Welcome to the COVID-19 and Cancer ECHO Series

Use the Q&A portal throughout today’s session to submit your questions! Our expert faculty will be answering your questions live.

All ECHOs take place on the Zoom platform. Review Zoom’s privacy policy at zoom.us/privacy.

This ECHO will be recorded.
Erin Kent, PhD, MS
Associate Professor
University of North Carolina at Chapel Hill
Today’s agenda

Introductions
Erin Kent, PhD, MS
5 minutes

Didactic presentations
Rachel Cannady
J. Nicholas Dionne-Odom, PhD, APRN, ACHPN, FPCN
20 minutes

Question and answer session
Expert faculty panel
25 minutes

Wrap-up
Richard Killewald, MNM
3 minutes
Introductions
I N T R O D U C T I O N S

Expert faculty panel

Durado Brooks, MD, MPH
Vice President, Prevention and Early Detection
American Cancer Society

Rachel Cannady
Strategic Director, Cancer Caregiver Support
American Cancer Society

J. Nicholas Dionne-Odom, PhD, APRN, ACHPN, FPCN
Assistant Professor, School of Nursing
University of Alabama at Birmingham
Co-Director, Caregiver and Bereavement Support Services, UAB Center for Palliative and Supportive Care

Matthew Loscalzo, L.C.S.W., APOS Fellow
Liliane Elkins Professor in Supportive Care Programs (NPI 1437690500)
City of Hope
Didactic presentation
Today’s presenter

Rachel Cannady
Strategic Director, Cancer Caregiver Support
American Cancer Society
Cancer impacts the entire family, including close friends
- Emotional distress (especially guilt), physical demands, activity restrictions
- Altered job responsibilities and financial hardships

Most stressed caregiver is female, employed, caring for children and a cancer patient simultaneously

Positive effects
- Post-traumatic growth/benefit-finding
- Improved self-esteem and self-worth/satisfaction with life
DIDACTIC PRESENTATION

Myriad of Caregiver Experiences

- Work and financial concerns
- Fear of Recurrence
- Social Isolation
- Poor Physical Health
- Psychosocial Distress
- Lost in the healthcare system
- Lack of medical training

Psychosocial Distress

Work and financial concerns

Fear of Recurrence

Social Isolation

Poor Physical Health

Lost in the healthcare system

Lack of medical training
Caring for someone with cancer has become even more serious because of the coronavirus pandemic.

People with lymphomas, multiple myeloma, and most types of leukemia are at the highest risk for infections. These cancers cause changes that make the immune system unable to work as well as it should. ALL cancer patients are immuno-compromised.

Follow all guidelines from the CDC to avoid the spread of germs.

Don’t Forget…

- Take a break each day to recharge and refresh
- Make sure you’re exercising each day – it’s as simple as a walk around the block or doing a 30-minute online class
- Make sleep a priority (at least 7-9 hours per CDC)
Impact of Caregiving During COVID-19

- Stress and anxiety
- Loneliness and isolation
- Chronic illnesses
- Financial problems
### Caregiving and Social Distancing

<table>
<thead>
<tr>
<th>Topic</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Food Prep</strong></td>
<td>Contact-free delivery; small portions; include plastic cutlery and straws; gift cards to favorite restaurants</td>
</tr>
<tr>
<td><strong>Rides to Treatment</strong></td>
<td>If you’re the patient’s only ride to medical appointments, make sure to fully sterilize the car before and after</td>
</tr>
<tr>
<td><strong>Point of Contact</strong></td>
<td>If applicable, become the patient’s point of contact for medical appointments to help coordinate care</td>
</tr>
<tr>
<td><strong>Connection</strong></td>
<td>Regular video calls with family and friends; watch the same movie together; play online games together</td>
</tr>
<tr>
<td><strong>Self-Care</strong></td>
<td>Recharge daily; healthy nutrition and regular exercise; online caregiver support groups; GET OUTSIDE</td>
</tr>
<tr>
<td><strong>Stay Healthy</strong></td>
<td>Following the CDC Guidelines on how to prevent the spread of the virus will keep you healthy and will protect the patient</td>
</tr>
</tbody>
</table>
DIDACTIC PRESENTATION

