"We're both dealing with the same thing, but on different sides of it"
Understanding metastatic breast cancer through a dyadic lens: a qualitative assessment of patient and caregiver perspectives and experiences

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Introduction

- Due to advances in survival for patients with metastatic breast cancer (MBC), patients' informal caregivers may experience an extended duration of caregiving.
- **Using a dyadic approach, this study explored how patients with MBC and their caregivers perceive a MBC diagnosis and subsequent caregiving needs over time on an individual and dyadic level.**

Methods

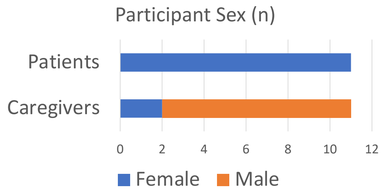
- 11 patient-caregiver dyads recruited at Iowa Health Care
- Patient was defined as an individual with a diagnosis of MBC, informal caregiver was defined as an unpaid individual who provides ≥50% of a patient's care needs
- Semi-structured interviews conducted separately with patients and caregivers from July 2024-March 2025
- Data analyzed first using a combined inductive-deductive coding approach, followed by an adapted framework method to explore the dyadic relationship.

Results - Participants

Dyad types

- Wife-Husband (n=7)
- Wife-Wife (n=1)
- Fiancée-Fiancée (n=1)
- Daughter-Mother (n=2)

Patient Average Age: 45 (range 40-72)
Caregiver Average Age: 46 (range 48-74)



Results - Key Themes

Contrast of a prior cancer diagnosis to current MBC experience
- MBC has no anticipated return to "normal"
- Lifestyles changed (e.g., working vs. retired)
- Older age since prior diagnosis was a factor for both parties

Concerns related to individual health after MBC diagnosis and its role in caregiving needs
- Non-MBC health issues increased caregiving burden
- Caregiver health sometimes required mutual caregiving or trading roles within dyad

MBC as a shared diagnosis and experience
- Patients reported guilt that caregiver was going through experience too
- Caregivers felt they should prioritize patient, but also needed support themselves

Impact of MBC on the dyadic relationship
- Most dyads reported relationship either didn't change or strengthened
- MBC changed or restricted shared activities, including sexual intimacy

Conclusions and Future Research

- A dyadic approach highlights the unique perspectives and experiences of both sides of this relationship, as well as the interpersonal dynamic between the individuals involved.
- Exploring caregiving from a dyadic perspective is essential to addressing caregiver burden in MBC and may have clinical implications.
- Findings from this study will inform the development of interventions to reduce caregiver burden and improve caregiver and patient health and wellness.

In Participants' Own Words…*

[When patient lost her hair after the first diagnosis] …she went into the bathroom, comes out about a half an hour later with one sprig of hair sticking up from the front of her head. And she says, "[Caregiver], how's my hair look?"...she had a pretty good humor on that at the time…Made me laugh…I don't think she's laughing quite as much [now]. -Caregiver

I can see, this time around, physically she is older, and it has a toll on her. When I wasn't as capable, it physically had a toll on her…She's not gonna say it, but she's tired. -Caregiver

Well, like I said, since [patient] was a nurse, she'll remind me. "What's your blood sugar?" I'll have to take my meter out and show her…And she'll remind me, and say, "Okay, you need to do this. You can't eat that…" So, like I said, we kind of give each other our healthcare problems. So, we take care of it. -Caregiver

One of the things we prioritize is that I complete six to eight rounds of this cycle of this chemotherapy… What that has meant is a crazy Jenga game. Every time somebody gets sick... My daughter has COVID. My husband's sick right now, terribly sick…I mask, I hide away. This time I haven't been able to leave the house because I can't leave him to take care of kids while he's super sick. -Patient

…when [patient's] having a bad day…I feel somewhat alone…it's not like I get mad at her, because how can somebody get mad at somebody if their body's doing this?...But sometimes I feel alone. -Caregiver

Probably some of the biggest challenges for me have been not knowing always how [patient name] is thinking or feeling about the diagnosis or about her prognosis … if she is feeling especially depressed about it … and I come into a conversation feeling optimistic … that has from time to time created tension. Then I end up feeling like, "All right, well, now I'm doing a bad job of providing support…." -Caregiver

In some ways I think [our relationship] has probably grown stronger. I think we're both dealing with the same thing, but on different sides of it. -Caregiver

It has affected our sexual life. Arthritis in my back doesn't help. The fatigue thing. I don't have the desire. I feel bad about it a lot. It's hard. I love him. -Patient

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