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### Financial Toxicity During Breast Cancer Treatment: A Qualitative Analysis to Inform Strategies for Mitigation

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# Financial Toxicity During Breast Cancer Treatment: A Qualitative Analysis to Inform Strategies for Mitigation

Laila A. Gharzai, MD, LLM<sup>1,2</sup>; Kerry A. Ryan, MA<sup>2</sup>; Lauren Szczygiel, PhD<sup>2</sup>; Susan Goold, MD<sup>2</sup>; Grace Smith, MD, PhD<sup>3</sup>; Sarah Hawley, PhD, MPH<sup>4</sup>; John Pottow, JD<sup>5</sup>; and Reshma Jagsi, MD, DPhil<sup>1,2</sup>

**QUESTION ASKED:** Can patients who suffered financial toxicity during breast cancer treatment inform a framework for understanding financial toxicity and offer strategies for mitigation?

**SUMMARY ANSWER:** Patients confirmed an existing financial toxicity framework and identified expectations as a novel theme affecting financial toxicity. Knowledge gaps identified by patients offered insights into strategies for mitigating financial toxicity.

**WHAT WE DID:** We performed qualitative semi-structured interviews with patients who received financial assistance from a philanthropic organization during treatment of breast cancer. Interviews were transcribed and coded until thematic saturation was reached, and findings were contextualized within an existing financial toxicity framework.

**WHAT WE FOUND:** We found that an existing financial toxicity framework incorporating objective financial burden and subjective financial distress described lived experiences of patients with breast cancer who experienced financial toxicity, adding a novel insight that expectations regarding treatment costs affected both objective financial burden and subjective distress. We identified knowledge gaps in treatment

expectations, provider conversations, identification of resources, and support-finding as areas in need of further efforts to mitigate financial toxicity.

**BIAS, CONFOUNDING FACTORS:** Patients were interviewed 1-3 years after obtaining financial assistance, which may lead to recall bias. This population consisted of patients who were able to identify and seek out financial assistance during treatment; further identification and exploration of marginalized groups, who may lack even the resources necessary to identify philanthropic organizations, should be the focus of future work. Participants received a small monetary incentive, which may have potentially influenced the decision to participate.

**REAL-LIFE IMPLICATIONS:** Financial toxicity is a complex phenomenon, and a better understanding of the components that together create this challenging experience can offer direction for interventions to address it. Insights from patients who experienced financial toxicity provide valuable guidance to inform future patient-facing efforts to mitigate financial toxicity, such as through leveraging support from decision aids and allied providers.

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## ASSOCIATED CONTENT

Appendix

[Data Supplement](#)

Author affiliations and disclosures are available with the complete article at [ascopubs.org/journal/op](https://ascopubs.org/journal/op).

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# Financial Toxicity During Breast Cancer Treatment: A Qualitative Analysis to Inform Strategies for Mitigation

Laila A. Gharzai, MD, LLM<sup>1,2</sup>; Kerry A. Ryan, MA<sup>2</sup>; Lauren Szczygiel, PhD<sup>2</sup>; Susan Goold, MD<sup>2</sup>; Grace Smith, MD, PhD<sup>3</sup>; Sarah Hawley, PhD, MPH<sup>4</sup>; John Pottow, JD<sup>5</sup>; and Reshma Jagsi, MD, DPhil<sup>1,2</sup>

## abstract

**PURPOSE** Financial toxicity from cancer treatment is a growing concern. Its impact on patients requires refining our understanding of this phenomenon. We sought to characterize patients' experiences of financial toxicity in the context of an established framework to identify knowledge gaps and strategies for mitigation.

**METHODS** Semistructured interviews with patients with breast cancer who received financial aid from a philanthropic organization during treatment were conducted from February to May 2020. Interviews were transcribed and coded until thematic saturation was reached, and findings were contextualized within an existing financial toxicity framework.

