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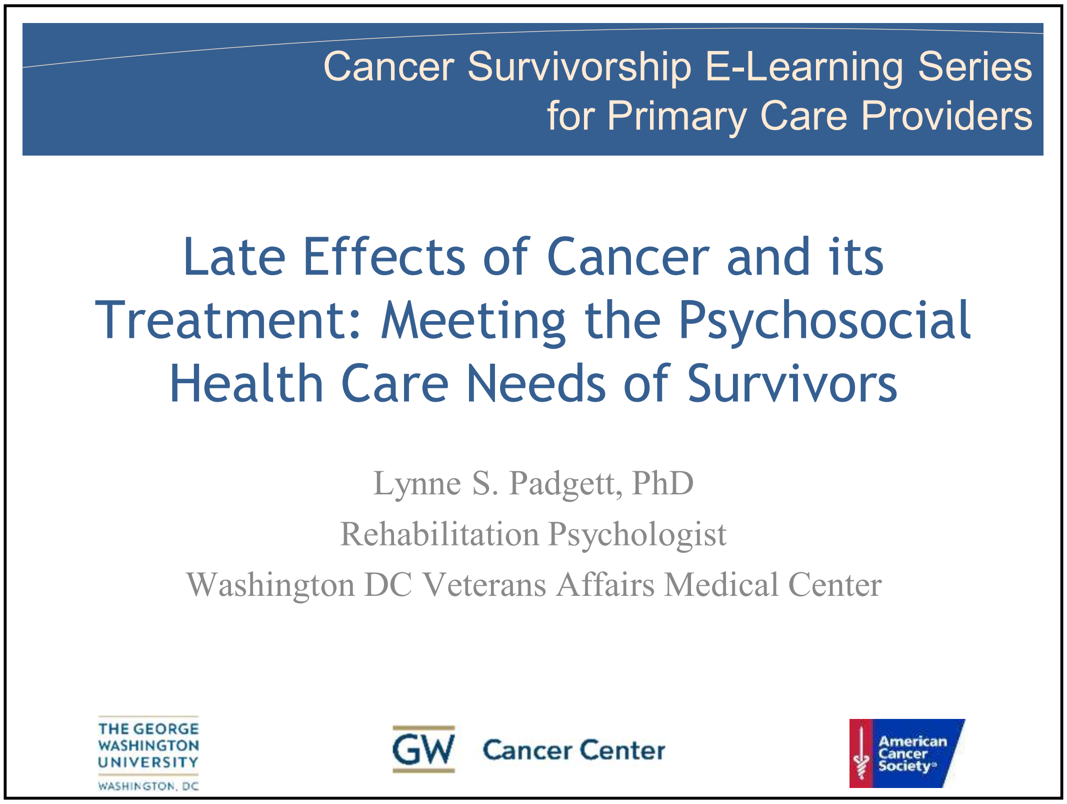

Cancer Survivorship E-Learning Series
for Primary Care Providers

Late Effects of Cancer and its Treatment: Meeting the Psychosocial Health Care Needs of Survivors

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Washington DC Veterans Affairs Medical Center

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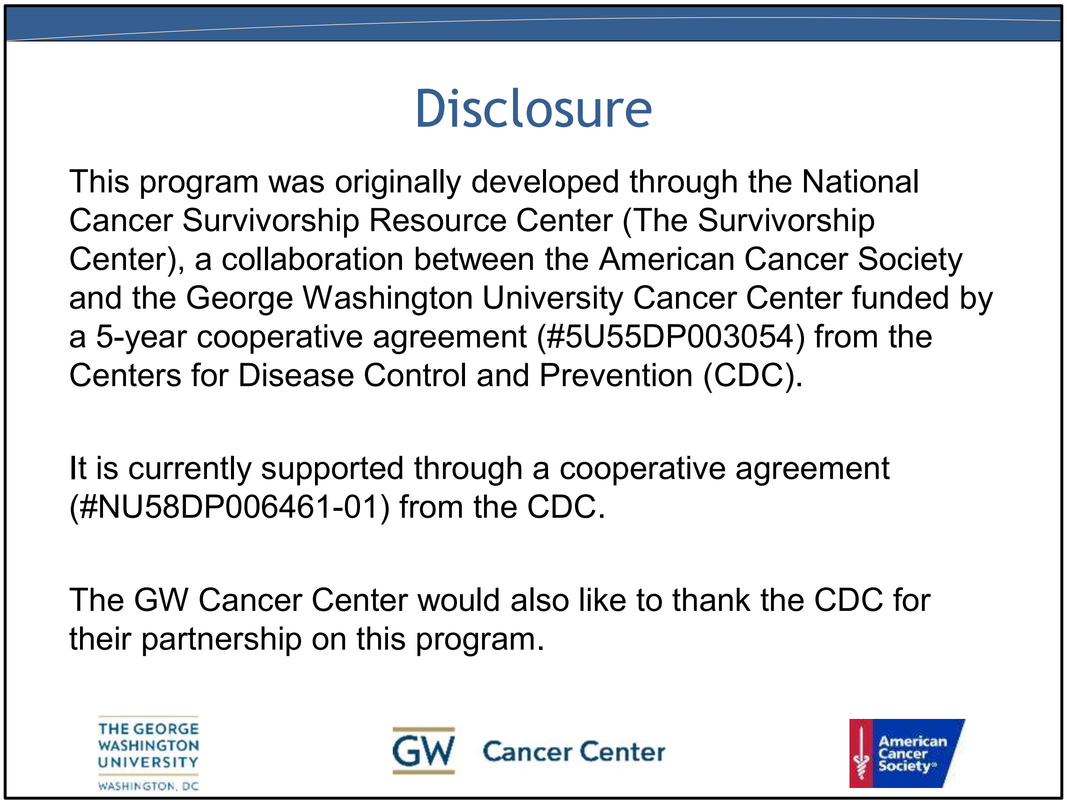
Welcome to this presentation on Late Effects of Cancer and its Treatment: Meeting the Psychosocial Health Care Needs of Survivors.

I am Lynne Padgett, a Rehabilitation Psychologist at the Washington DC Veterans Affairs Medical Center.

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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The GW Cancer Center would also like to thank the CDC for their partnership on this program.

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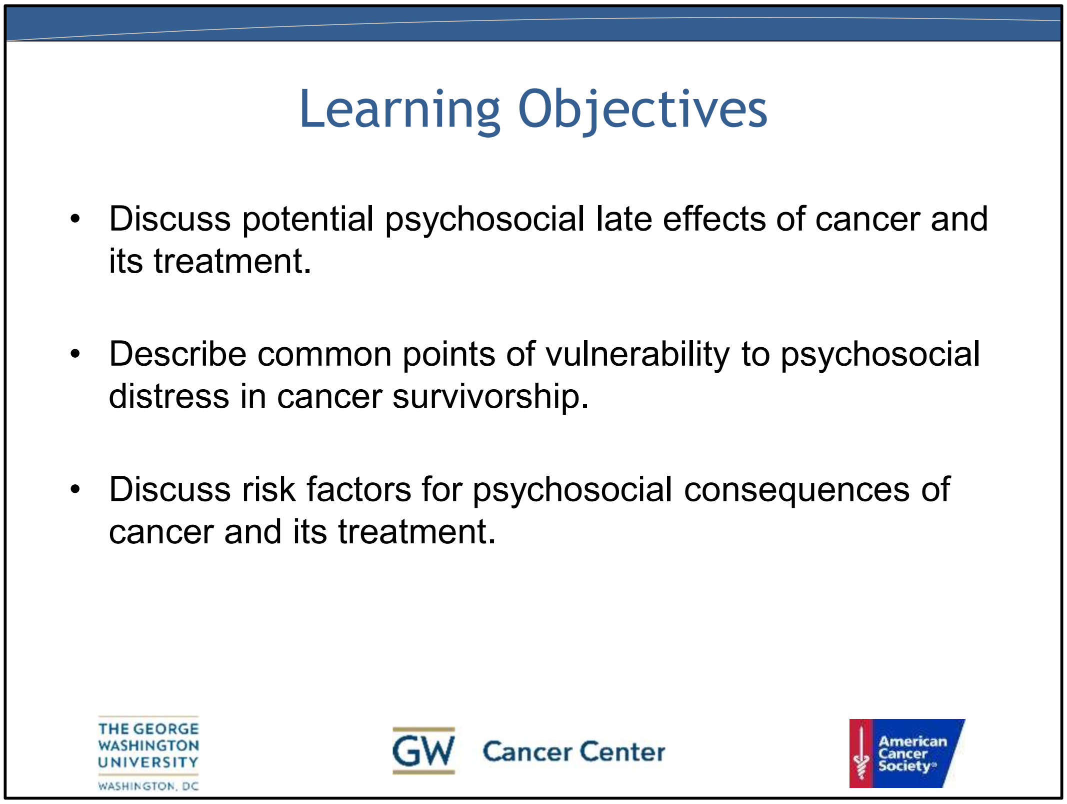
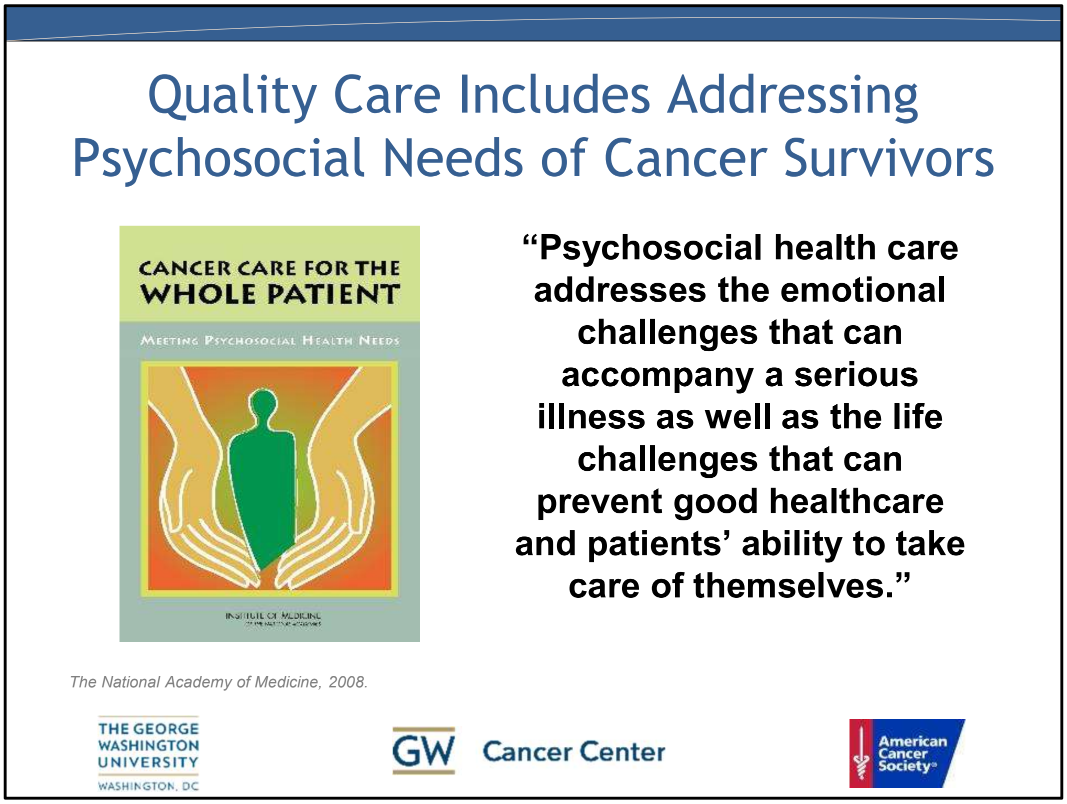


