

# Navigating the changing landscape of early-stage breast cancer

Psychological impacts of new treatments, testing, and the fear of recurrence



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Session 2: Psychological impacts of new treatments,

testing, and the fear of recurrence

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# Agenda for today

- Discuss what data shows us about distress generally in early stage breast cancer patients
- Discuss the fear of recurrence using three subcategories
  - Life
  - Diagnosis/Medical
  - Societal
- Discuss strategies to address
- Take the Audience questions

# Community Meeting: Modified



How are you Feeling today?

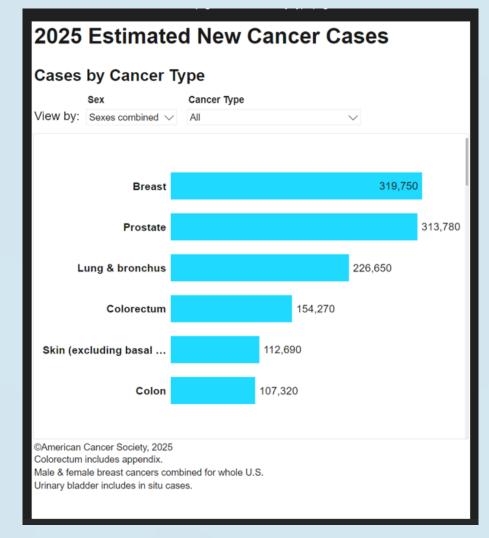
What is your goal for today?

Who can you ask for Help?

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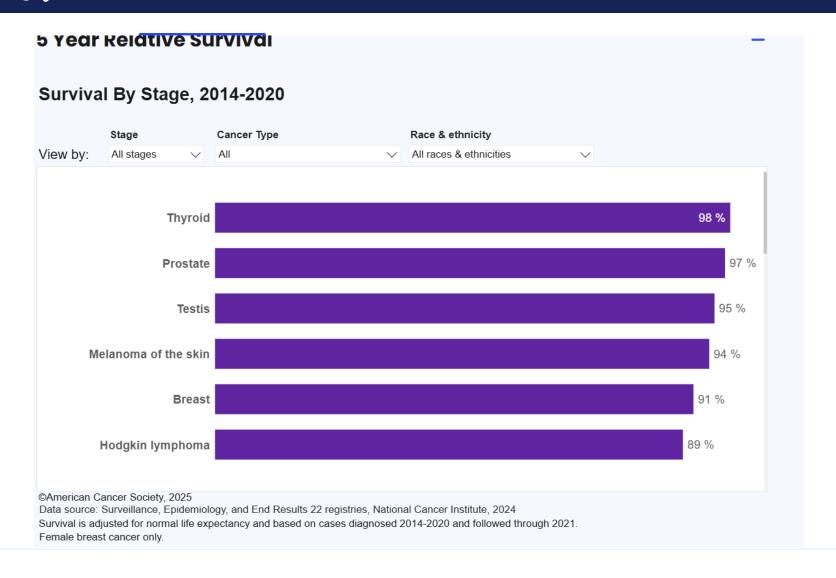
# Cancer Incidence

Breast
Cancer
remains to be
projected the
most
diagnosed
cancer



©American Cancer Society, 2025
Data source: Surveillance, Epidemiology, and End Results 22 registries, National Cancer Institute, 2024
Survival is adjusted for normal life expectancy and based on cases diagnosed 2014-2020 and followed through 2021.
Female breast cancer only.

