The Future of Cancer Survivorship

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Cancer Survivors– a growing number!!!

• 14.5 million cancer survivors as of June 2014
• >20 million cancer survivors by 2022
• 24% are breast cancer survivors
• Keep in mind these numbers only include those actually diagnosed…
  – Prostate cancer in the future will show very different stats
• Baby boomers now in midlife
• Better cancer treatments
• Better detection technologies
• More awareness
Who will become diagnosed?

- 1 in 2 men*
- 1 in 3 women*
- And 1 in 3 households has a caregiver taking care of a loved one with cancer

* Life threatening cancers
Cancer Treatment is not without side effects

• Short term side effects
• Long term side effects
• Late effects, even decades later
  – My own personal experience with this…
  
  – Why has this been acceptable? Because there was one goal—survival. Not survival with quality of life
According to a survey from the living strong organization, out of 2,307 participants:

1,356 cancer survivors had concerns about Energy - 56% of these did not receive care
1,261 about Concentration - 83% did not receive care
1,058 about sexual function – 71% did not receive care
963 about Neuropathy - 60% did not receive care
780 about pain - 37% did not receive care
527 about Lymph edema – 33% did not receive care
503 about Incontinence – 69% did not receive care
367 About Lungs – 47% did not receive care
184 About Heart – 32% did not receive care

Baseline Projected Supply and Demand for Oncologist Visits

<table>
<thead>
<tr>
<th>Supply</th>
<th>Demand</th>
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</thead>
<tbody>
<tr>
<td>• Train more fellows?</td>
<td>• Increased proportion of new cases/follow-ups</td>
</tr>
<tr>
<td>• Greater use of EMR?</td>
<td>• Increased visit rates among age &gt; 70</td>
</tr>
<tr>
<td>• Increase # NPs/PAs?</td>
<td>• Greater use of hospice services</td>
</tr>
<tr>
<td>• Delay retirement of cancer specialists?</td>
<td>• Greater use of PCPs to monitor cancer patients not in first</td>
</tr>
<tr>
<td>• Maintain productive peak achieved ~ age 45?</td>
<td>year of Dx or last year of life?</td>
</tr>
</tbody>
</table>

*Erikson et al. J Oncol Practice 3:79, 2007*
Projected by 2020, demand for oncology services will significantly outpace the supply of oncologists available to provide patient care.

**Deficit of oncologists projected to be between 41- 48% by 2020**

**Onc work force will only grow 14%**

JCO Vol 25, No 12 (April 20, 2007)
The New Paradigm of “Seasons of Survival”

Acute → Transitional → Extended Survivorship, Cancer Free →
- Permanent Survivorship, Cancer Free-Free of Cancer
- Permanent Survivorship, Long-Term/Late Problems
- Permanent Survivorship, Second Cancers
- Permanent Survivorship, Secondary Cancers

Extended Survivorship, Maintained Remission
Chronic Survivorship, Living with Cancer
Essential Components of Survivorship Care

• Prevention of recurrent & new cancers, and of other late effects
• Surveillance
  – Cancer spread, recurrence, or second cancers
  – Assessment of medical and psychosocial late effects
• Intervention for consequences of cancer and its treatment
  – Medical problems (e.g., lymphedema, sexual dysfunction); symptoms (e.g., pain, fatigue); psychological distress (survivors, caregivers); employment, insurance, and disability
• Coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met.

Cancer Patient to Cancer Survivor: Lost in Transition (IOM 2005)
# Essential Components of Survivorship Care

## Table 1: Essential Components of Survivorship Care

<table>
<thead>
<tr>
<th>Care Component</th>
<th>Goal</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rehabilitation</td>
<td>Optimize survivor’s health potential</td>
<td>Physical therapy program for urinary continence rehabilitation following prostate cancer surgery</td>
</tr>
<tr>
<td>Surveillance for cancer recurrence</td>
<td>Early detection of cancer recurrence</td>
<td>Regularly scheduled colonoscopies for colorectal cancer survivors</td>
</tr>
<tr>
<td>Detection of and intervention for late consequences of cancer and its treatment</td>
<td>Early intervention for therapy-related complications when they are most amenable to treatment</td>
<td>Regular mammograms and breast MRIs in young women treated with chest radiation for Hodgkin’s lymphoma to allow for early detection of radiation-related breast cancer</td>
</tr>
<tr>
<td>Health promotion</td>
<td>Reduction of risk for development of subsequent malignancies and comorbid conditions</td>
<td>Smoking cessation program for bladder cancer survivors to reduce risk of developing pulmonary dysfunction and future tobacco-related cancers</td>
</tr>
<tr>
<td>Psychosocial support</td>
<td>Optimize psychosocial functioning following cancer treatment</td>
<td>Local psychosocial support group for breast cancer survivors</td>
</tr>
<tr>
<td>Evaluation of and intervention for socioeconomic consequences of cancer and its treatment</td>
<td>Normalize access to work, school, and insurance for cancer survivors</td>
<td>Referral for advocacy services for survivors experiencing employment discrimination</td>
</tr>
</tbody>
</table>

[http://www.psychiatrictimes.com/display/article/10165/1399859](http://www.psychiatrictimes.com/display/article/10165/1399859)
Models of Care

- Linear model
  - Hands off, no feedback

- Parallel model
  - “Shared care”
  - Most older cancer survivors receive care from a cancer specialist and a primary care physician
Shared-Care Model

- Cancer care domain
  - Short/mid-term surveillance
  - Acute/short term complications
  - Screening for 2^{nd} cancers

- Primary care domain
  - Preventive services (diabetes, heart disease, osteoporosis, vaccinations, …)
  - Screening for 2^{nd} cancers
  - Long-term surveillance (if necessary)
  - Long-term complications (if applicable)
ASCO 2006 Update of the Breast Cancer Follow-Up and Management Guidelines in the Adjuvant Setting

• Shared-Care Model
  – An evolving field of evidence-based practice; the mechanism of care transfer, level of shared-care among providers, and likelihood of success of this strategy will depend on the characteristics of the local clinical setting

Khatcheressian, Wolff, Thomas et al. JCO 24:848, 2006
Shared Care Model

• Has demonstrated to improve patient outcomes and enhance patient management of patients with various chronic diseases including diabetes, chronic renal disease and those receiving anticoagulant therapy.
• With monitoring, some late effects will be diagnosed at an earlier more treatable stage.
• With interventions the risk of some late effects can be reduced.