Learning Objectives

- Discuss potential psychosocial late effects of cancer and its treatment.
- Describe common points of vulnerability to psychosocial distress in cancer survivorship.
- Discuss risk factors for psychosocial consequences of cancer and its treatment.

After completing this lesson, you will be able to:

- Discuss potential psychosocial late effects of cancer and its treatment.
- Describe common points of vulnerability to psychosocial distress in cancer survivorship.
- Discuss risk factors for psychosocial consequences of cancer and its treatment.

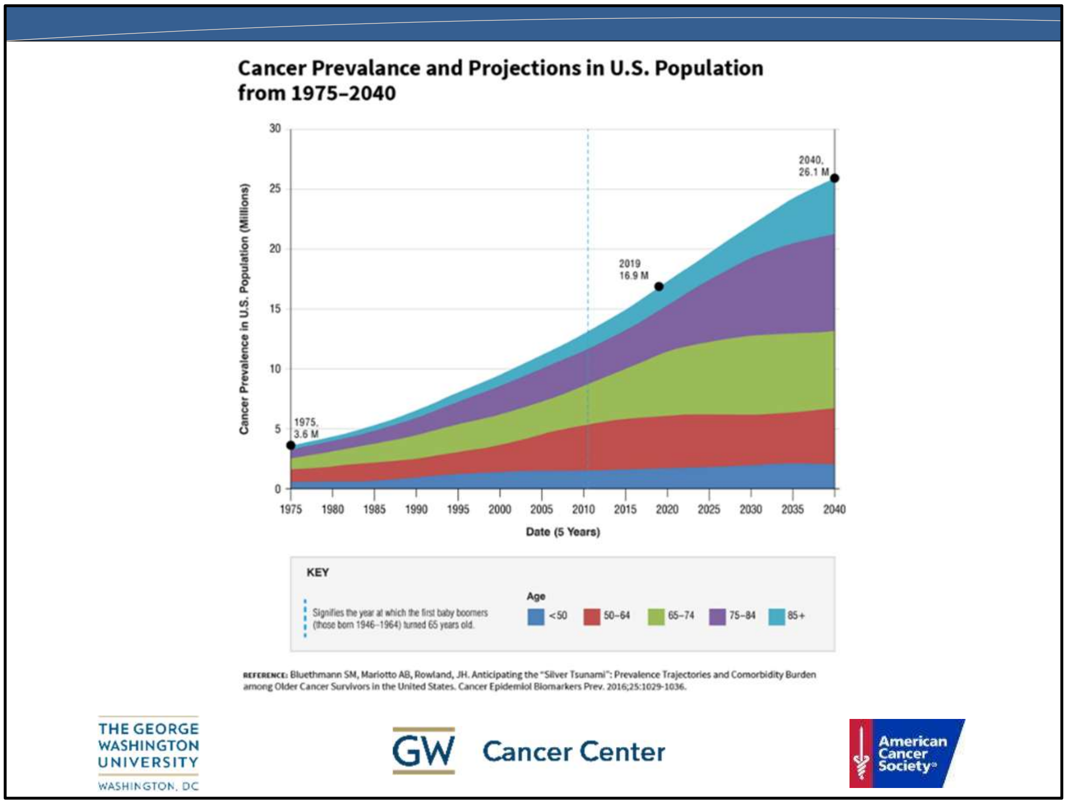


Quality Care Includes Addressing Psychosocial Needs of Cancer Survivors

“Psychosocial health care addresses the emotional challenges that can accompany a serious illness as well as the life challenges that can prevent good healthcare and patients’ ability to take care of themselves.”

The National Academy of Medicine, 2008.

In 2008, the National Academy of Sciences released the report “Cancer Care for the Whole Patient”. They emphasized the point that quality cancer care must include addressing cancer survivors’ psychosocial needs.



Cancer Prevalance and Projections in U.S. Population from 1975–2040

Signifies the year at which the first baby boomers (those born 1946–1964) turned 65 years old.

REFERENCE: Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. Cancer Epidemiol Biomarkers Prev. 2016;25:1029-1036.

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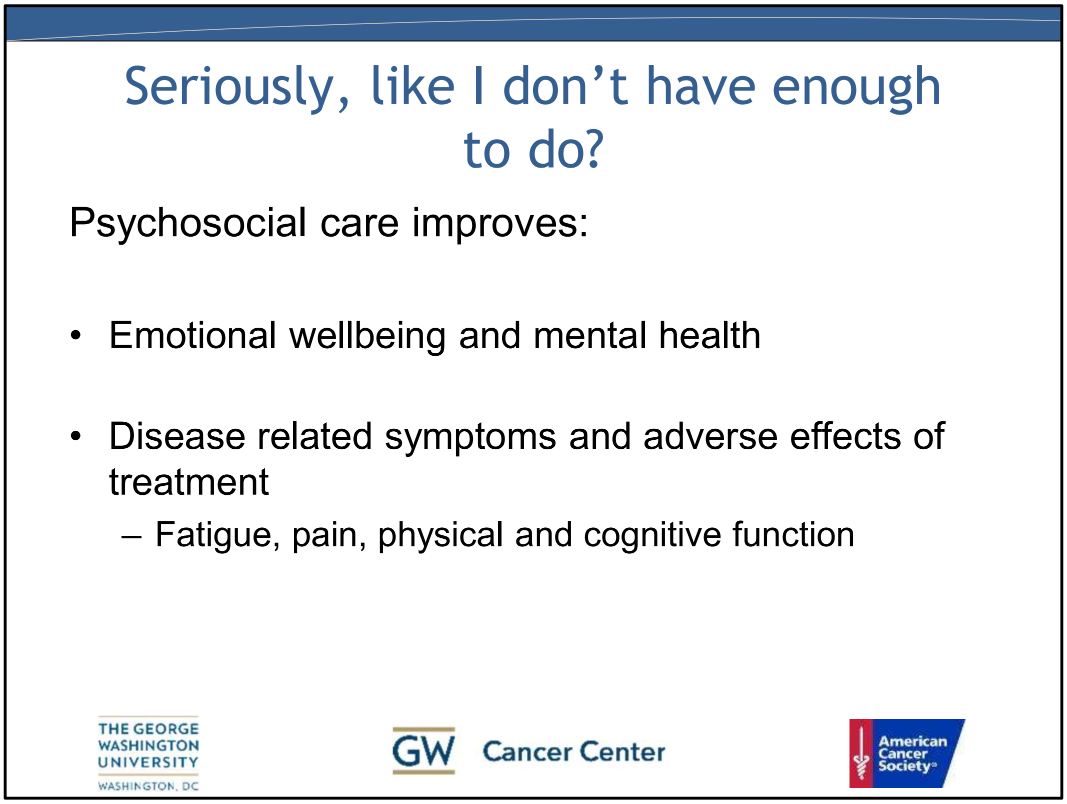
As you can see from this chart on Cancer Prevalence in the US, the story of cancer is an increasing number of survivors, with a new wave or "tsunami" of survivors greatly expanding both the number of cancer survivors and the survivors who are older adults.

These survivors, some of them who have no evidence of disease, and those who are living with disease or on maintenance therapies, can still suffer from the psychosocial effects of cancer and its treatments.



Seriously, like I don't have enough to do?

Psychosocial care improves:

- Emotional wellbeing and mental health
- Disease related symptoms and adverse effects of treatment
  - Fatigue, pain, physical and cognitive function

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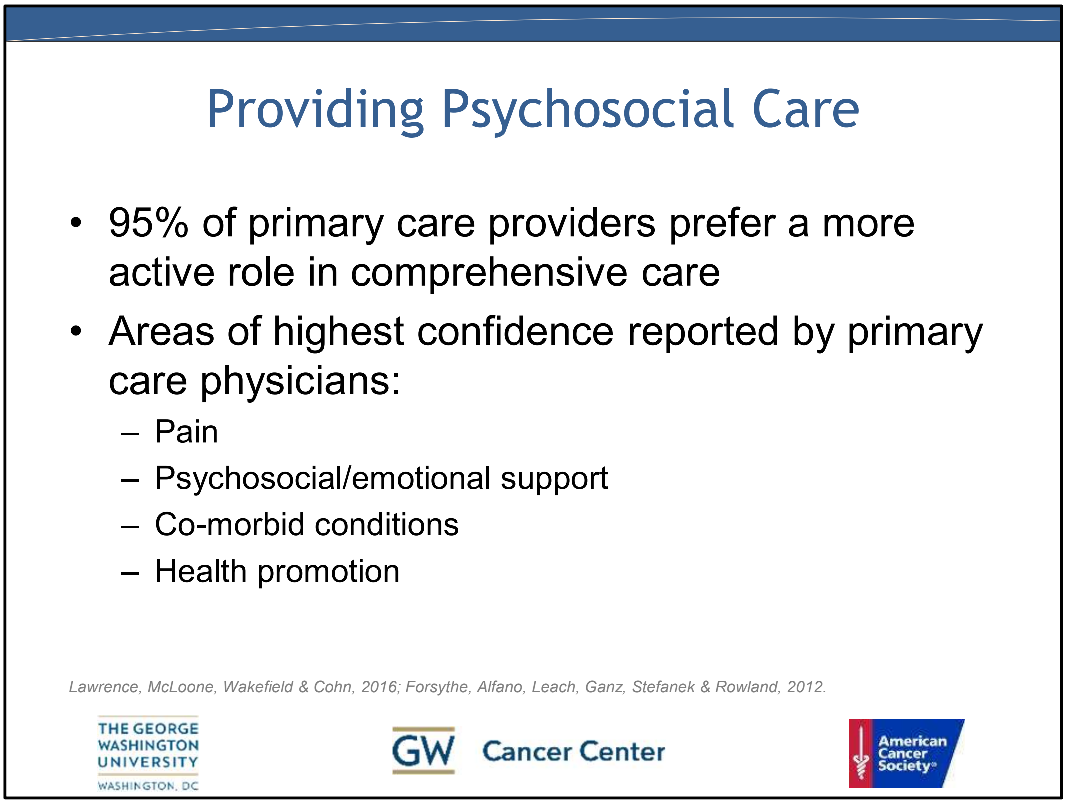
As a provider or clinician, you may be thinking, don't I already have enough to do? Isn't managing their overall physical health and wellbeing enough to keep me busy?

