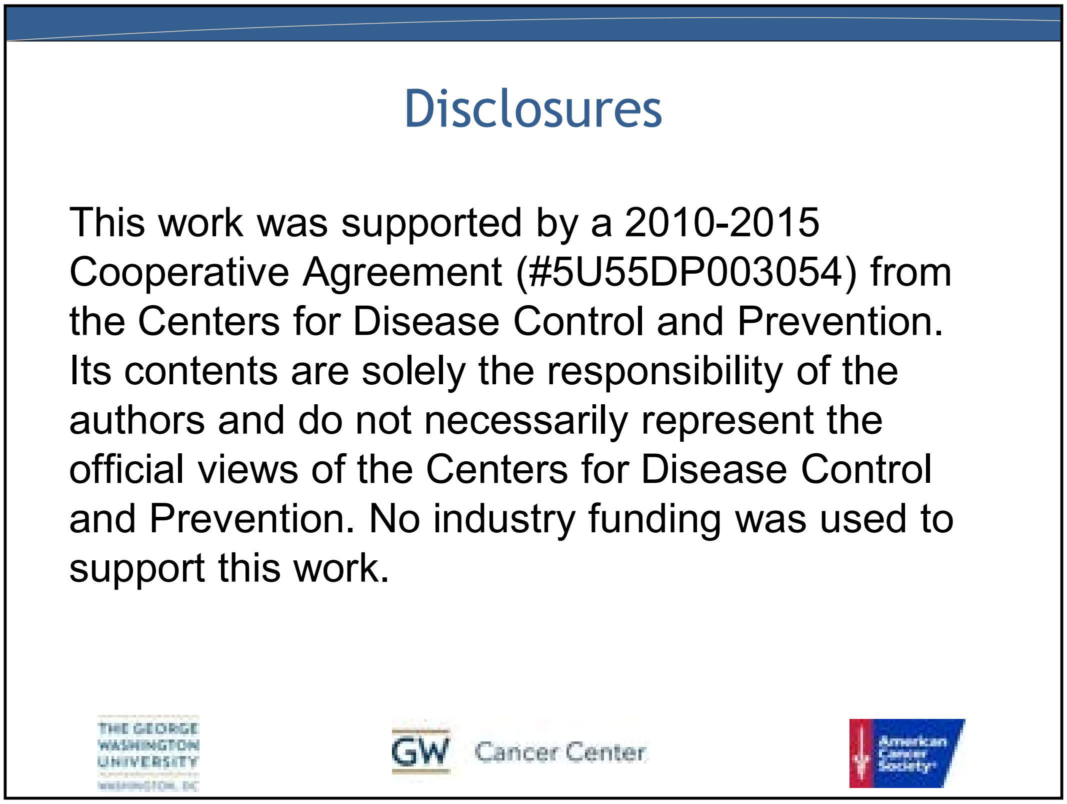
Welcome to the National Cancer Survivorship Resource Center e-learning series. I'm Mandi Pratt-Chapman, co-PI of the Survivorship Center with Dr. Catherine Alfano at the American Cancer Society. The Cancer Survivorship e-learning Series was developed by the GW Cancer Center as part of the National Survivorship Resource Center. We are grateful to the Centers for Disease Control and Prevention as a partner and funder of this work.



Disclosures

This work was supported by a 2010-2015 Cooperative Agreement (#5U55DP003054) from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention. No industry funding was used to support this work.

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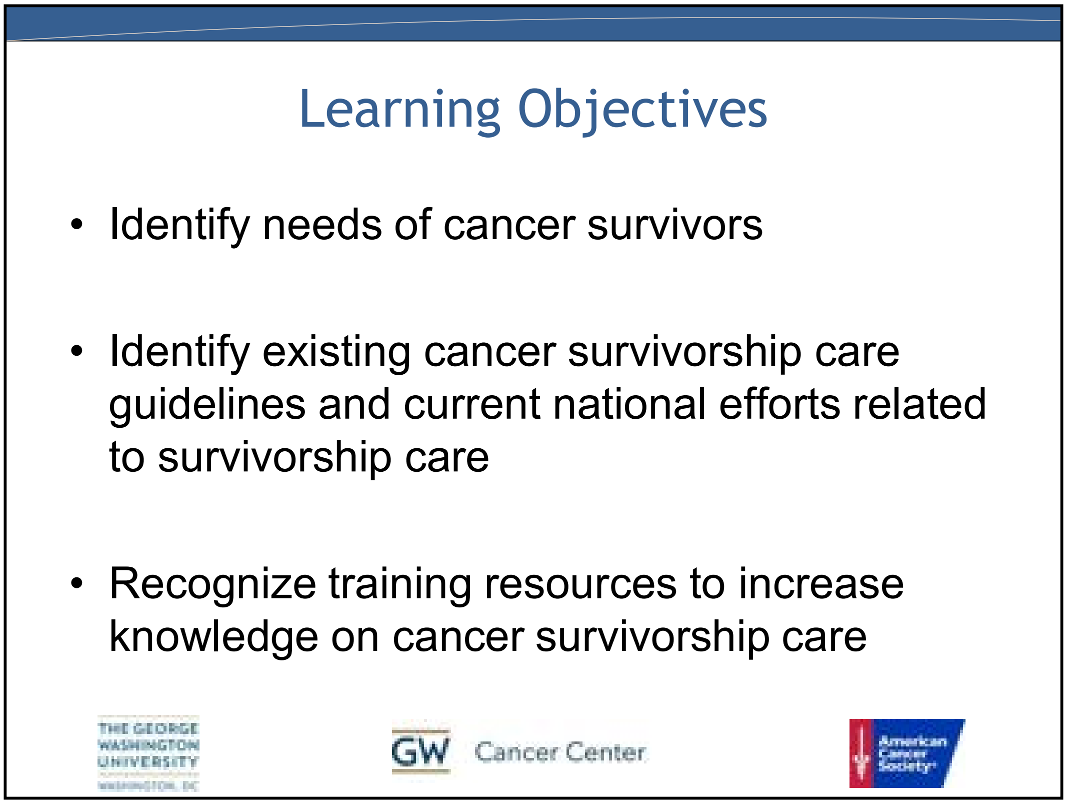

Learning Objectives

- Identify needs of cancer survivors
- Identify existing cancer survivorship care guidelines and current national efforts related to survivorship care
- Recognize training resources to increase knowledge on cancer survivorship care

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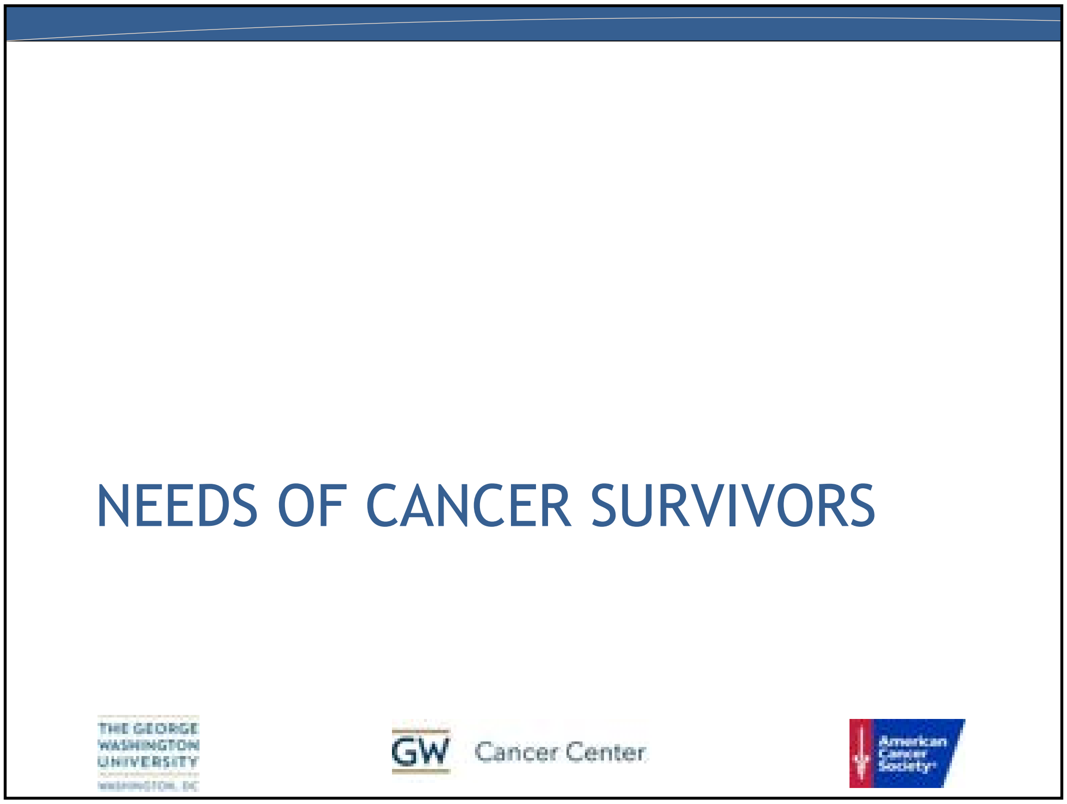
At the end of my presentation, you should be able to…

Identify needs of cancer survivors

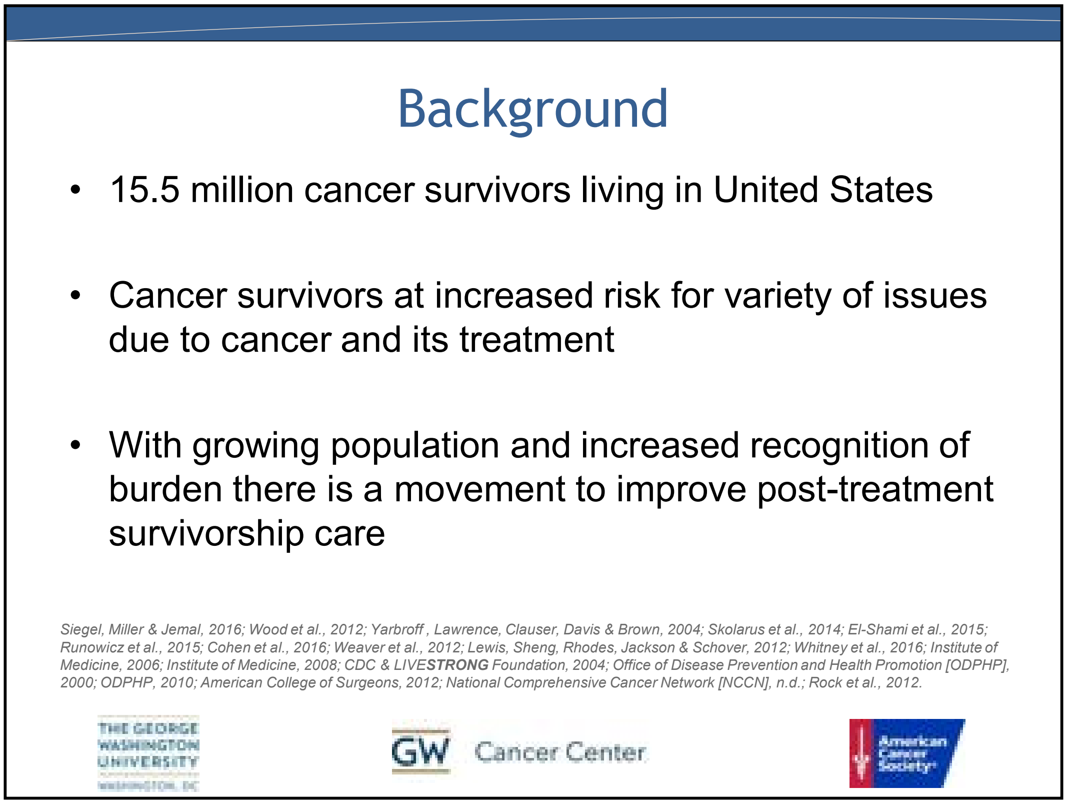
Identify existing cancer survivorship care guidelines and current national efforts related to survivorship care

Recognize training resources to increase knowledge on cancer survivorship care



NEEDS OF CANCER SURVIVORS

Let’s start with the needs of cancer survivors.



Background

- 15.5 million cancer survivors living in United States
- Cancer survivors at increased risk for variety of issues due to cancer and its treatment
- With growing population and increased recognition of burden there is a movement to improve post-treatment survivorship care

*Siegel, Miller & Jemal, 2016; Wood et al., 2012; Yarbroff , Lawrence, Clauser, Davis & Brown, 2004; Skolarus et al., 2014; El-Shami et al., 2015; Runowicz et al., 2015; Cohen et al., 2016; Weaver et al., 2012; Lewis, Sheng, Rhodes, Jackson & Schover, 2012; Whitney et al., 2016; Institute of Medicine, 2006; Institute of Medicine, 2008; CDC & LIVE**STRONG** Foundation, 2004; Office of Disease Prevention and Health Promotion [ODPHP], 2000; ODPHP, 2010; American College of Surgeons, 2012; National Comprehensive Cancer Network [NCCN], n.d.; Rock et al., 2012.*

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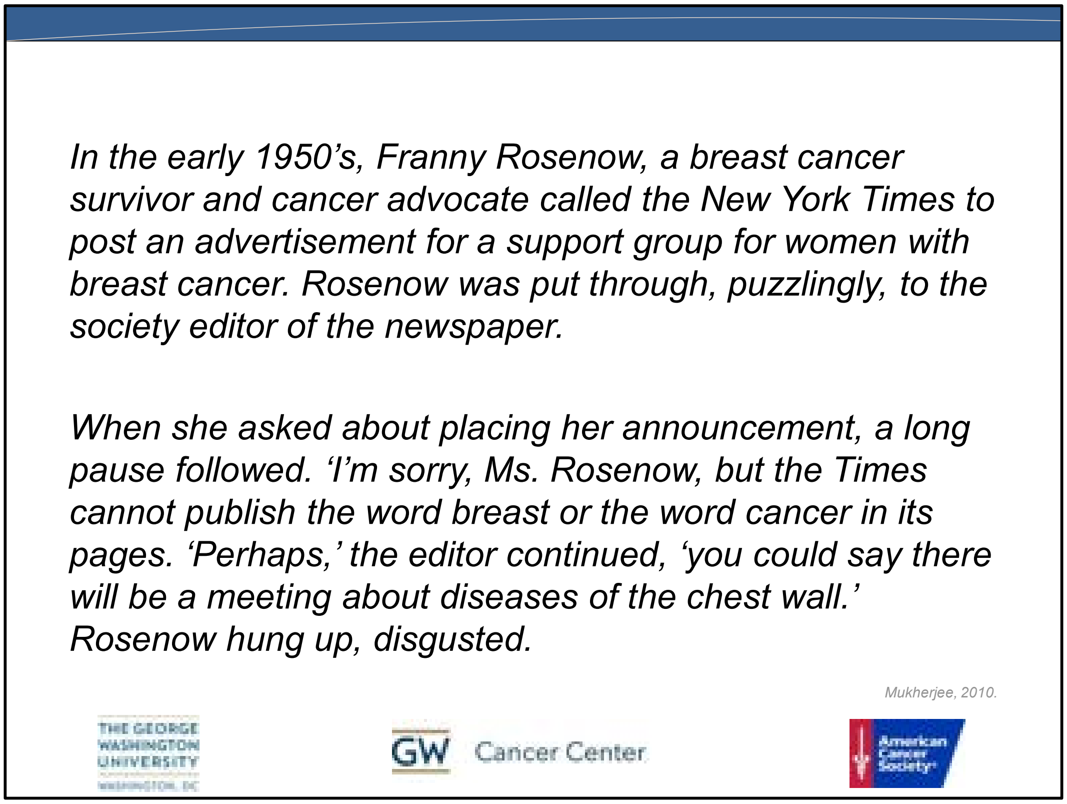
There are about 15.5 million cancer survivors living in the United States as of 2016. Cancer survivors are at increased risk for long term and late effects resulting from cancer and cancer treatment.