Caregiver Resource Guide: cancer.org/caregiverguide

- Cancer Caregiving
- Caregiver Self-Care
- Communication
- Cancer Information
- Cancer Treatment
- Patient Nutrition
- Coping
- Caregiver Resources

Online, interactive Guide
Free copy at 1-800-227-2345
DIDACTIC PRESENTATION

Caregiver Support Video Series: cancer.org/caregivervideos

**CAREGIVER SELF-CARE**
- Healthy Eating
- Physical Activity
- Stress Management
- Fear of Recurrence
- Relaxation

**PHYSICAL CARE TRAINING**
- Drain Care
- Pain Management
- Management of Side Effects
- Medication Management
- Signs of Infection
- Lifting

**ADVOCACY**
- How to effectively communicate the patient’s needs to the cancer care team
J. Nicholas Dionne-Odom, PhD, APRN, ACHPN, FPCN
Assistant Professor, School of Nursing
University of Alabama at Birmingham
Co-Director, Caregiver and Bereavement Support Services, UAB
Center for Palliative and Supportive Care
COPING WITH STRESS WHILE SUPPORTING SOMEONE WITH CANCER

J. Nicholas Dionne-Odom, PhD, RN, ACHPN
Assistant Professor | UAB School of Nursing
Co-Director | Caregiver and Bereavement Support Services
UAB Center for Palliative and Supportive Care
Email: dionneod@uab.edu
Twitter: @N_DionneOdomPhD
Common challenges faced by families

**Practical**
- Meds/Symptoms
- Finances
- Transportation
- Getting help
- End of life

**Decisional**
- Domestic
- MD visits
- Personal care
- Locations of care
- Self-care
- Medications
- Guilt
- Sadness
- Overwhelmed

**Emotional**
- Loneliness
- Guilt
- Sadness
- Overwhelmed
- Anxiousness
- Uncertainty
- Feeling unappreciated

**Social**
- Relative with serious illness
- Spouse/partner
- Children
- MDs/other healthcare professionals
- Other family and friends
- Managing one's own health conditions
- Sleep
- Time for enjoyable activities
- Diet
- Physical activity

**Physical**
- Sleep
- Time for enjoyable activities
- Diet
- Physical activity
- Managing one's own health conditions

**Spiritual and Religious**
- Isolation from faith community
- Trouble relating to God
- Loss or crisis of faith, purpose, and/or meaning in life
- Loss of time for spiritual practices
- Trouble relating to God
- Isolation from faith community
How does stress work?

**Stressor**
- Juggling work & home
- Providing transportation
- Watching a relative struggle with symptoms
- Talking with your loved one about the future

**Thoughts & Feelings**
- “I can’t cope!”
- “How are we going to pay for this!”
- “Ugh!! I didn’t sign up for this!”
- Worry, anxiousness, sadness, anger, guilt, frustration, fear

**Behaviors & Habits**
- Forgetting things
- Ignoring or avoiding problems
- Bad temper
- Avoiding friends
-Missing medical appts.
- Drinking or smoking more
- Eating poorly

**Physical Symptoms**
- Feeling tired all the time
- Can’t sleep
- Headaches
- Change in appetite
- Pain
- Upset stomach
- Difficulty concentrating
- Lower sex drive
Ways to cope with stress

- **AVOID** unnecessary stress
- **ALTER** the situation
- **ADAPT** to the stressor
- **ACCEPT** the things you cannot change
AVOID unnecessary stress

- Learn to say “no”
- Avoid people who stress you out
- Take control of your environment
- Shorten your to-do list
ALTER the situation

- Talk about how you’re feeling instead of bottling them up
- Create a balanced schedule
- Leverage assistance and other resources
ADAPT to the stressor

- Reframe problems
- Adjust your standards
- Practice gratitude
ACCEPT the things you cannot change

- Don’t try to control the uncontrollable
- Look for the upside; consider challenges growth opportunities
- Learn to forgive
- Share your feelings
Getting and Asking for Help…3 options for getting tasks done

1. Do the job yourself
2. Coordinate family or other volunteers
3. Hire outside help
10 beliefs that prevent families from asking for help