However, what we know that psychosocial care improves cancer survivors' emotional wellbeing and mental health. Moreover, survivors' mental health can be negatively impacted by disease-related symptoms and adverse effects of treatment. Such as fatigue, pain and challenges in physical and cognitive function.



Providing Psychosocial Care

- 95% of primary care providers prefer a more active role in comprehensive care
- Areas of highest confidence reported by primary care physicians:
  - Pain
  - Psychosocial/emotional support
  - Co-morbid conditions
  - Health promotion

Lawrence, McLoone, Wakefield & Cohn, 2016; Forsythe, Alfano, Leach, Ganz, Stefanek & Rowland, 2012.

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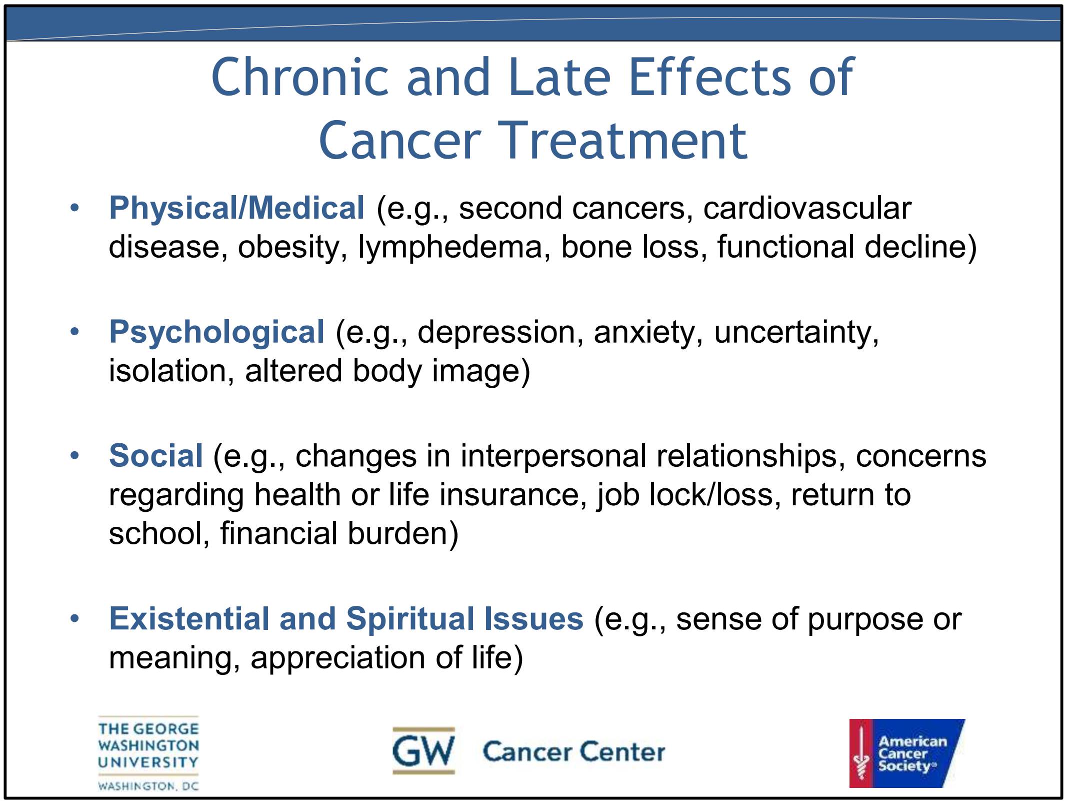
A large national survey in 2012 found that both oncologist and primary care physicians felt they should provide psychosocial care to cancer survivors.

In 2016, a systematic review of primary care providers preferences found that:

- 95 percent of preferred a more active role in comprehensive cancer care
- 55-65 percent expressed a desire to be involved earlier in cancer care
- Prefer a shared model of care with ongoing collaboration—not reinitiating care when the patient has completed active treatment
- Areas they felt were appropriate to primary care included pain, psychosocial & emotional support, co-morbid conditions and health promotion.

So, lets now shift to discuss the psychosocial effects of cancer and its treatments.



Chronic and Late Effects of Cancer Treatment

- **Physical/Medical** (e.g., second cancers, cardiovascular disease, obesity, lymphedema, bone loss, functional decline)
- **Psychological** (e.g., depression, anxiety, uncertainty, isolation, altered body image)
- **Social** (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, return to school, financial burden)
- **Existential and Spiritual Issues** (e.g., sense of purpose or meaning, appreciation of life)

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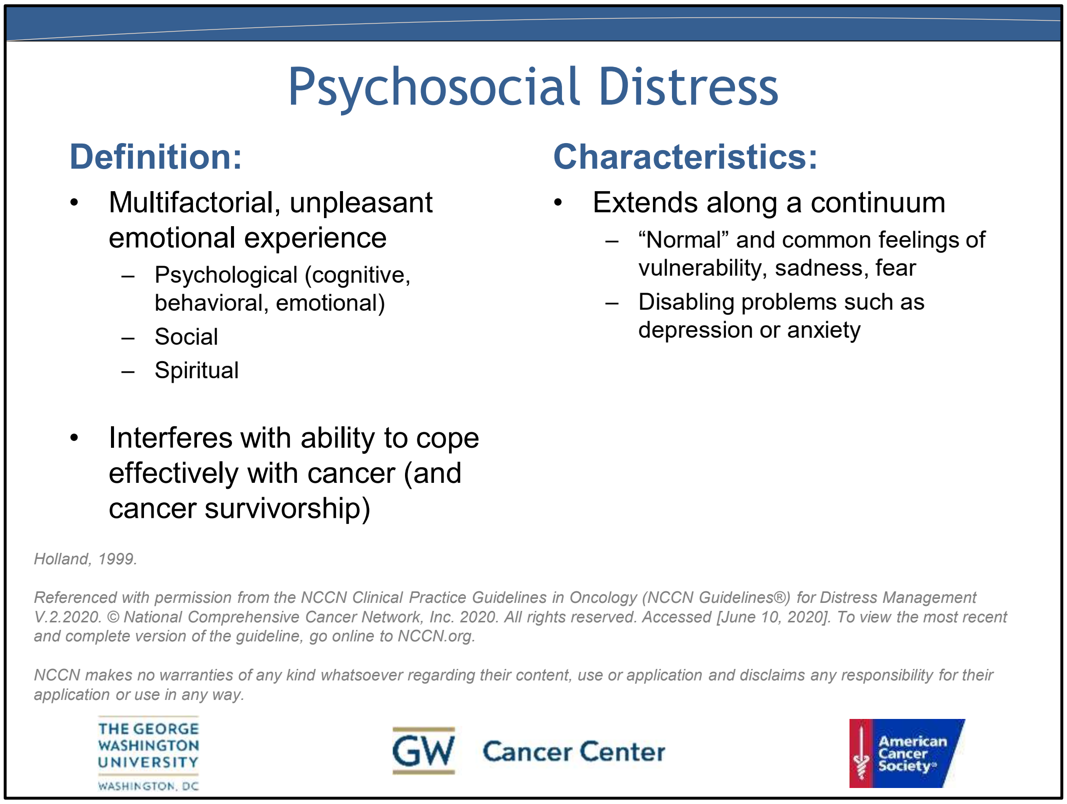
Chronic and late effects of cancer treatment are something many patients experience.

Chronic effects are those side that begin during treatment and continue through survivorship

Late effects are side effects of cancer treatment that surface in survivorship, typically after treatment has ended

These chronic and late effects span many domains, including physical and psychological effects, as well as social and existential challenges.



Psychosocial Distress

Definition:

- Multifactorial, unpleasant emotional experience
  - Psychological (cognitive, behavioral, emotional)
  - Social
  - Spiritual
- Interferes with ability to cope effectively with cancer (and cancer survivorship)

Characteristics:

- Extends along a continuum
  - "Normal" and common feelings of vulnerability, sadness, fear
  - Disabling problems such as depression or anxiety

Holland, 1999.

