


Cancer Survivors: A Growing Population with Unique Health Care Needs

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Objectives

- ▶ At the end of this presentation the participant will be able to:
 - Identify cancer survivors
 - Identify guidelines for survivorship care
 - Identify models of survivorship care delivery
 - Identify the unique needs of cancer survivors

The Numbers Are Growing

- ▶ By 2020 twenty million people/year will be diagnosed with cancer and there will be 18 million survivors.
 - ▶ Advancements in screening lead to earlier diagnosis when disease is curable.
 - ▶ Advancements in treatment mean survivors live longer with the disease.
 - ▶ Survivors expect a good quality of life.
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“From cancer Patient to Cancer Survivor”

Title of Institute of Medicine’s 2006 report (Hewitt, Greenfield & Stovall) which:

Identified survivorship as a distinct phase of cancer care

- ▶ Addressed issues faced by survivors
- ▶ Provided direction for delivering care to survivors through the use of a survivorship care plan

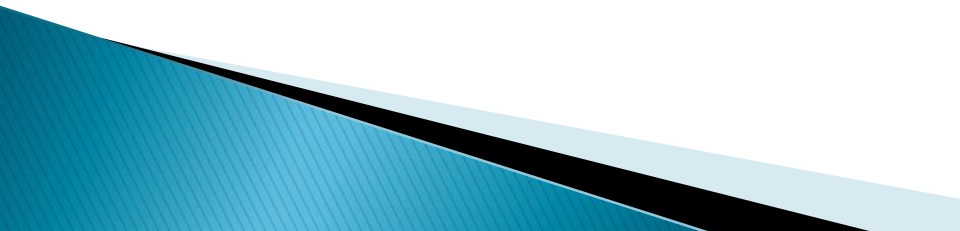
Issues Faced by Survivors

- ▶ Lack of coordinated care
- ▶ Inadequate attention to long term effects of cancer treatment
- ▶ Inadequate attention to late effects of cancer treatment
- ▶ Complexity of care after treatment

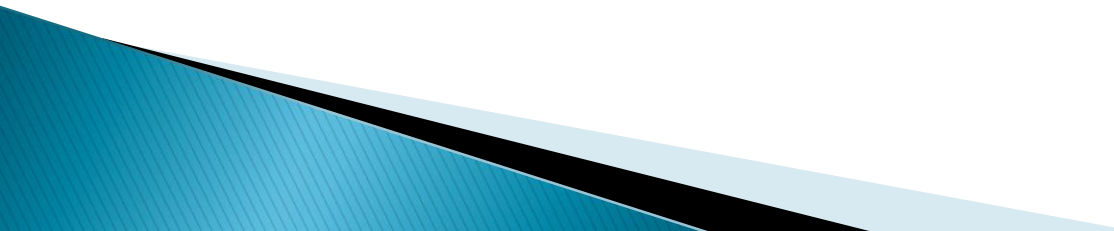
(Hewitt, Greenfield & Stovall, 2006)



Survivorship Care Plans

- ▶ Address post-treatment health needs by:
 - ▶ Serving as a communication tool between the Primary Care Provider, the patient and the oncologist.
 - ▶ Delineating who is responsible for specific components of care.
 - ▶ Includes a treatment summary, schedule for follow up, recommendations for improving health and resources
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Who are Cancer Survivors?

- ▶ Survivors are defined as anyone who has been diagnosed with cancer; covers the time from diagnosis to death (Mullan, 1985).
 - ▶ The National Coalition for Cancer Survivorship expands this definition to include the experience of living with, through and beyond a cancer diagnosis including the impact on family, friends and caregivers (2014).
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Survivors by the Numbers

- ▶ Over 15.5 million children and adult survivors as of 1 / 1 / 16 (American Cancer Society)
 - 67% were diagnosed more than 5 years ago
 - 17% were diagnosed more than 20 years ago
 - 61% are over 65 years of age. 47% of those survivors are over 70 years of age
- ▶ By January 2026 an estimated 20.3 million cancer survivors will be alive.

