

Exploring the Experience of Care Partners

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1

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 - The work presented is unrelated to these relationships.



2

Thank you to the team

Metastatic Breast Cancer Study Team

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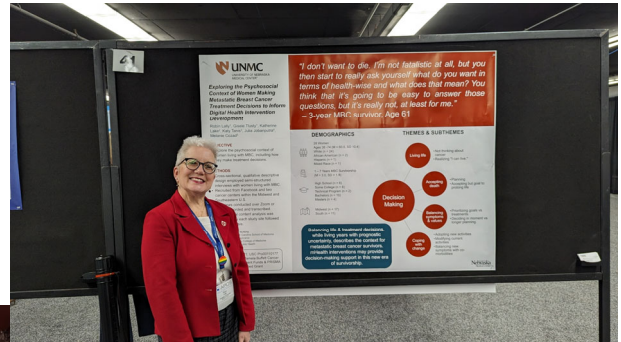
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3

Who am I?



Photos courtesy of Robin Lally



4

Presentation Objectives

1. Identify components of the experience and roles of non-professional care partners for women living with metastatic breast cancer.
2. Describe components of the experience and roles of non-professional care partners for sexual/gender diverse individuals living with breast cancer.



5

Cancer Survivor

“An individual is a cancer survivor from the day of diagnosis throughout their lifetime.”
(National Cancer Institute)

“Living with, through, and beyond cancer.”
(National Coalition for Cancer Survivorship –
founded 1986)



6

Survivorship landscape is changing

- Currently ~18.1 million cancer survivors in the U.S. and climbing.
- 5-year survival for all cancers combined increased from 49% to 69% (1970s – 2019)
- Overall lower survival rate among African American/Black persons due to disadvantage associated with structural racism.
- Survival among Black persons increased from 27% to 63% (1960s – 2017) but cancer survival overall is 68% less than among White people.



(American Cancer Society, 2022)



7

Who are Care Partners?

Are any of you care partners for a person with cancer?



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8

Where do we lack knowledge about care partners?

Metastatic (Stage IV) breast cancer (abbrev. MBC)



LGBTQIA+ persons

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Care partners of sexually/gender-diverse breast cancer survivors



Searched published research literature from 1998 to 2023.



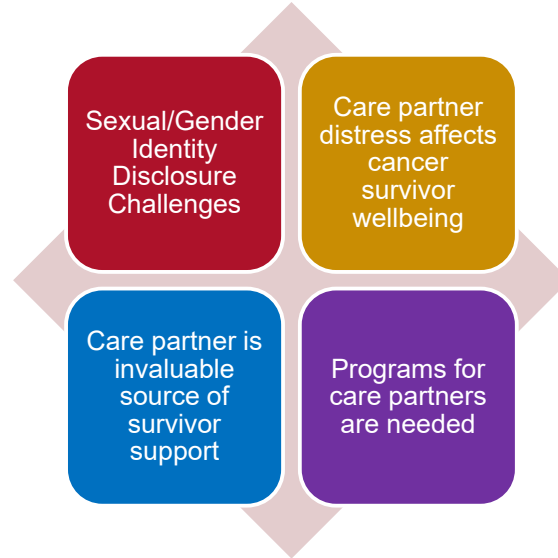
Reviewed 121 research reports & eliminated those that did not study the experiences of care partners of lesbian, gay, bisexual, transgender, etc. persons with breast cancer.



Seven articles reporting data from only 4 research studies met the criteria to be retained. Published 2005 – 2023. No studies researched outcomes of programs for care partners.



What did we learn from the published research on these care partners?



11

Learning about Care Partners in MBC

Women with MBC recruited through oncologists, flyers, and Facebook.

Eligible care partners included spouse/partners, family members, or friends who identified as primary confidantes/supporters of women living with MBC.

Semi-structured interviews were conducted via Zoom, phone, or in-person.

Women and care partners were interviewed together or independently.

Qualitative, conventional content analysis of transcribed interviews was conducted independently and then jointly by team members.

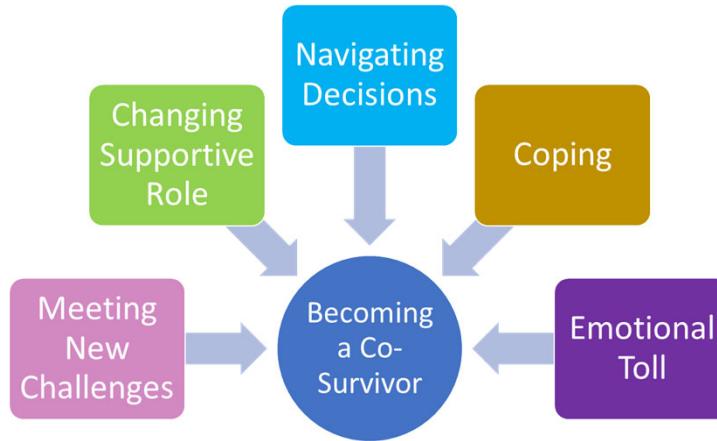
- **12 care partners**
 - 6 husbands
 - 2 daughters
 - 1 sister
 - 3 parents
- **Age range:** 29 – 79 years
- **Living with MBC** < 1 to 5 years (median 2 years)



12

What we found...

“Becoming a Co-Survivor of MBC”



Theme: Meeting New Challenges

- Balancing Life
- Learning about Treatment
- Uncertainty
- Financial

“It’s terrible. The hardest thing I’ve ever done in my entire life. I’ve been through hell, and this is worse than anything.” USC CG1, Husband (2-year MBC Survivor)

“Trying to maintain the budget and still be able to go out and do fun things, live life, but within our fixed income, and constantly knowing it’s not getting better over the years.” NE2001, Husband (5-year MBC Survivor)

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Theme: Changing Supportive Role

- ❖ Listening
- ❖ Being There
- ❖ Remembering
- ❖ Physical Support



"Just her memory. Between the two of us, though, we usually remember everything." NE4001, Husband (1-year MBC Survivor)

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"I don't have a good memory, but remembering, writing stuff down, and keeping up with her appointments, it's kind of hard to do." USC CG1, Husband (2-year MBC Survivor)



Theme: Navigating Decisions



Communication

Healthcare Team Experience

"We would sometimes discuss the questions she wanted to ask beforehand, and when she might not be in a state to be able to ask them, we would step in and say, [to the physician] wait a minute, you're not getting out of the room yet, we've got a few more questions." NE 101, Father (4-year MBC Survivor)

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Theme: Emotional Toll

“Struggles with fluctuating emotions. I call it tidal waves, because you’ll be driving along and you’re fine, and then all of a sudden, think, she could be gone in two days, or two weeks, or two years, we don’t know.” NE 4001, Husband (1-year MBC Survivor)

Guilt

Mad/anger

Don’t talk about Death

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17

Theme: Coping



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“I guess, really the challenge is to try to stay in today and realize that we’re both breathing, we’re both relatively healthy today... We have to re-center ourselves almost on a daily basis.” USC CG 3, Husband (1-year MBC Survivor)



18

Key Takeaways

1

Not all women living with MBC report having a care partner.

2

Assess who a women's care partner may be.

3

Assess the psychosocial wellbeing and information needs of persons in the care partner role.



19

References for MBC section

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20