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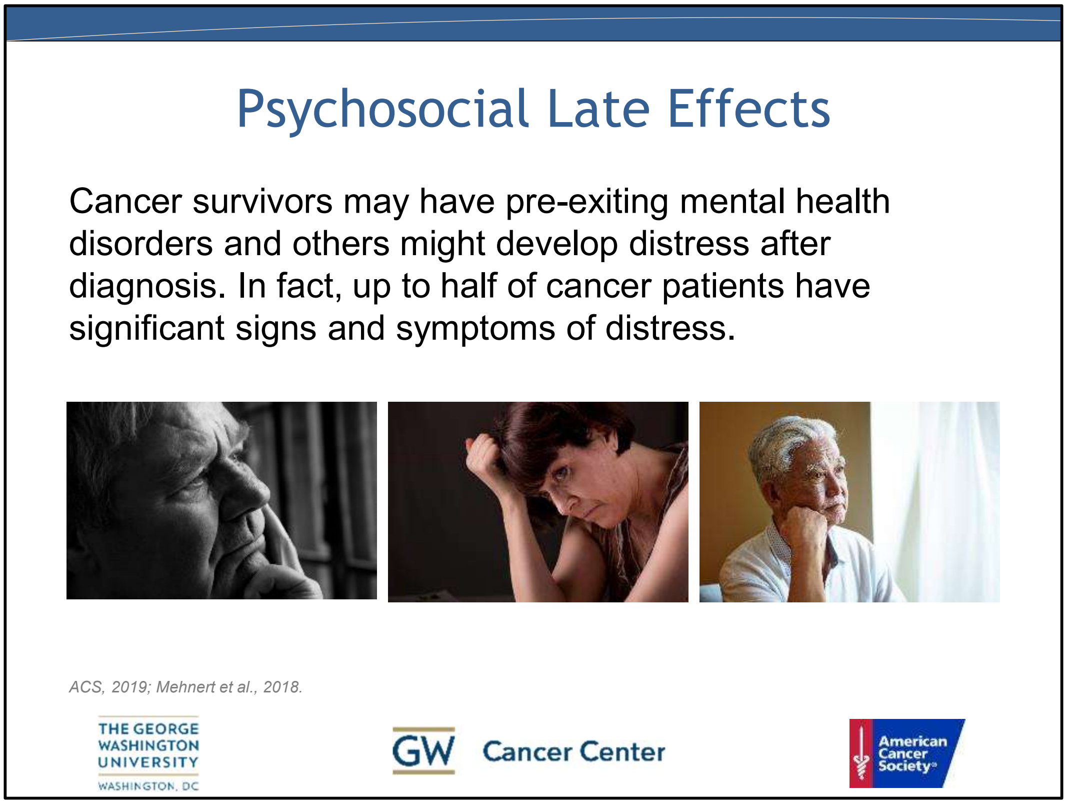
I've used the term "psychosocial distress", but it's important to define what the term means.

Psychosocial distress is a multifactorial, unpleasant emotional experience. In can consist of psychological, such as cognitive, behavioral, or emotional symptoms. Social challenges or spiritual or existential distress.

Psychosocial distress interferes with the ability to cope effectively with cancer and cancer survivorship.

The trajectory or characteristics of psychosocial distress extends along a continuum and ranges from "normal" and common feelings of vulnerability, sadness, and fear to disabling problems such as depression and anxiety.

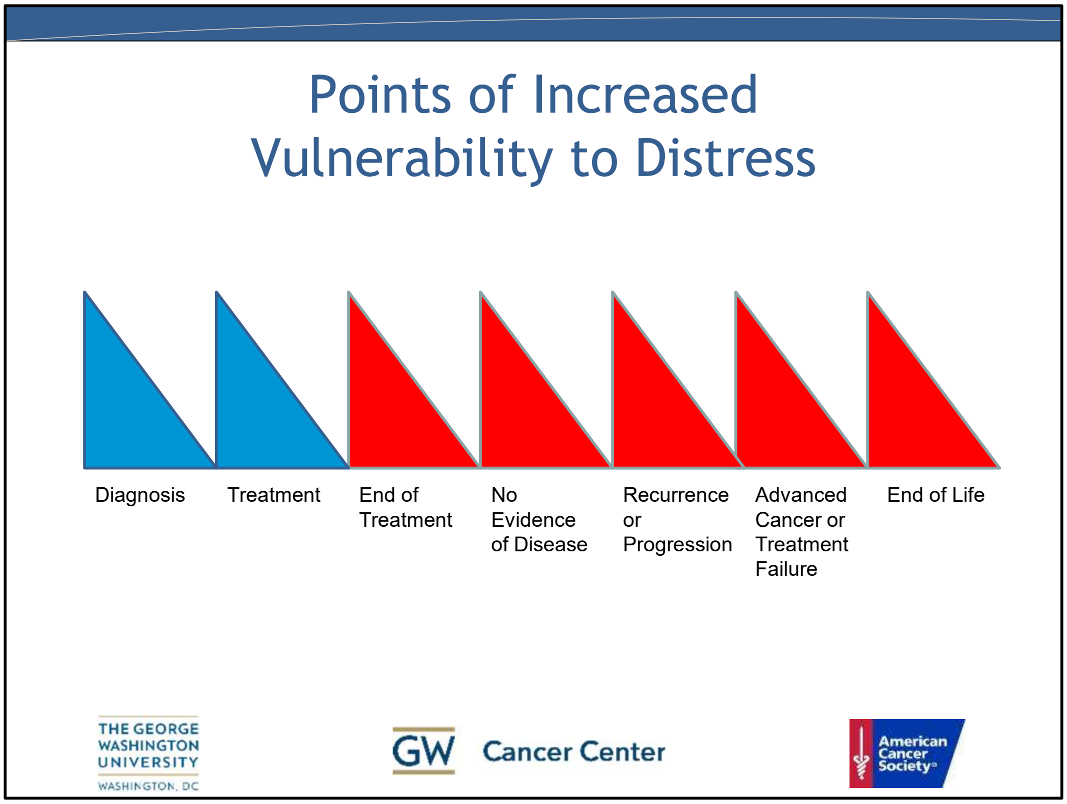


Psychosocial Late Effects

Cancer survivors may have pre-exiting mental health disorders and others might develop distress after diagnosis. In fact, up to half of cancer patients have significant signs and symptoms of distress.

ACS, 2019; Mehnert et al., 2018.

It’s important to remember cancer survivors may have pre-existing mental health disorders. Where other might develop distress after their diagnosis. In fact, up to half of cancer patients and survivors have significant symptoms of distress.



Points of Increased Vulnerability to Distress

Diagnosis

Treatment

End of Treatment

No Evidence of Disease

Recurrence or Progression

Advanced Cancer or Treatment Failure

End of Life

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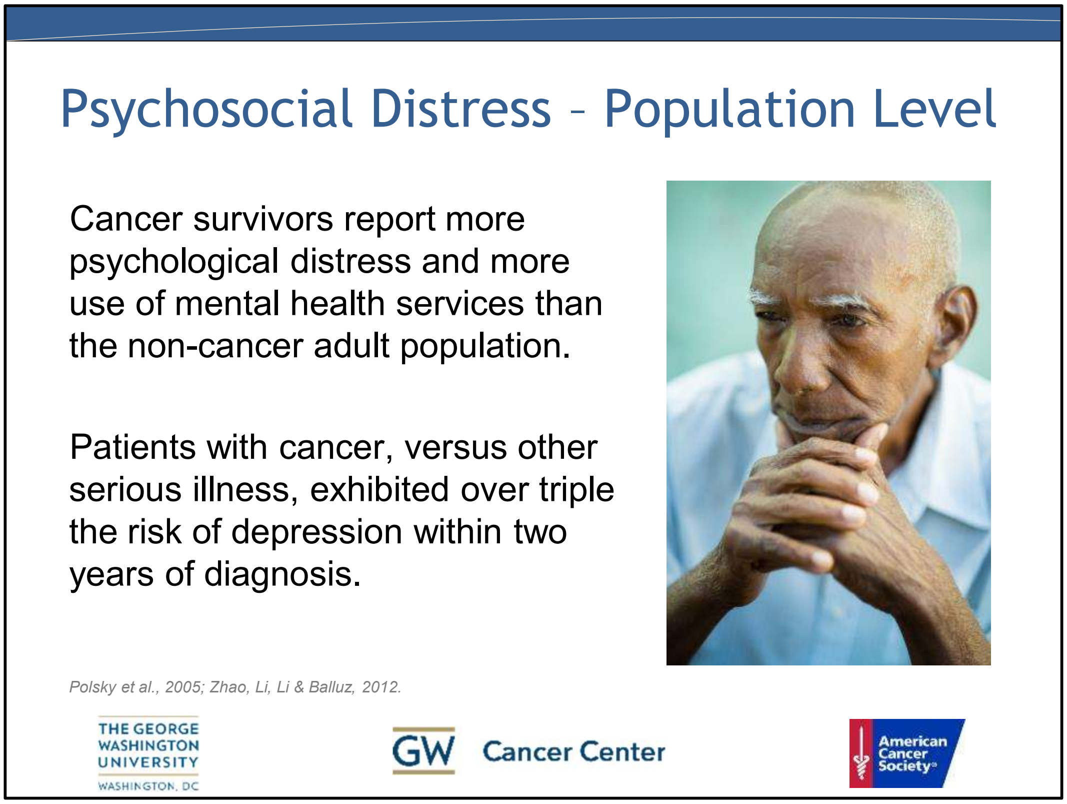
Here you can see common points of increased vulnerability to distress, spanning a continuum from diagnosis to survivorship or end of life.

As you can see, the increased vulnerability may result in increased distress that tends to taper off over time. In one study of colorectal cancer patients, male patients showed higher levels of distress. Of these distressed male patients, those who were younger had poor social support, lower levels of education and later disease stage at diagnosis, were more likely to have severe psychosocial distress.

Patients who did not exhibit high levels of distress during treatment were often “missed” as their distress did not emerge until survivorship. Why would a patient navigate treatment successfully and then have increased distress during survivorship? There could be several causes including the withdrawal of informal social support from the treatment team, frustration when they don’t feel normal as they did prior to their cancer diagnosis, or continuing symptoms or emergence of new symptoms, to chronic and late effects.



Psychosocial Distress – Population Level

Cancer survivors report more psychological distress and more use of mental health services than the non-cancer adult population.

Patients with cancer, versus other serious illness, exhibited over triple the risk of depression within two years of diagnosis.

Polsky et al., 2005; Zhao, Li, Li & Balluz, 2012.