The growing population of cancer survivors requires us, as health care and public health professionals, to pay attention to the post-treatment needs of survivors. We can do this by engaging patients in their care and disseminating evidence-based practice as well as practice-based evidence to improve the quality of care that cancer survivors receive.



In the early 1950's, Franny Rosenow, a breast cancer survivor and cancer advocate called the New York Times to post an advertisement for a support group for women with breast cancer. Rosenow was put through, puzzlingly, to the society editor of the newspaper.

When she asked about placing her announcement, a long pause followed. 'I'm sorry, Ms. Rosenow, but the Times cannot publish the word breast or the word cancer in its pages. 'Perhaps,' the editor continued, 'you could say there will be a meeting about diseases of the chest wall.' Rosenow hung up, disgusted.

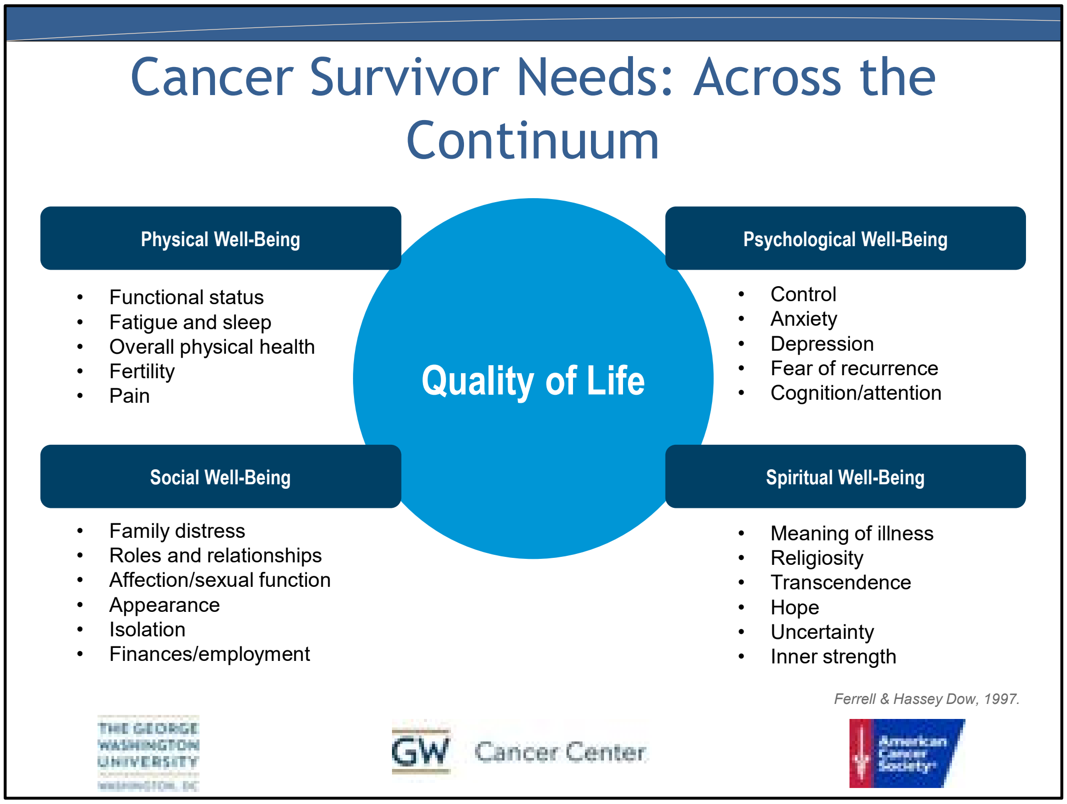
Mukherjee, 2010.

This excerpt from The Emperor of All Maladies highlights that the impact of the disease and its treatment has not always been talked about or acknowledged publicly.

In the early 1950's, Franny Rosenow, a breast cancer survivor and cancer advocate called the New York Times to post an advertisement for a support group for women with breast cancer. Rosenow was put through, puzzlingly, to the society editor of the newspaper.

When she asked about placing her announcement, a long pause followed. 'I'm sorry, Ms. Rosenow, but the Times cannot publish the word breast or the word cancer in its pages. 'Perhaps,' the editor continued, 'you could say there will be a meeting about diseases of the chest wall.' Rosenow hung up, disgusted.

This story illustrates the reluctance of American society and the media to address cancer head on in the 1950s. If a cancer patient, did survive their treatment for cancer, there was a general expectation that the patient would just "move on" after treatment. Yet, for many people impacted by cancer that was not enough. Cancer advocates, advocacy groups, caregivers, health care providers and many others have worked and continue to work to improve the quality of care for cancer patients and survivors as well as their quality of life.



Cancer Survivor Needs: Across the Continuum

Quality of Life

Physical Well-Being

- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain

Psychological Well-Being

- Control
- Anxiety
- Depression
- Fear of recurrence
- Cognition/attention

Social Well-Being

- Family distress
- Roles and relationships
- Affection/sexual function
- Appearance
- Isolation
- Finances/employment

Spiritual Well-Being

- Meaning of illness
- Religiosity
- Transcendence
- Hope
- Uncertainty
- Inner strength

Ferrell & Hassey Dow, 1997.

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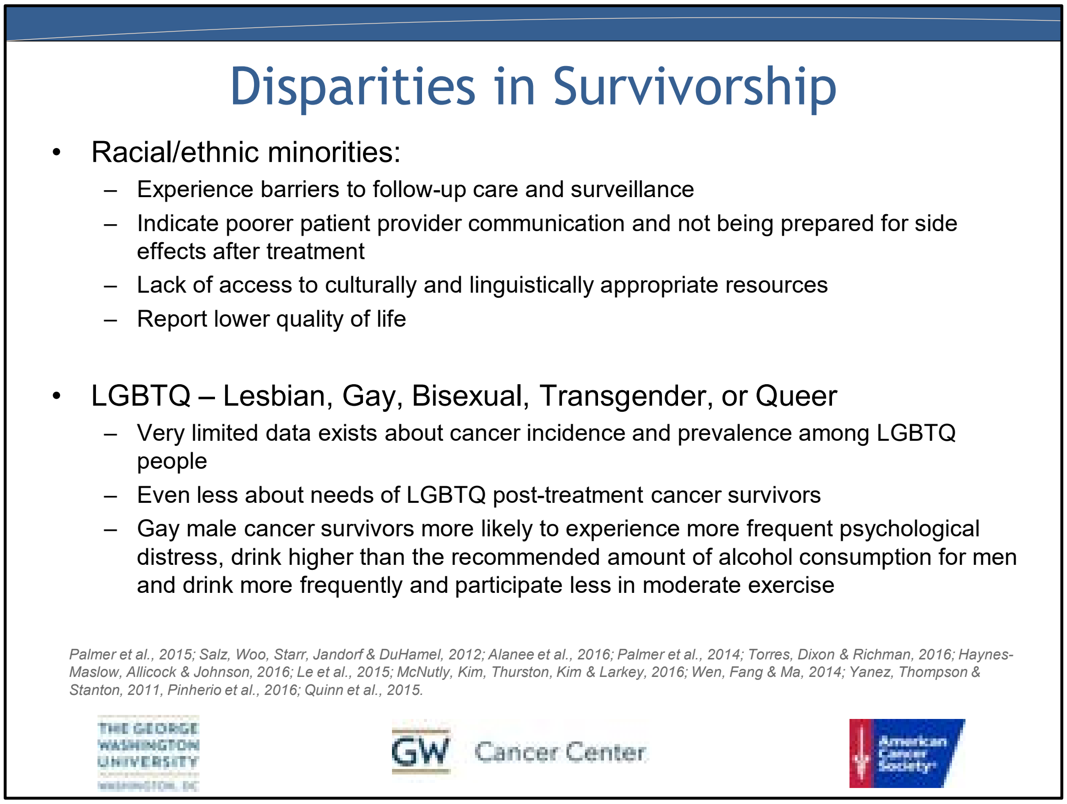
Cancer can impact quality of life across these 4 major domains: physical well-being, psychological well-being, social well-being and spiritual or existential well-being. These domains are all interrelated. For example, a survivor who fears recurrence may be less likely to seek treatment for physical issues, which may impact their social and spiritual well-being. The example constructs within each domain are illustrative, but not exhaustive. Their may be other impacts that cancer survivors experience, as well. This model, developed by Betty Ferrell and colleagues at the City of Hope provides a helpful starting point as we consider the needs of cancer survivors generally.

https://www.ncbi.nlm.nih.gov/pubmed/9130276



Disparities in Survivorship

- Racial/ethnic minorities:
  - Experience barriers to follow-up care and surveillance
  - Indicate poorer patient provider communication and not being prepared for side effects after treatment
  - Lack of access to culturally and linguistically appropriate resources
  - Report lower quality of life

- LGBTQ – Lesbian, Gay, Bisexual, Transgender, or Queer
  - Very limited data exists about cancer incidence and prevalence among LGBTQ people
  - Even less about needs of LGBTQ post-treatment cancer survivors
  - Gay male cancer survivors more likely to experience more frequent psychological distress, drink higher than the recommended amount of alcohol consumption for men and drink more frequently and participate less in moderate exercise

Palmer et al., 2015; Salz, Woo, Starr, Jandorf & DuHamel, 2012; Alanee et al., 2016; Palmer et al., 2014; Torres, Dixon & Richman, 2016; Haynes-Maslow, Allicock & Johnson, 2016; Le et al., 2015; McNutly, Kim, Thurston, Kim & Larkey, 2016; Wen, Fang & Ma, 2014; Yanez, Thompson & Stanton, 2011, Pinherio et al., 2016; Quinn et al., 2015.

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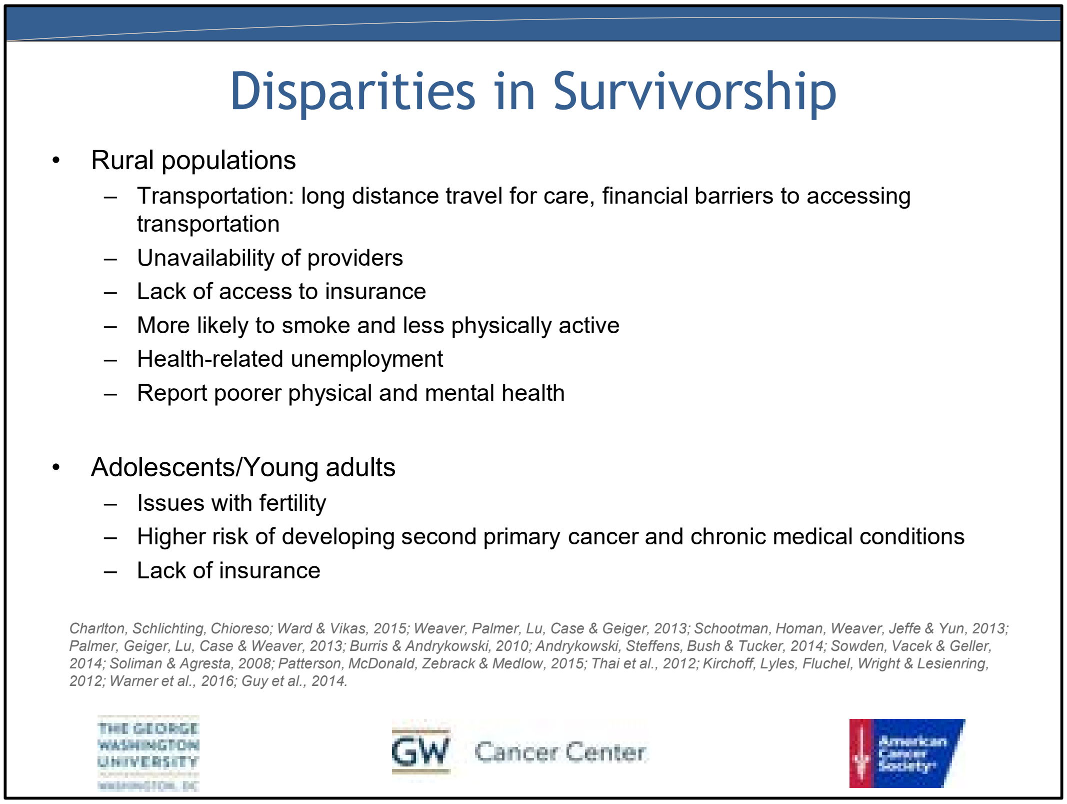
Cancer survivor needs are as diverse as cancer survivors themselves. Just as there are disparities in screening and treatment, there are disparities in overall survival as well as survivorship quality of life. Cancer survivors that are part of traditionally underserved or minority populations may experience greater barriers to follow up care and cancer surveillance. Cancer survivors who have health care providers that do not share the same life experiences in terms of racial, ethnic, sexual or gender identity may experience worse communication with providers. Resources for cancer survivors are often not culturally tailored. And the other aspects of life that a cancer survivor experiences – including geography, income and employment status along with treatment sequelae – can result in lower quality of life for some survivors.

