

Characterizing unique supportive care needs among women living with metastatic breast cancer: A qualitative study

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Abstract

Background: Women with metastatic breast cancer face unique challenges as they cope with life-limiting prognoses and arduous treatments. However, the vast majority of research has focused on optimizing quality of life in women with early-stage, nonmetastatic breast cancer and little is known about supportive care needs among women living with metastatic cancer. As part of a larger project that sought to inform the development of a psychosocial intervention, the aim of this study was to characterize supportive care needs among women with metastatic breast cancer and elucidate challenges unique to living with a life-limiting prognosis.

Methods: Four, 2-hour focus groups with 22 women were audio-recorded, transcribed verbatim, and analyzed in Dedoose using a general inductive approach to code categories and extract themes.

Results: A total of 16 codes emerged from 201 participant comments regarding supportive care needs. Codes were collapsed into four supportive care need domains: (1) psychosocial, (2) physical and functional, (3) health system and information, and (4) sexuality and fertility needs. The most prevalent needs were breast cancer-related symptom burden (17.4%), lack of social support (14.9%), uncertainty (10.0%), stress management (9.0%), patient-centered care (7.5%), and sexual functioning (7.5%). More than half of needs (56.2%) were in the psychosocial domain, and more than two-thirds of needs (76.8%) were in the psychosocial and physical and functional domains. Supportive care needs unique to living with metastatic breast cancer included the cumulative effects of continuously undergoing cancer treatment on symptom burden, worry from scan-to-scan regarding response to cancer treatments, diagnosis-related stigma and social isolation, end-of-life concerns, and misconceptions regarding metastatic breast cancer.

Conclusions: Findings suggest that women with metastatic breast cancer have unique supportive care needs compared with women with early-stage breast cancer that are specific to living with a life-limiting prognosis and are not typically captured in existing self-report measures of supportive care needs. The results also highlight the importance of addressing psychosocial concerns and breast cancer-related symptoms. Women with metastatic breast cancer may benefit from early access to evidence-based interventions and resources that specifically address their supportive care needs and optimize quality of life and well-being.

Keywords: breast cancer, metastatic, stage IV, needs, supportive care

Approximately one in eight women in the United States will receive a diagnosis of breast cancer in her lifetime.¹ Only 6–10% of breast cancer cases are classified as stage IV at initial diagnosis (known as de novo metastatic breast cancer).² However, 20–30% of breast cancers initially diagnosed as nonmetastatic will spread beyond the breast to other organs in the body (most commonly

the bones, lungs, liver, and brain) and subsequently be classified as stage IV.^{3,4} Although there is no cure for metastatic breast cancer, developments in disease-modifying and palliative treatments have significantly increased survival such that women may now live with metastatic disease for several years.^{5,6} Despite the fact that women with metastatic breast cancer face unique

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This article was originally published with the incorrect phrase "Focused research with more representative samples, including men and sex, sexual, and racial/ethnic minorities, is urgently needed in order to ensure that all individuals impacted by metastatic breast cancer are represented and supported" in the "3.1. Limitations" section. The section should read as "Focused research with more representative samples, including men and gender, sexual, and racial/ethnic minorities, is urgently needed in order to ensure that all individuals impacted by metastatic breast cancer are represented and supported." This was due to publisher error and has been updated in the published version.

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challenges as they cope with life-limiting prognoses and arduous treatments,⁷ the vast majority of research has focused on optimizing quality of life in women with early-stage, non-metastatic breast cancer. Therefore, more research is needed to understand the specific supportive care needs among women living with metastatic cancer.⁸

Unmet supportive care needs are defined as concerns or needs that individuals with cancer report have not been adequately addressed or met by the health care team.^{9–14} These needs are typically assessed across multiple domains, including psychosocial, health system and information, physical and daily living, and sexuality needs.^{9,15–17} Importantly, unmet supportive care needs are associated with worse quality of life and greater distress and symptom burden among both individuals with early-stage, nonmetastatic cancer^{12–14,18–20} and individuals with advanced cancer.^{21,22} Despite some evidence that women and individuals with advanced stage cancer may have greater unmet supportive care needs,^{14,23} there is a paucity of research examining unmet supportive care needs specifically among women living with metastatic breast cancer. A better understanding of supportive care needs is needed to inform the development of evidence-based interventions tailored to this population with the goal of optimizing quality of life and well-being.²⁴

Previous research in mixed samples of women with regionally advanced or metastatic breast cancer (stages III and IV) demonstrates that unmet supportive care needs are similarly associated with worse quality of life, greater distress, and lower satisfaction with cancer care.^{25–28} These women report that they frequently seek medical information about their breast cancer diagnosis and prognosis, cancer-related symptom burden, and available treatments and their potential side effects.^{29,30} They also report a diverse psychosocial needs, including seeking support and strategies to manage fear of cancer progression, plan for the future, make end-of-life decisions and arrangements, and manage the impact of cancer and its treatment on their family and friends and on their emotional well-being.^{29,30} A study by Aranda et al³¹ examining the Supportive Care Needs Survey¹⁰ specifically among women with metastatic breast cancer found that psychological and health system and information needs, such as concern for close others, uncertainty about the future, fears about physical deterioration, and health promotion strategies, were the most commonly endorsed unmet needs. However, to the best of our knowledge, no previous study has characterized supportive care needs among women living with metastatic breast cancer using a qualitative approach. Although well-validated self-report measures of supportive care needs exist,^{10,32,33} these measures were not developed to specifically assess needs among individuals coping with metastatic cancer and may not fully capture the unique challenges associated with living with metastatic breast cancer, such as ongoing surveillance and treatment, life-limiting prognoses, and existential concerns. Therefore, the aim of this study was to characterize supportive care needs among women living with metastatic breast cancer. This qualitative study was conducted as part of a larger project that sought to inform the development of an Acceptance and Commitment Therapy (ACT) intervention tailored for women with metastatic breast cancer.

