

WELCOME TO THE BREAST CANCER RESOURCE CENTER'S HEALTHCARE PROVIDER AND ALLIED HEALTH PROFESSIONAL FORUM

Introduction:

Ray Anne Evans, Executive Director-BCRC

Needs Assessment Findings:

**Heather Becker, PhD, Research Scientist-The University of Texas at
Austin**

**Deborah Vollmer Dahlke, DrPH, Adjunct Associate Professor and
Senior Fellow-Texas A&M University**

Applying Needs Assessment Findings to Your Everyday Practice:

Kathryn Hudson, MD, Medical Oncologist- Texas Oncology



**BREAST CANCER
RESOURCE CENTER**



**Centers for Disease
Control and Prevention**

HOUSEKEEPING

- ❖ All participants are muted and your videos are off
- ❖ Please use the chat feature to engage and connect with other attendees
- ❖ You can use the Q&A function to ask our presenters any questions



OUR MISSION AND VISION

Mission: To empower those affected by breast cancer with personalized support and compassion.

Vision: A future where no one faces breast cancer alone.



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Heather Becker, PhD
Research Scientist, University of Texas
at Austin, School of Nursing

FOCUS GROUPS/INTERVIEWS IN SUMMER

- ❖ 12 key informant telephone interviews conducted with:
 - ❖ Nurse navigators
 - ❖ Social workers
 - ❖ A physical therapist
 - ❖ A genetics specialist
- ❖ 5 focus groups held by Zoom with each of the following:
 - ❖ African American women
 - ❖ Hispanic women
 - ❖ Underinsured women
 - ❖ Women living outside of Austin metro area
 - ❖ Women with metastatic cancer



“WE DO THE BEST WITH WHAT WE HAVE” : KEY INFORMANT INTERVIEWS

- ❖ Barriers to accessing services include financial constraints, transportation, lack of child-care, long wait lists, and lack of referrals

“We really should do better for unfunded, working poor people that don’t qualify for assistance”.

“Part of the beauty of being in rural, small communities is people pull together because they know you.”

- ❖ Women may not be aware of what is available to them
- ❖ We do not want to overwhelm women with too much information



THINKING COMPREHENSIVELY ABOUT AYAS NEEDS

“Yes, there is cancer, but there’s a woman who has to function in her life throughout treatment and after treatment and so if we can address all of her issues early on instead of just being hyper-focused on her cancer.”

“The measures for oncologists for a long time have been mortality, and not quality of life or patient reported outcomes... and they don’t always have the time to always follow up on those reported impairments.”



FINDINGS FROM FOCUS GROUPS

- ❖ Women have different needs, depending upon their stage in life and other contextual factors, such as distance from services or family situation.

“I’m happy and grateful that I was able to push back. I just wished that other women know or knew that they, you don’t have to do what... is asked of them.”

- ❖ Variability exists in services women receive; some Black women described delays in treatment, or receiving different treatments compared to White women

“As black women, we constantly have to dig for information.”

- ❖ Women in all groups expressed the need for financial help, such as navigating insurance.

“It’s almost like you have to be ... completely out of money to get some assistance.”

“SO CONFUSING AND SO TERRIFYING.”

- ❖ Complementary therapies, particularly mental health services, were helpful, but often difficult to afford.

“Mental health is super important when treatments end because you don’t have a network around you”.

- ❖ Many women wanted more information from providers, such as long-term effects.

“Doctor tends to just worry about like the cancer and making sure that's under control and less about the side effects caused by like the chemotherapy and stuff.”

“Less paper and pamphlets; give me a real person (especially when you finish active treatment)”.

- ❖ When women finish active treatment, they experience the loss of the intensive support they had experienced from their oncology team.

“It all crashed down when I went in for (the last treatment)”.



METASTATIC BREAST CANCER IS: “A MARATHON, NOT A SPRINT”

“People forget about you as the years go by.”

“It just destroyed my financial situation.”



TAKE HOME MESSAGE

- ❖ Women need sustained support that is tailored to the individual's needs.
- ❖ Good resources exist in Austin, but there is lack of awareness to access them, and they are sometimes fragmented and difficult to navigate.
- ❖ The financial burden was discussed by virtually everyone.
- ❖ Women are seeking trusted information sources, and some are wary of information available on-line.
- ❖ Women and providers spoke about the importance of good communication, but survivors discussed communication somewhat differently than key informants.
- ❖ Stress negatively impacts cognitive functioning, including decision-making, but we ask women to make critical decisions (ex: fertility preservation) when they may be least able to process the information to make good choices.