In terms of sexual and gender minorities – or lesbian, gay, bisexual, transgender and queer cancer survivors – we have very little data. We do know that LGBTQ individuals tend to have higher behavioral risk factors due to tobacco industry targeting and risky coping strategies that may be due to ongoing stigma and societal stress. LGBTQ individuals have unique psychological, social and sexual experiences post-treatment, as well. We need much more research on LGBTQ cancer patients and survivors in order to better serve these groups.

Palmer et al., 2015; Salz, Woo, Starr, Jandorf & DuHamel, 2012; Alanee et al., 2016;

Palmer et al., 2014; Torres, Dixon & Richman, 2016; Haynes-Maslow, Allicock & Johnson, 2016; Le et al., 2015; McNutly, Kim, Thurston, Kim & Larkey, 2016; Wen, Fang & Ma, 2014; Yanez, Thompson & Stanton, 2011, Pinherio et al., 2016

Quinn et al., 2015



Disparities in Survivorship

- Rural populations
  - Transportation: long distance travel for care, financial barriers to accessing transportation
  - Unavailability of providers
  - Lack of access to insurance
  - More likely to smoke and less physically active
  - Health-related unemployment
  - Report poorer physical and mental health

- Adolescents/Young adults
  - Issues with fertility
  - Higher risk of developing second primary cancer and chronic medical conditions
  - Lack of insurance

Charlton, Schlichting, Chioreso; Ward & Vikas, 2015; Weaver, Palmer, Lu, Case & Geiger, 2013; Schootman, Homan, Weaver, Jeffe & Yun, 2013; Palmer, Geiger, Lu, Case & Weaver, 2013; Burris & Andrykowski, 2010; Andrykowski, Steffens, Bush & Tucker, 2014; Sowden, Vacek & Geller, 2014; Soliman & Agresta, 2008; Patterson, McDonald, Zebrack & Medlow, 2015; Thai et al., 2012; Kirchoff, Lyles, Fluchel, Wright & Lesienring, 2012; Warner et al., 2016; Guy et al., 2014.

Rural populations also have unique barriers to accessing treatment as well as long-term follow up care. The need to travel long distances to reach cancer specialists is a clear obstacle for rural cancer survivors. There are fewer health care providers in rural areas. And residents of rural areas are more likely to have health-related unemployment as well as poorer physical and mental health.

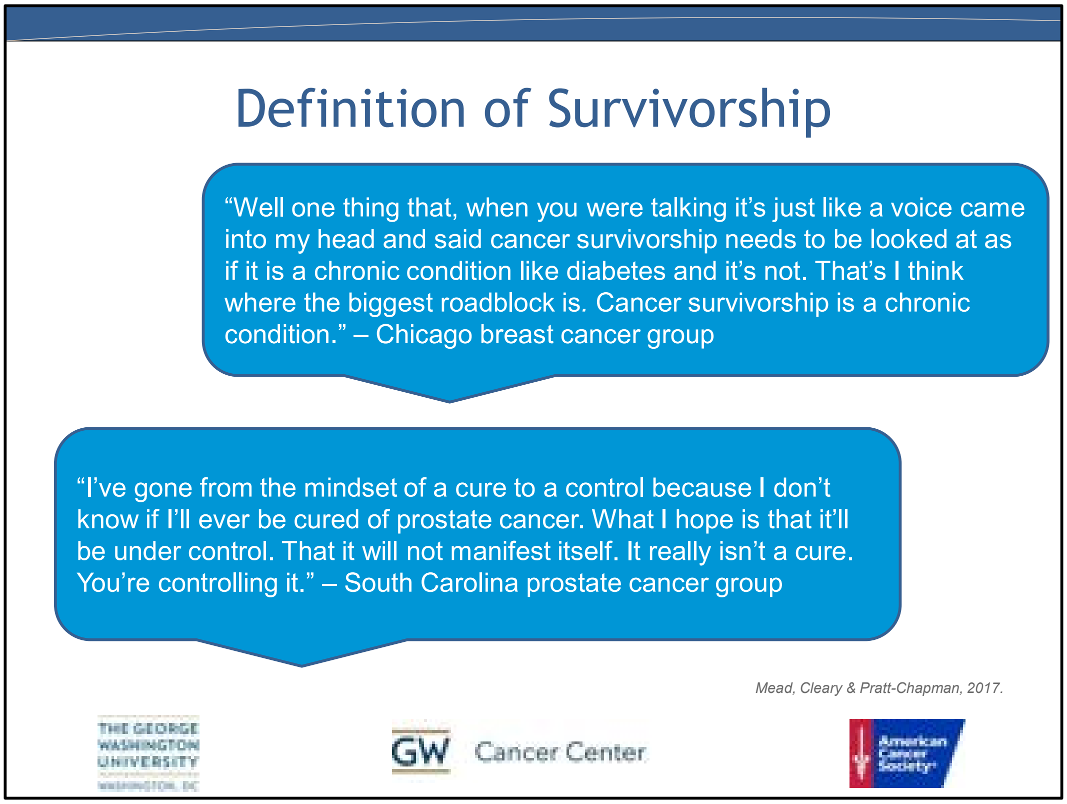
Adolescents and young adults who experience cancer face a disruption in their lives during a critical developmental period – issues of fertility preservation may be a concern for these patients. Adolescent and young adult cancer survivors are also at greater risk for developing second cancers and other chronic illnesses.

Both rural and young adults have historically been at a higher risk of being uninsured. The Affordable Care Act provided some important consumer protections to cancer patients, making it illegal to drop a cancer patient from insurance or deny insurance because of a cancer diagnosis. The ACA also allowed young adults to stay on their parent's insurance plans until age 26.

Charlton, Schlichting, Chioreso, Ward & Vikas, 2015

Weaver, Palmer, Lu, Case & Geiger, 2013; Schootman, Homan, Weaver, Jeffe & Yun, 2013; Palmer, Geiger, Lu, Case & Weaver, 2013; Burris & Andrykowski, 2010; Andrykowski, Steffens, Bush & Tucker, 2014; Sowden, Vacek & Geller, 2014

Soliman & Agresta, 2008; Patterson, McDonald, Zebrack & Medlow, 2015; Thai et al., 2012; Kirchoff, Lyles, Fluchel, Wright & Lesienring, 2012; Warner et al., 2016; Guy et al., 2014



Definition of Survivorship

"Well one thing that, when you were talking it's just like a voice came into my head and said cancer survivorship needs to be looked at as if it is a chronic condition like diabetes and it's not. That's I think where the biggest roadblock is. Cancer survivorship is a chronic condition." – Chicago breast cancer group

"I've gone from the mindset of a cure to a control because I don't know if I'll ever be cured of prostate cancer. What I hope is that it'll be under control. That it will not manifest itself. It really isn't a cure. You're controlling it." – South Carolina prostate cancer group

Mead, Cleary & Pratt-Chapman, 2017.

From 2012 through 2016, I worked with my colleagues Holly Mead and Sean Cleary at GW to better understand what cancer survivors wanted in terms of post-treatment health care. Here are some of the things we heard in survivor focus groups:

"Well one thing that, when you were talking it's just like a voice came into my head and said cancer survivorship needs to be looked at as if it is a chronic condition like diabetes and it's not. That's I think where the biggest roadblock is. Cancer survivorship is a chronic condition." – Chicago breast cancer group

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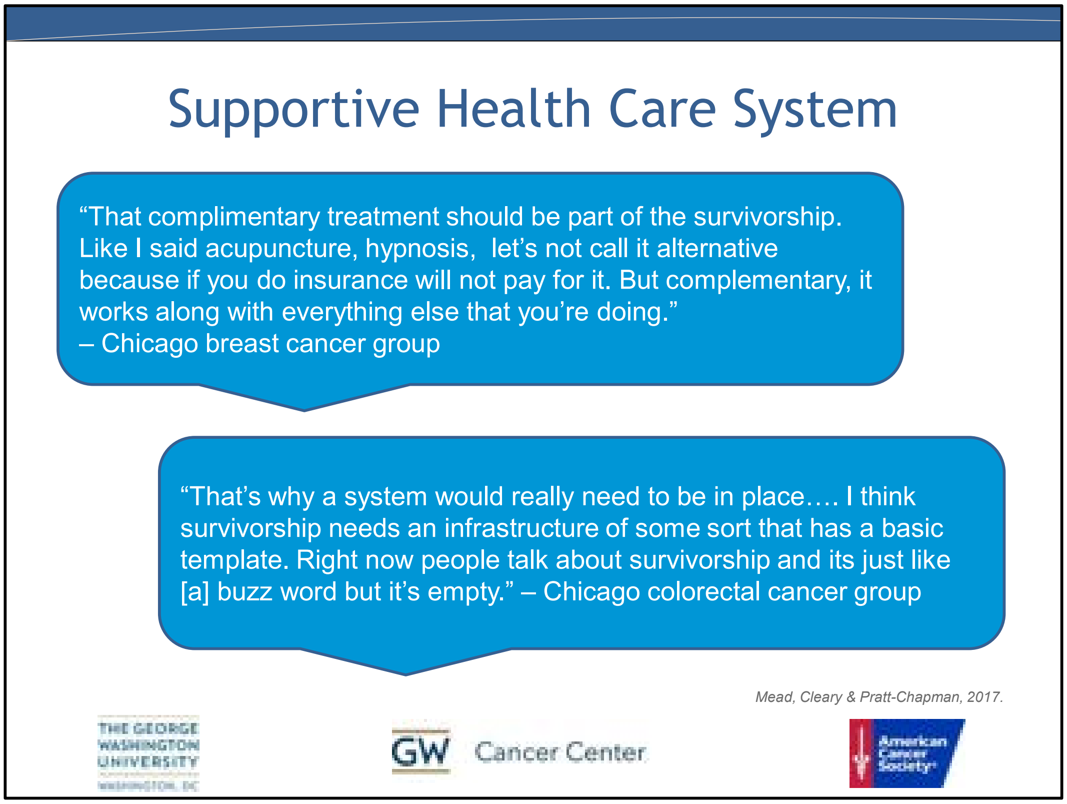
Here we see survivors expressing the long-term nature of cancer survivorship, the need to adjust to that experience of having been diagnosed with cancer and potentially continuing to need specialized health care long term.

Mead, K.H., Cleary, S., Pratt-Chapman, M. (2017). *Development of a Patient-Prioritized Quality of Care Framework for Cancer Survivorship*. Manuscript in preparation.



Supportive Health Care System

“That complimentary treatment should be part of the survivorship. Like I said acupuncture, hypnosis, let’s not call it alternative because if you do insurance will not pay for it. But complementary, it works along with everything else that you’re doing.”
– Chicago breast cancer group

“That’s why a system would really need to be in place…. I think survivorship needs an infrastructure of some sort that has a basic template. Right now people talk about survivorship and its just like [a] buzz word but it’s empty.” – Chicago colorectal cancer group

Mead, Cleary & Pratt-Chapman, 2017.

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Cancer survivors also noted the need for supportive health care systems. Those systems require a holistic approach and infrastructure to support survivorship services.

One breast cancer survivor in Chicago said,

“That complimentary treatment should be part of the survivorship. Like I said acupuncture, hypnosis, let’s not call it alternative because if you do insurance will not pay for it. But complementary, it works along with everything else that you’re doing.”

– Chicago breast cancer group

Another survivor noted,

“That’s why a system would really need to be in place…. I think survivorship needs an infrastructure of some sort that has a basic template. Right now people talk about survivorship and its just like [a] buzz word but it’s empty.” – Chicago colorectal cancer group

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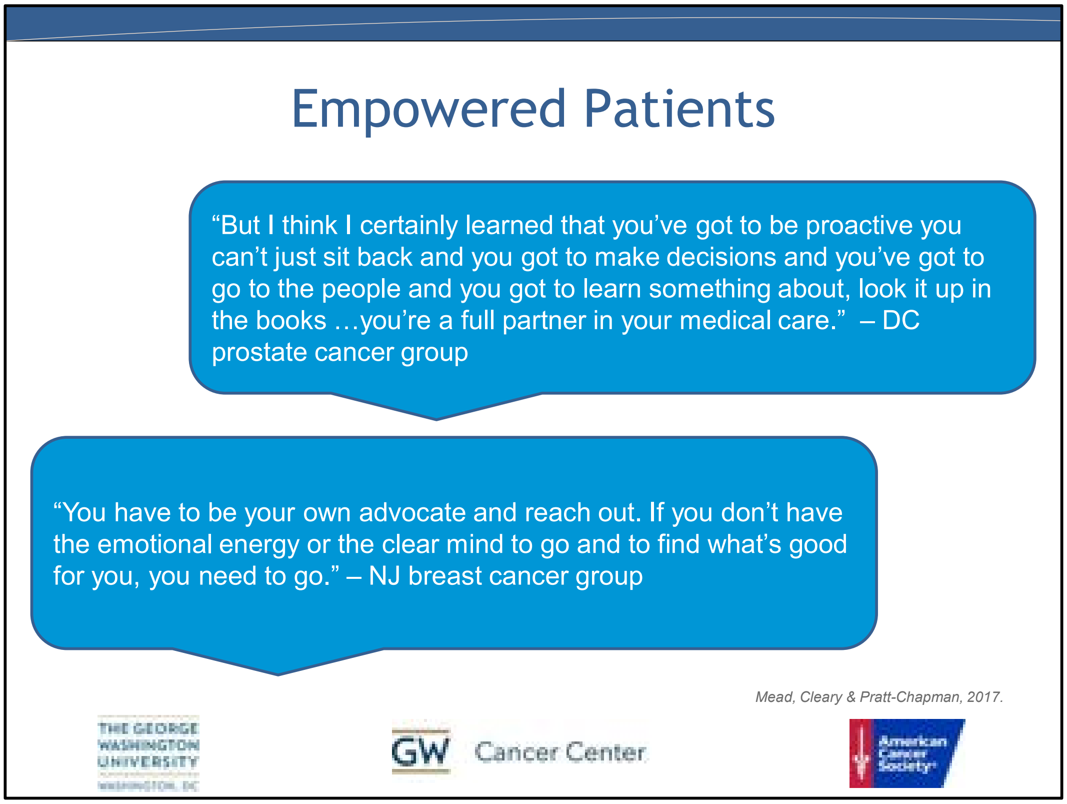

Empowered Patients

"But I think I certainly learned that you've got to be proactive you can't just sit back and you got to make decisions and you've got to go to the people and you got to learn something about, look it up in the books …you're a full partner in your medical care." – DC prostate cancer group

"You have to be your own advocate and reach out. If you don't have the emotional energy or the clear mind to go and to find what's good for you, you need to go." – NJ breast cancer group

Mead, Cleary & Pratt-Chapman, 2017.