1. Methods

1.1. Participants

Participants were women living with metastatic breast cancer. Women were eligible if they were 18 years or older, diagnosed

with stage IV (M1) breast cancer, and comfortable speaking and reading in English. Women could have received any form of cancer treatment, including hormone therapy, radiation, chemotherapy, and/or immunotherapy. Potential participants were excluded if they had severe and impairing psychiatric illness that would limit compliance with study requirements.

Multiple methods of recruitment were used, including (1) consent to contact lists from the Northwestern University Enterprise Data Warehouse service and study investigators; (2) metastatic breast cancer support groups hosted by Robert H. Lurie Comprehensive Cancer Center of Northwestern University; and (3) community-based organizations (Gilda's Club). Women identified by electronic medical records (EMRs) received a letter and study flyer introducing the study at least 1 week before a recruitment phone call from study staff. During the EMR prescreen, staff identified any recent psychiatric hospitalizations or psychiatric diagnoses. Members of support groups and community-based organizations were sent an email introducing the study with an attached flyer and provided with contact information for the study coordinator. Potential participants underwent eligibility screening over the phone with study staff. Participants with a recent psychiatric hospitalization and/or psychiatric diagnoses were still advanced to phone screening to fully assess eligibility and ability to participate. (Only one potential participant was identified to have a psychiatric diagnosis during the EMR prescreen; she opted out of participation during the phone screening.) Of 106 potentially eligible women, 71 women were reached through phone call to complete the screening process: 15 declined phone screening and 56 completed the phone screening (13 ineligible, 43 eligible). Of the 43 women who were eligible after the phone screening, 25 women consented to participate in one of the four focus groups. The other 18 women did not actively decline participation, but rather were unable to attend one of the four available focus group dates. Of the 25 women who consented, 22 participated in a focus group (3 no-shows): $n = 7$ first focus group, $n = 5$ second focus group, $n = 6$ third focus group, and $n = 4$ fourth focus group. It was estimated that four focus groups would result in data saturation, which is likely to occur within three to six focus groups.³⁴

1.2. Procedures

This study was approved by the Institutional Review Board at the Northwestern University Feinberg School of Medicine. Participants had the option of providing informed consent online or in person. All participants completed informed consent before focus group participation.

A licensed clinical psychologist with expertise in oncology facilitated four 2-hour in-person focus groups using a standardized semistructured format with open-ended questions. All focus groups took place at the Northwestern University Feinberg School of Medicine campus in Chicago, IL. Participants in the first two focus groups discussed psychosocial concerns and quality-of-life challenges related to living with metastatic breast cancer, as well as relevant topics of interest to be included in tailored intervention content, including stress, coping strategies, social support, body image, sex, and health behaviors (for first phase interview guide, see Supplementary Table 1, Supplemental Digital Content 1, <http://links.lww.com/OR9/A41>). These data were also used to develop an ACT intervention protocol tailored for this population. Participants in the second two focus groups also discussed psychosocial concerns and quality-of-life

challenges related to living with metastatic breast cancer and relevant topics of interest in addition to providing feedback regarding the proposed structure and content of an ACT intervention protocol (for second phase interview guide, see Supplementary Table 2, Supplemental Digital Content 1, <http://links.lww.com/OR9/A42>). Focus group discussions were audio-recorded for transcription to code data and extract central relevant themes. Field notes were also recorded by JLT. Focus groups were approximately 2 hours in length and ranged from 1 hour and 47 minutes to 2 hours and 3 minutes. Participants were compensated \$50 for focus group participation and received parking reimbursements. Transcripts were not provided to participants, and their feedback regarding study findings was not solicited.

1.3. Data analysis

A general inductive approach was used to analyze the qualitative data.³⁵ A doctoral graduate student and masters-level research coordinator with previous experience in qualitative research read the first two transcripts to familiarize themselves with participants' responses and created an initial codebook. Codes emerged directly from the analysis of raw data (ie, participants' responses). The codebook was iteratively refined based on input from the research team. The two coders subsequently independently analyzed the first two transcripts and met regularly to discuss ratings and revisions to the codebook. Based on the interview guide for the second two focus groups and participants' responses, the codebook was updated to include new codes. The same coding process described above was used for the last two transcripts. A review of 40% of the four focus group transcripts was used to assess intercoder agreement.³⁶ Transcripts from the first and third focus groups were selected to ensure representativeness across the first and second phase interview guides (100% of the first focus group and 50% of the third focus group). Percentage of agreement was used as an indicator of intercoder agreement and calculated by the number of times both authors assigned the same code to a text segment. Raters initially agreed on 80% of the independently coded data and reached 100% consensus through group discussion. Transcript coding and data analysis were performed with Dedoose software (version 8.0.35).³⁷ All data were coded; however, responses regarding supportive care needs, and the challenges of living with metastatic breast cancer were most pertinent to the aims of this study. Unifying themes were identified after multiple additional readings of the raw data and coded text to capture core messages expressed by the participants. The themes were subsequently grouped into domains (eg, Psychosocial Needs).

