



Results of an Academic- Community Partnership for People Living with MBC

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Authored by: Joshua Woods, BA; Mya Roberson, PhD, MSPH

Authored for: Lesley Glenn; Deltra James; Julia Maues

Summary

This report summarizes major themes from interviews conducted with 36 members of the Project Life community and centers the lived experience of people with MBC. In presenting these findings, this study supports the critical role patient organizations play in MBC quality of life as complements to clinical care. Through doing so, this study represents an important step in informing MBC care with patient-centered policy and practice made possible through community-engaged qualitative research.

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This report re-imagines medical care for MBC patients from the perspective of MBC patients.



Introduction

In the United States, an estimated 150,000 people¹ live with metastatic breast cancer (MBC).² Based on 2019 figures, 16,000 MBC cases each year are diagnosed, either as de novo (diagnosed stage IV) or as recurrent (stage IV after initial diagnosis).³ **People with MBC can live years, with around one third living up to, or beyond, five years after initial diagnosis.⁴ During these years, people living with MBC become intimately familiar with the specific lived experiences⁵ of MBC care.**

Support from family and friends plays a vital role in quality of life⁶ for those living with the effects of MBC and its treatment, and so too do psychological interventions.⁷ Besides these influences, **social support programs also serve as a source of resilience⁸, through virtual and in-person formats^{9–11}** that vary in structure¹⁷ from those led by biomedical professionals to those driven by patient-led or community-based efforts.

Through a partnership cultivated by GRASP (a non-profit organization dedicated to empowering patients, clinicians, and researchers to exchange impactful ideas) **we worked with Project Life, a patient-led, non-profit virtual wellness house for those living with MBC, to understand and re-imagine the medical care of those living with MBC as well as the role of patient-run organizations in that care.**

Methods

We recruited participants from MBC patient-members of Project Life. Study materials were created jointly by study team members and Project Life leadership. Project Life distributed recruitment information to its membership. Potential participants were asked to complete a brief screener survey to determine eligibility, which hinged on being 18 years or older, being a Project Life member, identifying as a person living with MBC, having a way to be contacted, being able to speak English, and consenting to be involved in the study. Following registration through REDCap, an online survey tool designed by Vanderbilt University for secure data collection, which captured demographics, the study team conducted one, one-hour interview with each Project Life member over Zoom, using a co-created interview guide while recording audio as permitted. **The interview covered diagnostic experience, experience with current care, opinions on the quality of care received, ideas for how to improve care, experience with**



150,000 people live with MBC in the United States, and more are living longer, creating sustained contact with biomedical care and its variable effects.



Project Life, and the effect of Project Life on wellness. Data collection spanned March 14, 2022, to May 31, 2022, with analysis performed between March 14, 2022, and August 1, 2022.

Guided by standards for qualitative research set by the Patient-centered Outcomes Research Institute (PCORI)¹², data were processed in MAXQDA—software designed to aid researchers in organizing, classifying, and combining data. **Using a process called Phronetic Iterative Data Analysis (PIA)¹³, data was synthesized** and made sense of. The first step of PIA is identifying what is in the data. For instance, in the statement, “My medicine was too expensive, so I had to quit taking it,” a researcher would highlight the text and label, or code, it with the phrase “affordability” to identify that the patient is having trouble affording some part of their care. These labels are constantly modified as more responses are received. For instance, affordability may need to be more specific if more participants identify that medicine is the specific thing unable to be afforded rather than care in totality. Once this basic description of what is in the data is completed, another round of labeling is done whereby codes are related to one another as they correlate or directly affect each other. As an example, say that a patient states, “I could not afford my medicine, and so my symptoms got worse. That caused me to lose my job because I couldn’t do what I needed to.” In this statement, the descriptive codes could be “drug affordability,” “symptom progression,” and “career disruption,” and the relationship created would be “drug affordability affects career.”

Through the process of creating codes and relating them together larger themes emerge. Once no more unique themes emerge from coding, theoretical saturation is said to be achieved and interviews can cease. Though we feel theoretical saturation was achieved in this study, there is always, of course, room for further nuance and spectrums of experience. **Throughout the process of analysis, input from Project Life and GRASP, coupled with research team backgrounds in anthropology and public health, helped triangulate (or refine)¹⁸ analysis by incorporating various types of expertise.**

Using Phronetic Iterative Analysis, this report re-imagines MBC care by examining semi-structured interviews with members of the MBC wellness house, Project Life.