Another major insight of our study was cancer survivors acknowledging a need to be proactive about their own health and health care experiences.

A prostate cancer survivor from Washington DC noted,

"But I think I certainly learned that you've got to be proactive you can't just sit back and you got to make decisions and you've got to go to the people and you got to learn something about, look it up in the books …you're a full partner in your medical care." – DC prostate cancer group

And a New Jersey breast cancer survivor said:

"You have to be your own advocate and reach out. If you don't have the emotional energy or the clear mind to go and to find what's good for you, you need to go." – NJ breast cancer group

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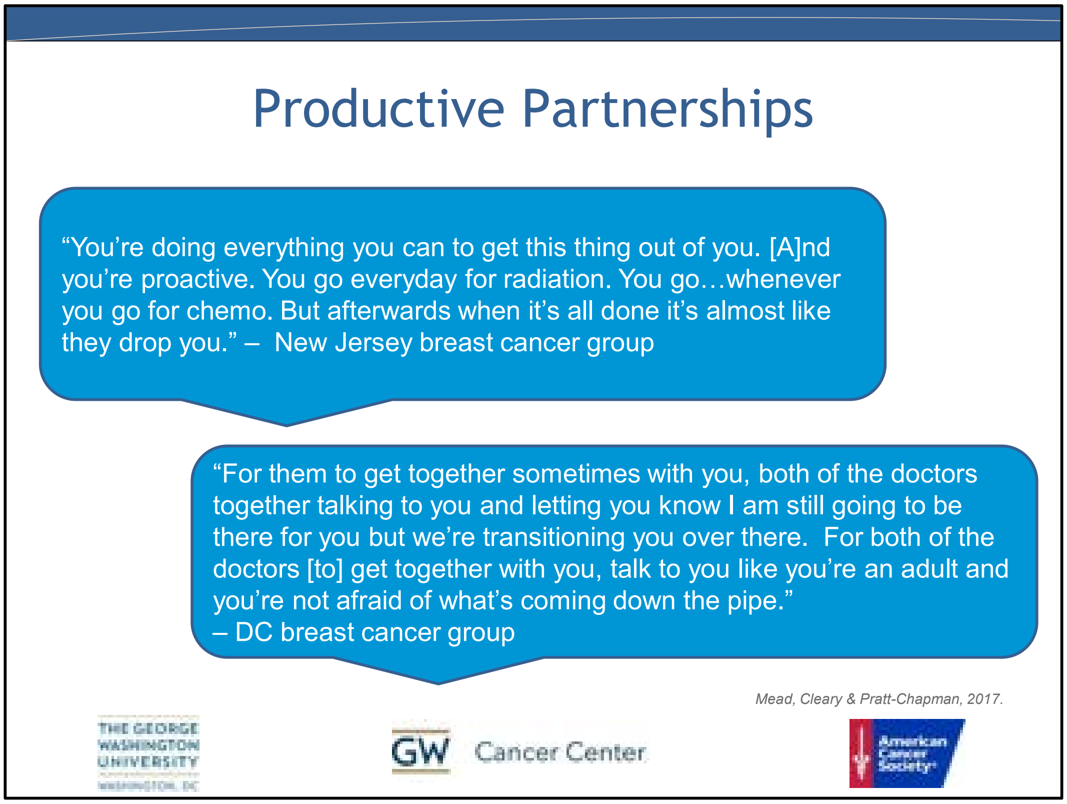

Productive Partnerships

“You’re doing everything you can to get this thing out of you. [A]nd you’re proactive. You go everyday for radiation. You go…whenever you go for chemo. But afterwards when it’s all done it’s almost like they drop you.” – New Jersey breast cancer group

“For them to get together sometimes with you, both of the doctors together talking to you and letting you know I am still going to be there for you but we’re transitioning you over there. For both of the doctors [to] get together with you, talk to you like you’re an adult and you’re not afraid of what’s coming down the pipe.”
– DC breast cancer group

Mead, Cleary & Pratt-Chapman, 2017.

Finally, we heard from cancer survivors that they need better care coordination between their health care providers and ongoing support after treatment.

One survivor said:

“You’re doing everything you can to get this thing out of you. [A]nd you’re proactive. You go everyday for radiation. You go…whenever you go for chemo. But afterwards when it’s all done it’s almost like they drop you.” – New Jersey breast cancer group

Another said:

“For them to get together sometimes with you, both of the doctors together talking to you and letting you know I am still going to be there for you but we’re transitioning you over there. For both of the doctors [to] get together with you, talk to you like you’re an adult and you’re not afraid of what’s coming down the pipe.”
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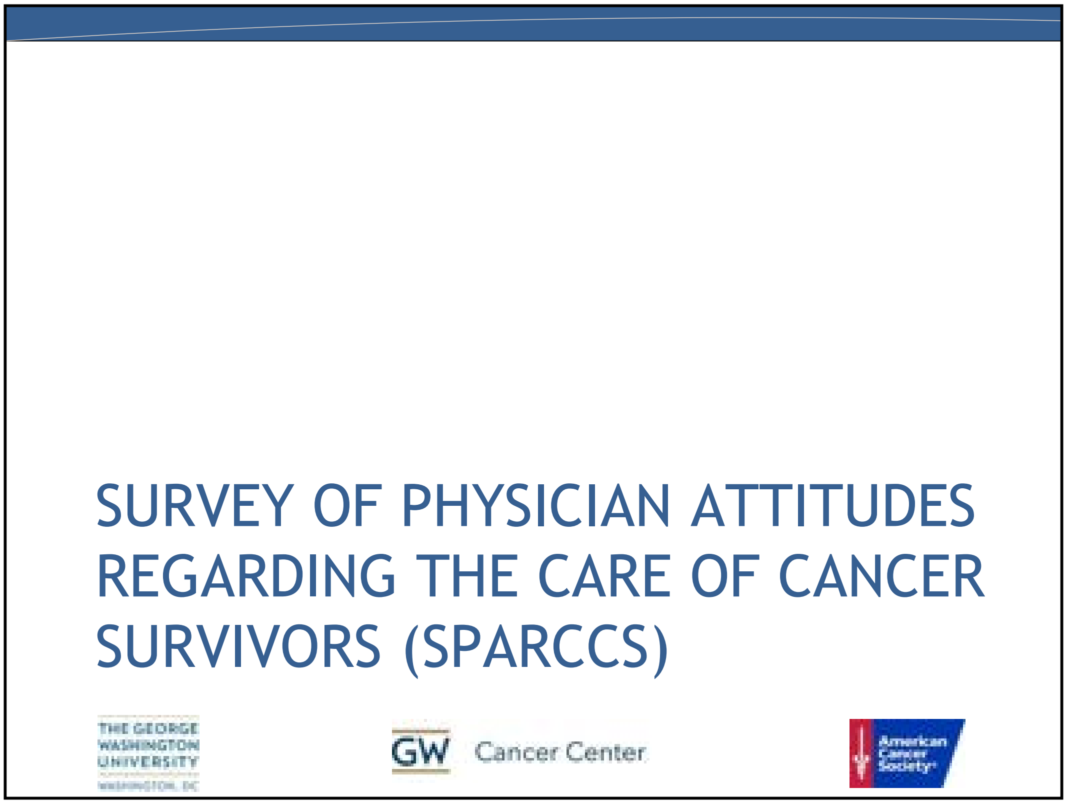

SURVEY OF PHYSICIAN ATTITUDES REGARDING THE CARE OF CANCER SURVIVORS (SPARCCS)

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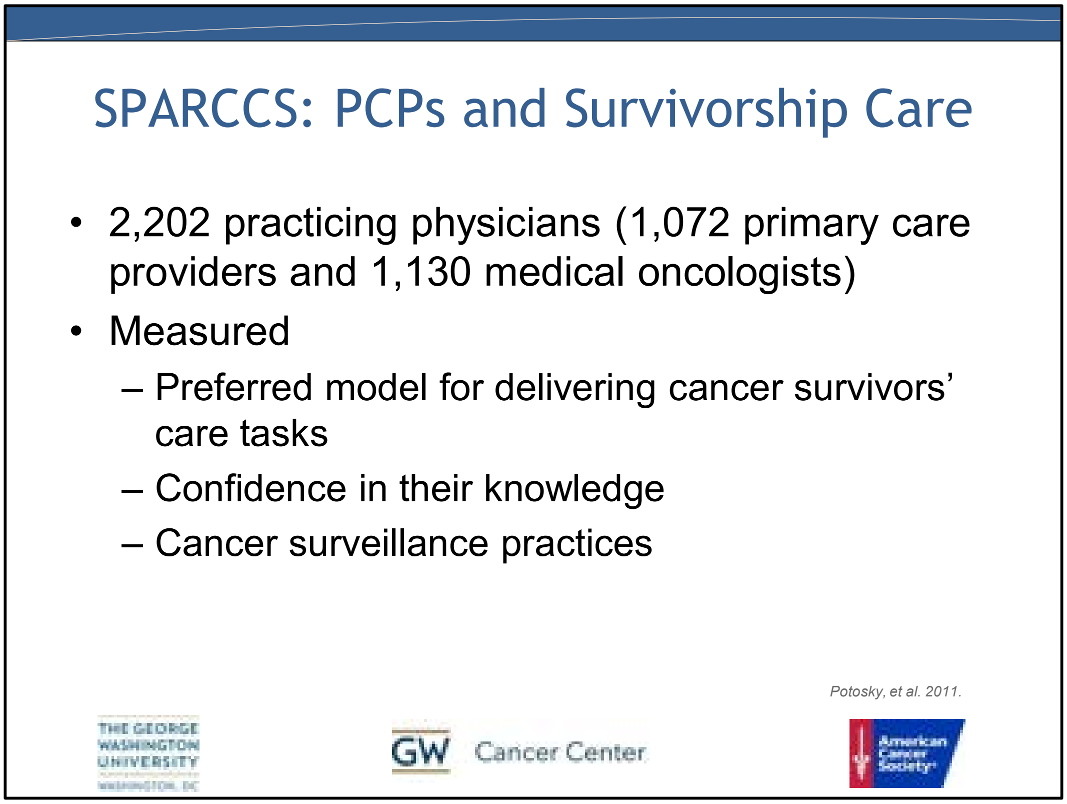
One of the seminal studies in the field of cancer survivorship was the SPARCCS study which examined physician attitudes about care of cancer survivors.



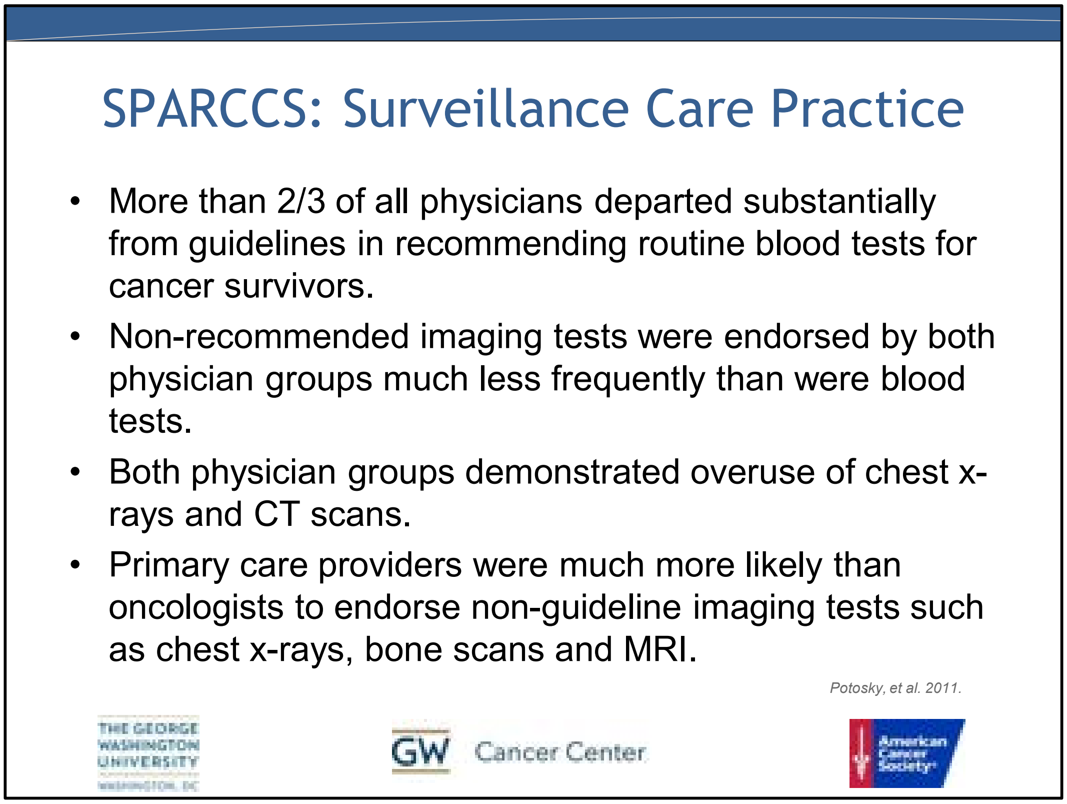
SPARCCS: PCPs and Survivorship Care

- 2,202 practicing physicians (1,072 primary care providers and 1,130 medical oncologists)
- Measured
  - Preferred model for delivering cancer survivors' care tasks
  - Confidence in their knowledge
  - Cancer surveillance practices

Potosky, et al. 2011.

A sample of 2,202 physicians assessed differences between medical oncologists and primary care providers in terms of preferences for delivering cancer survivorship services, confidence in survivorship knowledge and self-reported cancer surveillance practices.

Potosky, A. L., Han, P. K. J., Rowland, J., Klabunde, C. N., Smith, T., Aziz, N., … Stefanek, M. (2011). Differences Between Primary Care Physicians' and Oncologists' Knowledge, Attitudes and Practices Regarding the Care of Cancer Survivors. *Journal of General Internal Medicine*, *26*(12), 1403–1410. http://doi.org/10.1007/s11606-011-1808-4



SPARCCS: Surveillance Care Practice

- More than 2/3 of all physicians departed substantially from guidelines in recommending routine blood tests for cancer survivors.
- Non-recommended imaging tests were endorsed by both physician groups much less frequently than were blood tests.
- Both physician groups demonstrated overuse of chest x-rays and CT scans.
- Primary care providers were much more likely than oncologists to endorse non-guideline imaging tests such as chest x-rays, bone scans and MRI.