Common Symptoms After Breast Cancer Diagnosis/Rx

<table>
<thead>
<tr>
<th>Problems/Symptoms (based on Hayes, NEJM 2007)</th>
<th>Who should be involved?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cancer specialist</td>
</tr>
<tr>
<td>Bone health</td>
<td>x</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>x</td>
</tr>
<tr>
<td>Cognitive dysfunction</td>
<td>x</td>
</tr>
<tr>
<td>CHF</td>
<td>x</td>
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<tr>
<td>Depression</td>
<td>x</td>
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<tr>
<td>Fatigue</td>
<td>x</td>
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<tr>
<td>Hot flashes</td>
<td>x</td>
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<tr>
<td>Lymphedema</td>
<td>x</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>x</td>
</tr>
<tr>
<td>Sexual dysfunction</td>
<td></td>
</tr>
<tr>
<td>Weight gain</td>
<td>x</td>
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</tbody>
</table>
Who is responsible for what? example---

• **PCP** to follow patient for general health needs and wellness—vaccines, management of chronic illness, acute respiratory illnesses, etc.

• **Gyn**---pelvic health, breast health

• **Oncology specialist (primarily an NP)** for cancer recurrence screening; side effects management
Barriers to shared care model

- Cancer diagnosis rules—patient disconnects from the PCP
- Mild diabetes, borderline hypertension, mild clinical depression, elevated cholesterol take a back seat to cancer
- Patient doesn’t want to return to PCP—patient wants to utilize oncologist as PCP
- Oncologist may allow this to also happen.
- PCP doesn’t encourage patient to return.
Planning on becoming a Survivor

- Survivorship care must start at the time of diagnosis
  - What are your life goals?
    - expand family, studying to be a concert pianist
  - Let's see if we can keep you on track for those life goals
  - Refer to prehabilitation before beginning any treatments
    - Don't allow deconditioning that requires reconditioning
  - Need or want to work during your treatment?
    - Let's decipher a treatment plan that dovetails with your job
  - Create/design your “new normal” instead of adjust to it…
  - Don’t disconnect from your PCP
  - Instead of a Survivorship Care Plan— a Survivorship Life Plan!
  - If you don’t feel you can advocate for yourself, get an advocate
It Takes a Multidisciplinary Team

- Nurse navigator
- Oncology NP
- Surgical oncologist
- Medical oncologist
- Radiation oncologist
- Genetics/High Risk
- Cancer Rehab Therapist
- Psychotherapist
- PCP
- Gynecologist / fertility expert
Who we need post treatment

• Nurse navigator—prepare you for the transition
• NP – conduct a transitional consultation
  – Treatment summary—all of the treatment done to date
  – Survivorship life plan ---
    • on track for those original life goals?
    • Have new life goals to add?
    • Lifestyle behavior changes you are willing to take on to reduce your risk of cancer in the future
    • Surveillance schedule for breast cancer and other cancers.
    • Who is to do what and when
    • Timing of when to see your PCP, your oncologist (if on hormonal therapy), rehab if still needed, even psychotherapist

• Staying abreast of new information—newsletters, seminars, webinars, support group ed mtgs
What do YOU need to do

• Take charge of your health
• Commit to exercise, healthy eating, no smoking, and limit alcohol.
• Adhere to hormonal therapy
• Keep your surveillance appointments
• Rely on your PCP and gynecologist as your providers of care.
Forgotten Cancer Survivors

• More and more people are living in harmony with their metastatic cancer
  – They are forgotten survivors
  – They don’t “fit” in support groups
  – They don’t “fit” in celebratory events
    • Cancer Survivors’ Day
  – Improvements in treatments have them living longer
What these survivors need

- To not feel isolated
- To be honest with them
- To make sure their personal goals match with the treatment goals
  - “I am hopeful your tumor will respond to the next treatment.”
- Quality of life over quantity of life
The right to experience a good death…

- Purpose
- Legacy
- Spoken of fondly
- Leave no financial debt associated with cancer treatment or care
- Pain free
- Spiritually at peace
- Affairs in order—legal and financial
- Nothing left unsaid—‘I love you’s, thankfulness, foregiveness, gratefulness
The Cost of Hope

- Cancer is the most expensive illness today and will remain that way.
- Drugs are skyrocketing in price – a dose of a chemo agent can be $80K a dose.
- Doctors are to tell the patient today the risks, benefits, and cost of the treatment.
- Out of pocket expenses – commonly leads to bankruptcy.
- Family wants patient to keep getting treatment; the patient wants to stop.
Communication and philosophy

• There needs to be ongoing communication and palliative care involved from the beginning

• Oncologists are taught to treat the disease; they need to be taught to listen to what the patient is hoping for.

• My goal—orchestrate a good death.
Fulfill their goals/hopes in alternative ways -
Jack – Witnessing son’s wedding
-- becoming a grandfather

24 year old bride…knew her mother was “there”
If you need me

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  – Phone: 410-614-2853