# 5 year Relative Survival rate



# Cancer related distress



### Distress symptoms

- Commonly identified and expressed emotional experiences:
  - Fear, worry, helplessness
  - Sadness
  - Depression, anxiety, panic
  - Poor sleep, appetite or concentration
  - Concerns about illness and treatment
  - Isolation
  - Frequent thoughts of illness or death

### What does the research tell us about impact of cancer diagnosis

### Physical impact

- Disrupted routines impacting health of patient, caregiver and other household members
- Sleep patterns impacted
- Nutrition
- New health issues
- Existing issues more symptomatic

### **Emotional impact**

- Distress
- Mental Health disorders new or previosly diagnosed

### Relational impact

- Changing roles
- Unpredictability impacting existing structures/routines
- Communication changes

### Defining Fear of Recurrence (FCR)

#### Psycho-Oncology

Psycho-Oncology 26: 424-427 (2017)

Published online 18 February 2016 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.4103

#### **Invited Perspective**

# Current state and future prospects of research on fear of cancer recurrence

Sophie Lebel<sup>1</sup>\*, Gozde Ozakinci<sup>2</sup>, Gerald Humphris<sup>2</sup>, Belinda Thewes<sup>3</sup>, Judith Prins<sup>3</sup>, Andreas Dinkel<sup>4</sup> and Phyllis Butow<sup>5</sup>

University of Ottawa, Ottawa, Ontario, Canada

"Fear of cancer recurrence (FCR) has been described as the sword of Damocles that hangs over survivors for the rest of their lives. FCR is usually defined as 'the fear or worry that the cancer will return or progress in the same organ or in another part of the body".

That fear can have associated with it:

- Increased functionating impairment
- Psychological distress
- Stress response symptoms, and lower quality of life

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# Distress/Worry Category: Life

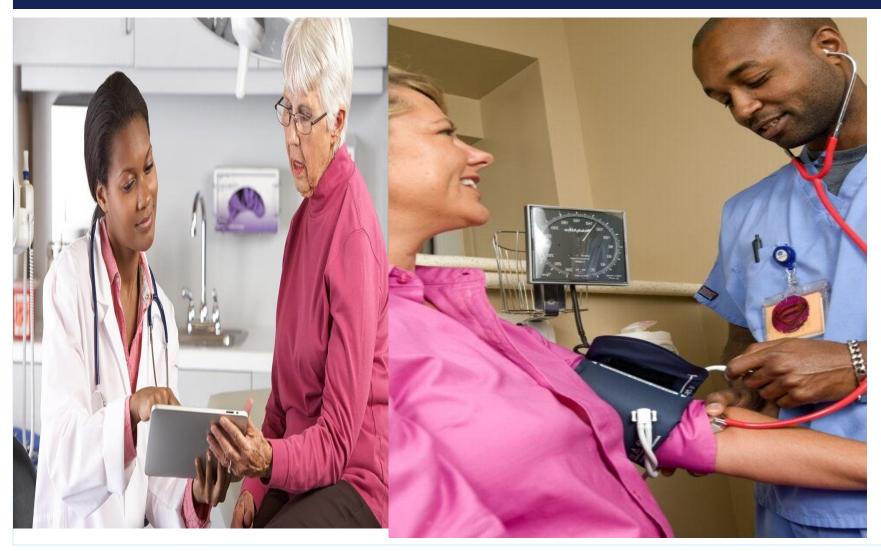
### Cancer Care



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# Distress/Worry Category: Diagnosis/Medical issues

# Medical decision making: Complexity compounded



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# Distress/Worry Category: Societal/Community

# Community and Society worry





This model used often in public health was developed by Urie Bronfenbrenner. Conceptualizing that individuals and the environments they live in are mutually influential.

Factors such as Social Drivers of Health [SDOH] (where we live, work, play, etc) are key components which impact health, health outcomes and quality of life.

# What Helps

# What helps

- Is your glass half full or half empty?
- Whom can you share how your fears, frustrations, worries?
- What works for you?





### Psychological and Emotional Wellness

- Internal coping skills and resilience
  - What tools do you have in your toolbox?
  - What lessons have you learned from facing adversity in the past?
- External support networks: What is available
  - Family, friends
  - Hospital or Community based support groups
  - Psychiatric and/or supportive counseling/therapy
  - Complementary Medicine

\*Who do you talk to about the above and how do you get to additional resources if needed?

Coordination of Care between Navigators and other members of the care team

## **Supportive Counseling**

Getting connected to supportive counseling:

 Checking in with care team can help navigate these steps, but not required

Key questions to reflect on as you look at your setting:

What insurance base options are there?

