Gen S: The Next Generation of Cancer Survivorship Standards
Who is a Cancer Survivor?

- “The term cancer survivor includes anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life.” – NCCS, 1986

- Historically, a subset of survivors who completed active treatment and are five years post-diagnosis
Estimated Number of US Cancer Survivors

US Persons Alive Diagnosed with Cancer, By Site
Survivors are also Older

A Surge in Older Survivors: Estimated Number of U.S. Cancer Survivors by Age Group

Impacts of Cancer Treatment

American Cancer Society, 2016. Available at:
http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/toolsforhealthcareprofessionals/index
Cancer Survivor Needs

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
Survivorship: Cancer as a Turning Point

• Most cancer survivors describe “life before cancer” and ”life after cancer”

• For many it is an opportunity to re-evaluate priorities, decide what is most important, to see life as “more precious”

• For many others, cancer becomes a chronic disease that poses challenges to identity, function, and meaning

• For all, cancer changes one’s life, either temporarily or permanently
The IOM Recommendation for Pediatric and Adult Cancer Survivors.
(2007 IOM Report)

- Treat survivorship as a distinct phase of cancer care
- Utilize evidence-based clinical practice guidelines
- Increase awareness of late effects and the need for survivorship care
- Improve professional education and training
- Improve access to care for survivors
- Increase research to prevent/ameliorate late effects
- Create individual survivor care plans
The Mandate:

- An expected part of cancer care (ASCO)

- SCP’s: Progress was slow
  - Survey of all NCI designated cancer centers
    - Only 43% of centers delivered SCP’s
    - None included all of the IOM components (CA Cancer J Clin, 2012: 62)
  - Survey of 7 NCI-designated cancer centers and 6 community-based centers
    - Less than ½ of IOM recommendations were met.
    - No site achieved greater than 75%

(J Can Surv. 2011)
The Original Survivorship Standard: 3.3
(developed in 2012-Implementation began in 2015)

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

• Patients being treated with curative intent
  • 2015 SCP’s given to 25% of eligible patients
  • End of 2016 SCP’s given to 50% of eligible patients
  • End of 2017 SCP’s given to 75% of eligible patients
  • End of 2019 SCP’s given to all eligible patients
Challenges to Implementation of Standard as Originally Written

• Unfunded Mandate: some cancer centers responded by adding resources, others did not
• Lack of auto-population of document by EMR (care plans required 30 minutes to 4 hours to complete- not reimbursed time)
• Many services not reimbursed
• Lack of research to indicate that care plans changed patient behavior

• Consequences:
  • Some cancer centers considered pulling out of the CoC
  • The original intent of Survivorship was overshadowed by emphasis on the SCP itself
The Revised CoC Survivorship Standard

The cancer committee oversees the development and implementation of a survivorship program directed at meeting the needs of cancer patients treated with curative intent.

• **Requirements**
  • Designate a coordinator of survivorship care program who must be a member of the cancer committee
  
  • An identified team responsible for the development of survivorship care delivery models and activities
  
  • A survivorship program that addresses the needs of cancer survivors through care and consultative services either on-site or by referral
  
  • Report that describes program and future development
The Hope: To make it more meaningful AND achievable

**Examples of Services:**

- Treatment summaries and care plans
- Screening for recurrence
- Screening for new cancers
- Physical therapy/rehab services
- Nutritional services
- Psychological support
- Cardiac consultation
- Educational partnership with Primary Care or community organizations

The new standard allows programs to develop services that make sense for their own setting/patients
Examples of survivorship services:
Rehab, exercise classes, nutrition classes (specific to survivorship)
Other Examples:
Psychosocial support, stress management- (specific to survivorship)
Other Examples:

Survivor Retreats, Reunions, Celebrations, Conferences

CELEBRATE LIFE EVERYDAY
What are we doing at OHSU?

• Survivorship care plans/packets with SW questionnaire
• BMT Survivorship series – now available on website
• Pediatric Survivorship program
Equity, Inclusion, and Diversity

• Be thoughtful about your offerings
• Engage with community partnerships
• Think about barriers
• Listen to your patients
• Ask the right questions
Resources

Available through the Commission on Cancer:
• FAQ’s

• Survivorship Program Examples

• Standards Resource Library of the CoC

Available through GW: Training education for PCPs
Take Aways

- Make the program yours, be creative
- Focus on the process of delivering quality survivorship care
- Evaluate what you may already be doing and how to adapt it to survivorship OR what others are doing in your community that you can partner with
- Query your patients
- Make it meaningful and measurable
“Expect change. Analyze the landscape. Take the opportunities. Stop being the chess piece; become the player. It’s your move.”

- Tony Robbins
“The world (survivorship) is but a canvas to the imagination.”

— Henry David Thoreau
Thank You

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