The frequencies and percentages were calculated by counting each comment related to supportive care needs that was shared by participants across the four focus groups (ie, if one participant shared multiple comments regarding supportive care needs, each comment was counted). This total number of supportive care needs comments was subsequently used as the denominator to calculate the frequency and percent of comments within each code (eg, Uncertainty: 20 of 201 total comments, 10.0%) and within each domain (eg, Psychosocial Needs: 113 of 201 total comments, 56.2%). We also reported the percent of each code within a domain (eg, Uncertainty in Psychosocial Needs: 20 of 113 comments, 17.7%). Study methods and results are reported in accordance to the Consolidated Criteria for Reporting Qualitative Research and the Standards for Reporting Qualitative Research.^{38,39}

2. Results

2.1. Sociodemographic and medical characteristics

Twenty-two women participated in focus groups and provided data for qualitative analysis. On average, women were aged 60.32 years (SD = 12.21, min = 34, max = 84) and diagnosed with stage IV breast cancer 6.56 years before participation (SD = 5.96, min = 0.42, max = 20.50). Women were primarily non-Hispanic/Latina White (86.5%) with some representation of Asian (4.5%), Black/African American (4.5%), and Hispanic/Latina (4.5%) women. A slightly higher percentage of women were diagnosed with metastatic disease after breast cancer recurrence (54.5%) than were diagnosed with metastatic breast cancer de novo (45.5%). Women were currently receiving chemotherapy (59.1%), hormone therapy (50.0%), radiation (9.1%), and/or immunotherapy (4.5%).

2.2. Supportive care needs

A total of 16 codes emerged from 201 participant comments regarding supportive care needs. Codes were collapsed into supportive care need domains, and themes were categorized within domains (Table 1). The final thematic map comprised 4 domains and 7 themes as follows: (1) Psychosocial Needs (3 themes; 10 codes); (2) Physical and Functioning Needs (1 theme; 2 codes), (3) Health System and Information Needs (2 themes; 2 codes), and (4) Sexuality and Fertility needs (1 theme; 2 codes). Of the 201 participant comments regarding supportive care needs, 56.2% were Psychosocial Needs, 20.4% were Physical and Functional Needs, 14.4% were Health System and Information Needs, and 9.0% were Sexuality and Fertility Needs. Across these domains, the five most prevalent supportive care needs codes were (1) breast cancer-related symptom burden (17.4%), (2) lack of social support (14.9%), (3) uncertainty (10.0%), (4) stress management (9.0%), (5) (tie) patient-centered care (7.5%) and sexual functioning (7.5%). Illustrative quotes for supportive care need domains are provided in Table 2.

2.3. Psychosocial needs

2.3.1. Theme 1: Psychological impact of living with metastatic breast cancer. Stage IV Diagnosis. Women described significant initial shock and emotional distress associated with receiving a metastatic breast cancer diagnosis, including feeling lost and experiencing anger and difficulty functioning. They stated that receiving a diagnosis of metastatic breast cancer “rocks your world” and “turns your world upside down.” Women tried to make sense of the diagnosis and asked themselves what may have caused the cancer to metastasize (“what did I do wrong?”). This was particularly true for women who were health-conscious (ie, exercised regularly, maintained a healthy diet, had regular health screenings and check-ups). Women also described the need to initiate cancer treatments quickly after their diagnosis and experiencing significant disruptions to their daily lives as a result, such as quitting a job or relocating. Women reported that “it takes a long time to find your feet under you again” after receiving a diagnosis of metastatic breast cancer.

Uncertainty. Women reported difficulty coping with the uncertainty of living with metastatic breast cancer. In particular, women described significant concern about cancer treatments no longer working or running out of viable treatment options if their cancer did not respond to available treatments. Women also worried about being unable to tolerate treatments because of side

Table 1**Supportive care needs.**

Domains and themes	Codes	Total	%Total Needs	%Within Domain
Psychosocial needs		113	56.2%	
1. Psychological impact of living with metastatic breast cancer	Uncertainty	20	10.0%	17.7%
	Stress management	18	9.0%	15.9%
	Initial impact of diagnosis	12	6.0%	10.6%
	Body image	6	3.0%	5.3%
	General psychosocial challenges	3	1.5%	2.7%
2. Experiencing social isolation and stigma	Lack of social support	30	14.9%	26.6%
	Stigma	9	4.5%	8.0%
	Buffering	6	3.0%	5.3%
3. Coping with loss	Anticipatory grief	5	2.5%	4.4%
	Grief	4	2.0%	3.5%
Physical and functional needs		41	20.4%	
4. Managing breast cancer–related symptoms and comorbid conditions	Breast cancer–related symptom burden	35	17.4%	85.4%
	Medical comorbidities	6	3.0%	14.6%
Health system and information needs		29	14.4%	
5. Defining patient-centered, goal-concordant care	Patient-centered care	15	7.5%	51.7%
6. Need for accurate information from reliable sources	Misinformation	14	7.0%	48.3%
Sexuality and fertility needs		18	9.0%	
7. Addressing sexual and fertility concerns	Sexual functioning	15	7.5%	83.3%
	Fertility	3	1.5%	16.7%
Total supportive care needs		201	100 %	