Potosky, et al. 2011.

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Results of the study showed that….

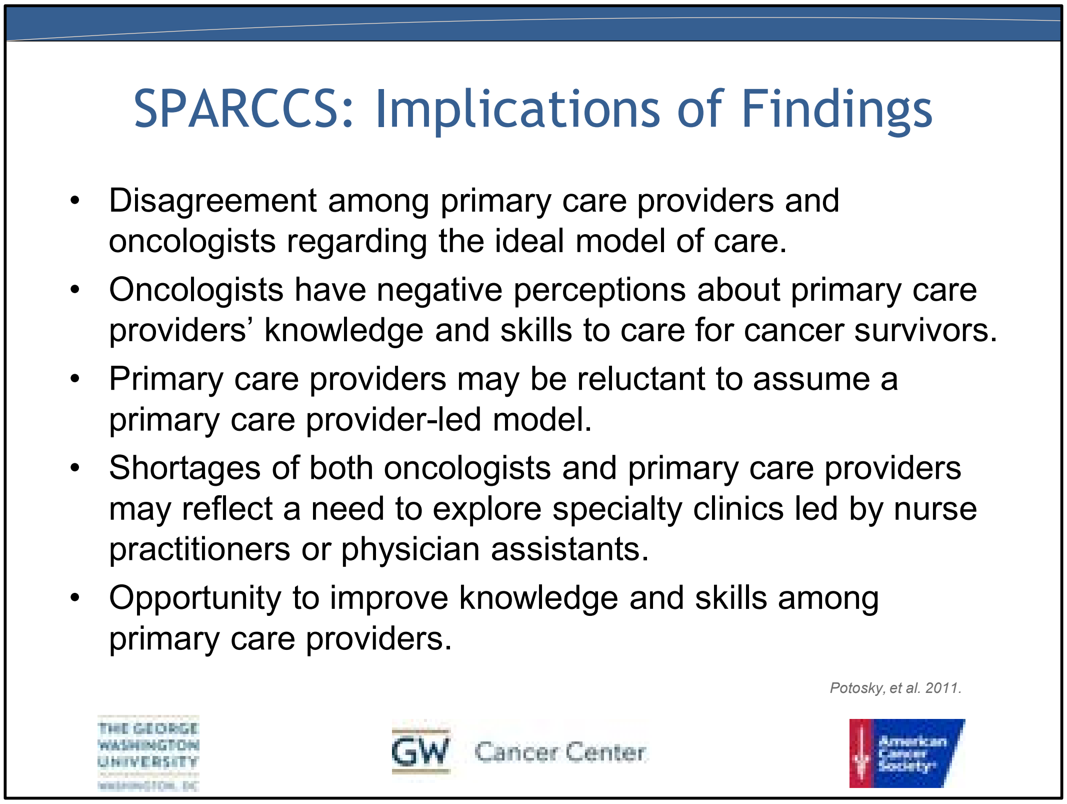
More than 2/3 of all physicians departed substantially from guidelines in recommending routine blood tests for cancer survivors.

Non-recommended imaging tests were endorsed by both physician groups much less frequently than were blood tests.

Both physician groups demonstrated overuse of chest x-rays and CT scans.

Primary care providers were much more likely than oncologists to endorse non-guideline imaging tests such as chest x-rays, bone scans and MRI.

Potosky, A. L., Han, P. K. J., Rowland, J., Klabunde, C. N., Smith, T., Aziz, N., … Stefanek, M. (2011). Differences Between Primary Care Physicians' and Oncologists' Knowledge, Attitudes and Practices Regarding the Care of Cancer Survivors. *Journal of General Internal Medicine*, *26*(12), 1403–1410. http://doi.org/10.1007/s11606-011-1808-4



SPARCCS: Implications of Findings

- Disagreement among primary care providers and oncologists regarding the ideal model of care.
- Oncologists have negative perceptions about primary care providers' knowledge and skills to care for cancer survivors.
- Primary care providers may be reluctant to assume a primary care provider-led model.
- Shortages of both oncologists and primary care providers may reflect a need to explore specialty clinics led by nurse practitioners or physician assistants.
- Opportunity to improve knowledge and skills among primary care providers.

Potosky, et al. 2011.

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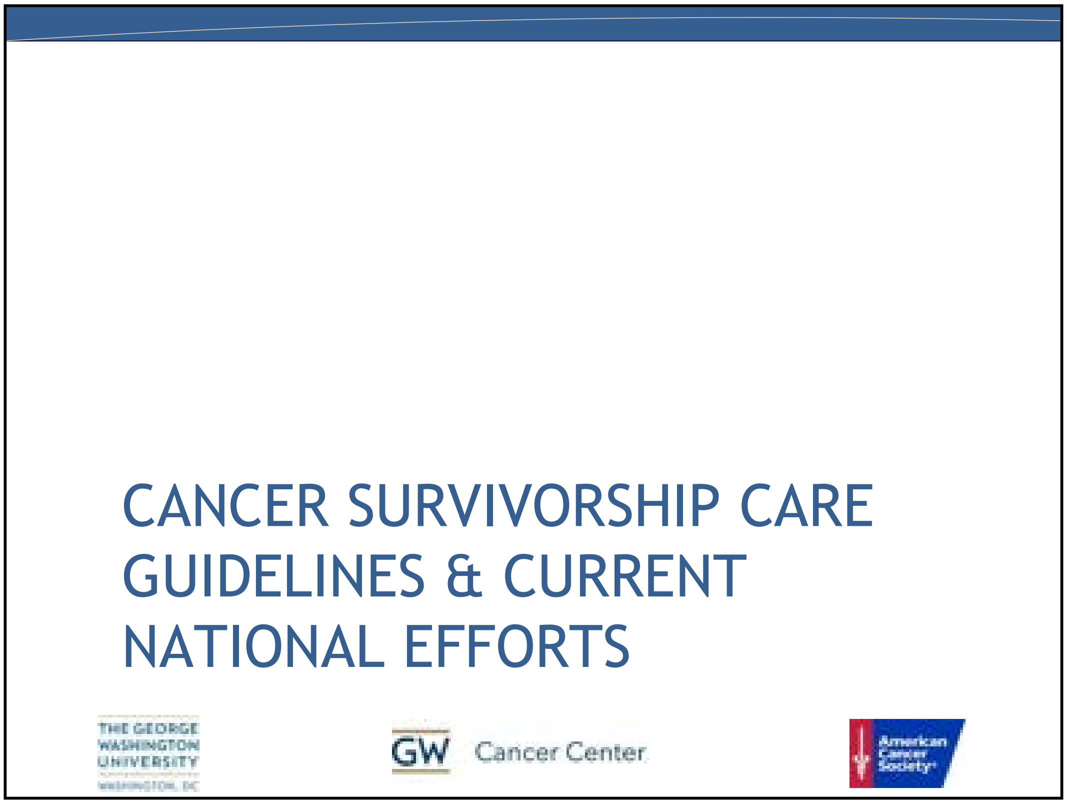
So what do we do with these findings?

We know there is disagreement between physicians regarding what cancer survivorship care should look like and who should deliver that care. However, the shortage of both oncologists and primary care providers mean we need to work together to be efficient and provide high quality, highly coordinated care. Nurse practitioners and physician assistants play a key role in cancer survivorship care.

Finally, primary care providers need training on cancer survivorship to increase knowledge and confidence in providing care to cancer survivors. This Cancer Survivorship e-Learning series was developed in response to that need to broadly build capacity in the existing health care professional workforce to provide quality survivorship services to cancer survivors.

Potosky, A. L., Han, P. K. J., Rowland, J., Klabunde, C. N., Smith, T., Aziz, N., … Stefanek, M. (2011). Differences Between Primary Care Physicians' and Oncologists' Knowledge, Attitudes and Practices Regarding the Care of Cancer Survivors. *Journal of General Internal Medicine*, *26*(12), 1403–1410. http://doi.org/10.1007/s11606-011-1808-4



CANCER SURVIVORSHIP CARE GUIDELINES & CURRENT NATIONAL EFFORTS

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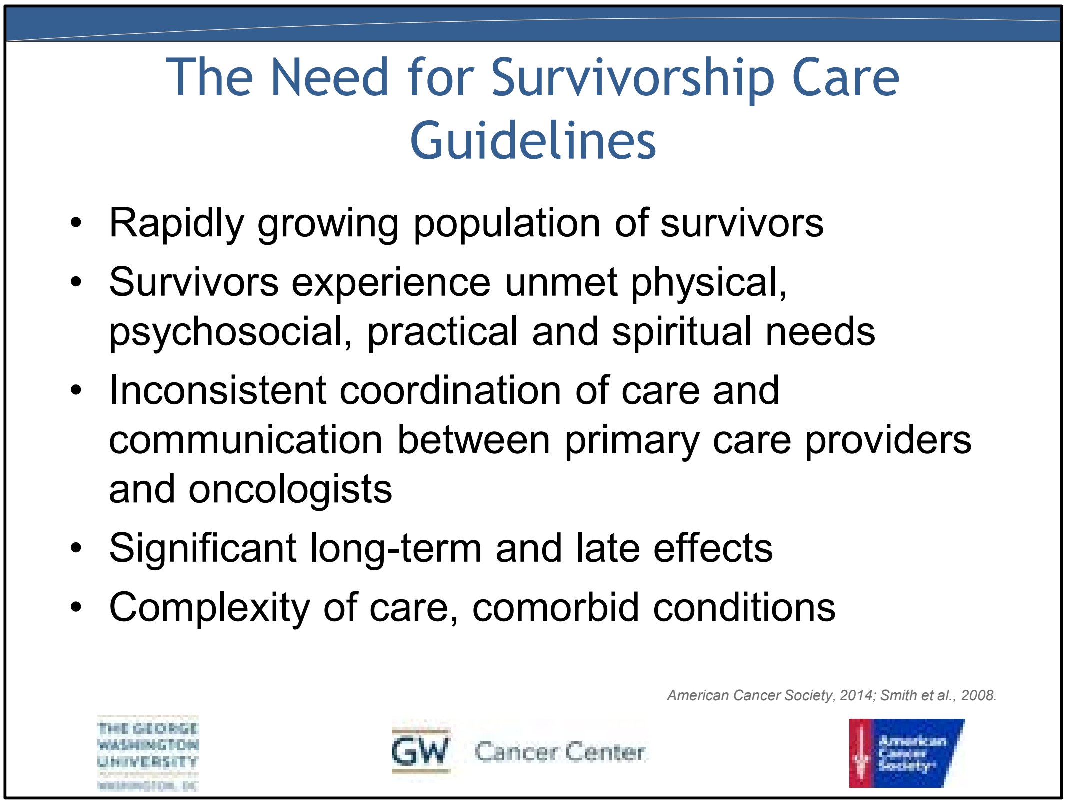
Now we will move on to national efforts and progress in the cancer survivorship field. I’m particularly excited to share with you progress in developing cancer survivorship care guidelines.



The Need for Survivorship Care Guidelines

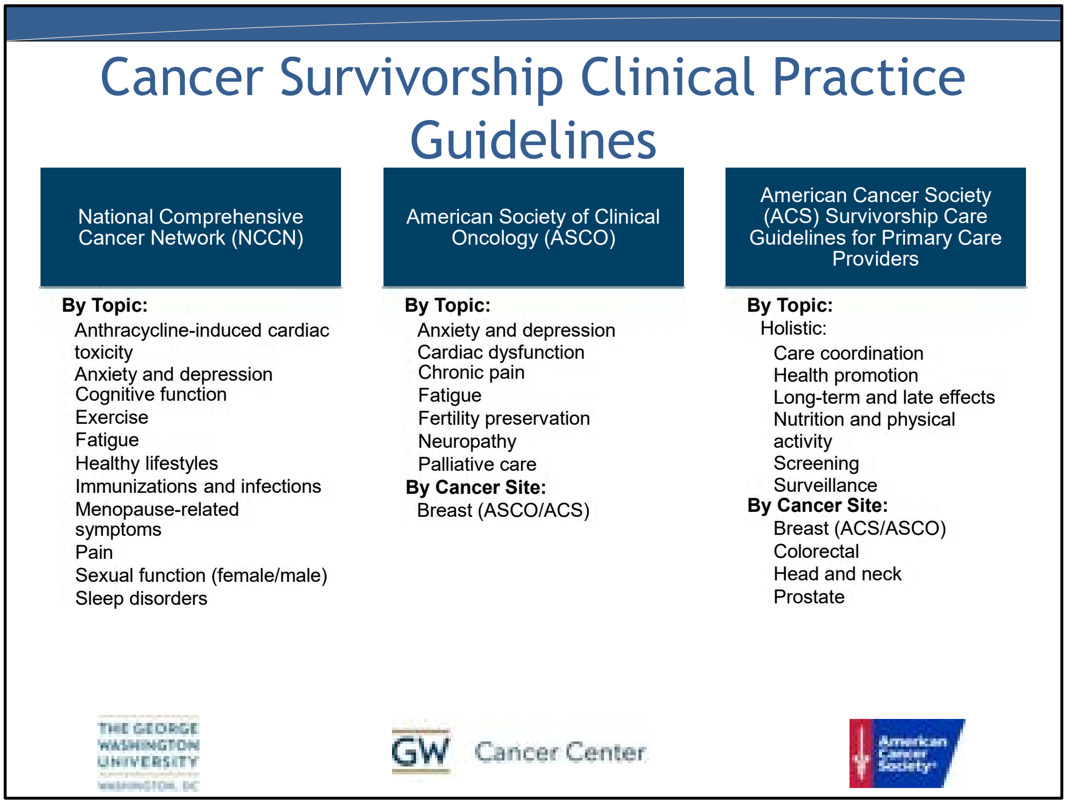
- Rapidly growing population of survivors
- Survivors experience unmet physical, psychosocial, practical and spiritual needs
- Inconsistent coordination of care and communication between primary care providers and oncologists
- Significant long-term and late effects
- Complexity of care, comorbid conditions

American Cancer Society, 2014; Smith et al., 2008.

We know there is a rapidly growing population of survivors with unmet needs.

We have heard from survivors that they need better care coordination and communication from and between their health care providers.

And while we don’t know everything there is to know about cancer and treatment impacts, we do know that both cancer and cancer treatment can lead to serious long-term and late effects including other cancers and other chronic illnesses.