**RESULTS** Thirty-two patients were interviewed, of whom 58% were non-Hispanic White. The mean age was 46 years. Diagnoses ranged from ductal carcinoma in situ to metastatic breast cancer. Concordant with an established framework, we found that direct and indirect costs determined objective financial burden and subjective financial distress stemmed from psychosocial, behavioral, and material impact of diagnosis and treatment. We identified expectations as a novel theme affecting financial toxicity. We identified knowledge gaps in treatment expectations, provider conversations, identification of resources, and support-finding and offer strategies for mitigating financial toxicity on the basis of participant responses, such as leveraging support from decision aids and allied providers.

**CONCLUSION** This qualitative study confirms an existing framework for understanding financial toxicity and identifies treatment expectations as a novel theme affecting both objective financial burden and subjective financial distress. Four knowledge gaps are identified, and strategies for mitigating financial toxicity are offered. Mitigating patients' financial toxicity is an important unmet need in optimizing cancer treatment.

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## INTRODUCTION

Financial toxicity describes the increasingly recognized financial impact of health care on patients.<sup>1</sup> This affects patients throughout treatment, particularly in oncology, where costs have eclipsed other areas of health care in the United States. Almost half of patients with breast cancer experience at least moderate financial distress,<sup>2</sup> which affects treatment choices,<sup>3</sup> quality of life,<sup>4,5</sup> medication adherence,<sup>6</sup> bankruptcy rates,<sup>7,8</sup> and even mortality.<sup>8</sup>

Developing interventions for financial toxicity requires a comprehensive understanding of the complex factors underpinning this phenomenon. Efforts to advance understanding led to the development of theoretical frameworks to understand mechanisms conspiring to produce this phenomenon. This study builds on a

systematic review of 41 instruments investigating financial toxicity that identified three domains of subjective financial distress, which were combined with two domains of objective financial burden to create a framework<sup>9</sup> aimed at improving further development of survey instruments for financial toxicity.

We sought to characterize patients' experiences of financial toxicity in the context of this framework<sup>9</sup> to identify theoretical gaps. Strengths of this framework include its understanding of both objective components of financial toxicity, such as out-of-pocket costs and loss of income, and subjective components, which interact synergistically to create the devastating experience of financial toxicity. Empirically developed frameworks can be strengthened using qualitative data. In this study, we discuss how qualitative data

Author affiliations and support information (if applicable) appear at the end of this article.

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from patients with breast cancer experiencing financial toxicity fit this framework, suggest an additional domain, and identify areas for mitigation of financial distress.

## METHODS

This study conducted from November 2019 to November 2020 was reviewed and approved by the institutional review board (HUM00160526). Participants eligible for this study received aid from The Pink Fund, a nonprofit organization based in Michigan with a nationwide reach. The organization aims to offset financial toxicity by providing \$3,000 US dollars (USD) for patients actively undergoing breast cancer treatment, who worked at the time of diagnosis, experienced loss of income, and had a household income  $\leq$  500% of federal poverty level.

From 116 potential participants who returned signed consent forms after receiving mailed invitation letters, 32 participants were purposefully selected to be diverse in race, income, education, and presence of dependents; this included deliberate oversampling of racial and/or ethnic minorities. Participants were assumed to have experienced financial toxicity because all required financial aid during breast cancer treatment, confirmed by experiences described in interviews. Participant demographics were provided at initial application for philanthropic support. Participants completed a semistructured recorded telephone interview, following an interview guide (Data Supplement, online only) iteratively developed by the study team and included input from experts in survey design, qualitative interviewing, financial distress, bankruptcy law, and oncology. Domains of the interview guide included subjective and objective burdens, provider interactions, advice for future patients, and support provided by philanthropic organizations (Data Supplement, online only).

