Project ECHO Session One

Introduction and Survivorship 101

January 11, 2024

Recording: Project ECHO Session One 1.11.24
SURVIVORSHIP PROJECT ECHO
(Extension for Community Healthcare Outcomes)

Collaborators:
NYSDOH/NYSCCCP
SUNY Upstate (The Upstate Foundation, Inc.)
NYS Survivorship Action Team

Subject matter team leads:
Maureen Killackey M.D.
Tessa Flores, M.D.
Christina Crabtree-Ide, PhD, MPH

Funding: Centers for Disease Control and Prevention
HOUSEKEEPING ITEMS

Please type your name (first and last), health center or organization, and your email address into the Chat Box.

Please mute your line and remain on camera.

If you have a question, please type it in the Chat Box. Questions will be answered after the speakers’ presentations.

This ECHO session is being recorded and a link will be e-mailed to attendees and posted on the NYS Cancer Consortium Website (nyscancerconsortium.org)

Do NOT share any personal information about any patient.

The Session PowerPoint and materials will be sent to attendees after each ECHO Session along with the CME survey.
INTRODUCTIONS

Facilitator: Christina Crabtree-Ide, PhD, MPH
Epidemiologist and Health Services Researcher and Implementation Scientist at Roswell Park Comprehensive Cancer Center

Sylvia K. Wood Ph.D., DNP, ANP-BC, AOCNP
Clinical Associate Professor, Director, Ph.D. Program in Nursing, Department of Doctoral Studies Stony Brook University School of Nursing

Tessa Faye Flores, M.D.
Medical Director of Cancer Screening and Survivorship at Roswell Park Comprehensive Cancer Center and a board-certified Internist and Pediatrician

Maureen Killackey, MD, FACS, FACOG
Chair, NYS Cancer Advisory Council and American College of Surgeons Commission on Cancer Site Reviewer

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Speakers have no disclosures or conflicts to report. Crabtree-Ide reports funding support from Genentech, and stock ownership of Danaher, Fortive, Vontier, and Veralto Corps.
PARTICIPANT INTRODUCTIONS

Please type your name (first and last), health center or organization, and your email address into the Chat Box.
Welcome
Survivorship ECHO Series

Session 1
Introduction and Survivorship 101

SPEAKERS
Maureen Killackey, MD, FACS, FACOG
Tessa Flores, MD
Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP

Facilitator: Christina Crabtree-Ide, PhD, MPH
What is a Project ECHO?

- Collaborative, hub & spoke model of medical education and care management
- Goal is to form long-lasting partnerships between community-based provider teams and specialized providers to create bi-directional learning networks
- Increases workforce capacity to provide best-practice specialty care to patients wherever they may live; reduces health disparities

“Moving knowledge, not people”
Patient Expectations of High-Quality Cancer Care, 2024

1. Higher Health Literacy, Well-Informed Patient & Family
2. Primary Care
   - Cancer Prevention
   - Cancer Screening
   - Diagnosis
   - Cancer Treatment
     - Recovery/Survivorship
     - End-of-Life Care
3. Psychosocial & Palliative Care
4. Targeted Navigation Based on Need
5. Clinical Research
SO, HOW ARE WE DOING IN NYS?

- ~70% NYS CoC Cancer sites have Survivorship Programs (required)
- Survivorship Care Plans when developed, <50% routinely share with PCPs
- Barriers: EMR issues, prep time, reimbursement, value?
- <50% coordinate survivorship care with local PCPs
- 50% that do coordinate with PCPs experience challenges such as provider knowledge, confidence
- Bidirectional collaboration and communication lacking
- Few programs provide training or educational opportunities for PCPs, Ob/Gyns and nurses about survivors’ cares and needs

(How NYS Cancer Programs Implement Survivorship Care: CoC Program Assessment Findings Responses from 55/62 ~90%- Eligible NYS CoC-Accredited Programs)
The goal of the Survivorship ECHO program is to improve knowledge and access to high-quality, evidence-based information related to Survivorship Care for healthcare teams who care for patients with a history of cancer.