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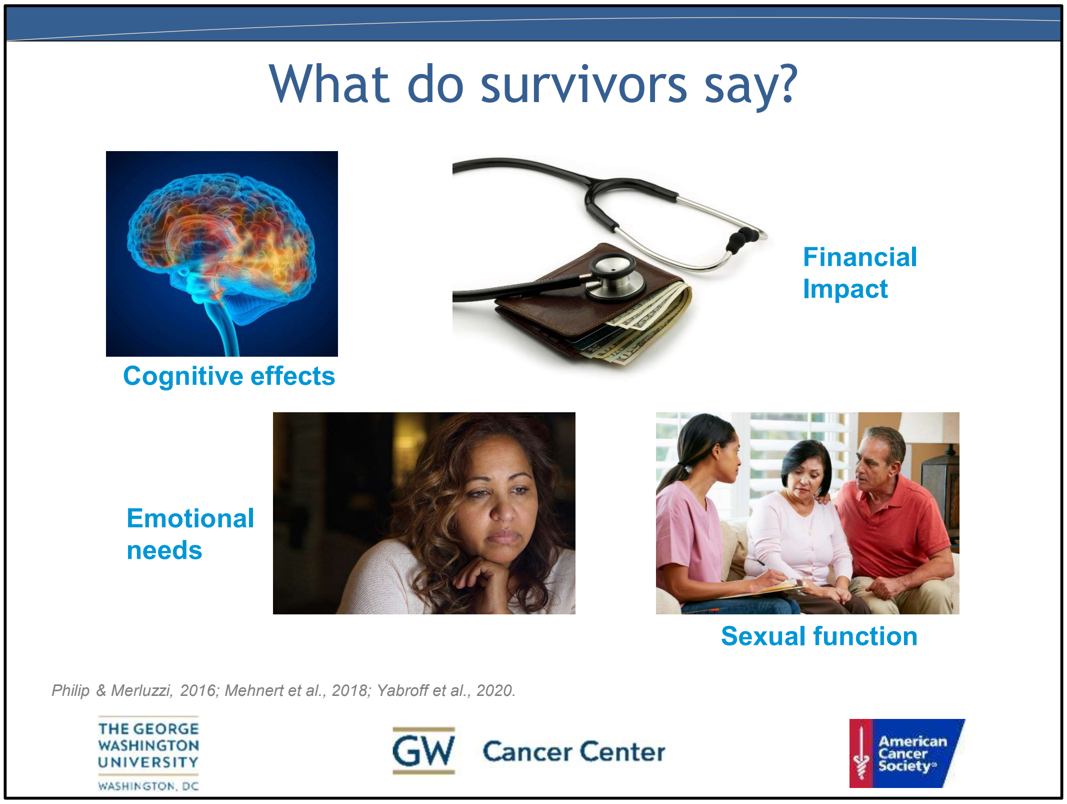
Overall, 6.6 percent of cancer survivors (versus 3.7 percent of adults without cancer, P<0.001) reported having Serious Psychological Distress, and 14 percent of cancer survivors reported receiving mental health care services in contrast to the 10 percent of adults without cancer (P<0.001).

After navigating treatment, there is an expectation of “returning to normal.” Unfortunately, cancer survivors may not be able to return to their previous activities because of functional limitations or because they may not “feel normal.” Either of these can lead to psychosocial distress.

This information comes from studies looking at claims and diagnostic data. What happens when we ask survivors about their experience? What do they say?



What do survivors say?

Cognitive effects

Financial Impact

Emotional needs

Sexual function

Philip & Merluzzi, 2016; Mehnert et al., 2018; Yabroff et al., 2020.

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Philip and Merluzzi conducted a study of just over 300 cancer survivors in the Midwest who were an average of 10 years post-treatment. They reported an average of 1.7 psychosocial needs.

These needs included the following:

- Cognition effects, such as memory and concentration were reported by 35.6 percent
- Financial challenges, reported by 26.5 percent
- Emotional needs, reported by almost 26 percent of these cancer survivors (25.9 percent)
- Challenges with sexual function, reported by 23.0 percent, almost a quarter of the survivors

Another large epidemiolocal study with over 3,700 adult patients with a variety of cancer diagnoses, sought to identify distress related problems in survivorship. These investigators found that 52 percent of patients and survivors reported cancer related distress. The most prevalent problems were fatigue (56 percent), sleep problems (51 percent), and problems getting around (47 percent), likely reflecting functional impairment or challenges with social participation. Sadness, fatigue, and sleep problems were most strongly associated with the presence of other problems.

We can see there are a host of stressors that encompass and can cause psychosocial distress. Lets shift our lens to see when patients are more vulnerable to distress.

Now, let’s shift to examine which patients are more vulnerable to distress and then we will move to a discussion of interventions and resources.

Study details:

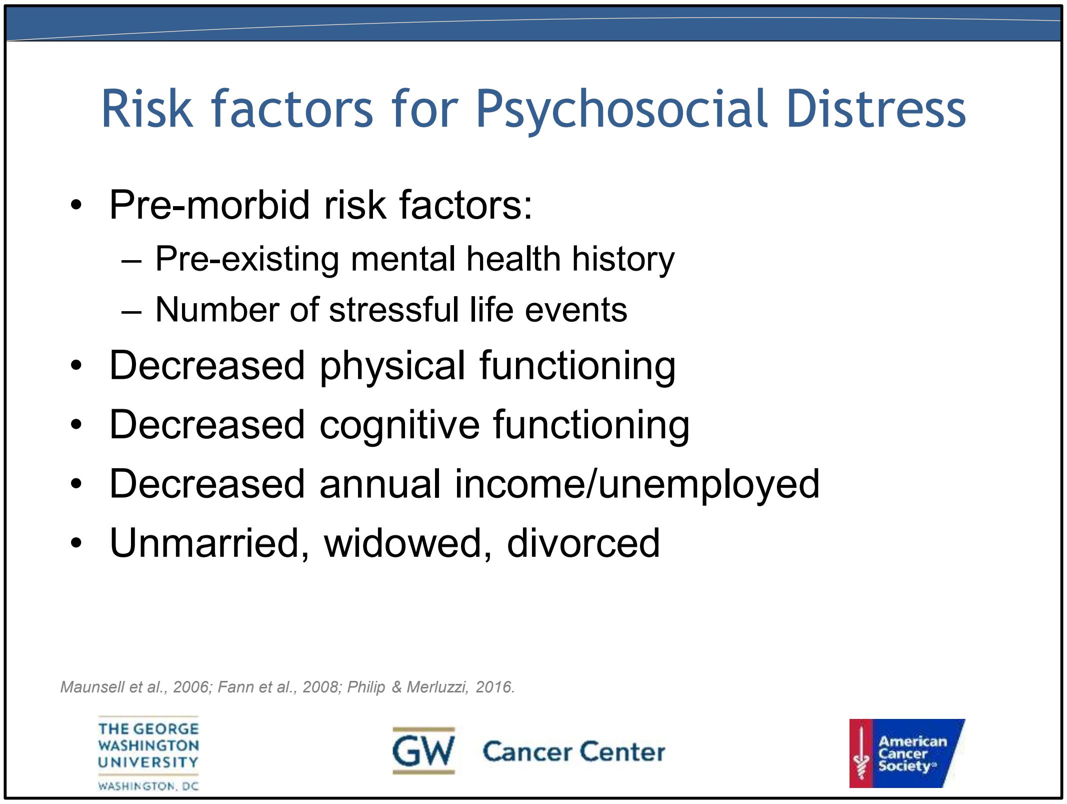
3,724 cancer patients (mean age 58 years; 57 percent women) across major tumor entities, enrolled in an epidemiological multicenter study. To identify distress-related problems, we conducted monothetic analyses.

High distress was present in 81.4 percent of patients reporting all 3 of these problems (DT M = 6.4). When analyzing only the subset of physical problems, fatigue, problems getting around and indigestion, results showed the strongest association with the remaining problems and 76.3 percent of patients with all 3 problems were highly distressed (DT M = 6.1).

Financial burden: Health insurance coverage disruptions are common and adversely associated with receipt of cancer care and survival.

Cognitive and emotional needs - more likely to report desire for follow-up with a health professional. This group had a higher level of depression and anxiety with less coping resources and social support.

We will discuss evidenced-based interventions and resources at the end of this presentation.



Risk factors for Psychosocial Distress

- Pre-morbid risk factors:
  - Pre-existing mental health history
  - Number of stressful life events
- Decreased physical functioning
- Decreased cognitive functioning
- Decreased annual income/unemployed
- Unmarried, widowed, divorced

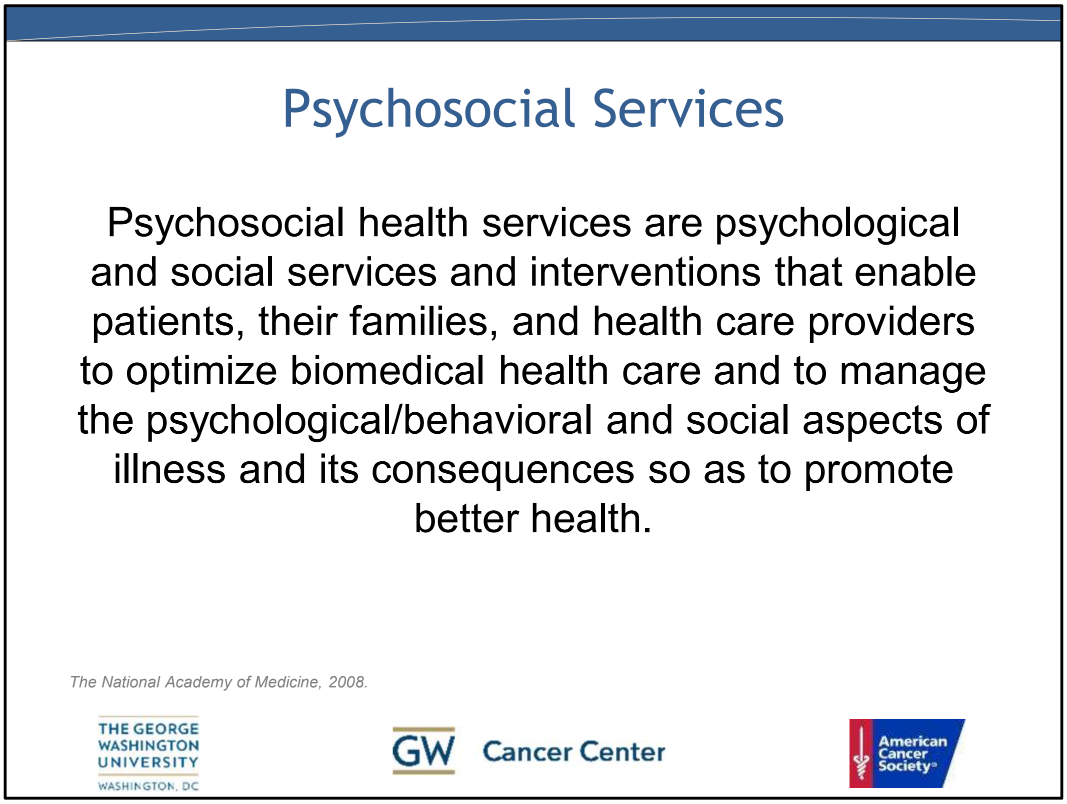
Maunsell et al., 2006; Fann et al., 2008; Philip & Merluzzi, 2016.