effects and acknowledged that undergoing cancer treatment indefinitely is overwhelming. Women stated that “each day is different” with respect to symptoms and that planning for future trips, events, and projects is a challenge given the uncertainty of their health. Women also described mortality salience and difficulty living day-to-day with a life-limiting prognosis: “metastatic means you could die tomorrow, you could die a year from now, you could die 5 years from now,” “sometimes you feel like you’re about to go over a cliff but you’re not sure exactly when. And you’re living with that all the time...”

Body Image. Metastatic breast cancer can also significantly affect women’s body image. Women described experiencing hair loss, changes in weight, radiation burns, and other treatment-related effects on the skin, as well as changes to breasts such as scar tissue, swelling, changes in shape, and asymmetry. Women stated that body image was a “daily struggle” and “something that you think about every day.” Strategies to camouflage changes to breasts were described, including wearing prosthetics, specialty bras, or loose-fitting clothing. The impact of treatments on body image was framed as a “trade off” for potentially life-prolonging treatment: “I don’t like it. But I’m here talking about it, and that probably wouldn’t be the case if I didn’t have all these treatments. So you know, it’s a tradeoff ... I’m willing to camouflage but I have to think about how to do it.”

Stress Management. As a result of living with metastatic breast cancer, women described difficulty managing stress and diffuse anxiety. Scans were described as a particularly potent source of stress and anxiety given their importance for managing metastatic breast cancer and their implications on treatment trajectories. Women stated that anxiety-related intrusive thoughts often peak at night because they are usually able to stay busy during the day. Women noted the need to slow down and manage or reduce their responsibilities. They also described the importance of balance and their desire to keep busy without overdoing it: “One of the challenges is realizing your limits. Sometimes I forget my limits.”

Learning to live day-to-day without metastatic breast cancer “at the forefront of your mind all the time” is also a challenge. Women noted that coping with other life stressors (eg, a family member’s diagnosis of cancer) can be overwhelming when one is already coping with her own metastatic breast cancer experience.

General Psychosocial Challenges. Women commonly reported experiencing exhaustion and burnout as a result of the frequency and intensity of their cancer treatment as well as the general psychosocial challenges associated with living with metastatic breast cancer. Women described getting in a “funk” and wondering how much more cancer treatment they could bear: “It’s a slow death for me. I’m living a slow death. Like I felt great, now I don’t feel great, and it’s just getting like worse and worse... You just get tired.”

2.3.2. Theme 2. Experiencing social isolation and stigma.

Lack of Social Support. Women described a general lack of understanding regarding metastatic breast cancer and the need for ongoing treatments and monitoring. Family and friends often fail to fully appreciate the effects of cancer treatment on women’s bodies, particularly their experience of chronic, functionally impairing fatigue. Women reported experiencing invalidating comments: “Someone will say, ‘Oh, well we’re all going to die sometime’ or ‘Oh, you could be hit by a bus.’ No. I have stage IV breast cancer. Don’t tell me that. You know it’s not the same.” Women also noted that they often have to manage loved ones’ anxiety about their health, which can be taxing and difficult for them. Family and friends also may constrain or shut down conversations that women initiate about death or dying. Women described feeling socially isolated and detached from others as a result of living with metastatic breast cancer and expressed a desire to meet other women with their diagnosis “who know exactly what they’re going through” to support one another.

Buffering. Another challenge women described was buffering or protecting close others through reassurance: “If someone says, ‘How

Table 2
Illustrative quotes.