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Deborah Vollmer Dahlke, DrPH
Senior Fellow, TX A&M Center for
Population Health and Aging

SURVEY DISTRIBUTION AND PARTICIPATION

Survey Distribution

- ❖ Healthcare providers who care for women with breast cancer
- ❖ BCRC clients and networks of women with breast or metastatic breast cancer across the state of Texas.
- ❖ Non-profit organizations across Texas and their clients
- ❖ Cancer Alliance of Texas (CAT)'s member organizations, agencies, institutions and individuals.
- ❖ BCRC's CDC Grant Advisory Council

Participation

- ❖ Total = 126 complete surveys
- ❖ 30 by women diagnosed ≤ 45 years average age ~42
- ❖ 80 by women diagnosed ≥ 46 average age ~58
- ❖ (16 surveys did not include date of birth, but completed all the questions)



WHAT CONCERNS BREAST CANCER PATIENTS MOST?

Scale 0-100: 0= Least Concerning; 100= Most Concerning

Average Ratings

Breast Cancer Patients Find These Areas Most Concerning (N=126)

- ❖ Fear of cancer returning: **78.2**
- ❖ Chemo Side Effects: **76.1**
- ❖ Reconstructive surgery: **75.3**
- ❖ Understanding healthcare/insurance benefits: **74.5.**
- ❖ Mastectomy: **73.5**
- ❖ Having enough energy to make it through the day: **74.1**
- ❖ Managing pain /discomfort: **72.7**

Breast Cancer Patients ≤ 45 (N=30) Ranked These Concerns Higher than Older Patients

- ❖ Maintaining Employment
- ❖ ≤ 45 : **69.0** vs ≥ 46 : **57.7**
- ❖ Access to fertility preservation
- ❖ ≤ 45 : **38.9** vs ≥ 46 : **2.6**
- ❖ Emotional Support for Kids
- ❖ ≤ 45 : **69.0** vs ≥ 46 : **53.7**
- ❖ Keeping up with school coursework
- ❖ ≤ 45 : **38.9** vs ≥ 46 : **25.2**



YOUNGER WOMEN FELT THE NEED FOR GREATER ASSISTANCE FROM THEIR HEALTHCARE PROVIDERS

Scale: 0= Healthcare team *least* helpful; 100 = Healthcare team *most* helpful

Average Ratings

- ❖ Lack of Emotional Support: ≤ 45 : 40.4 vs > 46 : 62.0
- ❖ Lack of Energy: ≤ 45 : 47.0 vs ≥ 46 : 66.2
- ❖ Understanding My Insurance Benefits: ≤ 45 : 47.8 vs ≥ 46 : 62.5
- ❖ Having Financial Resources: ≤ 45 : 41.3 vs ≥ 46 : 59.5
- ❖ Feeling Isolated/Alone: ≤ 45 : 39.4 vs ≥ 46 : 53.8
- ❖ My Ability to Relate to My Significant Other: ≤ 45 : 31.4 vs ≥ 46 : 49.4
- ❖ Getting Enough Exercise: ≤ 45 : 42.6 vs ≥ 46 : 56.1
- ❖ Ability to Maintain a Healthy Weight: ≤ 45 : 43.5 vs ≥ 46 : 56.7



YOUNGER WOMEN FELT LESS SUPPORTED DURING THE TRANSITION TO POST-TREATMENT

Scale from 0 to 100 0 =no discussion to 100 =an in-depth discussion

Average ratings for each group

- ❖ Which doctor will handle post-treatment care? ≤ 45 : 49.9 vs ≥ 46 : 64.6
- ❖ What long-term treatment effects to expect? ≤ 45 : 47.9 vs ≥ 46 : 66.9
- ❖ How frequently to have follow-up tests/appts? ≤ 45 : 56.8. vs ≥ 46 :72.2
- ❖ How frequently to have scans/tests? ≤ 45 : 49.1 vs ≥ 46 : 69.5
- ❖ What are my chances for recurrence/mets? ≤ 45 : 48.5 vs ≥ 46 :63.9
- ❖ What symptoms should I look for for recurrence or mets? ≤ 45 : 42.0 vs ≥ 46 : 59.7
- ❖ Survivorship/Treatment Care Plan/Next Steps Summary? ≤ 45 : 46.2 vs ≥ 46 : 55.6
- ❖ Need for Financial Service Counseling/Support? ≤ 45 : 25.6 vs ≥ 46 : 47.7
- ❖ Need for Ongoing Emotional/Mental Support? ≤ 45 : 23.3 vs ≥ 46 : 40.9