Essential Components of Survivorship Care


- ▶ Health maintenance and prevention of cancer recurrence and development of a new primary cancer
 - ▶ Surveillance for metastasis, recurrence for a new primary cancer and assessment for late effects
 - ▶ Interventions for the consequences of cancer and its treatment
 - ▶ Coordination of care among all health care providers involved in the patient's care
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Stages of Cancer Survivorship


- ▶ Acute stage – from diagnosis to the end of the initial treatment
- ▶ Transition – period immediately following the initial treatment
- ▶ Extended survival stage
- ▶ Permanent Survivor

The trajectory of survivorship varies from living with intermittent periods of active disease, living cancer free for a period of time but developing late effects, recurrence or a new primary cancer to living cancer free for the rest of life.

Elements of the Treatment Summary

- ▶ Contact information for the treating institution(s) and the names of all providers.
 - ▶ Diagnosis, Stage, histology and metastasis if any
 - ▶ Record of all care received with the dates of treatment
 - ▶ Overview of toxicities or adverse effects and information on the likely course of recovery
 - ▶ Results of genetic testing
 - ▶ Reason treatment ended & response to treatment
 - ▶ Performance status at the end of treatment
 - ▶ Referrals provided during treatment
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Elements of the Survivorship Care Plan

- ▶ Detailed follow up plan outlining schedule of surveillance visits and testing to be done
 - ▶ Possible symptoms of recurrence
 - ▶ List of likely significant late and/or long term effects
 - ▶ Cancer screening tests for early detection of new primary cancer
 - ▶ Health promotion/health maintenance strategies
 - ▶ Referral resources for physical, psychosocial and practical needs
 - ▶ Outline of which providers will be responsible for particular aspects of care
 - ▶ Survivorship care resources
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Are Care Plans Effective?

- ▶ Few studies have directly measured the effectiveness of survivorship care plans. A few that have:

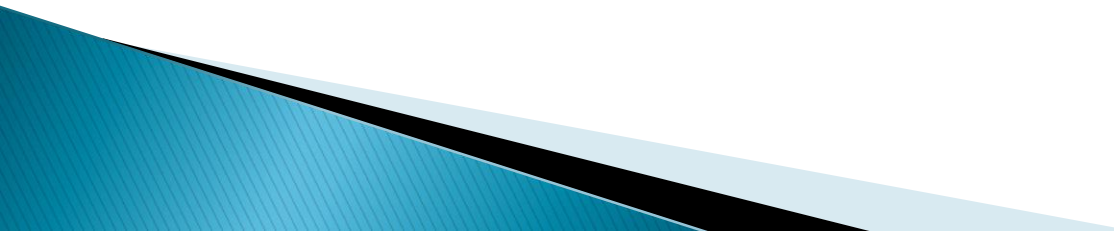
Grinfeld et al, 2011 found no difference in distress levels between a group of breast survivors who received a care plan and another group who did not.

Hershman et al, 2013 found the same result.

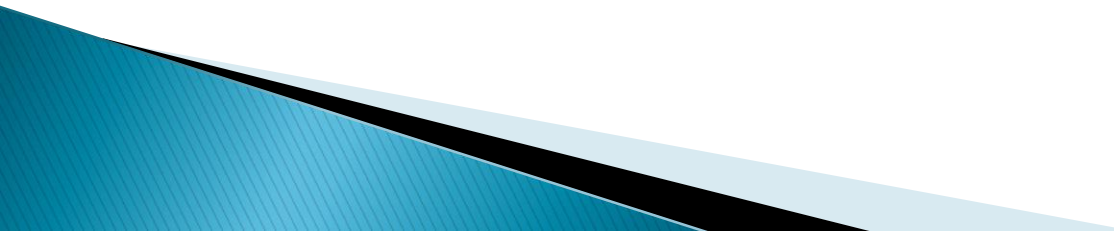
Brothers et al 2012 found that gyn oncology survivors who received a care plan as well as those who did not receive them rated their care highly.