Broad Categories	Themes	Codes	Illustrative Quotes	
Psychosocial needs	1. Psychological impact of living with metastatic breast cancer	Initial impact of diagnosis	P15: I Think when I first found out I had metastatic breast cancer, I kept on saying, "What did I do wrong? What did I do wrong?" I'm so health—like why did it come back? Because I get so frustrated, and I get—like going positive but sometimes I get negative, like I'm so tired of seeing these survivors on TV, and this, and I'm like, what about—there's so many of us! I want to see us on TV, like you don't know what it's like! You know? Like what did I do wrong, what did you do—like, you picked me? I'm pissed! You know? (age 60; NHW; stage IV diagnosis at recurrence)	
		Uncertainty	P8: I Think though, there is a lot of anxiety around it, there is a lot of worry about scan-to-scan, what's happening, what are we going to do, and um, what's next? And you know, how do you live your life knowing that at any moment, it's all going to come crashing down around you again? (age 53; NHW; stage IV diagnosis at recurrence)	
		Body image	P6: This is going to sound really superficial. The thing that bothers me the very most—because they pumped as much in me as a human being can take. And they shot me with so much rad[iation]—and the burns just... You know—but they never hurt me! The doctor would look at me and he'd be like "Uh does that hurt?" Losing my hair... I know it sounds so shallow. It sounds so shallow. But that really—and I thought "You're asking me to go through all of this, and I have to do it without hair." (age 63, NHW, de novo stage IV diagnosis)	
		Stress management	P8: It's a matter of figuring out the balance. How—because we're all going to have stress. And some stress is necessary, right? Right? Little bit. People say that some stress... (Age 53; NHW; stage IV diagnosis at recurrence) P10: Acute stress is great, chronic stress is no bueno (Age 40; NHW; stage IV diagnosis at recurrence)	
		General psychosocial challenges	P8: Right! You don't want to be in fight or flight all the time. And that's kind of what, in this day and age, everyone is living in. But, you know, ok fine you've got some stress but how are you coping with it? How are you managing it? P20: I don't know why I need something like that, you know, 'cause you would think, with this kind of diagnosis, that you'd want to, you know, do everything you can, but... it's exhausting... I mean I'm down here every month, you know, for labs, and every 3 months, for my scans, and it gets old. (age 55; NHW; stage IV diagnosis at recurrence)	
	2. Experiencing social isolation and stigma	Lack of social support	P12: One other experience I'll share when I was first diagnosed, and I don't know if you all felt like this, I felt like I was in a bubble. I felt like I was in the world—I could see it, I could feel it—but I was separate from the world because of this. And I didn't say a lot to people, a few people knew. But I just, it was a very odd experience for me... and they can see you, you can see them, but there's like this little membrane between... It's a very interesting experiencing of the world, that you are part of the world but you're not of it. (age 71; NHW; de novo stage IV diagnosis)	
		Stigma	P4: The only thing is when you ... tell them you have cancer and it's stage IV... you're dead. (Age 66; NHW; de novo stage IV diagnosis) P3: They either put you in a casket like right there, or they step away from you because even though they know it's not contagious, you've got cooties, you know you've got cooties. (age 66; NHW; stage IV diagnosis at recurrence)	
		Buffering	P2: And when I got sick I'm sitting there consoling them [family members]! Like trying to get through it, and I'm the one that's sick! And I'm like I'm the one telling them it's going to be ok... so it's really hard! (age 52; racial/ethnic minority; stage IV diagnosis at recurrence)	
		3. Coping with loss	Anticipatory grief	P5: One of the things that scares me the most is dying and leaving my daughter who just got married. And I have my first grandchild. That's the only thing I pray to be alive for, to be there, to see the child grow, or children if they have more, and see my son-in-law and my daughter, you know grow together, I really pray for that. (age 59; racial/ethnic minority; stage IV diagnosis at recurrence)
			Grief	P6: My sister passed away from this [metastatic breast cancer]—we were diagnosed, I was a year after she, she's one of my young sisters. And it was really hard letting go of her. We both have the same — well I mean we had different kinds of metastatic cancer, but breast cancer — but it's hard, it's really hard. (age 63, NHW, de novo stage IV diagnosis)
Physical and functional needs	4. Managing with breast cancer–related symptoms and comorbid conditions	Breast cancer–related symptom burden	P12: I have really bad neuropathy as a result of my chemo 20 years ago, I mean I can barely feel my feet and so I'm prone to falling and balance etc.. And I can't break any bones because it's all over my bones... But if they had told me, "You're going to get neuropathy if we do this chemo," I'm going to say "Who cares? You know, do it!"... And so, it's a, it's a conundrum, it really is. (age 71; NHW; de novo stage IV diagnosis)	
		Medical comorbidities	P1: I'm in the middle of cataract surgery. I have one fairly decent eye that was worked on last week and I'm going to get it done in the other eye next week. And it just got really bad, they think maybe chemotherapy made it get worse more quickly. (age 74; NHW; stage IV diagnosis at recurrence)	

(continued on next page)

Table 2 (continued)

Broad Categories	Themes	Codes	Illustrative Quotes
Health system and information needs	5. Defining patient-centered, goal-concordant care	Patient-centered care	P8: And that's the problem... everything they give you has those side effects, right? And the trade-offs. And I don't know that they're as good as they should be about explaining that to you ... in terms you can understand, especially when you are in a state of stress, right? And it's a shame that doctors can't spend more time with you. In the conventional medical model, insurance, and they got to [claps] move people through. It's not good. And that's why I go to an integrative doctor, and I get as much time as I need and I get all the explanation I need, and I get it ten times if I need it. It's just you really need to understand it. And you know, I can't go get my own medical degree so I can come back and understand it, I need someone who can really help me in simple terms really make my choices. (age 53; NHW; stage IV diagnosis at recurrence)
	6. Need for accurate information from reliable sources	Misinformation	P20: They always ask, "so when are you going to be done with chemo?" I'm like, "maybe never." (age 55; NHW; stage IV diagnosis at recurrence) P22: We're hoping it still works and I can stay on it, you know! (age 44; racial/ethnic minority; de novo stage IV diagnosis) P20: You know, "You still have your hair," well yeah 'cause not all chemo makes you look... there's just a lot of people [who] don't understand—and, you know, can't fault them for not knowing but... P19: Oh no no, they haven't encountered it before. It's not that I get upset, but it does get old. (age 65; NHW; stage IV diagnosis at recurrence) P20: It does.
Sexuality and fertility needs	7. Addressing sexual and fertility concerns	Sexual functioning	P19: I was on hormone therapy, so it dries you out right away... and this was years ago... but that wasn't brought up by my oncologist. (age 65; NHW; stage IV diagnosis at recurrence) P20: I don't even think it's brought up now. I never have talked (age 55; NHW; stage IV diagnosis at recurrence)
		Fertility	P19: And there's some easy things like Replens that nobody brought up to me. P7: I obviously don't have kids and that was something we were probably wanting... The person I talked to, because I talked about freezing my eggs, and I got "Oh, we don't really recommend that for metastatic patients." And I thought that was a really horrible thing to say... And then you hear of all these other options, but it's difficult... I kind of put that on the backburner with everything going on. But yeah it's a challenge, your friends are having kids. (age 34; NHW; de novo stage IV diagnosis)