The aims are to:

- Educate Primary Care Teams on issues faced by cancer survivors
- Develop integration, communication and coordination with the Oncology Team and Patient Navigation services
- Identify and utilize community resources; Link NYS state-wide expertise
NYS Survivorship ECHO: Target Participants

Primary care teams providing care to rural and underserved/under-resourced populations in NYS

Any multi-disciplinary teams who care for cancer survivors in NYS
After participating in this ECHO Session, participants will be able to:

1. Describe the goals, objectives and expectations of this ECHO Series
2. Understand the current landscape of survivorship in New York State
3. Identify available cancer survivorship resources and clinical guidelines.
4. Explain the role of the primary care provider in cancer survivorship care
Definition of a Cancer Survivor

An individual is considered a cancer survivor from the time of diagnosis, through the balance of 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.

National Cancer Institute-Office of Cancer Survivorship (2022, February 3).
What is Cancer Survivorship?

In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life.

This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond.

The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life.

Family members, friends, and caregivers are also considered part of the survivorship experience.

National Cancer Institute-NCI Dictionary of Cancer Terms. Survivorship
Phases of Cancer Survivorship

US Cancer Survivors Prevalence and Projections 1975-2040

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

REFERENCES
More than One Million Cancer Survivors Live in New York State

Cancer Survivors in New York State

Behavioral Risk Factor Surveillance System (BRFSS)

Figure 1. Age at first diagnosis of cancer (excluding nonmelanoma skin cancer) among NYS adult cancer survivors, BRFSS 2020

- 7.3% 75 years or older
- 47.7% 45-64 years
- 20.3% 65-74 years
- 21.8% 18-44 years
- 3.0% 17 years or younger

Figure 2. Years since first cancer diagnosis (excluding nonmelanoma skin cancer) among NYS adult cancer survivors, BRFSS 2020

- 42.6% More than 10 years
- 38.1% 0-5 years
- 19.2% 6-10 years

Figure 3. Types of cancer among NYS adult cancer survivors, BRFSS 2020

- 73.5% Only one type of cancer
- 21.8% Two types of cancer
- 4.7% Three or more types of cancer

### NYS Health Outcomes and Factors Variation

<table>
<thead>
<tr>
<th>County</th>
<th>Number of 5-year cancer survivors: all tumor types</th>
<th>Population/1 Primary Care Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Niagara</td>
<td>5,121</td>
<td>2,480</td>
</tr>
<tr>
<td>Chautauqua</td>
<td>3,255</td>
<td>1,800</td>
</tr>
<tr>
<td>Cattaraugus</td>
<td>1,831</td>
<td>2,170</td>
</tr>
<tr>
<td>Lewis</td>
<td>506</td>
<td>1,540</td>
</tr>
<tr>
<td>Oneida</td>
<td>4,957</td>
<td>1,310</td>
</tr>
<tr>
<td>Sullivan</td>
<td>1,481</td>
<td>2,710</td>
</tr>
<tr>
<td><strong>NYS County-level Range</strong></td>
<td><strong>400,900 5-year survivors</strong></td>
<td><strong>690-13,330</strong></td>
</tr>
<tr>
<td></td>
<td><strong>1.2M survivors</strong></td>
<td></td>
</tr>
<tr>
<td><strong>US Average</strong></td>
<td><strong>18.1M</strong></td>
<td><strong>1,170 Average</strong></td>
</tr>
</tbody>
</table>

