

Project ECHO Session Six

Supportive Care in Survivorship

June 13, 2024

Recording: [Project ECHO Session Six_6.13.24](#)

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



Anne Moyer, PhD

Professor of Social and Health Psychology in the Department of Psychology at Stony Brook University



Robin Eggeling, CPC

Regional Business Manager, Cancer Center
Bassett Healthcare Network



Facilitator: Christina Crabtree-Ide, PhD, MPH

Epidemiologist and Health Services Researcher and Implementation Scientist at Roswell Park Comprehensive Cancer Center

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 6

Supportive Care in Survivorship

SPEAKERS

Anne Moyer, PhD

Robin Eggeling, CPC

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”

Goals & Objectives ECHO Series



After participating in this ECHO Session, participants will be able to:

- Identify supportive care needs
- Describe financial hardships faced by cancer survivors
- Understand rural cancer care challenges
- Know formal and informal ways to assess distress or common problems
- Identify effective psycho-oncologic interventions for emotional distress and quality of life

Scheduled sessions and subject matter discussants

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
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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.
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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.
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Session 4: Survivorship Lifestyle Behaviors

April 11, 2024 12-1:00pm	Eileen Bird Timothy Korytko, MD Facilitator: Christina Crabtree-Ide, PhD, MPH
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Session 5: Survivorship and Sexual Health

May 9, 2024 12-1:00pm	Kristin Sobieraj, PA Lori Davis, DNP, FNP-C, ACNP-C, CSC, NCMP Facilitator: Tessa Flores, M.D.
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Session 6: Supportive Care in Survivorship

June 13, 2024 12-1:00pm	Anne Moyer, PhD Robin Eggeling Facilitator: Christina Crabtree-Ide, PhD, MPH
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Supportive Care in Cancer Survivorship

Robin Eggeling, CPC
Regional Business Manager, Cancer Center
Bassett Healthcare Network
Cooperstown, NY

Burdens that arise during and after the diagnosis of cancer:

- Identifying Supportive care needs
- Financial Toxicity
- Psychosocial Challenges
- Rural community challenges
- Working with community/referral resources

Identifying Supportive Care Needs

Supportive care starts when diagnosis begins through survivorship.

- **Nurse Navigation**
Nurse navigation receives referrals based on diagnosis. They bridge all appointments for Oncology needs such as labs, radiology (PET/CT Scans), and coordinate outside resources for oncotyping. This relieves the patient of having to make these appointments on their own.
- **Direct Nursing**
A distress screening tool is utilized in visits to identify any mental health, family and/or social support issues. Including access to proper nutrition. Documentation of education level and occupation that might trigger compliance barriers outside of treatment.
This will trigger a visit with social work, dietitian and a financial counselor.

- Social Work

Addressing all concerns related to the distress tool that signified that help might be needed/necessary for quality of life during and after treatment.

Assess the need to stop/continue employment.

- Financial Counselors

Meet with patients and their family/caregivers/support system prior to treatment starting.

Review current insurance and coverage of upcoming treatment.

If current coverage is not sufficient for treatment needs an overview of income and eligibility to change coverage is reviewed.

These possible changes could result in reduced or no out of pocket costs for the patient.

Research on financial assistance options for patient's that do not qualify for coverage changes occur with the financial counselors.

Financial Hardships

Financial Toxicity

- More than **43%** of cancer survivors ages 18 to 49 reported problems paying medical bills.
- Almost **31%** did not get or delayed medical care due to cost.
- **More than half** of US cancer survivors say they have high medical costs, stress from worrying about paying health bills, or have delayed health care due to costs with about **33%** saying they have more than one of those issues.
- The patient or caregiver is often the breadwinner, meaning a large portion of income is lost. Short term disability (when available) only covers a percentage of their income based on hours worked in a period of time.
- People with cancer are more likely to declare bankruptcy vs those without a history of cancer.
- Cancer costs in America exceed **\$80 billion** each year.
- Research shows **40%** of Americans cannot afford an unexpected expense over \$400.

**Unpaid medical debt as of December 13, 2023 will no longer appear in NY State residents' credit reports. Under a new bill, article 49A, which was added to the NY Public health Law, titled the Fair Medical Debt Reporting Act.*

Psychosocial Challenges

- Cancer survivors with financial burdens had significantly higher rates of **depression** as well as a higher **mortality risk** for those that filed bankruptcy due to medical bills.
- Studies about financial toxicity affecting the outcome of treatment and the stress that comes with that affects survivors mortality.
- Survivors may experience deterioration of self-concept, disturbance of body image, sexual problems and difficulties in social relationships.
 - I. Cancer not only causes physical pain but may also undermine patients' self-concept.
 - II. Survivors become vulnerable to changes in their self-perceptions.
 - III. Body image dissatisfaction may result in severely distorted psychosocial well-being.
 - IV. Many cancer patients and survivors are not prepared for potential sexual changes and do not receive the needed information and support.
 - V. Family dynamic changes due to the illness.