KEY “TAKE AWAYS”—AND HOW OUR SURVEY COMPARES WITH THE RESEARCH

- ❖ Women diagnosed with breast cancer at younger age (≤ 45) are at significant risk for emotional and psychosocial sequelae during and after breast cancer treatment. They require age-specific psychosocial support, ideally in the context of coordinated multidisciplinary care teams.
- ❖ A 2014 retrospective study of > 500 breast cancer survivors aged 25-50 years showed that long-term difficulties with emotional and social functioning increased with decreasing age at diagnosis. Younger breast cancer survivors experienced lower vitality and higher rates of depression in comparison to both age-matched healthy controls and women who were older at diagnosis.¹
- ❖ Younger women who had completed adjuvant chemotherapy for breast cancer 3-8 years earlier were at increased risk for difficulties with anxiety, sleep, marital satisfaction, and body image.¹
- ❖ Concerns about fertility, sexuality, body image, disruptions in peer and romantic relationships, financial and occupational difficulties, and death from cancer are more pronounced in younger breast cancer survivors than older survivors and may contribute to distress.²

1. Comparison of younger and older breast cancer survivors and age-matched controls on specific and overall quality of life domains. *Champion VL, Wagner LI, Monahan PO, Daggy J, Smith L, Cohee A, Ziner KW, Haase JE, Miller KD, Pradhan K, Unverzagt FW, Cella D, Ansari B, Sledge GW Jr Cancer. 2014 Aug 1; 120(15):2237-46.*

2.. Breast cancer in adolescents and young adults. *Johnson RH, Anders CK, Litton JK, Ruddy KJ, Bleyer Pediatric blood & cancer. 2018 Dec;65(12):e27397.*





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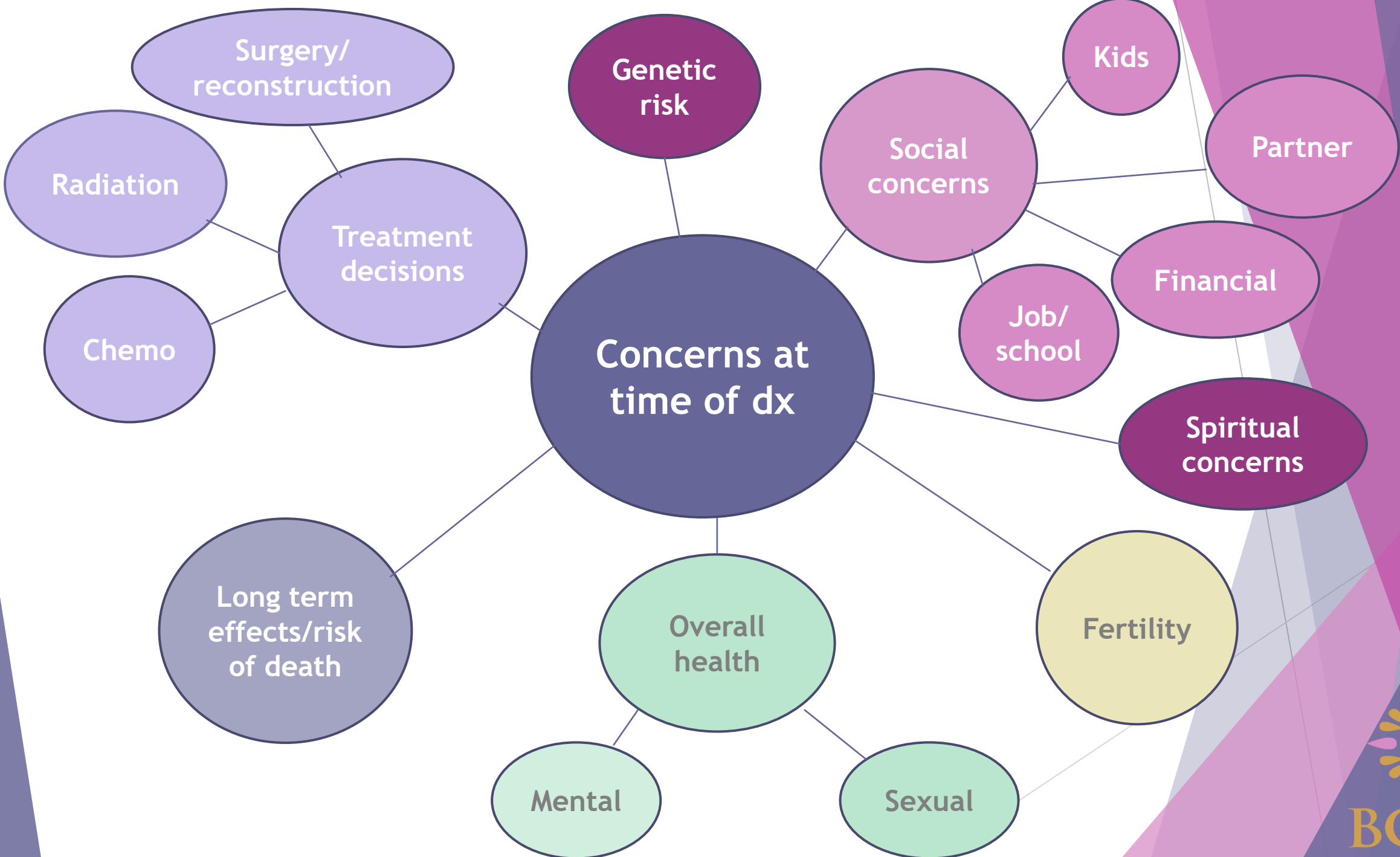
*Kathryn Hudson MD
Medical Oncologist
Director of Survivorship and Dietary Services
Texas Oncology
Austin, TX*