Estimates derived from NYS DOH Cancer Registry data for NYS Counties Statistics and Graphs | Division of Cancer Control and Population Sciences (DCCPS) New York | County Health Rankings & Roadmaps
<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>All Survivors</th>
<th>Male Survivors</th>
<th>Female Survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%*</td>
<td>95% CI*</td>
<td>%*</td>
</tr>
<tr>
<td>Breast</td>
<td>20.8</td>
<td>17.0-24.5</td>
<td>—**</td>
</tr>
<tr>
<td>Melanoma</td>
<td>16.8</td>
<td>13.3-20.2</td>
<td>19.1</td>
</tr>
<tr>
<td>Male reproductive(^b)</td>
<td>15.6</td>
<td>12.3-18.9</td>
<td>35.8</td>
</tr>
<tr>
<td>Leukemia/Lymphomas</td>
<td>9.9</td>
<td>6.5-13.3</td>
<td>13.0</td>
</tr>
<tr>
<td>Other cancer types(^c)</td>
<td>7.3</td>
<td>4.7-9.8</td>
<td>8.5</td>
</tr>
<tr>
<td>Female reproductive(^d)</td>
<td>6.7</td>
<td>4.7-8.7</td>
<td>NA***</td>
</tr>
<tr>
<td>Gastrointestinal(^e)</td>
<td>5.4</td>
<td>3.5-7.3</td>
<td>5.7</td>
</tr>
<tr>
<td>Head/Neck(^f)</td>
<td>5.1</td>
<td>2.7-7.4</td>
<td>3.0</td>
</tr>
<tr>
<td>Lung</td>
<td>4.3</td>
<td>2.5-6.0</td>
<td>3.8</td>
</tr>
<tr>
<td>Urinary tract(^g)</td>
<td>2.7</td>
<td>1.4-3.9</td>
<td>3.0</td>
</tr>
<tr>
<td>Unknown/Refused</td>
<td>5.6</td>
<td>3.9-7.3</td>
<td>6.5</td>
</tr>
</tbody>
</table>

*% = weighted percentage; 95% CI = 95% confidence interval
**suppressed
***NA=not applicable

\(^a\) For cancer survivors who reported more than one cancer diagnosis, the cancer type reported was the most recently diagnosed cancer.

\(^b\) Includes prostate and testicular cancers.

\(^c\) Includes bone, brain, neuroblastoma, and other not specified cancer types.

\(^d\) Includes cervical, endometrial, and ovarian cancers.

\(^e\) Includes colon, esophageal, liver, pancreatic, rectal and stomach cancers.

\(^f\) Includes head and neck, oral, pharyngeal (throat), thyroid, and larynx cancers.

\(^g\) Includes bladder and renal cancers.
Cancer Survivor Needs

**Physical Well-Being**
- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain
- Food-Quality, Enough?

**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*
Interdisciplinary Survivorship Care Providers

- Diagnosis, screening assessment, treatment, rehabilitation, survivorship or palliative care
- Nurses and APNs cut across the whole spectrum of care and survivorship trajectory

(ONS, 2022)
## Cancer Survivorship Clinical Practice Guidelines

### National Comprehensive Cancer Network (NCCN)

**Dr. Tessa Flores!**

**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

### The Children’s Oncology Group

**Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, & Young Adult Cancers**

**By Topic:**
- Any Cancer Experience
  - Psychosocial, Fatigue, Sleep, limitations in healthcare access, subsequent malignancy, malignancy risk offspring
  - Blood/Serum Products
  - Chemotherapy
  - Radiation
  - Hematopoietic Cell Transplant
  - Surgery
  - Other Therapeutic Models
  - General Health Screening

### 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
- Prostate
- Head and neck

### National Academy of Medicine

**Recommendation**

Cancer Survivorship Clinical Practice Guidelines

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**National Comprehensive Cancer Network (NCCN)**

**The Children’s Oncology Group**

**American Society of Clinical Oncology (ASCO)**

**American Cancer Society (ACS)**

**National Academy of Medicine**
<table>
<thead>
<tr>
<th>Helpful Resources</th>
<th>ASCO Treatment Summary and Survivorship Care Plan (PDF)</th>
<th>PDQ Cancer Information Summaries: Supportive Care</th>
<th>Coping with Cancer: Supportive and Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Download this survivorship care plan template, treatment summary and follow-up care plan, to enhance communication and coordination of care for the survivor.</td>
<td>Find descriptions of the cause and treatment of common complications of cancer, such as pain and nausea/vomiting.</td>
<td>Find answers to many commonly asked questions about supportive and palliative care.</td>
</tr>
<tr>
<td></td>
<td><strong>Facing Forward Series</strong></td>
<td><strong>News and Highlights</strong></td>
<td><strong>Evidence-Based Cancer Control Programs</strong></td>
</tr>
<tr>
<td></td>
<td>Designed to educate cancer survivors, family members, and health care providers about the challenges associated with life after cancer treatment.</td>
<td>View recent cancer survivorship news.</td>
<td>Search this database of evidence-based cancer control programs, designed to provide program planners and public health practitioners with access to program materials.</td>
</tr>
<tr>
<td></td>
<td><strong>Support for Caregivers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Providing care and support during cancer treatment can be difficult. Find resources for people who are helping a friend or family member through cancer diagnosis and treatment.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