From the epidemiological study previously mentioned, findings indicated high levels of distress were present in 81.4% of patients who recorded a cluster of 3 problems: fatigue, sleep, and functional impairment. Thus, physical symptoms and functional impairment are associated with high levels of distress.

Other research has indicated additional factors including: financial burden, for example health insurance coverage disruptions are common and are adversely associated with a receipt of cancer care and survival. This can cause significant distress. Cognitive and emotional needs. Patients who report these are more likely to report a desire for follow-up with a health professional. Those who reported cognitive and emotional needs have a higher level of depression and anxiety with less coping resources and social support.

Additional studies have found that patients who are unmarried, widowed, or divorced were at a higher risk for distress. As well as those with a decreased annual income. These patients were more likely to request to speak to a professional. The investigators contributed this to this group of patients having fewer financial and social support resources.

Philip and Merluzzi study – decreased annual income, unemployed, unmarried/widowed/divorced



Psychosocial Services

Psychosocial health services are psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health.

The National Academy of Medicine, 2008.

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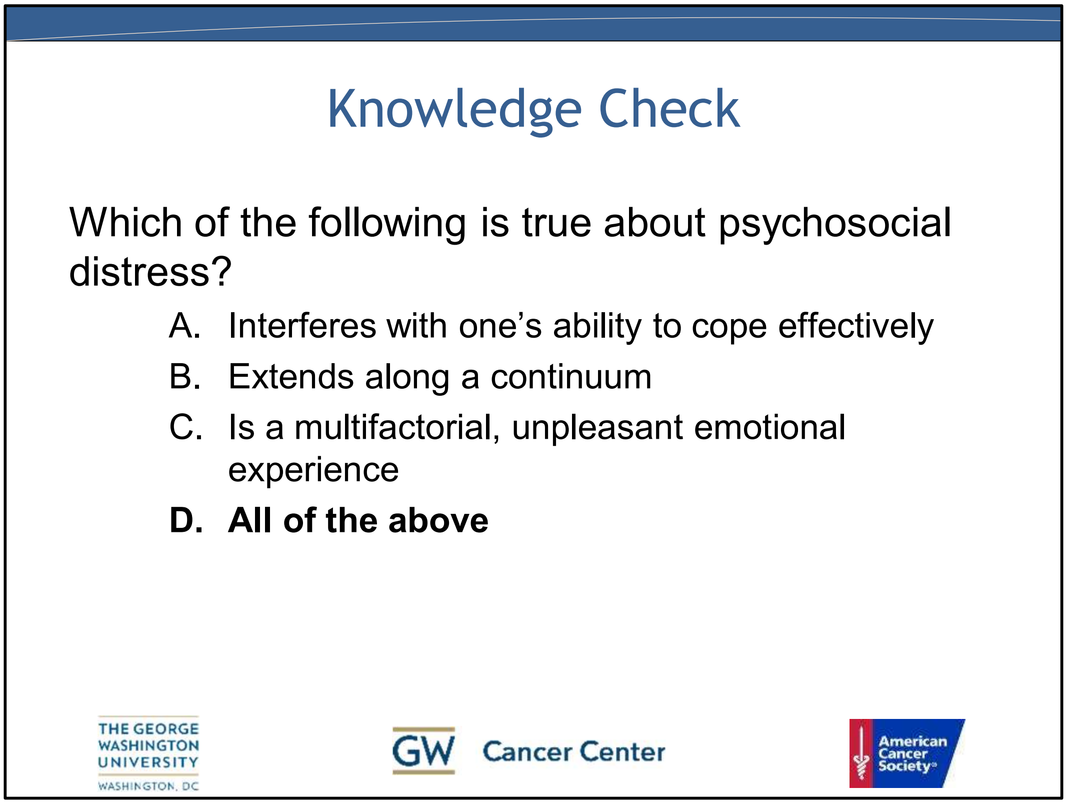
Now let’s shift and talk about resources and interventions. Psychosocial services for cancer patients can include psychological interventions and social services that enable patients, caregivers, and the treatment team to optimize healthcare and manage the psychological and social aspects of cancer to promote better health and health outcomes.



Knowledge Check

Which of the following is true about psychosocial distress?

A. Interferes with one’s ability to cope effectively
B. Extends along a continuum
C. Is a multifactorial, unpleasant emotional experience
D. All of the above

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Let’s pause for a knowledge check.

Which of the following is true about psychosocial distress? Read and select your answer.

The correct answer is D. All of the above.

Distress interferes with coping, extends along a continuum from normal or typical to severe, and is a multifactorial, unpleasant emotional experience.

There are many ways to improve quality of life and decrease distress

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There are many evidence-based interventions to improve cancer survivors’ quality of life and decrease distress.

What does the research say about interventions to decrease distress?

Interventions focus on:

- Knowledge and understanding of illness and treatment
- Functional and social wellbeing
- Mood (reduce depression and anxiety)
- Experience of treatment and disease-related symptoms

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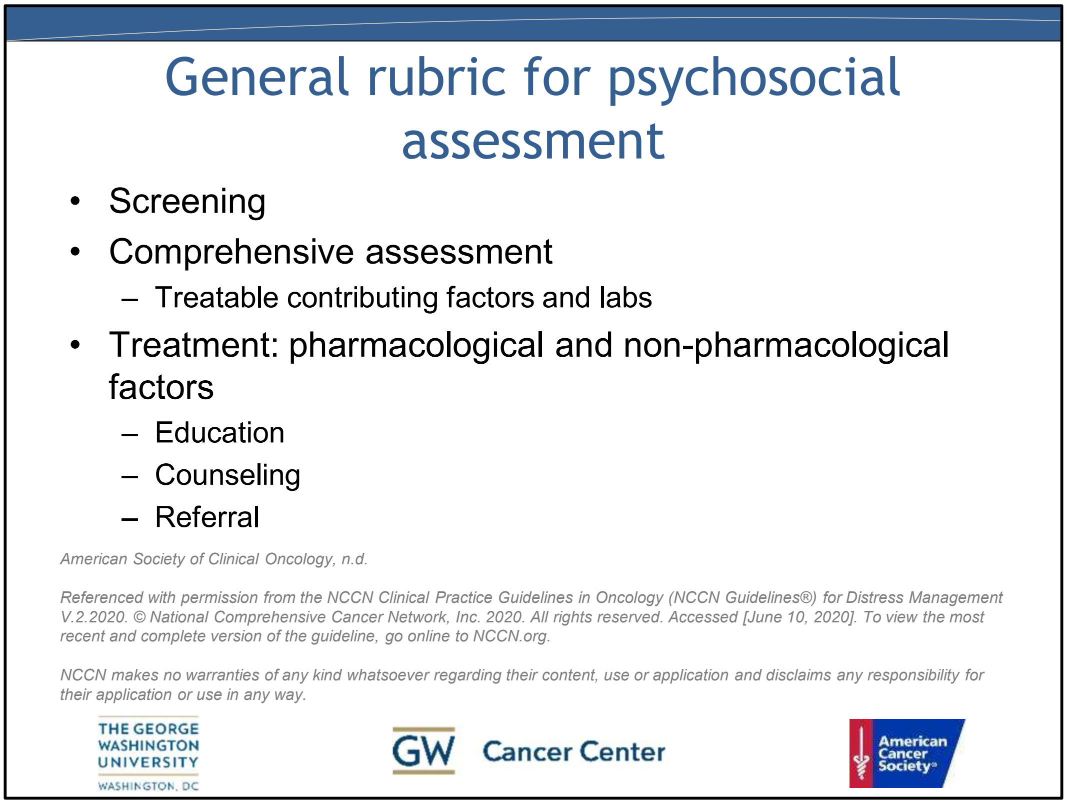
Several avenues of treatment research have generated evidence-based interventions to decrease distress.

Successful interventions are characterized by:

- Knowledge and understanding of illness and treatment
- Functional and social wellbeing
- Mood, by which we mean reducing depression or anxiety
- And, the experience of treatment and disease-related symptoms



General rubric for psychosocial assessment

- Screening
- Comprehensive assessment
  - Treatable contributing factors and labs
- Treatment: pharmacological and non-pharmacological factors
  - Education
  - Counseling
  - Referral

American Society of Clinical Oncology, n.d.