Cancer Survivorship Clinical Practice Guidelines

National Comprehensive Cancer Network (NCCN)

By Topic:
- Anthracycline-induced cardiac toxicity
- Anxiety and depression
- Cognitive function
- Exercise
- Fatigue
- Healthy lifestyles
- Immunizations and infections
- Menopause-related symptoms
- Pain
- Sexual function (female/male)
- Sleep disorders

American Society of Clinical Oncology (ASCO)

By Topic:
- Anxiety and depression
- Cardiac dysfunction
- Chronic pain
- Fatigue
- Fertility preservation
- Neuropathy
- Palliative care

By Cancer Site:
- Breast (ASCO/ACS)

American Cancer Society (ACS) Survivorship Care Guidelines for Primary Care Providers

By Topic:
- Holistic:
  - Care coordination
  - Health promotion
  - Long-term and late effects
  - Nutrition and physical activity
  - Screening
  - Surveillance

By Cancer Site:
- Breast (ACS/ASCO)
- Colorectal
- Head and neck
- Prostate

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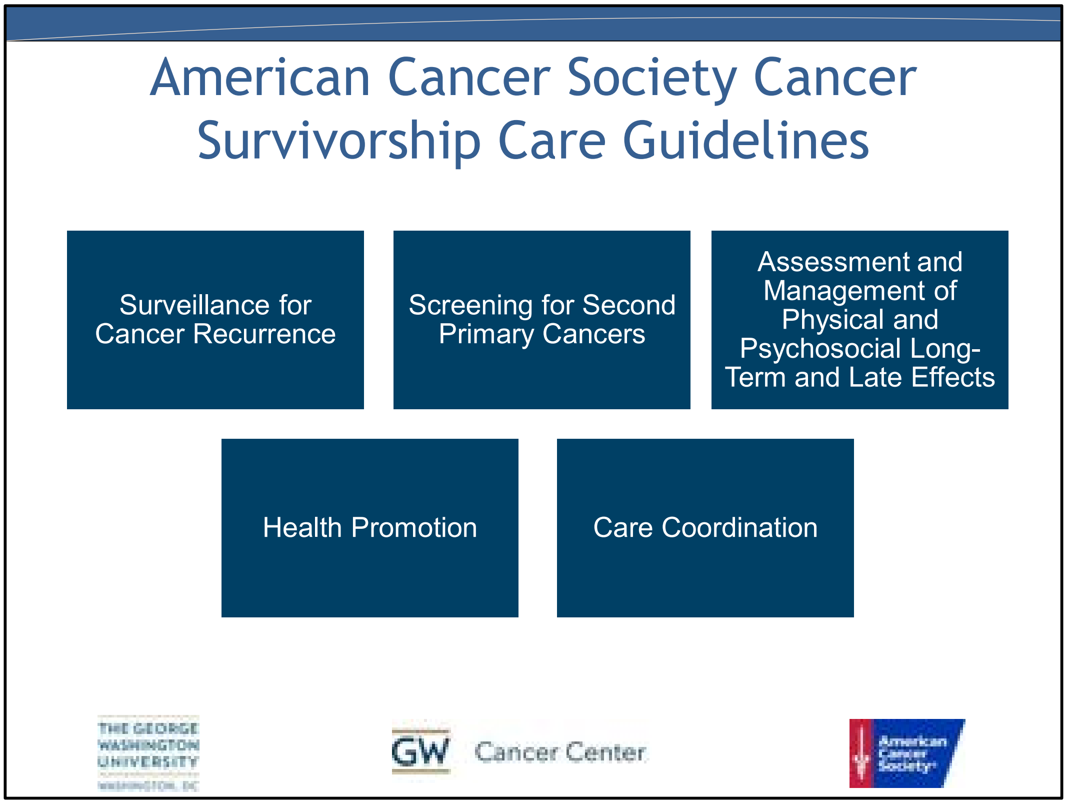
In recent years, the National Comprehensive Cancer Network, the American Society of Clinical Oncology and the American Cancer Society have been hard at work developing clinical care guidelines to help guide practitioners who care for cancer survivors. NCCN and ASCO have developed many symptom-based guidelines. And ACS developed four holistic guidelines for breast, colorectal, head and neck and prostate cancer as part of the National Cancer Survivorship Resource Center. ASCO jointly released the breast care guideline with ACS.



American Cancer Society Cancer Survivorship Care Guidelines

Surveillance for Cancer Recurrence

Screening for Second Primary Cancers

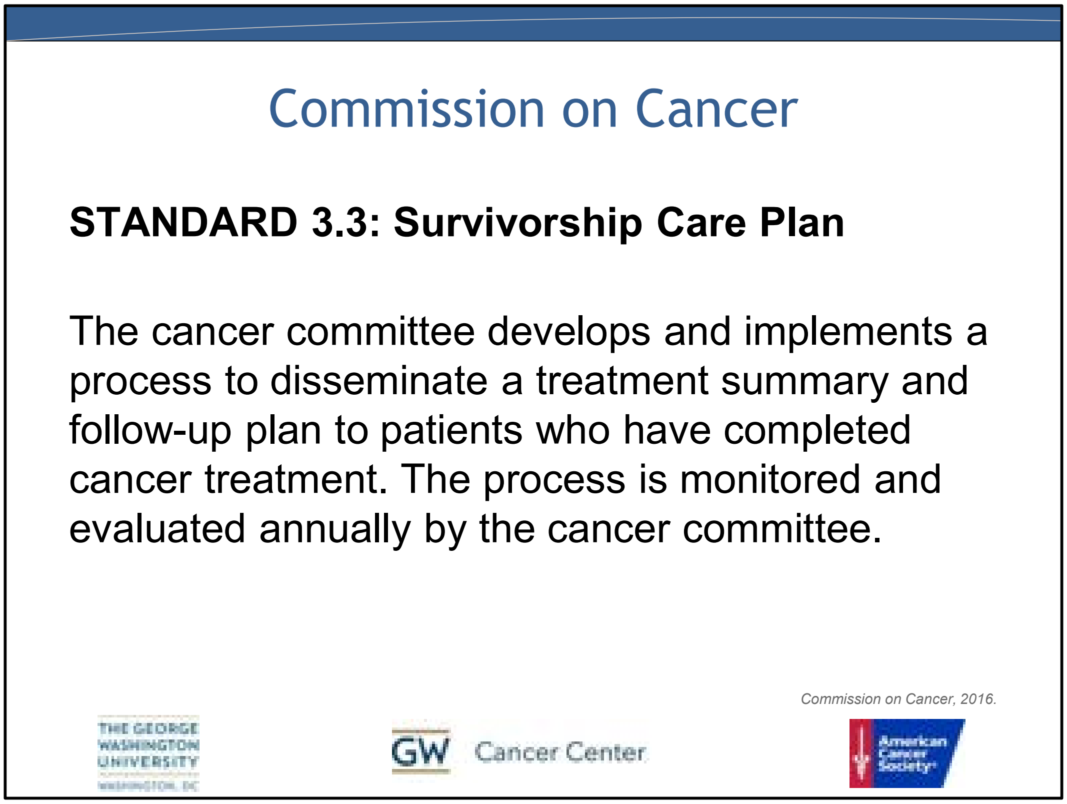
Assessment and Management of Physical and Psychosocial Long-Term and Late Effects

Health Promotion

Care Coordination

I was honored to be part of the development of all of the ACS guidelines, which cover:

- Surveillance for Cancer Recurrence
- Early Detection in Average Risk, Asymptomatic Individuals
- Assessment & Management of Physical & Psychosocial Long-Term & Late Effects
- Health Promotion and
- Care Coordination



Commission on Cancer

STANDARD 3.3: Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a treatment summary and follow-up plan to patients who have completed cancer treatment. The process is monitored and evaluated annually by the cancer committee.

Commission on Cancer, 2016.

Another major development in cancer survivorship was the stand that the American College of Surgeons' Commission on Cancer took in 2012 when it began requiring accredited programs to phase in provision of Survivorship Care Plans to patients treated with curative intent.

The CoC program guide specifies that: "The printed or electronic survivorship care plan must contain input from the principal physician and oncology care team who coordinated the oncology treatment as well as input from the patient's other care providers if applicable.

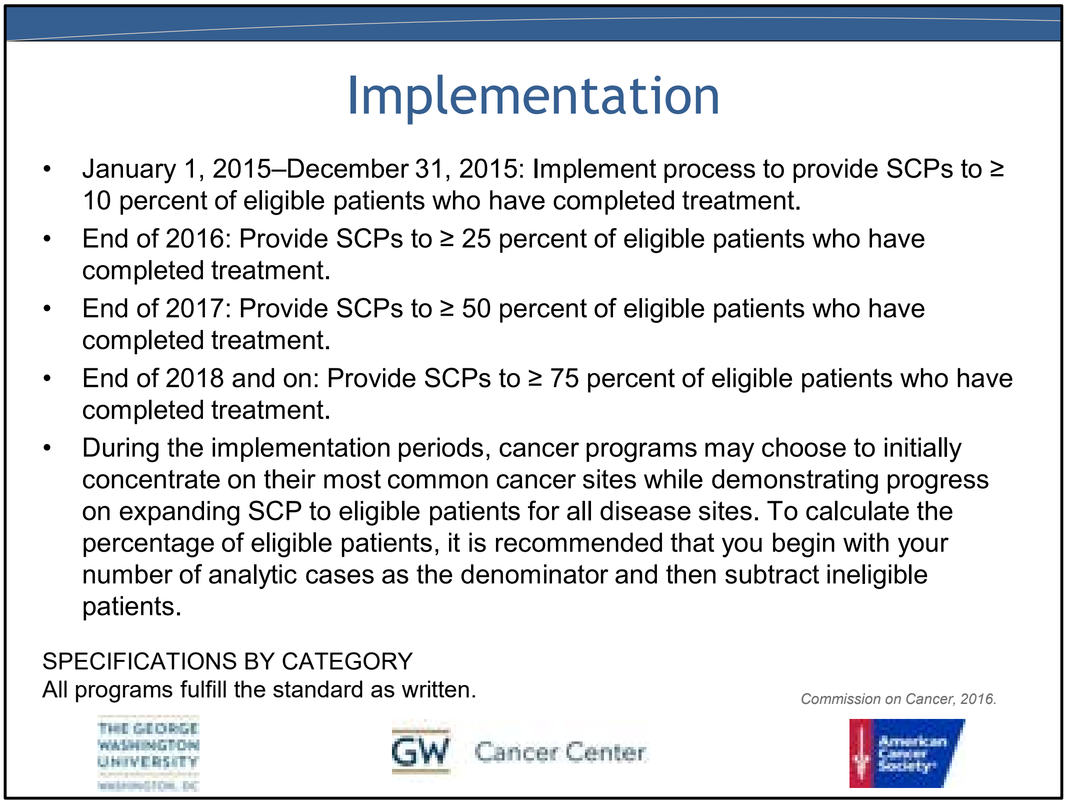
If two separate facilities are providing treatment, both facilities [must] collaborate to complete and provide the Survivorship Care Plan. In all cases, programs, hospitals, and physician offices should work together to provide the information necessary for completion of a Survivorship Care Plan that contains all required elements.

The Survivorship Care Plan is given and discussed with the patient upon completion of active, curative treatment and recorded in the patient medical record. The timing of delivery of the Survivorship Care Plan [must be] within one year of the diagnosis of cancer and no later than six months after completion of adjuvant therapy (other than long-term hormonal therapy)."

For those on long-term hormonal therapy, the Survivorship Care Plan should be delivered within 18-months of cancer diagnosis.

“Providing the Survivorship Care Plan by mail, electronically, or through a patient portal without discussion with the patient does not meet the standard.”

Note– All information from CoC excerpted from 2016 edition: https://www.facs.org/~/media/files/quality%20programs/cancer/coc/2016%20coc%20standards%20manual_interactive%20pdf.ashx



Implementation

- January 1, 2015–December 31, 2015: Implement process to provide SCPs to ≥ 10 percent of eligible patients who have completed treatment.
- End of 2016: Provide SCPs to ≥ 25 percent of eligible patients who have completed treatment.
- End of 2017: Provide SCPs to ≥ 50 percent of eligible patients who have completed treatment.
- End of 2018 and on: Provide SCPs to ≥ 75 percent of eligible patients who have completed treatment.
- During the implementation periods, cancer programs may choose to initially concentrate on their most common cancer sites while demonstrating progress on expanding SCP to eligible patients for all disease sites. To calculate the percentage of eligible patients, it is recommended that you begin with your number of analytic cases as the denominator and then subtract ineligible patients.

SPECIFICATIONS BY CATEGORY
All programs fulfill the standard as written.

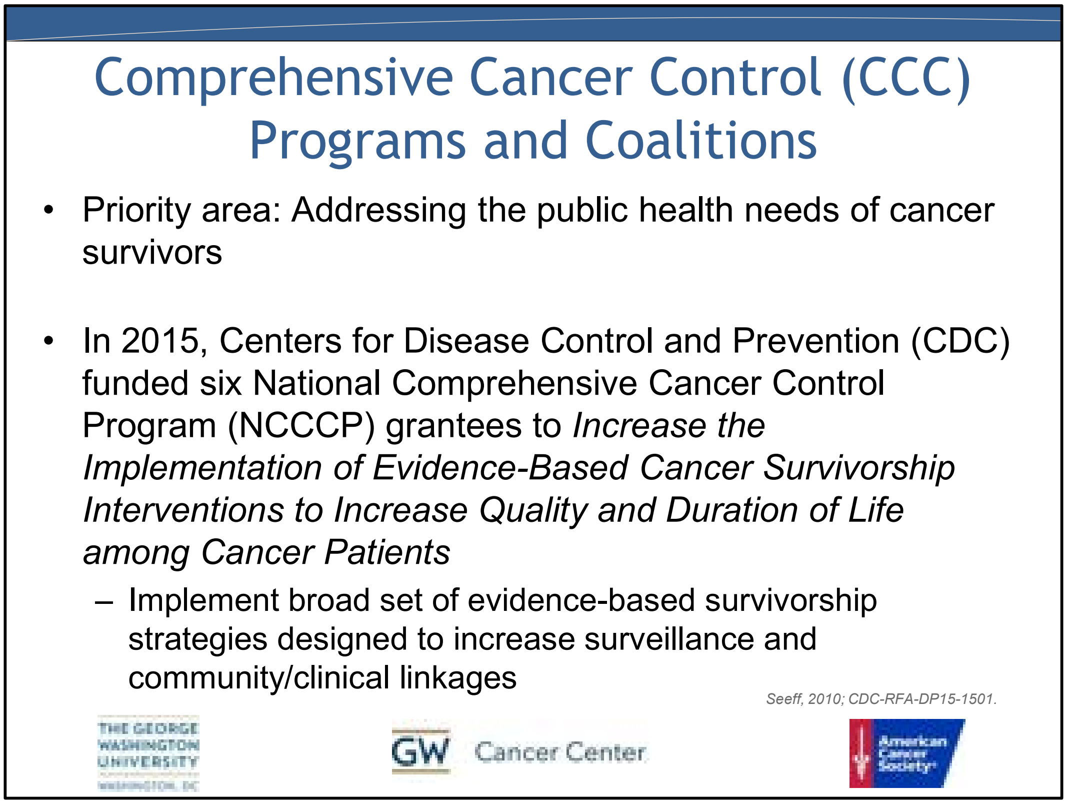
Commission on Cancer, 2016.