1) If I request help, my family will view me as selfish and uncommitted
2) Meeting all the needs of my loved one is my duty. No one can do as good a job or get it “right”
3) The person I’m caring for refuses help, guilt trips me or insists that I do everything
4) I guilt trip myself. I’ll feel bad or like a weak person if I don’t do it all.
5) No one else has stepped up.
6) Hiring help is too expensive. (It may be the case, but have you really explored the options?)
7) I don’t want to burden others with these problems.
8) I don’t know how or where to get help—or how to ask for it
9) No time, too busy to think about it.
10) I don’t trust outside help ("strangers"). How do I know what they’re doing when I’m not there?
Option 1: Do the job yourself

- Prioritize your time and responsibilities
- Explore employer benefits
- Learn caregiving skills
Option 2: Get help from friends/family

- Most family/friends appreciate the opportunity to be helpful
- Step 1: Get clear on what you want help with
- Step 2: Identify and make a list of who could help
- Step 3: Coordinate the support
Option 3: Pay for help

- Caregiver services in the community (e.g., American Cancer Society, Area Agency on Aging)
- Family member affiliations (e.g., fraternal organizations)
- Community transportation services
- Adult day care
- Personal care services
- Health care services (check with your insurance company)
- Meal programs
Having trouble deciding whether to delegate a task?

Think of a job or task that needs to be accomplished on a regular basis. Ask yourself:

How valuable is this task to helping my loved one have the best quality of life possible?
4 - It is essential and must be done.
3 - It helps in a small way.
2 - It has no impact, positive or negative.
1 - It has a negative impact.

How much personal value do I get from doing it?
5 - Definitely keep: It’s one of the best parts of supporting my loved one.
4 - Probably keep: I enjoy this activity.
3 - Not sure: This task has good and bad points.
2 - Probably drop: I find this task or activity tiresome
1 - Definitely drop: I dislike doing it.

To what extent could I let this task go?
4 - Essential: it is something that has to be done immediately
3 - Important: it’s not urgent but has to be done soon
2 - Discretionary: is something that can be done if there is time
1 - Unimportant/Optional: this could be cut immediately

To what extent could someone else do it on my behalf?
5 - Only I can handle this
4 - This task is best done by me
3 - If structured properly, this task could be handled by someone else
2 - This task could easily be done by someone else
1 - This task could be dropped altogether

10 or lower? Consider delegating.

Adapted from the Sept. 2013 Harvard Business Review article “Make Time for the Work that Matters”
Thank you!

J. Nicholas Dionne-Odom, PhD, RN, ACHPN
Assistant Professor
School of Nursing
University of Alabama at Birmingham
Email: dionneod@uab.edu  |  Twitter: @N_DionneOdomPhD
Question and answer session

Use the Q&A portal to submit your questions
What precautions should caregivers take to limit COVID-19 exposure?
What tips do you have to provide hope and motivation to a loved one with cancer during and after treatment?
What activities are safe if a parent is undergoing chemotherapy during COVID? Can kids play sports and go to in person school?
How do you convince your family you need help?
What materials do you have available for depression and coping with cancer during this pandemic (English and Spanish)?
What role do medical oncologists, surgical oncologists, have in promoting contact tracing in the COVID 19 pandemic?
Does ACS or another organization have some type of support group for the caregivers? Resources to share?
How is the absence of caregivers/family support during hospital visits, due to Covid restrictions, affecting patient morale and outcomes?
To protect the cancer patients undergoing treatment, is the best practice still to get two negative tests post-COVID positive?
Questions received through Q&A portal

Use the Q&A portal to submit your questions
Wrap up
For more information and COVID-19 resources, visit:

- cancer.org
- nccn.org/covid-19
- cdc.gov

For more about what Project ECHO is doing to respond to COVID-19, visit echo.unm.edu/covid-19
Join us Wednesday, September 2 at 2:00 ET

**WRAP UP**

**Matthew Loscalzo, L.C.S.W., APOS Fellow**
Liliane Elkins Professor in Supportive Care Programs (NPI 1437690500)
City of Hope

- Discussion will focus on finding strength as a caregiver during a pandemic.

**Rachel Cannady**
Strategic Director, Cancer Caregiver Support
American Cancer Society

- Discussion will focus on distilling information about diagnosis and treatment, communication within the patient-caregiver dyad, and advocating for patients within the health-care team.
Wrap Up

Evaluation

Complete the **post-survey evaluation** to submit your questions for our expert faculty panel!

Email **echo@cancer.org** with questions.