- ▶ Some non-randomized studies do support the use of survivorship care plans.

Survivor Needs

- ▶ Fall into 5 domains
 - Physical
 - Psychological
 - Social
 - Financial
 - Spiritual
 - ▶ Overlap between each of these
 - ▶ Problems may develop during active treatment or months to years later
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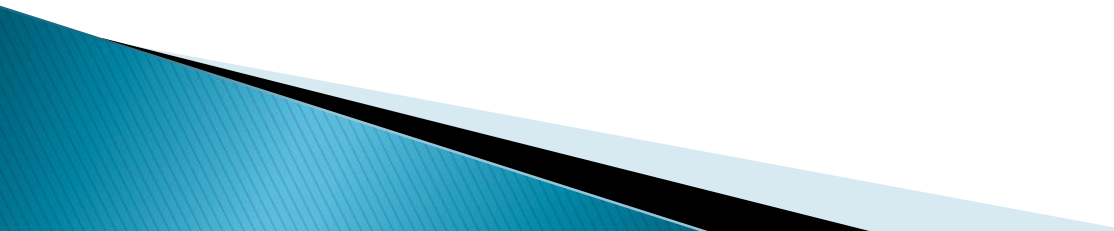
Livestrong Poll of Survivor Needs

- ▶ Secondary health problems (53%)
 - ▶ Infertility (33%)
 - ▶ 70% were dealing with depression but only 22% sought professional health
 - ▶ 58% had relationship problems
 - ▶ 43% had financial issues
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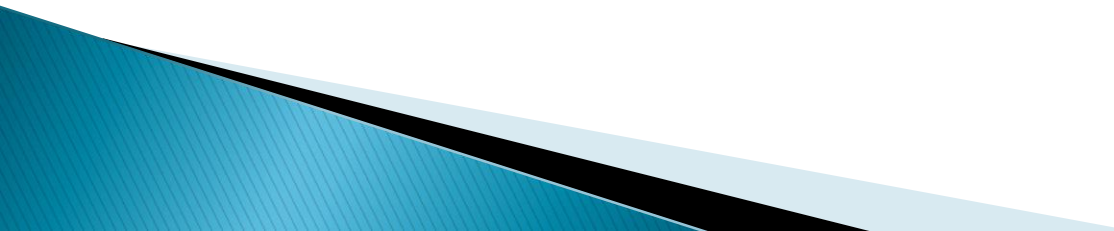
Physical Needs

- ▶ Hair, skin and nail changes
- ▶ Dry mouth, mouth sores
- ▶ Appetite changes
- ▶ Weight changes

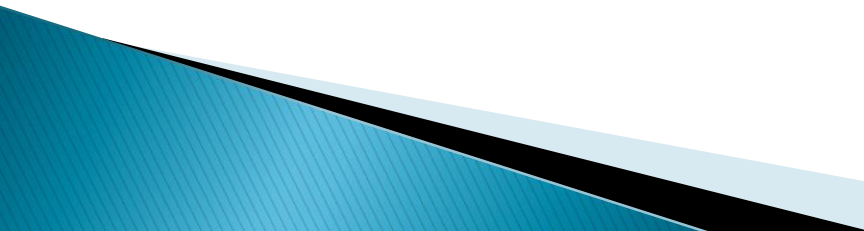
Weight gain and obesity are associated poorer survival outcomes.

- ▶ Nausea/vomiting
 - ▶ Bowel dysfunction
 - ▶ Cardiopulmonary
 - ▶ Sensory changes
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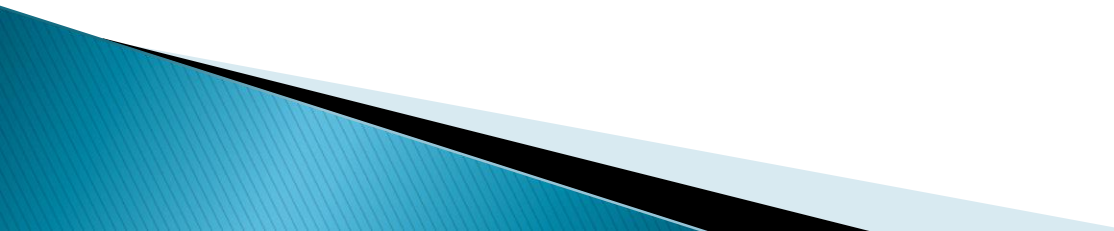
Physical Needs