Are there cancer specific options that do not go through insurance?

Are there community organizational supports?

Are there word of mouth recommendations from trusted persons?

### **Psychosocial Support**

### Cancer Center based treatment:

- Some Centers have Psychiatrists and/or therapists within the network.
  - Some services are also provided by Licensed Clinical Social Workers, some Psychologists, Licensed Professional Counselors

#### Insurance based treatment

Contact member services for specific Behavioral health providers that are in network

#### Community Based Support groups

Online and in person. \*may want to check with care team for well established organizations

### Nurse and Non-Clinical Navigation Support

- Oncology nurse navigators
- Non-clinical navigator
- Financial navigator/Financial counselors
- Insurance based advocates (RN/Non-clinical) provided by insurance carrier
- Community/Patient Advocates
- · Oncology. Pharmacy Navigator

# What helps

#### Communication

- About diagnosis
- About changes in treatment, symptoms
- Fears and concerns

Cultivating and mindful participation in fulfilling activities 'outside' of cancer experience

Making and keeping connections with others who are supportive and nurturing

Seeking professional help when needed:

- Paid or non paid additional help at home
- Mundane tasks: cleaning, yardwork, laundry, cooking, etc.

# What helps

Psychoeducation

Problem solving/skills building

Supportive therapy

Family/Couples therapy

Integrative/Complementary/Alternative therapy

 PDQ® Supportive and Palliative Care Editorial Board. PDQ Informal Caregivers in Cancer. Bethesda, MD: National Cancer Institute. Updated <MM/DD/YYYY>. Available at: <a href="https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq">https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq</a>. Accessed <MM/DD/YYYY>. [PMID: 26389284]

### Resources

### Crisis Hotlines

- National Suicide Prevention Lifeline 800-273-8255, 988
- Crisis Text Line- US and Canada text HOME to 741741
- National Alliance on Mental Illness 800-950-NAMI

### Cancer specific resources

- American Cancer Society <a href="https://www.cancer.org/">https://www.cancer.org/</a>
- Living Beyond Breast Cancer <u>www.lbbc.org</u>
- Susan G. Komen <a href="https://www.komen.org/">https://www.komen.org/</a>
- Cancer Support Community <a href="https://www.cancersupportcommunity.org/">https://www.cancersupportcommunity.org/</a>
- Triage Cancer <a href="https://triagecancer.org/">https://triagecancer.org/</a>
- Metavivor <a href="https://www.metavivor.org/">https://www.metavivor.org/</a>
- Innova Programs and virtual support <u>www.lifewithcancer.org</u>

### Resources

### <u>Specific Population focused resources</u>

- Therapy for Black Girls <a href="https://therapyforblackgirls.com/">https://therapyforblackgirls.com/</a>
- Inclusive Therapists of Color <a href="https://www.inclusivetherapists.com/search\_results">https://www.inclusivetherapists.com/search\_results</a>
- Psychology Today Listings for specific populations: <a href="https://www.psychologytoday.com/us/therapists">https://www.psychologytoday.com/us/therapists</a>
- Sharsheret <a href="https://sharsheret.org/">https://sharsheret.org/</a>
- The Chrysalis Initiative <a href="https://thechrysalisinitiative.org/">https://thechrysalisinitiative.org/</a>
- Grupo Monvrivi <a href="https://grupomorivivicancer.org">https://grupomorivivicancer.org</a>
- Touch the Black Breast Cancer Alliance: <a href="https://touchbbca.org/">https://touchbbca.org/</a>
- My Style Matters, Inc <a href="https://mystylematters.org/">https://mystylematters.org/</a>
- Tigerlilly Young Women's MBC Disparities
   alliance <a href="https://www.tigerlilyfoundation.org/programs/advocacy/young-womens-mbc-disparities-alliance/">https://www.tigerlilyfoundation.org/programs/advocacy/young-womens-mbc-disparities-alliance/</a>

# Application based **Options** Calm •Headspace Mindfulness App Stop Breathe & Think Shine: Calm Anxiety & Stress

### **Contact Information**

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