Results

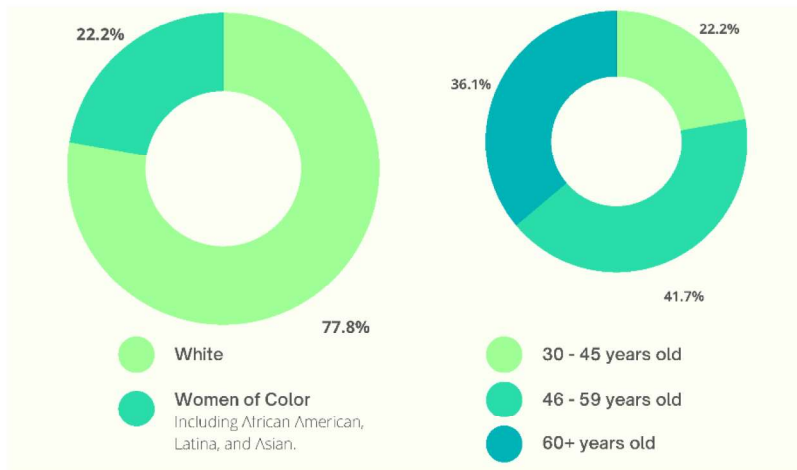


Figure 1. Participant Demographics (n = 36)

Prominent themes:

- ▶ **Gaps in Medical Care.**
- ▶ **Filling the Gaps: How Project Life and other Organizations Fill Gaps Left by Medical Care.**

Gaps in Medical Care

There were a multitude of gaps identified in medical care, with three of the most frequently mentioned being: (1) lack of social support services (or MBC-specific resources), (2) lack of, or trouble finding, insurance coverage for various procedures (financial toxicity), (3) poor patient-provider communication.

Many participants pointed out that their cancer centers lacked social support services, and when centers did have such services, MBC-specific offerings were not available. As an example of why having MBC-specific support groups is important, take the incompatibility between MBC support groups and breast cancer support groups more broadly as one patient had to say, “They [cancer centers, prominent breast cancer organizations] don’t want us in their early-stage support groups, because we frighten [the early stage] members.” In place of these support groups in-house, patients also pointed out an alternative desire to be linked to a comprehensive resource detailing the organizations that do provide support for MBC patients, but as these patients also noted, cancer centers lacked such lists. For instance, as one patient desired, “I think another thing that doctors aren’t aware of is the need to help the patients communicate, especially while going through metastatic breast cancer, with all the other support groups out there.”

36 participants identified gaps in medical care and how those gaps are filled by MBC organizations, like Project Life.



Besides social support, patients also felt they financially were not always supported by their insurance companies concerning their care. Not only did patients find insurance confusing, especially as concerned transitions to Medicare and disability benefits, they also found insurance financially unwilling to cover needed care, creating **situations of financial toxicity**. As one patient explained in-depth and in frustration:

I guess if I want to put something on the table, it would be Medicare for All. You know, I think there's way too much disparity depending on what kind of health insurance you have, what you're entitled to, and what your prescription plan will pay for. Why should a health insurance company decide that what an oncologist wants you to take is too expensive?

Such sentiments were repeated concerning the financial toxicity of medication, preventive and diagnostic scans, and in-clinic treatment regimens (e.g., intravenous chemotherapy).

Finally, support at the physician level was also felt to be lacking for those living with MBC. Besides reported instances of disrespect and lack of bedside manner, another element MBC patients found lacking was education on their illness. Specifically, issues emerged in understanding the course of illness, what treatments entailed, and what side effects would result from treatments. When it came to education on side effects, one participant with bone metastasis stated:

I had a compression fracture in my spine. My oncologist sent me up to a spine specialist for surgery, and, then, I did radiation after that. But those two specialists—they did their thing and then I was done.

But, I was still in pain, and I didn't know, is this what I'm supposed to feel like? What happens afterwards? And I kept saying to my oncologist, 'I'm still in pain. Is this what it's supposed to feel like? Like, what? Where am I supposed to be?'

I'm still in pain. I've been dropped out of all these groups. I don't know what I'm supposed to be feeling anymore.

Such stories of lack of education on side effects and symptoms were prominent given side effects and symptoms were heavily mentioned elements of the lived experience of MBC.

Filling the Gaps

Although medical care lacked social support, adequate insurance coverage, and competent provider-patient communication for those living with MBC, patient organizations like Project Life were

Patients found insurance financially unwilling to support them, creating situations of financial toxicity. They also found MBC-specific social support at cancer centers lacking.



identified as sources to fill these gaps to maintain multidimensional wellness.