[https://cancercontrol.cancer.gov/ocs/resources/health-care-professionals#helpful](https://cancercontrol.cancer.gov/ocs/resources/health-care-professionals#helpful)
National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaboration between the American Cancer Society and the George Washington University Cancer Institute funded by a 5-year cooperative agreement from the Centers for Disease Control and Prevention.
Challenges in cancer survivorship

- Widespread variation in models of cancer survivorship care delivery
- Lack of clarity in roles and responsibilities, communication and coordination between oncology team and PCPs
- Workforce shortages in oncology, primary care, and cancer survivorship
- Medical education specifically related to Cancer Survivorship is limited and informal
- Rural Patients and special populations:
  - Distance to care, limited options for transportation
  - Digital divide: internet services and health literacy
  - Fewer PCPs, oncologists, and cancer services
  - Social stigma, opiate epidemic, challenges to already stretched resources
Primary Care Challenges in Transition to Cancer Survivorship


**Knowledge or skills**
- Survivorship not integrated into medical education
- Few continuing education programmes
- Patients do not always trust PCP’s role in survivorship care
- Oncologists do not always trust PCP’s role in survivorship care
- Emerging evidence regarding late effects and surveillance

**Communication**
- Little consistent information passed on from oncologist to PCP
- Scarcely information from patients, dependence on patients as sources for communication exchange
- Insufficient dissemination of clinical guidelines
- Variable use of electronic medical records

**Financial or resources**
- Not enough time, or other clinical duties take priority
- Not enough reimbursement incentives
- Not the traditionally targeted population for quality improvement
- Restrictions of insurance coverage
- Poor access to appropriate providers or services

*Figure 3: Examples of barriers to the integration of primary care into the cancer survivorship pathway
PCP=primary care provider.*
Limited knowledge of survivorship care needs, late and long-term effects

Communication

• Oncology –PCP
• Care team-survivors

Care delivery

• Preventive care-responsible providers not clearly defined
• Duplication/Unnecessary testing
• Insurance restrictions
• Transfer care responsibilities
• Resources
• Access
• Comorbidity management

(Love et al., 2022; Washko et al. 2022)
Few Providers and Limited Oncology Workforce

Understanding How NYS Cancer Programs Implement Survivorship Care

(Responses from 55/62 ~90%-Eligible CoC-Accredited Programs)

Limited workforce, limited availability in rural and underserved regions

Map shows distribution of NYS Commission on Cancer-accredited Programs and Area Deprivation Index Score

Hospital and Facilities | ACS (facs.org)
Neighborhood Atlas - Home (wisc.edu)
Few Primary Care Providers and Limited Workforce

Average: 1,170 people per provider

Range: 690-13,330 people per provider
Current trends

(Fig 1. Primary care self-reported experience and comfort with providing aspects of cancer survivorship care. PCP, primary care physician.)

(McDonough et al., 2019)
Current PCP Self-Reported Barriers

Uncertainty about delegation of survivorship care responsibilities
Lack of training
Patients seem to prefer to have their oncologist manage cancer-related issues
Lack of information about the patient's screening needs
Lack of adequate time to address cancer issues
Oncologists seem to prefer to manage cancer-related issues
Lack of information about the patient’s cancer history
Discomfort caring for patients with a history of cancer

FIG 2. Primary care physicians' self-reported barriers to providing cancer survivorship care.

(McDonough et al., 2019)
Cancer Survivorship Care Quality Framework
Nearly All Cancer Survivors Return to Primary Care

Laura C. Pinheiro, Mangala Rajan, Monika M. Safford, David M. Nanus and Lisa M. Kern

The Journal of the American Board of Family Medicine July 2022, 35 (4) 827-832; DOI: https://doi.org/10.3122/jabfm.2022.04.220007
PCP Role in Cancer Survivorship Care

- Surveillance for metastatic disease, recurrence, screening for subsequent primary cancers
- Ongoing assessment for long-term effects of cancer & Rx
  - Psychological, physical, immunologic
- Ongoing assessment & management of cancer-related syndromes or issues
- Prevention, healthy lifestyle
- Referrals & Coordination of care
Survivorship Care Plans