Breast Cancer Care

Breast cancer treatment
(medicines, surgery,
radiation)



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HOW TO ADDRESS NEW PATIENT CONCERNS

- ❖ **Communication, communication, communication**
 - ❖ Include/invite support person
 - ❖ Communicate with other involved providers
 - ❖ Give opportunity for more discussion
- ❖ **Address each potential area of concern**
 - ❖ ASK about anxiety/fears, sexual concerns
 - ❖ ASK about fertility unless postmenopausal
 - ❖ ASK about financial barriers and social concerns
 - ❖ Express empathy
- ❖ **Connect and refer: team-based approach**
 - ❖ Navigators
 - ❖ Support groups
 - ❖ Social work
 - ❖ Financial counselors
 - ❖ Fertility



COMPLEX AND SHARED DECISION MAKING

❖ Shared decision making requires:

- ❖ Clear, accurate and unbiased medical evidence about the reasonable options and the risks, benefits, and burdens of each alternative
- ❖ Clinician expertise in communication and tailoring the evidence for the individual patient
- ❖ Patient goals, informed preferences and concerns, including treatment burden

❖ Patient education:

- ❖ Treatment plans are tailored to patient and tumor characteristics (not “one size fits all”)
- ❖ Overall goals of therapy
- ❖ Definition of recurrence and metastatic disease



TRANSITION TO SURVIVORSHIP PERIOD: PATIENT CONCERNS

- ❖ Emotional/psychological health
- ❖ Fear of recurrence
- ❖ Overall health
 - ❖ Exercise
 - ❖ Wellness
 - ❖ Weight
- ❖ Functional recovery
- ❖ Sexual health
- ❖ Long term side effects
- ❖ Financial issues
- ❖ Family issues
- ❖ Fertility
- ❖ Body image
- ❖ What to expect/screening
- ❖ What to monitor for



THE “NEW NORMAL”: THE GREATEST TIME OF DISTRESS FOR SURVIVORS

- ❖ Encourage frequent visits / “touches” during this time
- ❖ Survivorship visit: readdress and re-evaluate
 - ❖ ASK about mood and sexual health
 - ❖ Refer to specialists as needed (PT, dietician, counselor, psychologist)
- ❖ Encourage overall wellness and health
 - ❖ Healthy diet
 - ❖ Exercise
- ❖ Reassess survivor goals
- ❖ REMIND patient about risk of recurrence, what recurrence means, what symptoms to look out for
- ❖ Reconnect with PCP and other parts of care team



YOUNG BREAST CANCER SURVIVORS NEED MORE SUPPORT

- ❖ Address fear of recurrence
- ❖ Offer more frequent visits
- ❖ Encourage to prioritize their health and mental health
- ❖ Refer as needed to:
 - ❖ Financial counselors
 - ❖ Psychologists/counselors
 - ❖ Sex therapists
 - ❖ Dietician
 - ❖ PT
 - ❖ Cognitive therapy/assessment
- ❖ Support groups for connection



Q&A



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THANK YOU!

Reminders:

- ❖ Please complete survey by Friday March 5th
- ❖ Needs Assessment Summary



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