Rural Community Challenges

- Lower rates of cancer screening and experience of lower quality cancer care.
- Transportation: Having to travel long distances to get to healthcare facilities.
Limited public or affordable transportation.
- Poverty: Higher rates in rural areas making it difficult for patient to pay for services rendered.
- Food deserts: Areas with fewer grocery options and not as many available healthy foods.
- Low health literacy: Patients reluctant to seek healthcare due to frustrations related to communication. Incomplete perceptions of health.

Working with community/referral resources:

- Food Pantry (Town availability): Having an available food source for patients struggling financially or with nutritional needs.
- Cancer support group meetings (Hospital funded): Having available support for anyone with a cancer diagnosis.
- Mobile Mammography Coach (Grant funded): Easy access to screenings either covered by insurance or free to those without.

- Symphony Medical: lymphedema sleeves and prosthetic fittings for breast cancer patients. Insurance covered if available other specialized funding received through St. Agatha funds (Statewide foundation that donates to select hospitals).
- Tracey Lee Abrams: Wigs and spa experience for patients. Free services from owner.
- Transportation (Hospital and Medicaid funded): Medicaid will pay to transport patients for chemotherapy treatments. All other patients that are Medicare and commercial covered are scheduled for free transportations services if needed.
- Working with local Rotary clubs, religious groups, local manufacturers, fundraising organizations, private donations and local businesses.

Financial Assistance Programs available to help bury the burden of financial toxicity

- **St. Agatha Foundation (State)**: Provides financial support to breast cancer patients. Established by Laurie Mezzalingua, a breast cancer patient for 12 years, created in 2004 to provide financial assistance to individuals in New York state who are afflicted with Breast Cancer.
- **Bob Simon (Donors)**: Copay assistance for medications and medical bills.
- **PAN Foundation (National Organization)**: Offers financial assistance to people with serious illnesses afford their out-of-pocket treatment costs to improve their quality of life.
- **Healthwell Foundation (National Organization)**: Helping the underinsured afford critical medical treatments- because no one should go without essential care. (National Organization)
- **Cancer Care Co-Payment Assistance Foundation (National Organization)**: Helping people with cancer overcome financial access and treatment barriers by assisting them with co-payments for their prescribed treatments.
- **The Assistance Fund (National Organization)**: An independent charitable patient assistance organization that helps patients and families facing high medical out-of-pocket costs by providing assistance for their copays, coinsurance, deductibles and other health-related expenses.

- **Leukemia and Lymphoma Society (National Organization):** Provides copay assistance to leukemia and lymphoma patients up to a certain amount (usually \$7000) and provides emergency copay assistance up to \$500.
- **The Joseph Michael Chubbuck Foundation (Local/North):** Provides financial assistance to cancer patients and their families- provides needed equipment to hospitals, hospices and treatment centers.

Celebrating Cancer Survivors

Cancer Survivors Day is the first Sunday in June.

Bassett Healthcare has been participating in the celebration of survivor's day for over 30 years. We have hosted luncheons for survivors and their guests to take the opportunity to celebrate such wonderful milestones in their cancer journey. Anyone who has received a cancer diagnosis in their lifetime is able to join us for this celebration of life.

Survivor's look forward to this event each year as this is a way for patients to reconnect with other patient's and staff who have been part of their cancer journey. Being in a rural setting staff have not only been part of their treatment process but have become a support system for their recovery and continuation of healing.

This become another opportunity to supply survivor's with additional resources on available programs and services to support their ongoing needs.

Supportive Care in Cancer Survivorship

- Key Takeaways
 - Financial burdens begin when a patient is diagnosed.
 - Opportunities to address and manage cancer treatment challenges occur at all stages during a patient's cancer journey.
 - Implementing hard stops in an organization to flag these issues can allow for the management of supportive care needs both financially and psychosocially in order to limit any post treatment impact.
 - Rural areas often do not have resources readily available for cancer survivors compared to those in more urban/suburban areas.
 - Celebrating survivors allows patient's to reflect and celebrate life knowing that their cancer journey involves a vast supportive network.