In terms of implementation,

- If a program diagnoses a patient but does not treat the patient or provide follow-up care, the program is not required to provide a Survivorship Care Plan to that patient.
- For patients who have Stage 0 or Stage IV, metastatic disease, the program is not required to provide a Survivorship Care Plan.

Programs, of course, may choose to provide Survivorship Care Plans to metastatic patients as these patients have significant unmet needs and could benefit from clear and sensitive discussions to help them know what to expect and to help them make key decisions.

The American Society of Clinical Oncology (ASCO) has defined the minimum data elements to be included in a treatment summary and a Survivorship Care Plan. This core set of data elements as well as templates are available on the ASCO website. At a minimum, all SCPs must include ASCO's recommended elements for the treatment summary and follow-up care plan to meet the Commission on Cancer standard. Additional resources to assist with the development of Survivorship Care Plans are available through the National Coalition for Cancer Survivorship, Journey Forward, the American Cancer Society, and the LIVESTRONG Foundation.



Comprehensive Cancer Control (CCC) Programs and Coalitions

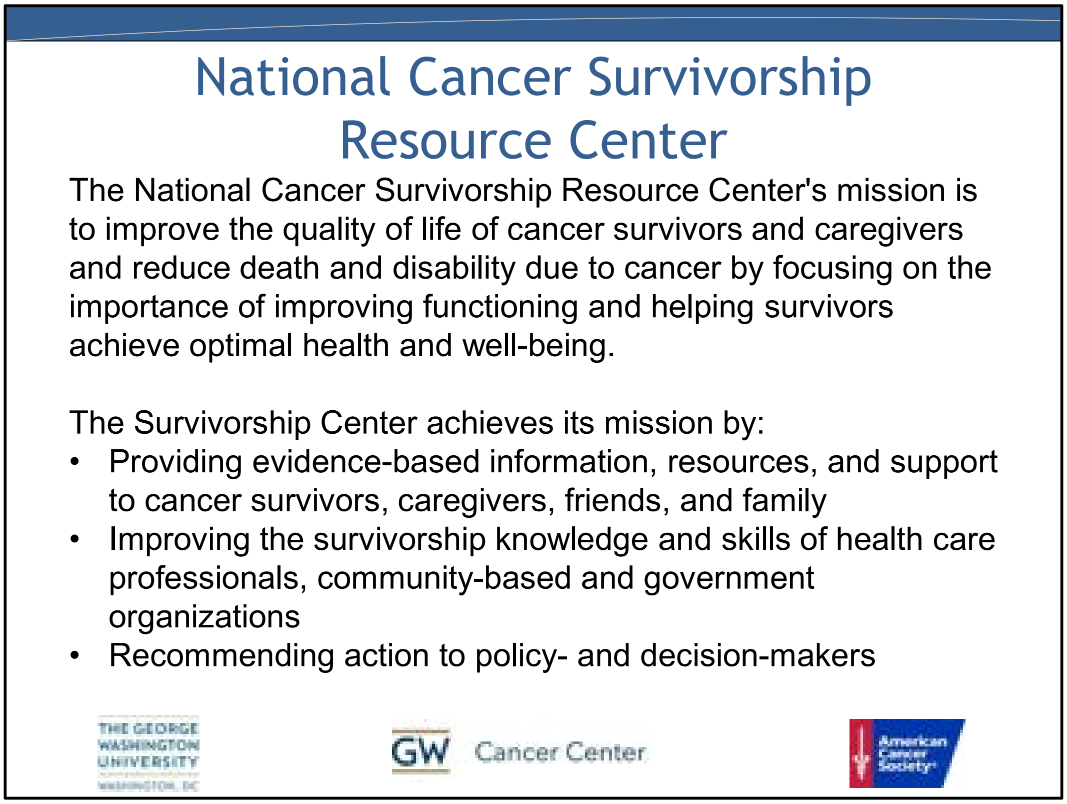
- Priority area: Addressing the public health needs of cancer survivors
- In 2015, Centers for Disease Control and Prevention (CDC) funded six National Comprehensive Cancer Control Program (NCCCP) grantees to *Increase the Implementation of Evidence-Based Cancer Survivorship Interventions to Increase Quality and Duration of Life among Cancer Patients*
  - Implement broad set of evidence-based survivorship strategies designed to increase surveillance and community/clinical linkages

Seeff, 2010; CDC-RFA-DP15-1501.

On the public health front, a recent evaluation of National Comprehensive Cancer Control Program grantees indicated that

- 38% of Comprehensive Cancer Control plans included survivorship objectives for three years
- 94% of plans from 2010 to 2013 included cancer survivorship for at least one year
- 64% of plans included objectives recommended in the CDC/Livestrong Foundation *National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* report

Harvey, A., Villalobos, A., Pratt-Chapman, M. (2016). Supporting Cancer Survivors through Comprehensive Cancer Control Programs. The George Washington University Cancer Center. Washington, DC.



National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center's mission is to improve the quality of life of cancer survivors and caregivers and reduce death and disability due to cancer by focusing on the importance of improving functioning and helping survivors achieve optimal health and well-being.

The Survivorship Center achieves its mission by:

- Providing evidence-based information, resources, and support to cancer survivors, caregivers, friends, and family
- Improving the survivorship knowledge and skills of health care professionals, community-based and government organizations
- Recommending action to policy- and decision-makers

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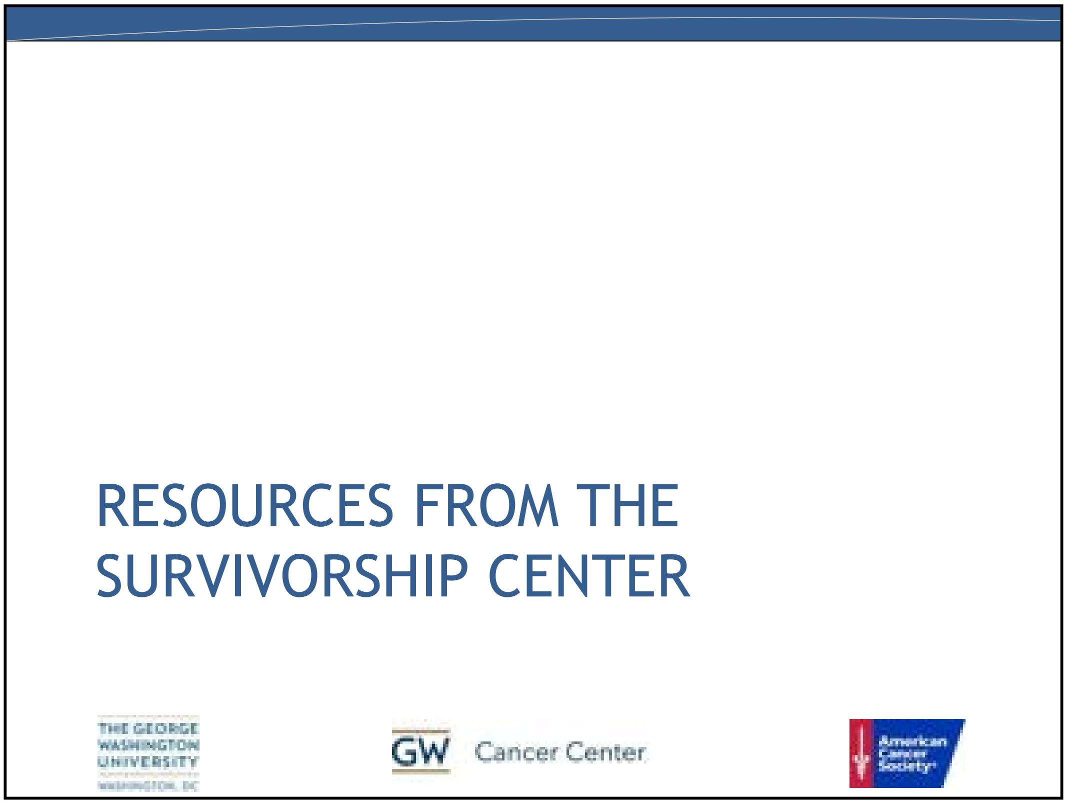
The National Cancer Survivorship Resource Center (The Survivorship Center) was established by the American Cancer Society, the GW Cancer Center and the CDC and was funded by a 5-year cooperative agreement from the CDC

The Survivorship Center has aimed to provide evidence-based information, resources and support to cancer survivors and their loved ones as health care practitioners and policymakers to improve capacity to provide quality survivorship care to cancer survivors.



RESOURCES FROM THE SURVIVORSHIP CENTER

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I want to end with some practical resources available to you from the Survivorship Center.

The Cancer Survivorship E-Learning Series

gwcehp.learnercommunity.com/elearning-series

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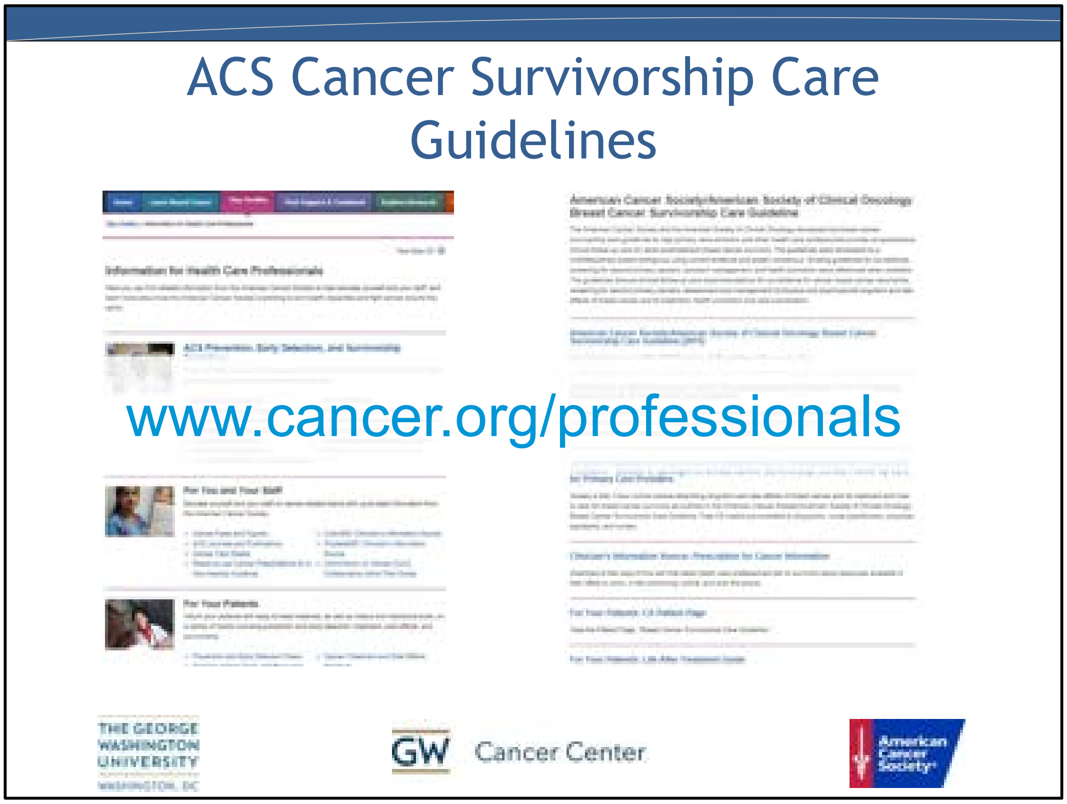
The GW Cancer Center established this e-learning series which provides free continuing medical education for physicians, nurse practitioners, physician assistants, nurses and Certified Health Education Specialists. Please explore the other modules of our e-learning series.



ACS Cancer Survivorship Care Guidelines

Information for Health Care Professionals

ACS Prevention, Early Detection, and Survivorship

For You and Your Staff

For Your Patients

American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline

Clinician's Information Source: Prescription for Cancer Information

For Your Patients: Life After Treatment Guide

www.cancer.org/professionals

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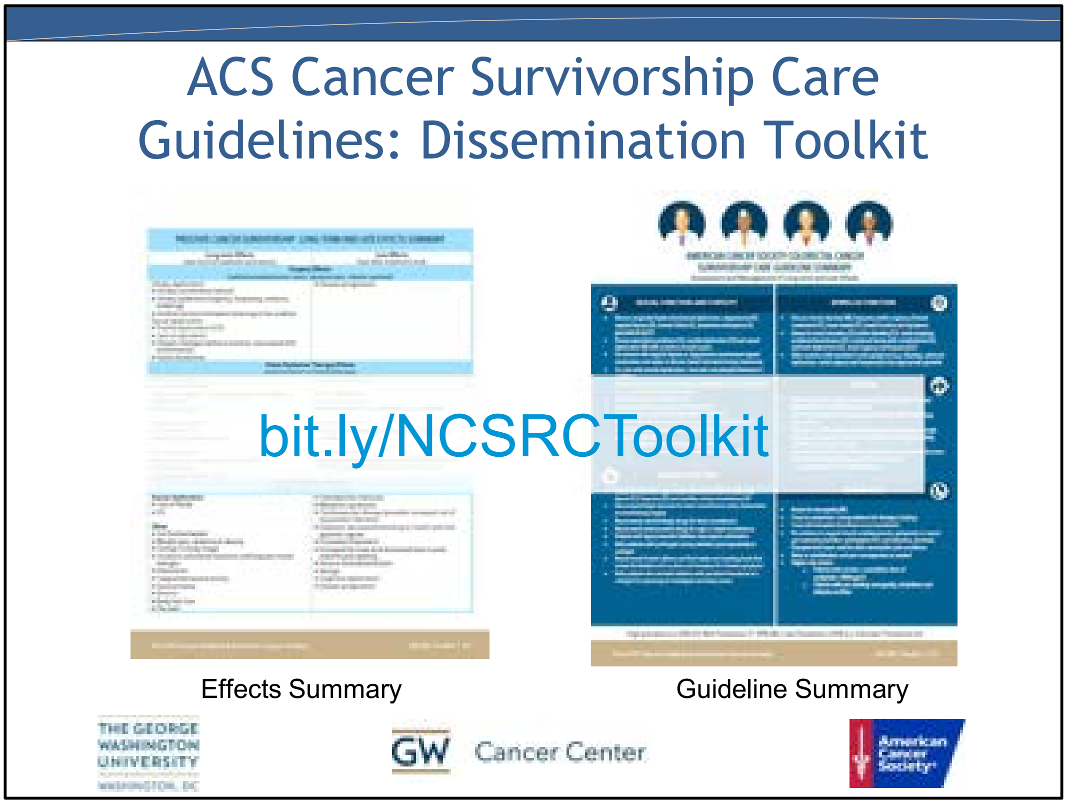
The American Cancer Society houses cancer survivorship clinical care guidelines as well as a cancer survivorship prescription pad that providers can use to prescribe resources to patients and other informational resources.