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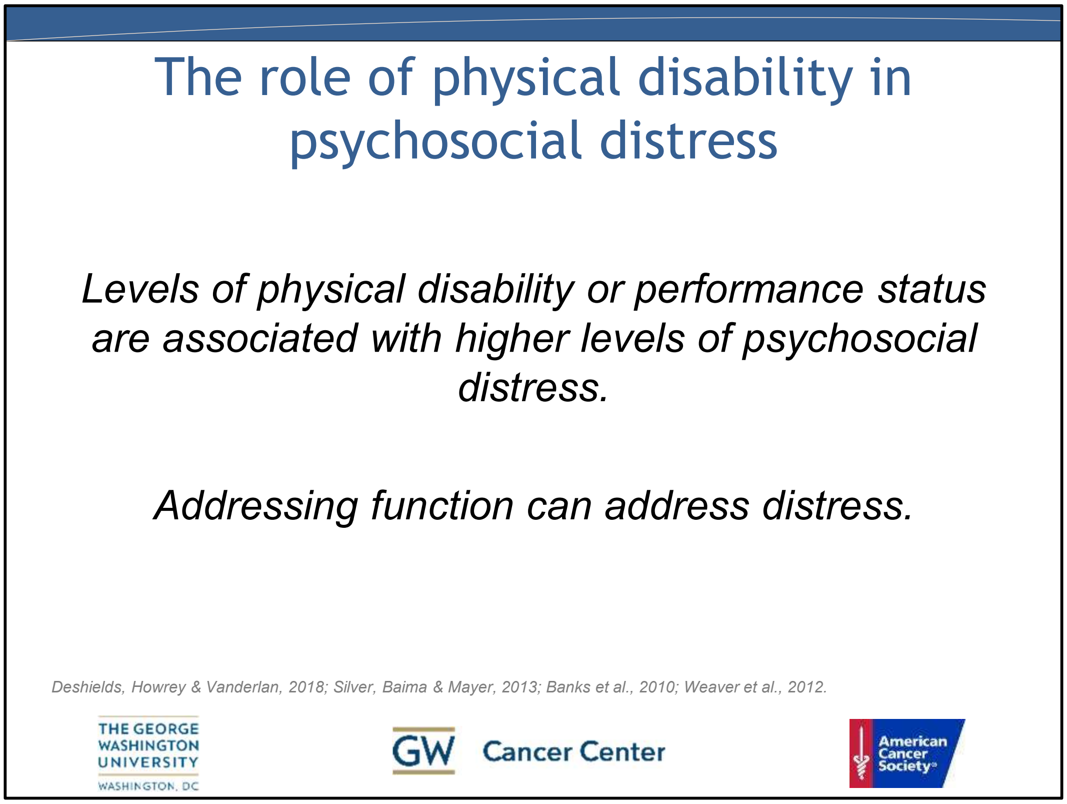
Psychosocial assessment for distress follows the common practice of screening and assessment.

Screening instruments such as the commonly used “distress thermometer” allow patients to report their overall stress and identify problems, such as physical or mental issues. Screening can also common screens for depression or anxiety.

Positive screens can then be referred or provided comprehensive assessment that identifies treatable, contributing factors. This may include psychosocial assessment or labs. Particularly for fatigue or depression to rule out medical causes of the symptoms.

Treatment can include both pharmacological or non-pharmacological treatment. These can be provided on site or through referral.



The role of physical disability in psychosocial distress

Levels of physical disability or performance status are associated with higher levels of psychosocial distress.

Addressing function can address distress.

Deshields, Howrey & Vanderlan, 2018; Silver, Baima & Mayer, 2013; Banks et al., 2010; Weaver et al., 2012.

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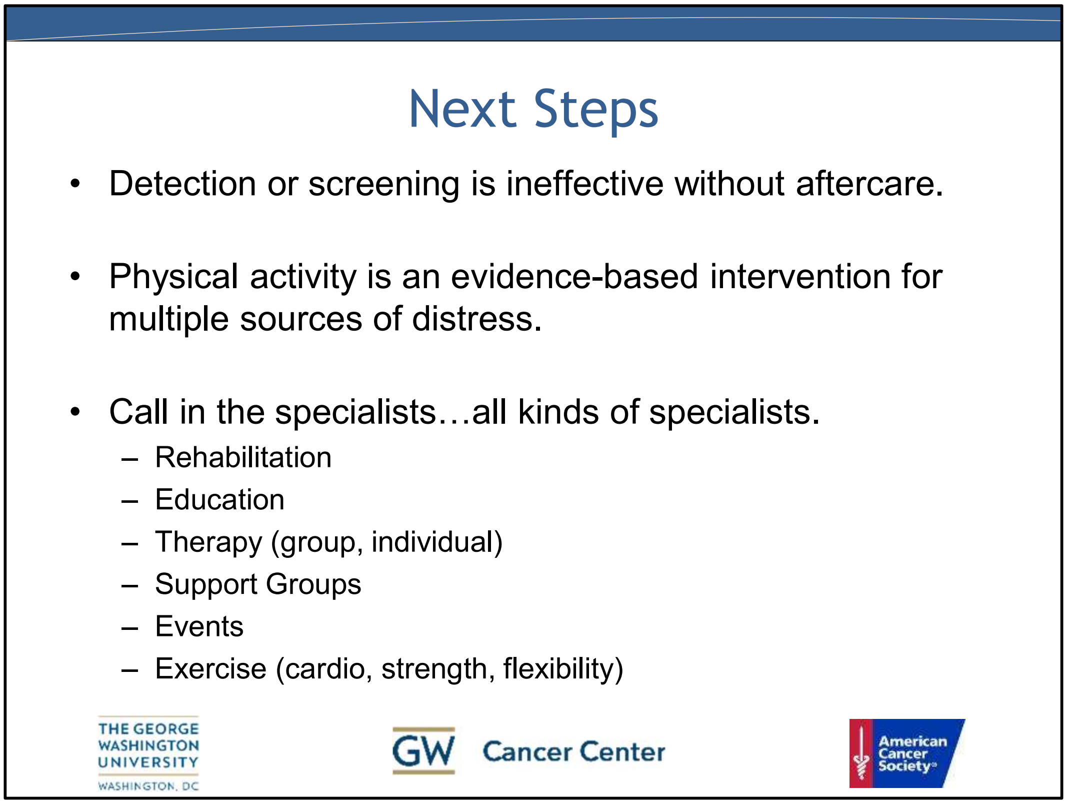
Let’s briefly discuss the role of physical disability in psychosocial distress.

Impairment or loss of function, including physical disability and decreased performance status are associated with higher levels of destress. Addressing function, including fatigue, through rehabilitation partnerships can address psychosocial distress and is often overlooked as a treatment option.



Next Steps

- Detection or screening is ineffective without aftercare.
- Physical activity is an evidence-based intervention for multiple sources of distress.
- Call in the specialists…all kinds of specialists.
  - Rehabilitation
  - Education
  - Therapy (group, individual)
  - Support Groups
  - Events
  - Exercise (cardio, strength, flexibility)

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Now that we've discussed psychosocial distress, risk factors, trajectory, assessment, and interventions, what are the next steps?

First, detection or screening is ineffective without aftercare. Your practice needs to have a plan in place for appropriate treatment and referrals for those who screen positive. And we need to ensure clinicians are aware of these resources.

Physical activity is an evidence-based intervention for multiple sources of distress, including fatigue, sleep, and mild to moderate depression and anxiety. Physical activity is a excellent adjunct to the cognitive behavioral theory for each of these symptoms.

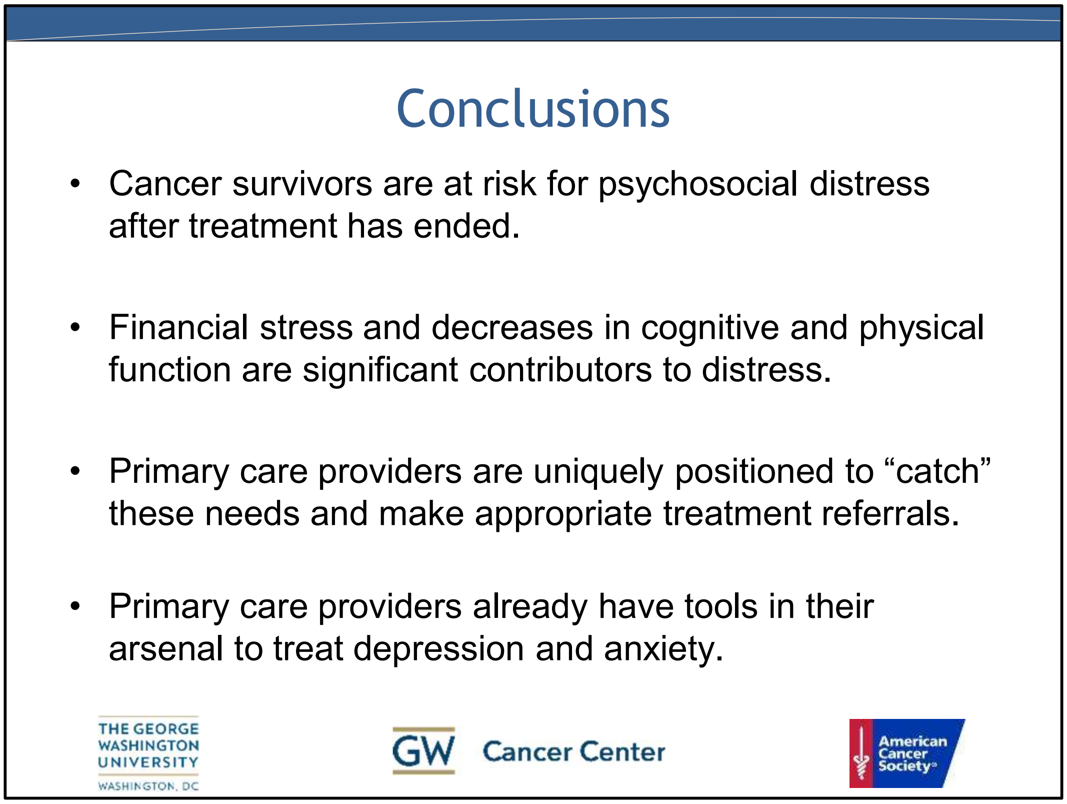
Lastly, it's important to call in the specialists.

As a clinician you don't have to have to provide all the necessary resources. There are all kinds of specialists that can provide assistance in addressing psychosocial distress. These include:

- Rehabilitation
- Education, perhaps through nursing or classes
- Therapy, group or individual

- Support groups
- Community events
- As well as community-based exercise. Including cardiovascular, strength and resistance training, and flexibility.

There are specialists there to help you, help your distressed patients.



Conclusions

- Cancer survivors are at risk for psychosocial distress after treatment has ended.
- Financial stress and decreases in cognitive and physical function are significant contributors to distress.
- Primary care providers are uniquely positioned to “catch” these needs and make appropriate treatment referrals.
- Primary care providers already have tools in their arsenal to treat depression and anxiety.

