



# Navigating your young breast cancer patients' emotional health

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# Learning Objectives

*Navigators who participate in the program will gain knowledge of:*

- Unique issues faced by young women with breast cancer (early stage and metastatic), including the impact of the pandemic*
- Emotional topics most frequently voiced as issues of concern by young women with breast cancer*
- Signs of emotional health concerns related to breast cancer and the pandemic*
- Barriers, including those related to health equity, which may impact the emotional health of young women with breast cancer*
- Tools and resources to support the emotional health of young women with breast cancer*

# Young Women and Cancer

Some of the most frequently voiced as issues of concern by young women with breast cancer

Fertility

Self-image and Sexuality

Intimate partnerships

Elder care

Parenting- different ages have different concerns

Employment related concerns

Social isolation

Discrimination based race, gender, sexual orientation

Financial Toxicity

Language Barrier and/or LEP



# Metastatic Breast Cancer

- Additional barriers may be present when a patient has MBC
  - Grief/loss of future roles
  - Disconnect with peer group of other cancer patients who are early stage
  - Financial barriers (some resources may be age specific)
  - Logistical barriers to care and limited support
  - Advanced Directive/goals of care discussions
  - Health care provider bias/inequity



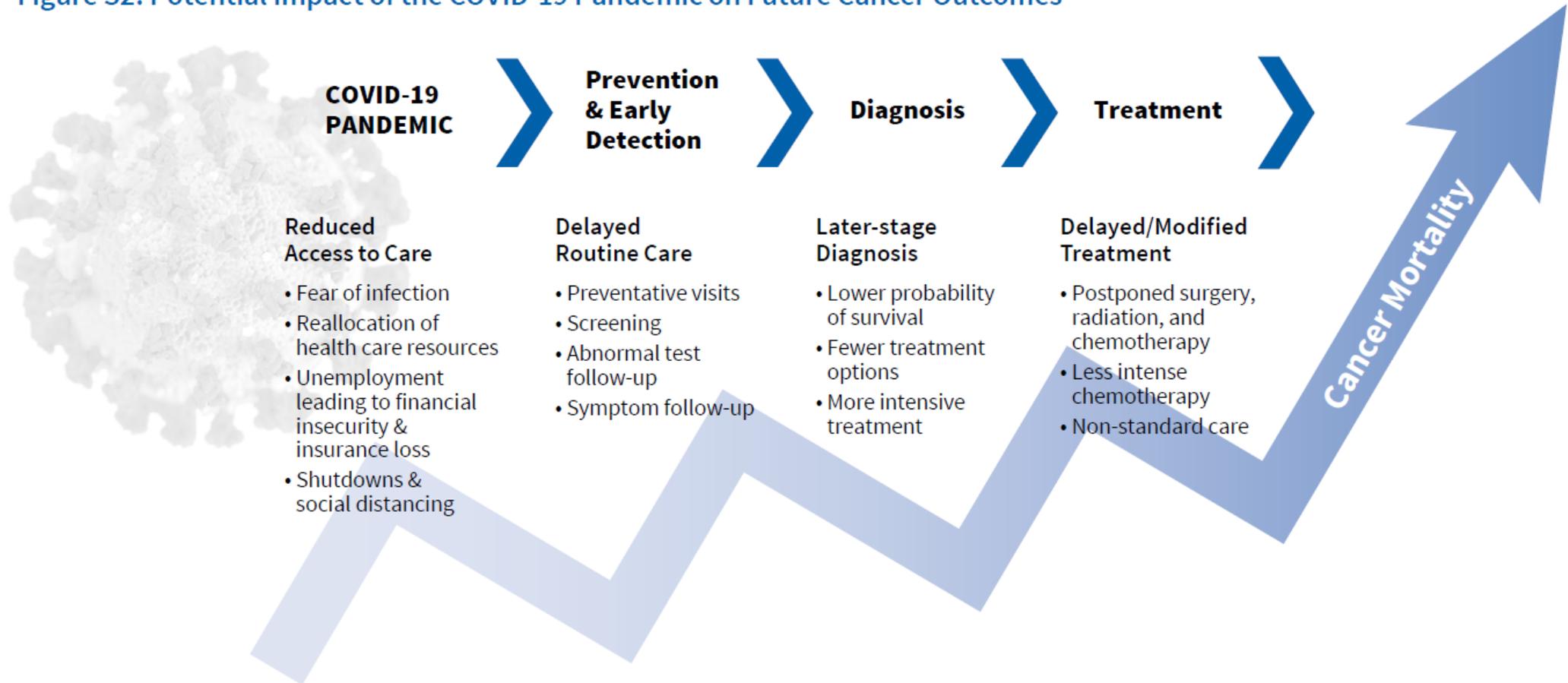
# Impact of COVID-19 on cancer patients

As with other areas of Health and Mental Health Care:

- Existing issues were exacerbated
  - Gaps in care: transportation, coordination of care
  - Stigma in asking for and accepting help i.e. food insecurity
  - Care that exists in silo's
  - Difficult to access resources
  - Increases in Anxiety, Depression and other MH diagnosis that impact treatment
  - Shifting risk assessments and calculations impacting health decision making
- A Closer Look into Food Insecurity:
  - A study published in the August 2019 issue of the Journal of Cancer Survivorship revealed that approximately 8% of 1,022 cancer survivors who participated in the National Health and Nutrition Examination Surveys experienced food insecurity, with rates higher in some groups, including survivors who were uninsured, young survivors, parents with children at home and Hispanic or black survivors.



Figure S2. Potential Impact of the COVID-19 Pandemic on Future Cancer Outcomes



Coronavirus image courtesy of CDC.

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# Delays and Disruptions in Cancer Health Care Due to COVID-19 Pandemic: Systematic Review



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Systematic review that looked at general and systematic databases found:

- Global analysis found 38 different categories of disruption
- Notable disruptions had impact on treatment, diagnosis, inpatient and outpatient services, cancer surgeries, radiotherapy and delay, reschedule and/or cancellation of outpatient visits
- Impacts in the long term are not fully known but thought to be concerning

## Investigating Long term impacts: A look towards a more comprehensive analysis

NCI has a COVID-19 in Cancer Patient Study with 2,000 people undergoing cancer treatment who also have been infected with COVID-19 who will be followed up for up to 2 years. Additionally American Cancer Society's Cancer Prevention-3 (CPS-3) is also collecting information to examine the impact on cancer outcomes.



## The Need for a Complete Cancer Care Team Is Critical as We Move Out of the Pandemic

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Leaders from the Academy of Oncology Nurse & Patient Navigators deliver a statement on appropriate planning to serve patients and their families in the wake of the COVID-19 pandemic:

- **We will have significant volume of newly diagnosed patients as well as more patients with advanced disease.** A clear impact of the pandemic has been the delay in screening and treatment of cancer patients. In fact, it is believed that this delay impact could affect cancer care delivery for years. ***Our oncology navigators and social workers will be essential in both managing and supporting this influx of patients as well as addressing the social inequities that exist in our community.***
- **Revenues and expenses will be impacted if we do not have a streamlined and efficient care organization.** Years of research indicate that navigation and social work in cancer care greatly improve the patient and caregiver experience and clinical outcomes, and control costs. ***In fact, navigation and social work are key to controlling costs such as no-shows, readmissions, cancellations, and nonadherence to the treatment plan.*** Revenue will be enhanced because bottlenecks in care delivery and efficiencies can be identified by our navigators and social workers.
- **It will be very difficult to reassemble the navigation team.** As it relates to the pandemic, evidence exists that trying to cut staff and then bring them back can be more costly and time-consuming. This is particularly true in ***highly trained support staff, such as navigators and social workers, who are integral to most cancer programs.***
- Navigation has been proved to address cancer disparities. **Navigation is a core evidence-based strategy to address health inequities across racial and ethnic minority populations.** To build community trust in our health systems and to move the needle on cancer outcome disparities, navigation is a critical tool in our toolbox.

# Health Disparities

- Cancer health disparities describe the measurable differences in cancer outcomes in various population groups. When the United States began collecting cancer data in January 1973 through the SEER program,<sup>2</sup> differences among populations became apparent in terms of incidence, prevalence, stage at diagnosis, morbidity, and mortality. (ASCO 2021)
- Disparate care can exist along multiple areas and intersect
  - Age and gender
  - Race and geography
  - Sexual orientation and all of the above
- For young women information regarding options regarding fertility preservation options prior to treatment are hugely variable.
- Navigators and Social Workers can provide valuable referrals, emotional support and linkages to internal and external resources in this area that make a huge impact in care of young women with cancer



# Impact of Stress, Bias and Inequity

- Per the American Cancer Society with research and statistics they have compiled:
  - African-Americans have a higher cancer burden and can face greater obstacles to cancer prevention, detection and treatment.
  - About a third of African-American women reported experiencing racial discrimination at a health provider visit.
  - Other racial and ethnic groups also face disparities
  - Overall death rates (prior to 2020) were declining. “By race/ethnicity, the breast cancer death rate during 2013-2017 declined annually by 2.1% in Hispanics, 1/5% in NH blacks, 1.0% in NH whites, and 0.8% in APIs, but was stable in AIAN’s”
- Inequity and disparities can fall within multiple categories
  - Social Economic Status
  - Educational level/ Health Literacy
  - Geographical region
  - Health insurance/access to care
  - Access to clinical trials
  - Sexual or Gender Minorities
  - Race and ethnicity
  - Language barriers
- Becoming an effective advocate and addressing issues can be a key step in improving care
  - Write down concerns
  - Discuss with family/support persons
  - Make care team , Social worker, patient navigator aware and discuss and develop plan of action to address
  - Connect with outside organizations that may provide assistance in advocating locally and/or nationally