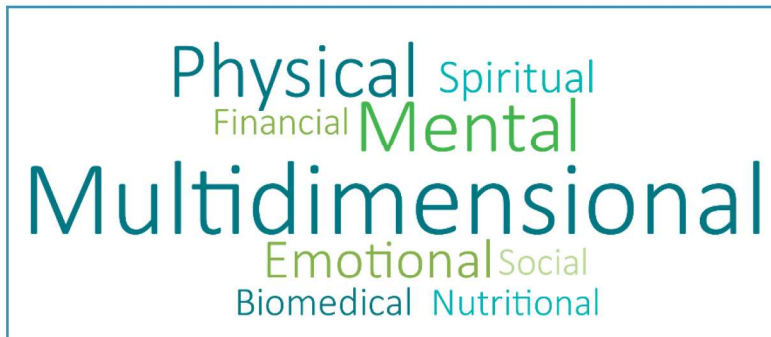


Figure 2. Wellness as Multidimensional

When it came to social support, participants overwhelmingly endorsed the importance of organizations like Project Life for feeling fulfilled. Specifically with Project Life, members felt that its healing circles, mentorship, therapeutic art, and Facebook group provided beneficial support. As one participant stated:

I think it's nice to be able to openly share, and I think it's also just not knowing the person, the people in the group and knowing that they're not in your community necessarily allows you to talk more freely and I just find it very open and non-judgmental.

Such sentiments were widely repeated.

Moving to the issue of insurance coverage and financial toxicity, while Project Life is not positioned to provide financial support directly, it does offer a legal clinic for education on end-of-life planning, medical insurance, and understanding patient rights.

With insurance, one participant stated:

They talk about [financial] toxicity, and there's a lot of stress with dealing with an insurance company turning down your treatments and your medication. So, that's how Project Life was a very good resource. I wish people knew about that resource because none of us that took that class [legal clinic] understood a lot of insurance companies are big on saving. Knowing your rights is huge.

This idea of insurance education also spanned beyond the legal clinic in how each patient could talk directly to others who had experienced similar things and thereby provide communal guidance and support.

Finally, when it came to understanding their illness itself, members of Project Life indicated that the organization was key to their survival and wellness management. As one participant stated:

“...the offerings Project Life has is really what got me from a place of being somebody dying from metastatic breast cancer to being somebody living with metastatic breast cancer.”



...through these different organizations and these groups and the support groups, we truly help each other navigate the side effects...

And as another noted more generally and powerfully:

...the offerings Project Life has is really what got me from a place of being somebody dying from metastatic breast cancer to being somebody living with metastatic breast cancer. And there's a lifetime's difference between those two things [...] that was a gift that you can't quite put a price tag on.

Overall, the general sense from Project Life's membership was that the organization was, as they would often phrase it, "another key tool to have in their toolbox" when it came to navigating life with MBC without adequate supports from medical centers.

Discussion

To our knowledge, this is the first study to partner with a metastatic breast cancer community organization to re-imagine MBC care from the perspective of patients. The women in this study highlighted thematic gaps in medical care and how organizations like Project Life fill those gaps.

Suggestions

There are several ways stakeholders can begin to address the gaps patients highlighted here. Concerning lack of social support in clinics, cancer centers could either establish MBC-specific support groups or work to form a comprehensive resource on available social support groups and resources beyond those offered by the center to MBC patients. As another alternative, one, or a group of, professional and non-profit cancer organizations could come together to create a curated resource of MBC-specific support groups and resources to be distributed widely to cancer centers nationally for dissemination to patients.

Concerning insurance and financial toxicity, besides increasing education and support for insurance navigation in clinics and in patient organizations, considerations should be made to larger frameworks governing the operation of insurance coverage concerning metastatic breast cancer, metastatic cancers broadly, or health widely to increase access to quality care.

As for provider-patient communication, provider communication around metastatic cancer continues to be an issue needing serious consideration as highlighted here. Focused attention on goals of care, metastatic survivorship, and advanced care planning is

We suggest establishing MBC-specific supports, revising of operational insurance frameworks, improving doctor-patient communication, supporting wellness organizations.



imperative. This would improve not only patient satisfaction but also patients' understanding of their treatments and illness.

Finally, if no action were to be taken by stakeholders directly to improve cancer care at a center or national policy level with these suggestions or others of similar tone, one position of compromise would be the support financially and logistically of organizations like Project Life so they can continue to improve the wellbeing of their members by supplementing services not provided by medical institutions as has been shown here.

Strengths and Limitations

This study benefits from a sample size large enough, and interviews deep enough, to reach thematic saturation in addition to its triangulated analysis, which had ample analytic input from an MBC patient organization's leadership, a public health policy professional, and a medical anthropologist.

In terms of limitations, **this study's sample population only represents women living with MBC** connected to a virtual support group, and thus by virtue of this connectedness may have had a more limited range of experiences and opinions than a broader population of those living with MBC.

Conclusion

This study supports the critical role patient organizations play in MBC quality of life as complements to clinical care. This work represents an important step in re-imagining MBC care with patient-informed policy and practice made possible through community-engaged qualitative research.

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The women in this study highlighted gaps in medical care and how organizations like Project Life fill those gaps, supporting the role patient organizations play in MBC quality of life.

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