- ▶ Myelosuppression
 - ▶ Fatigue and sleep disturbances
 - ▶ Cognitive changes
 - ▶ Sexuality and intimacy
 - ▶ Infertility
 - ▶ Loss of bone density
 - ▶ Lymphedema
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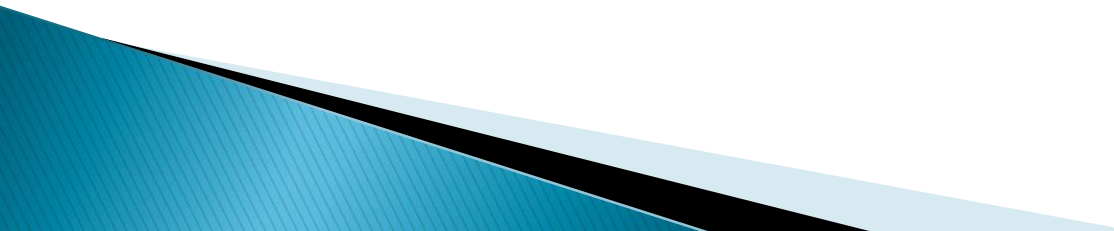
Psychosocial Needs

- ▶ Fear of recurrence
 - ▶ Anxiety
 - ▶ Depression
 - ▶ Loss of control
 - ▶ Adjusting to a “new normal”
 - ▶ Family distress
 - ▶ Role and relationship changes
 - ▶ Self image
 - ▶ Isolation
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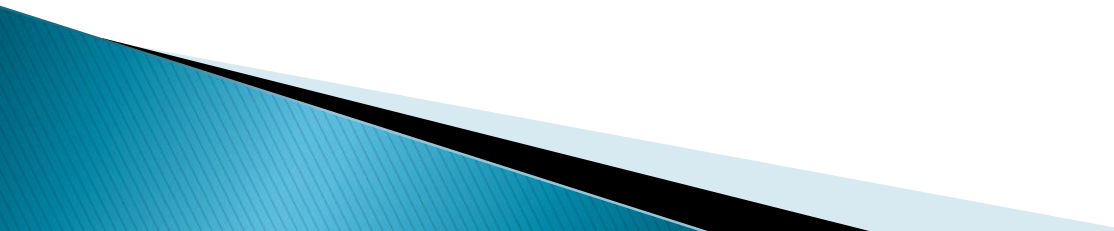
Spirituality Needs

- ▶ Finding meaning in the illness
 - ▶ Transcendence
 - ▶ Hope
 - ▶ Inner strength
 - ▶ Helps the patient and family cope with end of life issues
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Financial Needs

- ▶ Need to work to maintain health insurance or earn money to support self/family, afford medical care.
 - ▶ Caregivers also face financial hardships.
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Models of Survivorship Care

- ▶ Oncology Specialist Care Model
 - ▶ Shared Care Model
 - ▶ General Survivorship Model
 - ▶ Multidisciplinary Model
 - ▶ Consultative Model
 - ▶ Integrated Delivery Model
 - ▶ Community Generalist Model
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Challenges to Implementing A Survivorship Program

- ▶ Shifting focus of care from disease to wellness
 - ▶ Providers are unfamiliar with the ongoing needs of survivors
 - ▶ Limited resources to assist primary care providers with follow up care
 - ▶ Patients are unaware of late and long term effects
 - ▶ Lack of standardized tools for management and assessment of late and long term effects
 - ▶ Lack of resources to develop survivorship program
 - ▶ Insurance issues
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