NHW = non-Hispanic/Latina White.

are you doing?' sometimes it's just easier to say, 'I'm okay, I'm fine.' ... you really wonder, are they asking because they truly care?" Women also noted they often console close others who are struggling to cope with their diagnosis of metastatic breast cancer although, as patients, they are often struggling themselves. Some women reported selectively sharing their diagnosis of metastatic breast cancer or sharing the diagnosis exclusively with immediate family members. Women also described making advance preparations for their deaths to ease the burden on their spouses/partners and children, such as making decisions about their possessions and inheritance.

Stigma. Women noted that receiving a life-limiting diagnosis of metastatic breast cancer made them feel "labeled," particularly in "a society where most people don't ever consider mortality." Some women reported that others assume they are at end-of-life or imminently dying although many women live with metastatic breast for years beyond their diagnosis. As a result, women described being treated differently socially and missing out on work opportunities. Women also stated that they dislike the commonly used war terminology (eg, "lost their battle with cancer") to describe their experience with metastatic breast cancer "because it implies that the people who die didn't try hard enough."

2.3.3. Theme 3. Coping with loss. Anticipatory Grief. Women reported significant concern about how their loved ones, particularly spouses/partners and children, will cope with their death and expressed a desire to prepare them: "I will be dying of this [metastatic breast cancer] presumably... it's about preparation. And of course, the big worry is your loved ones, and

thinking about planning for them." Women also described a sense of loss and fear of missing important events in the future, such as the opportunity to see their grandchildren grow up. Although women valued the opportunity to connect with other women living with metastatic breast cancer for mutual support (see Lack of Social Support above), they also acknowledged that it can be difficult to integrate into a community that regularly experiences losses.

Grief. Women also described grieving the loss of close others such as family members, spouses/romantic partners, and other women with metastatic breast cancer: "[My husband] recently passed away. And it's extremely difficult without him. And when you have someone like that, hold on to them... do as much as you can with them while they're here. Because once they're gone, they're gone. And there's no bringing them back."

2.4. Physical and Functional Needs

2.4.1. Theme 4: Managing breast cancer-related symptoms and comorbid conditions. Breast Cancer-Related Symptom Burden. Women experienced multiple symptoms as a result of their cancer and its treatment, as well as several comorbidities associated with age, such as heart failure, cataracts, and joint pain. Some believed that cancer treatment may have exacerbated pre-existing comorbid conditions. Among the symptoms associated to their cancer, women reported experiencing significant and debilitating fatigue: "I find the exhaustion just terrible. And then I had radiation the last two weeks which added to the exhaustion... I didn't even feel like chewing." Pain was also a common concern, especially among

women with bone metastases who reported experiencing significant back and hip pain. In addition, some women reported spontaneous fractures related to low bone density and osteoporosis. Chemotherapy often caused neuropathy, including loss of sensation and feeling as if one is “walking on a bed of nails.” Hormone therapy also caused hot flashes. Other side effects described included muscle atrophy, labored breathing, and cold sores in the mouth. Despite the burden of cancer treatment side effects, women stated that they continued recommended treatment regimens because of their desire to manage their cancer and prolong life.

2.5. Health system and information needs

2.5.1. Theme 5: Defining patient-centered, goal-concordant care. Patient-Centered Care. Women stressed the importance of patient-centered care, such as more time with their oncology providers to thoroughly discuss the benefits and possible side effects of their cancer treatment. In particular, women wanted to be able to communicate their treatment goals to providers and be included in decisions regarding their care: “Because in the end, it is your body. They are the experts and professionals, but you know how you feel. Only you know that... and also what you want for yourself.” Given the frequency and intensity of their contact with the health care system, women expressed a desire for additional layers of support to facilitate their care (eg, free parking, a guest pass that does not have to be newly issued at each visit). They also expressed interest in integrative medicine and incorporating complementary and alternative approaches into their cancer care. Women described significant concerns regarding insurance coverage and the exorbitant cost of cancer treatments.