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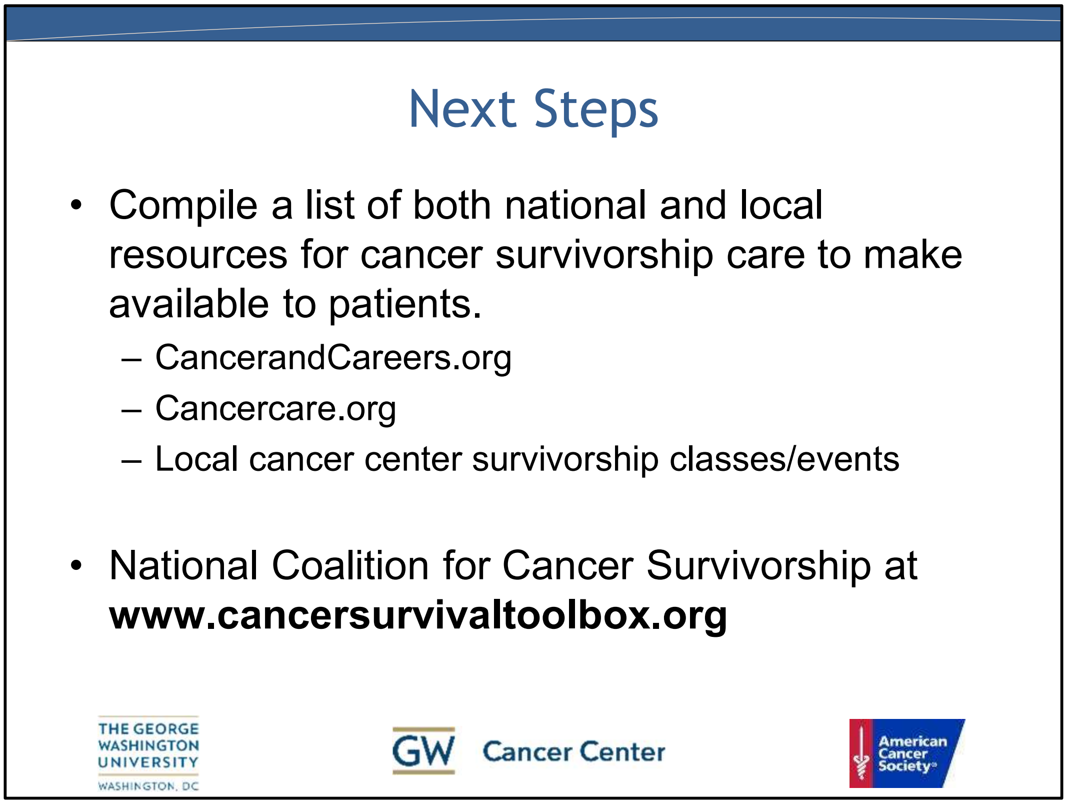
This information leads us to several conclusions, which will lead to further next steps.

First, cancer survivors are at risk for psychosocial distress after treatment has ended.

Second, financial stress and decreases in cognitive and physical function are significant contributors to distress.

Third, primary care providers are uniquely positioned to “catch” these needs and make appropriate treatment referrals.

Primary care providers already have tools in their arsenal to treat depression and anxiety.



Next Steps

- Compile a list of both national and local resources for cancer survivorship care to make available to patients.
  - CancerandCareers.org
  - Cancercare.org
  - Local cancer center survivorship classes/events

- National Coalition for Cancer Survivorship at **www.cancersurvivaltoolbox.org**

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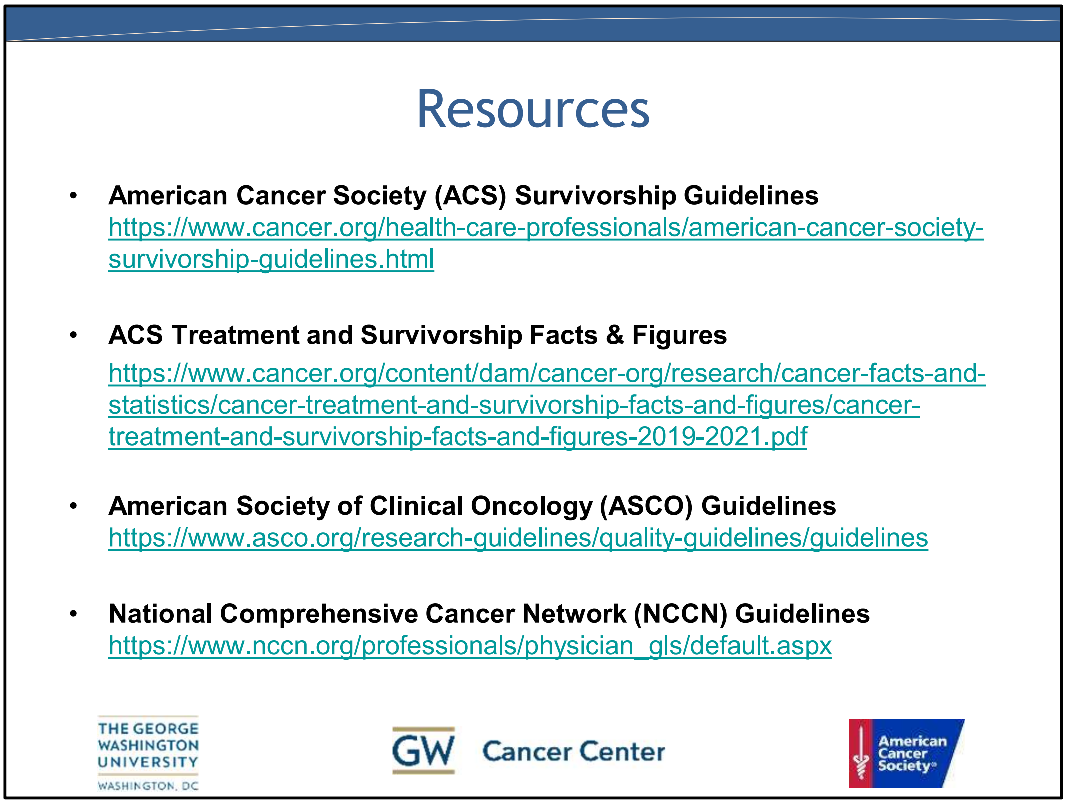
Given these conclusions what are the steps you can take today?

We’re going to list several activities and resources to help you provide high quality cancer survivorship care.

First, work with your practice to compile a list of both national and local resources for cancer survivorship to make available to patients. There are many resources available to you, with reliable, evidence-based information. These include sites such as:

- Cancerandcareers.org to help address work-related challenges
- Cancercare.org
- As well as local cancer center survivorship classes and events

The National Coalition for Cancer Survivorship at is located at this web address and includes a wide variety of tools.



Resources

- **American Cancer Society (ACS) Survivorship Guidelines**
  https://www.cancer.org/health-care-professionals/american-cancer-society-survivorship-guidelines.html
- **ACS Treatment and Survivorship Facts & Figures**
  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
- **American Society of Clinical Oncology (ASCO) Guidelines**
  https://www.asco.org/research-guidelines/quality-guidelines/guidelines
- **National Comprehensive Cancer Network (NCCN) Guidelines**
  https://www.nccn.org/professionals/physician_gls/default.aspx

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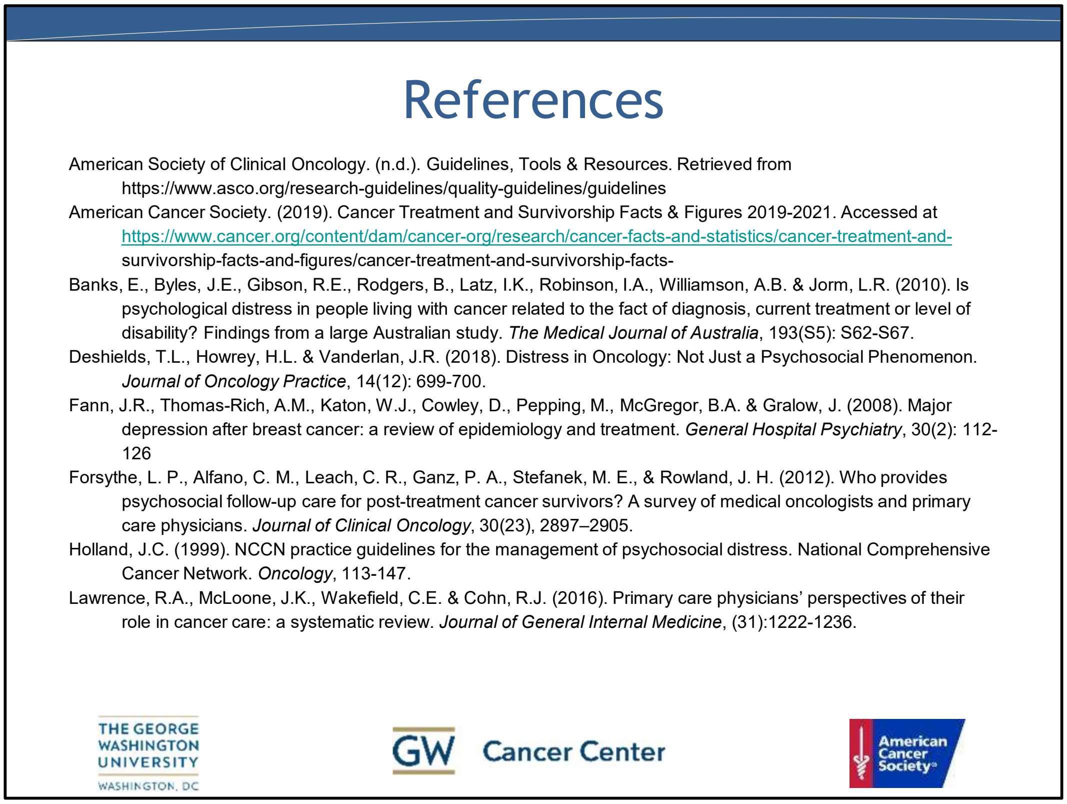
Other resources you may find help in providing care to cancer survivors include these guidelines and information from several cancer organizations. And these include:

- The American Cancer Society Survivorship guidelines.
- Their Treatment and Survivorship Facts and Figures: the common, prevalence, and incidence data
- ASCO, the American Society of Clinical Oncology also has treatment guidelines for survivorship and as well as suggestions on how to address survivorship needs
- And lastly, the National Comprehensive Cancer Network, provides guidelines for treatment as well as the use for identifying psychosocial distress through the use of the distress thermometer



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The next slides contain the reference list of the studies and guidelines cited in this presentation

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This concludes the presentation. Please continue to explore the remaining modules of the Cancer Survivorship E-Learning Series for Primary Care Providers.