# Psychosocial Distress and Mental Health Concerns

- Cancer care providers screen for emotional distress and psychosocial concerns at a variety of intervals during treatment
  - Different tools and metrics may be utilized that may identify specific areas that should be addressed:
    - PHQ-9 – a patient questionnaire that is validated as a screening for Depression and Suicide
    - NCCN Distress thermometer- assessing emotional and other needs
    - Social Determinants of Health (SDOH)
- Some types of distress will be managed by the cancer care team and some types of distress may be referred for additional resources and supports



# 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



# Connecting to resources

- Assessment: EMR, In-house referrals, community referrals
  - Navigators using specific metrics or measures
    - AONN+ Navigation Metrics Toolkit
- AONN+ has identified 35 evidence-based navigation metrics that are relevant to cancer care, and demonstrate the value and sustainability of oncology navigation.
- The GW Cancer Institute created core competencies for non-clinically licensed patient

How do we take knowledge that we know there are gaps in care:

Due to Pandemic

Complexity of Health Care system

Disparities and Inequality

We use one of the most important tools in our tool box, human connection



# 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:

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

1. What is the landscape of the setting in which you practice? I.e. Urban, rural, in community, embedded in Hospital or treatment center?
2. What is the scope of your practice?
3. How familiar are you with the internal and external resources available to the population you serve?

Are there barriers to getting patients connected ?

Are there culturally competent practitioners?

What modalities may be useful when working with this population?



# 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



# Communication and impact on emotional health and wellbeing

- Complex components that impact overall wellness as well as day to day functioning. There are no 'right' or 'wrong' ways to communicate however different styles may present different challenges specifically in your cancer journey
  - What is your general communication style
    - Internalize vs externalize
    - Outwardly emotive vs outwardly less emotive
    - Task oriented vs free flow
  - What is your general problem solving style?
    - Directive vs indirect
    - Lists/concrete vs abstract/conceptual

Important as we interact with patients that we also be aware of the above factors as they impact how they navigate through care.

AS we interact we can inquire and use the information to help better navigate patients and provide support.

Different ways to provide information- written forms, encouraging patients to write questions- bullet points fears, questions adding tool in the toolbox (how often do we ask as providers for the written questions of patients) Is this a tool we can assist in giving patients to use with their care team.



# Recognizing when to reach out for support

Cancer treatment is complex and stressful even when things go well.

Key things to remember:

- Your needs may and usually do change
- Be prepared to ask for help from others
  - Needing help could be short-term or last a longer period of time
  - Create a list of specific tasks that you want/need done
  - Think about who 'can' do those tasks and ask them
- Dealing with physical and emotional changes
  - Keep treatment team informed of any medical and/or psychosocial issues during treatment
    - \*nothing is too small
  - Your family/support team may also be dealing with changes
    - Roles, duties, daily routines
  - Seek additional support if/when needed for both yourself and caregivers
    - Buddy program, support groups, educational programs



# Application based Options

- Calm 
- Headspace 
- Mindfulness App 
- Stop Breathe & Think 
- Shine: Calm Anxiety & Stress 

# Resources

## Crisis Hotlines

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

## Cancer specific resources

- American Cancer Society <https://www.cancer.org/>
- Living Beyond Breast Cancer [www.lbbc.org](http://www.lbbc.org)
- Susan G. Komen <https://www.komen.org/>
- Cancer Support Community <https://www.cancersupportcommunity.org/>
- Triage Cancer <https://triagecancer.org/>
- Tigerlilly Young Women's MBC Disparities alliance <https://www.tigerlilyfoundation.org/programs/advocacy/young-womens-mbc-disparities-alliance/>
- Metavivor <https://www.metavivor.org/>

## Specific Population focused resources

- Therapy for Black Girls <https://therapyforblackgirls.com/>
- Inclusive Therapists of Color [https://www.inclusivetherapists.com/search\\_results](https://www.inclusivetherapists.com/search_results)
- Psychology Today Listings for specific populations: <https://www.psychologytoday.com/us/therapists>
- Sharsheret <https://sharsheret.org/>
- The Chrysalis Initiative <https://thechrysalisinitiative.org/>



Thank  
you