2.5.2. Theme 6: Need for accurate information from reliable sources. Misinformation. Women expressed concerns about the accuracy and quality of information available online (ie, websites and forums) and discussed the importance of verifying information with their health care providers. These concerns were particularly strong in relation to online recommendations regarding diet and supplements. Women also described receiving unsolicited health advice from family and friends, much of which felt unhelpful: “People in your life, people around you becoming doctors and telling you what to do... you shouldn’t be getting chemotherapy. You should do this, you should do that... so many people send you so many things, you get so tired!” In addition, women often encountered common misconceptions regarding metastatic breast cancer, including questions about when they would “be done” with their cancer treatment and the idea that if a woman looks well, she must be in good health or feel well:

P20: “A lot of people don’t understand—and, you know, can’t fault them for not knowing but...” (age 55; non-Hispanic/Latina White; stage IV diagnosis at recurrence)

P19: “Oh no no, they haven’t encountered it before. It’s not that I get upset, but it does get old.” (age 65; non-Hispanic/Latina White; stage IV diagnosis at recurrence)

P20: “It does.”

2.6. Sexuality and fertility needs

2.6.1. Theme 7: Addressing sexual and fertility concerns. Sexual Functioning. Women described the impact of living with metastatic breast cancer on sexual functioning. Some women

experienced low libido both as a side effect of their cancer treatment and as a result of stress associated with their demanding treatment schedule. Other women noted that they were still “definitely interested in having sex” but found that intercourse could be “very painful” and, at times, “terrible.” Hormone therapy, in particular, caused vaginal dryness and decreased pleasure and the ability to enjoy sex, which, in turn, affected women’s relationships with their spouses/partners. Even among those whose partners were “very understanding,” women expressed that such changes in their sex life felt “incredibly unfair.” Women were interested in strategies and solutions available to couples struggling with sexual functioning.

Fertility. For younger women, fertility preservation and family planning after the diagnosis of metastatic breast cancer can pose a significant challenge. For example, one participant who desired children was told by her health care team that they did not “really recommend [egg freezing] for metastatic patients,” which was very difficult for her to hear given her life stage.

In general, women expressed a desire for more open, compassionate communication with their health care providers to address sexuality and fertility concerns. A few women stated that sexual issues simply were not “brought up” by their oncologists. Others noted that some practical solutions exist (eg, lubricants) and wished that their health care providers had shared such information with them. Overall, women felt that sexuality and fertility issues for women living with metastatic breast cancer should be given more attention to better address their needs.

3. Discussion

The purpose of this study was to characterize supportive care needs among women with metastatic breast cancer and elucidate challenges unique to living with a life-limiting prognosis that may not be captured in existing self-report measures of supportive care needs.^{10,32} Findings from four focus groups demonstrate that women have diverse supportive care needs across several domains, including psychosocial, physical and functional, health system and information, and sexuality and fertility needs. The most endorsed needs across domains were breast cancer–related symptom burden, lack of social support, uncertainty, stress management, patient-centered care, and sexual functioning. Similar to previous findings examining supportive care needs among cancer survivors posttreatment completion,^{17,40,41} the most prevalent needs among women with metastatic breast cancer were in the psychosocial domain with more than half of endorsed needs in this domain. This finding suggests that needs related to the psychological impact of living with metastatic breast cancer, social isolation and stigma, and coping with loss, are areas of particular concern for this population. Furthermore, physical and functional needs highlight the importance of effectively managing breast cancer–related symptoms and comorbid conditions alongside psychosocial concerns.^{29,30} Physical symptoms and functioning have a synergistic relationship with emotional well-being, including in the context of advanced cancer.⁴² Therefore, to optimize quality of life among women with metastatic breast cancer, psychosocial and physical and functional needs should be carefully monitored and addressed by interdisciplinary cancer care teams that include psychosocial and palliative care providers. Women endorsed supportive care needs that overlapped with needs previously documented in women primarily diagnosed with nonmetastatic breast cancer using self-report measures (eg, uncertainty about the future, concern for

close others, need for patient-centered care, and issues related to body image and sexual functioning),^{14,43} suggesting that there are some concerns and needs that cut across the breast cancer continuum. Nevertheless, several significant challenges unique to living with metastatic breast cancer emerged across supportive care needs domains. Women described the difficulty of undergoing arduous cancer treatments indefinitely and its detrimental impact on their quality of life. Ongoing treatment for metastatic breast cancer introduces an uneven course, which is not circumscribed to a definitive period and does not include a “post-treatment” phase as with curative-intent treatment. Furthermore, exact treatment plans cannot be fully predetermined at diagnosis because they have to be adjusted according to treatment response.^{44,45} This paradigm introduces significant uncertainty and anxiety from scan to scan because women and their care teams must continuously evaluate how their cancer is responding to treatment and whether they need to adjust or change their treatment plan. Accordingly, women described significant treatment-related burnout and the cumulative effects of cancer treatment on worsening symptom burden. They emphasized the importance of patient-centered care, including ongoing discussion with their care providers of treatment goals and the possible benefits and side effects of cancer treatments. Given the nature of their treatment schedules, women also noted the frequency and intensity of their contact with health care systems and expressed a desire for additional, pragmatic layers of support such as free parking and guest passes that can be used across multiple visits. These findings are similar to previous studies among women with metastatic breast cancer that have documented a desire for greater systems-level and structural supports, such as accessible parking and monetary allowances for travel and treatment-related expenses.³¹

Women also commonly endorsed supportive care needs specific to living with a life-limiting prognosis, including mortality salience and end-of-life concerns, which are not typically captured in existing self-report measures of supportive care needs. They reported significant worry about cancer therapies no longer working and running out of viable treatment options. They also described the unique challenge of trying to live in the moment, day-to-day or plan for the future while being aware of the uncertainty of their prognosis. Women experienced anticipatory grief regarding the possibility of missing important events in the future and concern about how loved ones, particularly spouses and children, would cope with their passing. Women reported managing others’ anxiety about their health and trying to protect close others even in the midst of their own distress. Although they would like to discuss these issues and making advance preparations, they often found that others constrained or limited their attempts to discuss death or dying. Women reported that general, societal-level discomfort regarding mortality and lack of understanding regarding metastatic breast cancer often resulted in experiences of social isolation and stigma. Therefore, women emphasized the importance of support from other women living with metastatic breast cancer.