- Patient diagnosis and treatment summary
- Best schedule for follow-up tests
- Information on late and long-term effects of cancer treatment
- List of symptoms to look for
- List of support resources
Components of Survivorship Care Plans

- Tissue diagnosis, stage, treatment plan and dates of treatment, toxicities experience
- Expected short-and long-term side effects of therapy
- Surveillance plan for recurrence and secondary cancers
- Recommendations for late term monitoring
- Listing of providers responsible for care with contact information
- Evaluation of psychosocial needs
- Preventative, health promotion behaviors
- Follow-up care and referrals
Survivorship Care Planning Needs a Personalized Focus

• Consider patient’s disease type/stage, age, gender identity, comorbidities, and family history
• Social determinants of health
• Identify risk for recurrence, and/or high-risk factors for the development of secondary cancer or new primary cancer
• Consider needed physical, psychosocial supports & healthy lifestyle modifications
• Communication & Care coordination
Building a Cancer Survivorship Program at Stanford

Our mission is to improve the experience, and outcomes, of patients and caregivers throughout all phases of their cancer journey by advancing survivorship research, clinical care and education.

Our vision is to give people living with cancer the tools they need to manage their illness with confidence.

We are building interdisciplinary research teams to discover new ways of supporting patients and families, to understand the late effects of cancer therapy, and to integrate survivorship care within primary care.

Video on Survivorship

https://med.stanford.edu/aftercancer.html?tab=proxy
Advancing Patient-Centered Cancer Survivorship Care

Adapted from the National Cancer Survivorship Resource Center

www.cancer.org/survivorshipcenter

Dr. Maureen Killackey, GWU External Advisory Board, CoC Project

Development of this presentation was made possible by cooperative agreement #5U55DP003054 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not represent the official views of the Centers for Disease Control and Prevention. The views expressed here do not necessarily reflect the official policies of the U.S. Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. government.
Cancer Survivorship E-Learning Series

GWcanceradmin@gwu.edu
Explore GW Cancer Center Online Trainings

Courses include free continuing education credits for:
- CHES®/MCHES®
- Nursing CEU
- AMA PRA Category 1 Credit
- NASW, Certified Health Education Specialist/Master Certified Health Education, and more!

- Comprehensive list of disease site topics, clinical issues, supportive services such as navigation, addressing barriers to care, financial issues
About the New York State Cancer Consortium

The New York State Cancer Consortium is a network of individuals and organizations who work together to reduce the burden of cancer by implementing strategies outlined in the NYS Comprehensive Cancer Control Plan. Click Here for more information about what we do and how to get involved.

https://www.nyscancerconsortium.org/


References


### Session 1: Introduction and Survivorship 101

**January 11, 2024**  
12-1:00pm  
Maureen Killackey, MD, FACS, FACOG  
Tessa Flores, MD  
Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP  
Facilitator: Christina Crabtree-Ide, PhD, MPH

### Session 2: Survivorship Teams

**February 8, 2024**  
12-1:00pm  
Tessa Flores, MD  
Gregory P. Rys, NP  
Maura Abbott, PhD, AOCNP, CPNP-PC, RN  
Facilitator: Maureen Killackey, M.D.

### Session 3: Medical Issues in Survivorship

**March 14, 2024**  
12-1:00pm  
Craig D Hametz, MD, FACC, FASE, FASNC  
Tessa Flores, MD  
Facilitator: Maureen Killackey, M.D.

### Session 4: Survivorship Lifestyle Behaviors

**April 11, 2024**  
12-1:00pm  
Mara Ginsberg, Esq.  
Timothy Korytko, MD  
Facilitator: Christina Crabtree-Ide, PhD, MPH

### Session 5: Survivorship and Sexual Health

**May 9, 2024**  
12-1:00pm  
Kristin Sobieraj, PA  
Facilitator: Tessa Flores, M.D.

### Session 6: Supportive Care in Survivorship

**June 13, 2024**  
12-1:00pm  
Anne Moyer, PhD  
Robin Eggeling  
Facilitator: Christina Crabtree-Ide, PhD, MPH