Resources

[Cancer-related psychosocial challenges - PMC \(nih.gov\)](#)

[Rural-Urban Disparities in Cancer](#)

www.governor.ny.gov

[Rural Health Information Hub](#)

[Financial Toxicity \(Financial Distress\) and Cancer Treatment \(PDQ®\)-Patient Version - NCI](#)

[Cancer Survivors Face Significant Financial Problems](#)

[Financial Problems Can Affect Cancer Survivors for Years](#)



SUPPORTIVE CARE

Anne Moyer, Ph.D. Stony Brook University

Objectives/Outline

- Understand psychosocial challenges facing cancer patients and survivors
- Know formal and informal ways to assess distress or common problems
- Identify effective psycho-oncologic interventions for emotional distress and quality of life
- Consider ways of appropriately connecting screening and multiple sources of care
- Be able to identify specific types of supportive resources for referral

Psychosocial Challenges for Cancer Patients and Survivors

- Existential threat
- Decision making burden
- Body image
- Role function (family, occupation)
- Cognitive functioning
- Sexual functioning
- Symptom distress (fatigue, pain)
- Financial toxicity
- Fear of recurrence
- Spiritual functioning
- Sleep disruption
- Challenges in coping and distress leading to anxiety (13%) and depression (18%)
- Distress termed the “sixth vital sign”
- Patients themselves identify need for informational, emotional, spiritual, and financial support.

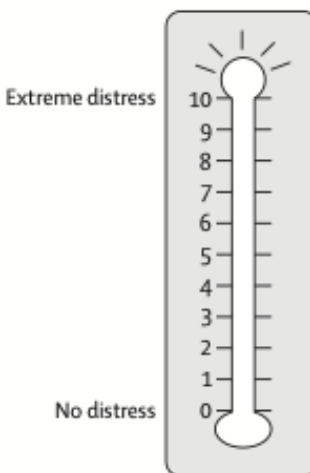
Distress screening

NCCN Guidelines version 1, 2022 distress management

NCCN Distress Thermometer

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress can make it harder to cope with having cancer, its symptoms, or its treatment

Instructions: please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today



Problem list

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical concerns

- ☐ Pain
- ☐ Sleep
- ☐ Fatigue
- ☐ Tobacco use
- ☐ Substance use
- ☐ Memory or concentration
- ☐ Sexual health
- ☐ Changes in eating
- ☐ Loss or change of physical abilities

Emotional concerns

- ☐ Worry or anxiety
- ☐ Sadness or depression
- ☐ Loss of interest or enjoyment
- ☐ Grief or loss
- ☐ Fear
- ☐ Loneliness
- ☐ Anger
- ☐ Changes in appearance
- ☐ Feelings of worthlessness or being a burden

Social concerns

- ☐ Relationship with spouse or partner
- ☐ Relationship with children
- ☐ Relationship with family members
- ☐ Relationship with friends or co-workers
- ☐ Communication with health-care team
- ☐ Ability to have children

Practical concerns

- ☐ Taking care of myself
- ☐ Taking care of others
- ☐ Work
- ☐ School
- ☐ Housing
- ☐ Finances
- ☐ Insurance
- ☐ Transportation
- ☐ Child care

Spiritual or religious concerns

- ☐ Having enough food
- ☐ Access to medicine
- ☐ Treatment decisions
- ☐ Sense of meaning or purpose
- ☐ Changes in faith or beliefs
- ☐ Death, dying, or afterlife
- ☐ Conflict between beliefs and cancer treatments
- ☐ Relationship with the sacred
- ☐ Ritual or dietary needs

Other concerns:

Note: all recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

Figure: The National Comprehensive Cancer Network (NCCN) Distress Thermometer

Adapted from the NCCN⁶⁶ with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for NCCN Clinical Practice Guidelines in Oncology: distress management (version 1, 2022). To view the most recent and complete version of the NCCN Guidelines, go online to https://www.nccn.org/docs/default-source/patient-resources/nccn_distress_thermometer.pdf?sfvrsn=ef1df1a2_6. The NCCN Guidelines are a work in progress that could be refined as often as new significant data become available.

Asking about common problems

- **Fear of recurrence:** do you worry about your cancer coming back and how often do you think about it coming back?
- **Sex and intimacy:** do you have any concerns about your sex life or sexual function and are these concerns causing you distress?
- **Cognitive function:** do you have difficulties multi-tasking or paying attention, and do you have difficulties remembering things?
- **Return to work and finances:** do you have concerns about how your cancer and the treatment has affected your ability to work and do you have concerns about financial problems resulting from your cancer or treatment?