As a result of the aging US population and improvements in available cancer treatments, the number of women living with metastatic breast cancer is increasing.⁵ Our findings suggest that women with metastatic breast cancer have specific supportive care needs that are unique from women with early-stage breast cancer. Advocacy groups such as the Metastatic Breast Cancer Network, Metavivor, Metastatic Breast Cancer Alliance, and others continue to raise awareness and advocate for increases in research, support, and resources specifically for individuals with metastatic breast

cancer. Clinicians and researchers should be aware of supportive care needs specific to women with metastatic breast cancer and thoughtfully consider how to address these needs in their work. Women experience significant distress and disruption immediately after receiving a stage IV diagnosis, underlining the importance of early intervention and ensuring that women have access to the appropriate support and resources after their diagnosis of metastatic breast cancer. Future research should focus on developing evidence-based programs and interventions that address these needs to optimize quality of life and well-being among this population.²⁴ Our findings suggest that cognitive behavioral approaches such as ACT^{46,47} that address salient concerns and shifting priorities, while allowing for the co-occurrence of feelings of grief and loss that are normal and expected when facing a life-limiting prognosis, maybe particularly well-suited.

3.1. Limitations

Findings of this study should be interpreted within the context of its limitations. Importantly, our data were collected as part of a larger project that aimed to inform the development of a psychosocial intervention. This focus may have limited a broader elicitation of supportive care needs given that the interview guides likely influenced participants’ responses and findings (eg, overrepresentation of psychosocial needs). Therefore, the frequencies and percentages reported must be cautiously interpreted within the context of the interview guides and should not be extrapolated beyond this study. Furthermore, although no new codes or themes related emerged in the fourth group, it is possible that data saturation could have been optimized by using the exact same interview guide across all four groups. Additional focus groups may have revealed new information and shifted the frequencies reported in this study because the interview guide for the third and fourth focus groups did not include all questions from the interview guide used in first two focus groups (eg, challenges and stress, social support, body image and sex, health behaviors). Finally, another limitation of this study is the lack of diversity of our sample. The overwhelming majority of participants were non-Hispanic/Latina White, and all participants identified as female. Focused research with more representative samples, including men and gender, sexual, and racial/ethnic minorities, is urgently needed to ensure that all individuals affected by metastatic breast cancer are represented and supported.

4. Conclusions

Findings from this study suggest that women with metastatic breast cancer have diverse supportive care needs across multiple domains, including needs that are specific to living with a life-limiting prognosis that are not typically captured in existing self-report measures of supportive care needs. Although women with metastatic breast cancer report several unique supportive care needs compared with women with early-stage breast cancer, they also endorsed some overlapping needs with those previously documented in women with early-stage breast cancer. Our results highlight the importance of addressing psychosocial concerns and breast cancer-related symptoms in this population. Women with metastatic breast cancer may benefit from early access to evidence-based interventions and resources that specifically address their supportive care needs and optimize quality of life and well-being.

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Conflicts of interest statement

Authors have no conflict of interests to declare.

Ethics approval

Study was approved by the Institutional Review Board at the Northwestern University Feinberg School of Medicine in accordance with the 1975 Declaration of Helsinki, as revised in 2008.

Consent to participate

All participants provided informed consent before participation.

Availability of data

Deidentified transcripts are available on reasonable request for review only when in accordance to institutional policy.

Authors' contribution

All authors contributed to this research and article. Conceptualization: P. I. Moreno, B. N. Esquives, J. L. Thomas, and F. J. Penedo. Funding acquisition: P. I. Moreno and F. J. Penedo. Investigation: P. I. Moreno, J. L. Thomas, F. S. Horner, J. B. Torzewski, W. Gradishar, D. Victorson, and F. J. Penedo. Methodology: P. I. Moreno and F. J. Penedo. Data curation: P. I. Moreno, B. N. Esquives, J. L. Thomas, and F. S. Horner. Formal analysis: P. I. Moreno, B. N. Esquives, and J. L. Thomas. Project administration: P. I. Moreno, F. S. Horner, and J. L. Thomas. Resources: P. I. Moreno. Supervision: P. I. Moreno. Validation: P. I. Moreno, B. N. Esquives, and J. L. Thomas. Writing-original draft: P. I. Moreno, B. N. Esquives, and J. L. Thomas. Writing-review and editing: P. I. Moreno, B. N. Esquives, J. L. Thomas, F. S. Horner, J. B. Torzewski, W. Gradishar, D. Victorson, and F. J. Penedo.

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