ACS Cancer Survivorship Care Guidelines: Dissemination Toolkit

bit.ly/NCSRCToolkit

Effects Summary

Guideline Summary

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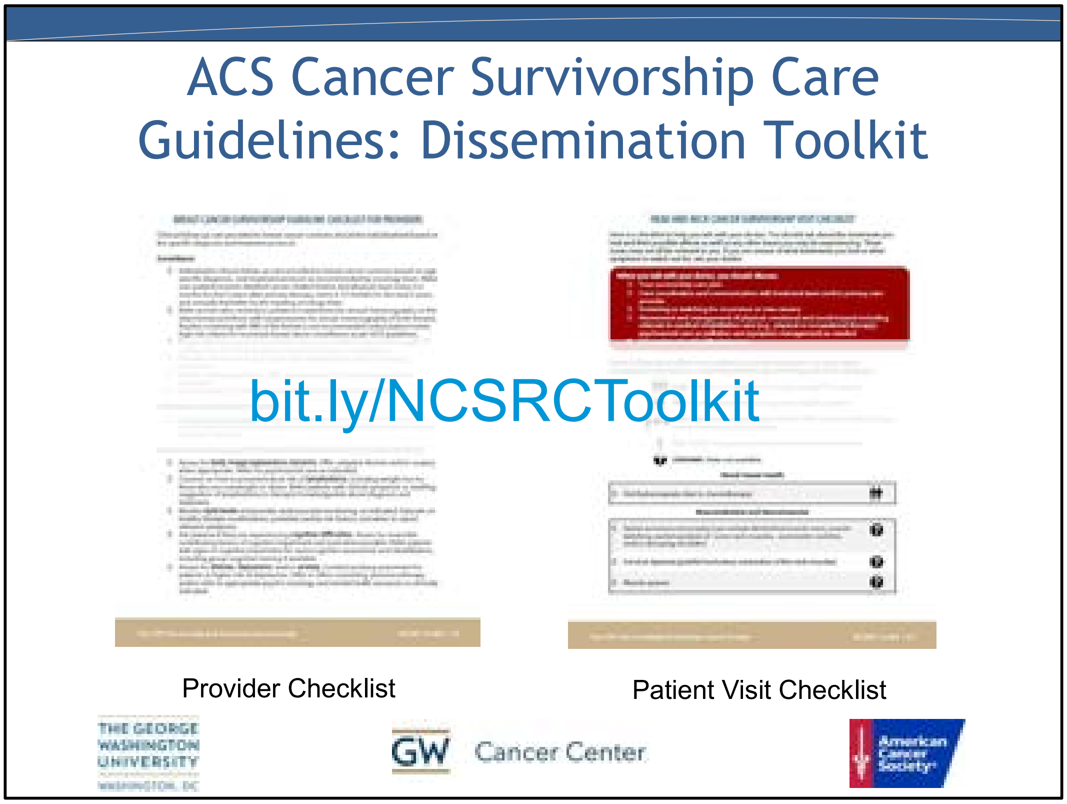
The GW Cancer Center created a Toolkit that you can download that provides long term and late effect summaries by cancer type, summaries of the ACS cancer survivorship guidelines and other resource to help a variety of public health and clinical stakeholders implement the ACS guidelines in practice.



ACS Cancer Survivorship Care Guidelines: Dissemination Toolkit

bit.ly/NCSRCToolkit

Provider Checklist

Patient Visit Checklist

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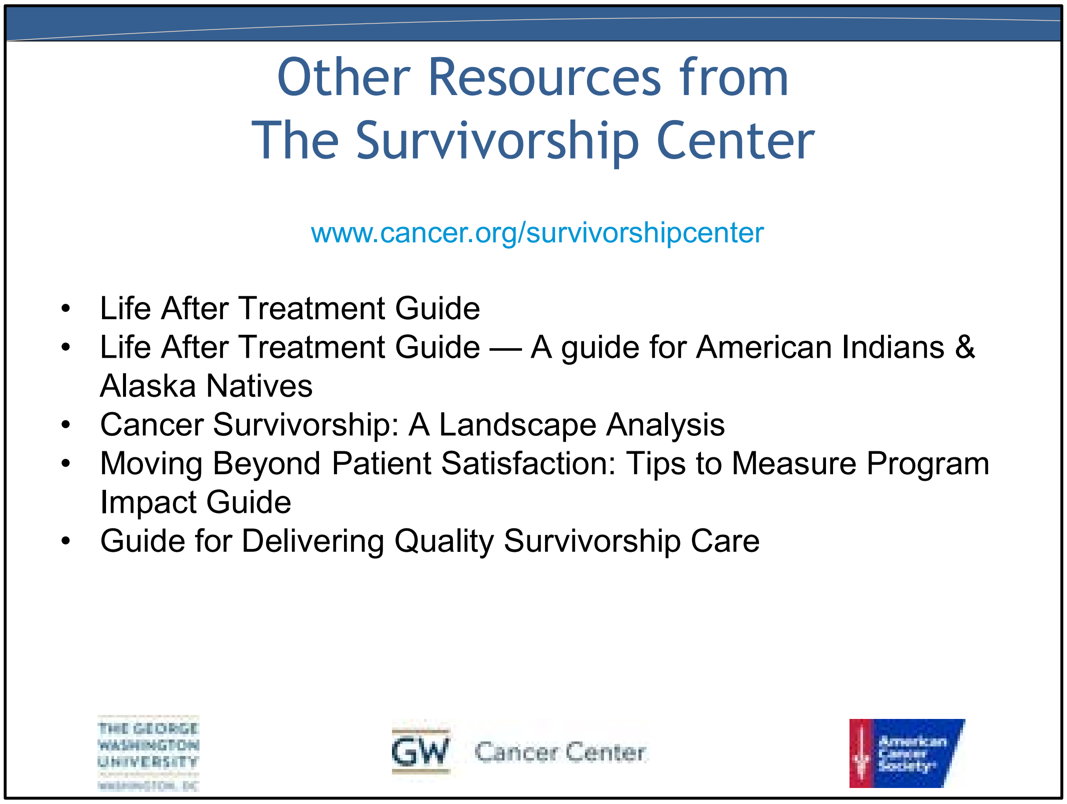
The toolkit also provides checklists for providers and patients as well as information on provider training opportunities and patient education materials.



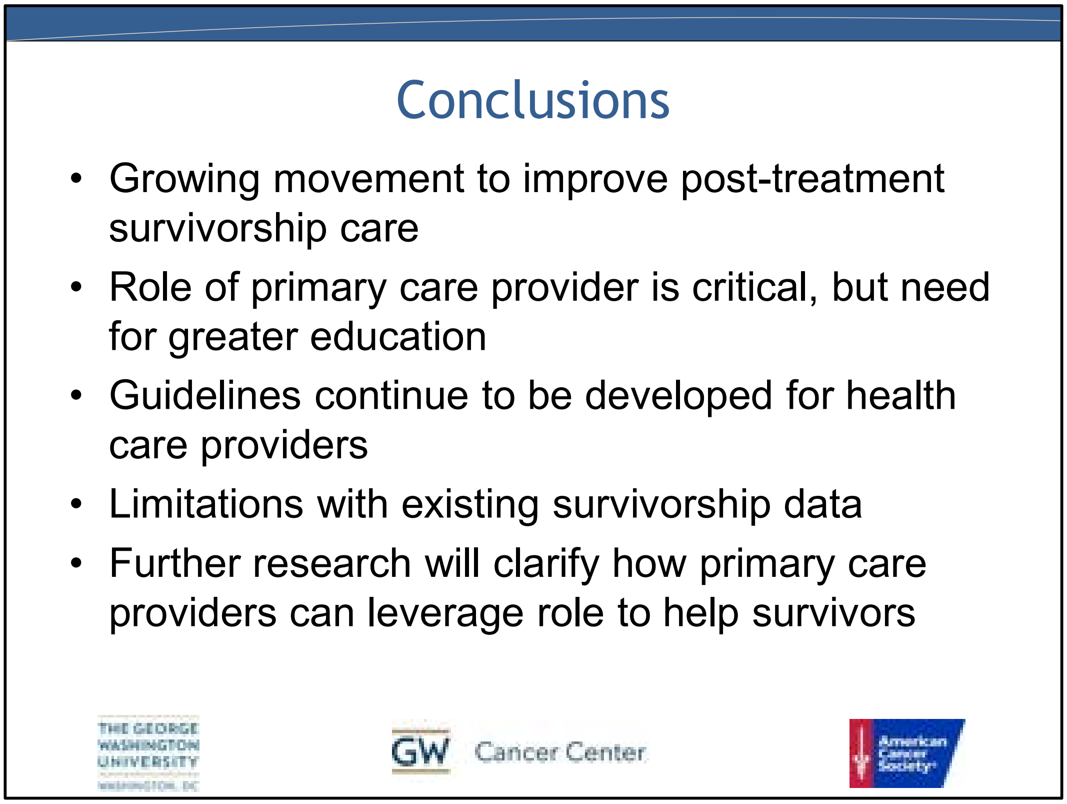
Other Resources from The Survivorship Center

www.cancer.org/survivorshipcenter

- Life After Treatment Guide
- Life After Treatment Guide — A guide for American Indians & Alaska Natives
- Cancer Survivorship: A Landscape Analysis
- Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide
- Guide for Delivering Quality Survivorship Care

These are some other resources provided by the Survivorship Center:

- Life After Treatment Guide
- Life After Treatment Guide — A guide for American Indians & Alaska Natives
- Cancer Survivorship: A Landscape Analysis
- Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide
- Guide for Delivering Quality Survivorship Care

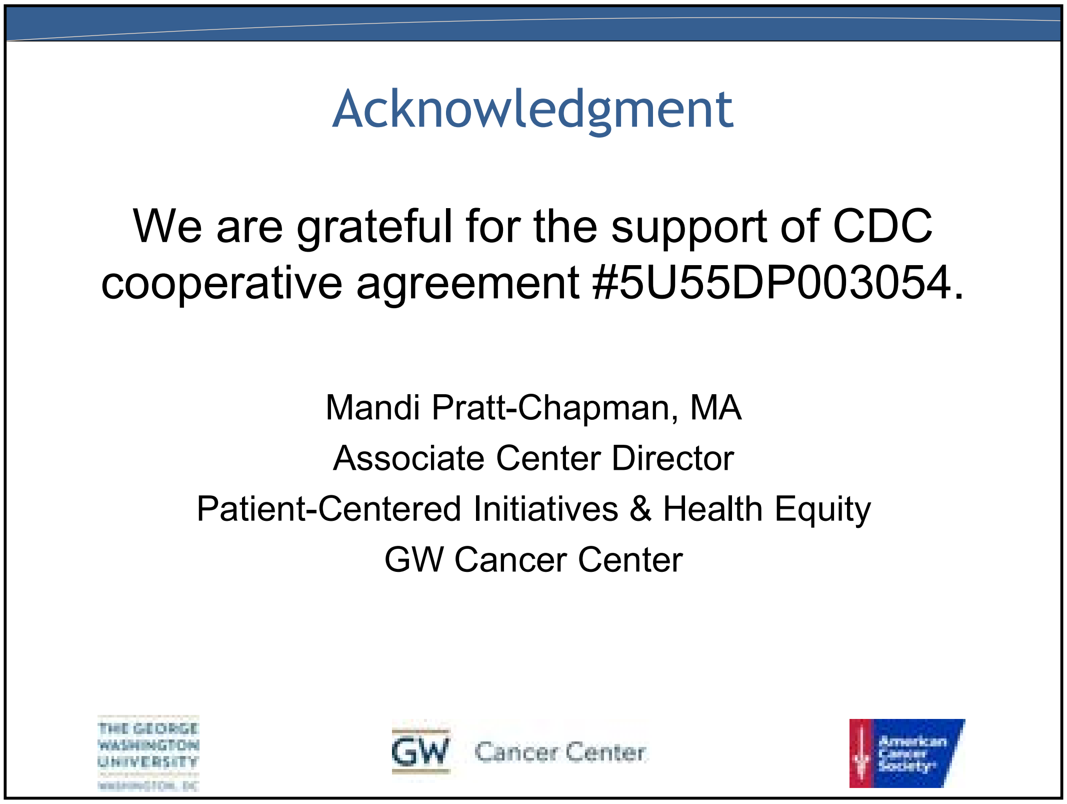


Conclusions

- Growing movement to improve post-treatment survivorship care
- Role of primary care provider is critical, but need for greater education
- Guidelines continue to be developed for health care providers
- Limitations with existing survivorship data
- Further research will clarify how primary care providers can leverage role to help survivors

In summary, there is a growing population of survivors and a growing demand for quality post-treatment survivorship services. Oncology health care team members and primary care providers play critical roles for providing high quality long-term follow up care for survivors.

There are a number of cancer survivorship education opportunities and clinical care guidelines currently available to practitioners, although we need more research to continue to improve our knowledge on how to best care for diverse survivors long-term.



Acknowledgment

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Mandi Pratt-Chapman, MA
Associate Center Director
Patient-Centered Initiatives & Health Equity
GW Cancer Center

Thank you for your participation in this module of the Cancer Survivorship e-learning series – and thank you for being part of this movement to improve health care services for cancer survivors.