Effective Psycho-Oncologic Interventions for Emotional Distress and Quality of Life

- Psychotherapy and counseling (coping skills training; cognitive behavioral therapy [CBT], supportive expressive therapy) delivered to individuals, groups, or couples
- Comprehensive multimethod psychoeducation (health education, coping skills training, stress management, psychological support)
- Relaxation training (relaxation and imagery)
- Mindfulness (MBSR)
- Physical Activity
- Support Groups (peer-led, professionally-led, education-focused)
- Professionals include: Psychiatrists, psychologists, licensed clinical social workers, oncology social workers, psychiatric nurse practitioners, licensed counselors, licensed marriage and family therapists, and licensed pastoral counselors.

Connecting Screening with Care

- Relatively low uptake of psychosocial care even with referral
- Barriers: higher distress, non-White, male, older, stigma, fear, uncertainty about psychosocial support; desire to manage distress alone or lack of perception of need for professional help
- Facilitators: reduced cost, past positive experience with a mental health provider, motivation to cope, accessibility
- “Many patients with cancer are unwilling to accept a referral for psychosocial care and we believe that this is due to a mismatch between patient needs and the provision of care.”
- Suggestion to focus on adaptive versus maladaptive *types* of distress regardless of level
- Many welcome support from relatives, friends, peers, religious communities, social groups, online communities, and primary providers. Professional mental health care suitable for those with maladaptive distress.

Resources

- ASCO Cancer.net Resources for Survivors (approved by the Editorial Board):
<https://www.cancer.net/survivorship/survivorship-resources>

COPING WITH CANCER

More in this section

- Managing Emotions
- Physical, Emotional, and Social Effects of Cancer
- Talking With Family and Friends
- Caring for a Loved One
- ▼ Finding Social Support and Information
 - Counseling
 - Support Groups
 - Finding a Support Buddy
 - Online Communities for Support
 - Telephone and E-mail Cancer Helplines
 - Wish Fulfillment Organizations for People With Cancer
 - General Cancer Groups
 - Cancer-Specific Resources
 - Finding Information and Support Resources for Rare Cancers
 - Resources for LGBTQ+ People with Cancer

Finding Social Support and Information

After a diagnosis of cancer, it is important to find credible information and seek support.

- **Counseling**
When to seek it and how it helps
- **Support Groups**
Reasons to join and how to find one
- **Finding a Support Buddy**
How to get matched with a survivor of the same type of cancer for one-on-one support
- **Online Communities for Support**
Options for joining an online community
- **Telephone and E-mail Cancer Helplines**
List of organizations that offer general medical information
- **Wish Fulfillment Organizations for People With Cancer**
List of organizations for people with cancer and their families
- **General Cancer Groups**
Resources for additional information, services, and support
- **Cancer-Specific Resources**
National organizations that offer support to people with cancer and their families.
- **Finding Information and Support Resources for Rare Cancers**
Tips and resources to help you obtain information about rare cancer diagnosis and treatment options
- **Resources for LGBTQ+ People with Cancer**
National organizations that offer support for LGBTQ+ people with cancer and caregivers



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support for anyone
affected by cancer



Cancercare.org

WHAT DO WE DO

What is Oncology Yoga?

yoga4cancer (or y4c) is an evidence-informed Oncology Yoga method tailored to address the specific physical and emotional needs left by the cancer and cancer treatments. The approach matches breath and movement to stimulate the immune system, improve flexibility & strength, reduce anxiety and boost overall well-being.

Based on the latest research and recommendations, we mitigate the short and long term side effects that cancer patients and survivors face like bone loss, lymphedema, scar tissue, constipation, neuropathy, fatigue, anxiety and many more.

Oncology yoga is designed to help cancer survivors achieve the **American Cancer Society** and the **U.S. Department of Health and Human Services** exercise recommendation of between **150 – 320 minutes of exercise per week** to speed recovery or defend against cancer reoccurrence.





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Our recurring programs, which play a crucial role in supporting our community, include:

- Support Groups
- Healing Circles
- Yoga and Movement
- Creativity and Writing
- Meditation and Mindfulness
- Nutrition & Cooking

About Us

Founded in 1996, Smith Center for Healing and the Arts (formerly Smith Farm) is a Washington, DC-based nonprofit health, education, and arts organization.

Our mission is to develop and promote healing practices that explore physical, emotional, and mental wellness and lead to life-affirming changes. We offer programs for the community and specialize in serving people with cancer and utilizing the arts in healing.

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