Audio recordings were transcribed by a Health Insurance Portability and Accountability Act–compliant transcription service and redacted to protect confidentiality. Patients received a small monetary incentive after completion. The qualitative coding scheme was developed using thematic analysis<sup>10,11</sup> to develop major themes and placed into context using the aspects of the framework method.<sup>12</sup> All transcripts were coded and reviewed by two study team members, a radiation oncologist (L.A.G.) and a sociologist trained in qualitative methods (K.A.R.), with differences in coding resolved by consensus. Transcripts were analyzed in MAXQDA (VERBI Software, 2017). We followed the Standards for Reporting Qualitative Research reporting guideline.<sup>13</sup> The results were reviewed and revised by the whole study team.

## RESULTS

All 32 interview participants were women with breast cancer. Fifty-eight percent were non-Hispanic White, 25.8% Black, and 9.7% Hispanic, with a mean age of 46

years at the time of philanthropic application (applications were submitted from 2017 to 2019). Participants were diagnosed with a spectrum of disease, from ductal carcinoma in situ to metastatic breast cancer. The majority were college-educated, with 65.7% having a bachelor's degree or higher. One-quarter had an adjusted gross income of  $<$  \$25,000 USD, and 22% had an income of  $>$  \$75,000 USD per year in the year before diagnosis. Half of participants were the sole breadwinner in their household, and half had dependents. Three-quarters worked full-time before diagnosis, and only one participant worked full-time after diagnosis (Appendix Table A1, online only).

Regardless of economic, social, and familial circumstances, respondents experienced emotional and financial stress and disruption because of their cancer diagnosis in addition to objective costs, confirming the established framework. Many respondents explicitly discussed the double whammy impact of worrying about finances on top of a cancer diagnosis, confirming the synergistic effect of objective burdens and subjective distress.

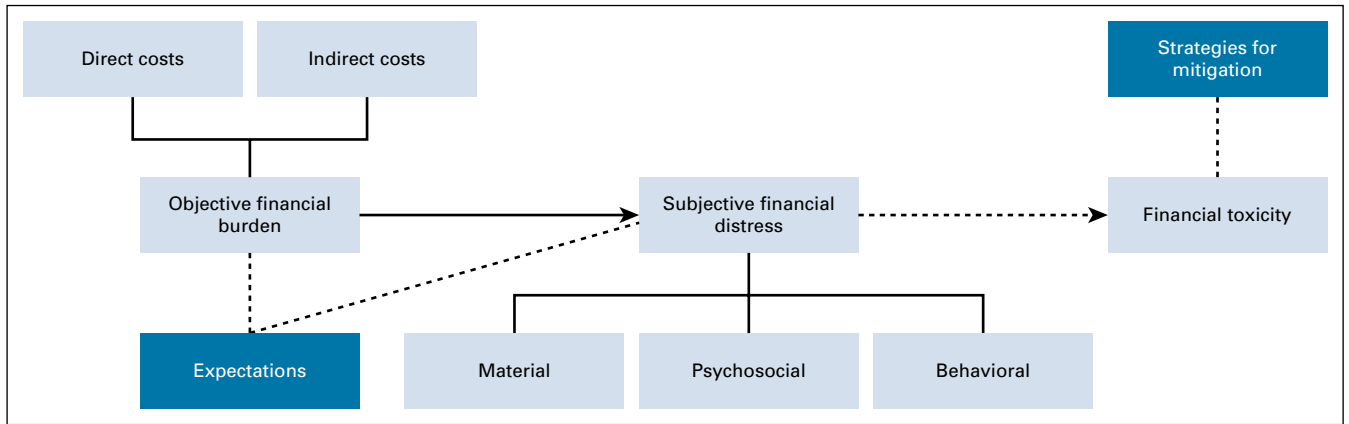
I think that's the hardest thing for a cancer patient—for me, wasn't the treatments themselves. It was the stress and the burden of the financial hardship that you go through, the loss of losing your hair and losing your breasts and your eyelashes, and feeling like you've lost your identity. Then the financial burden on top of all of it is unbelievably stressful. You feel like it's never going to end or that you see the light at the end of the tunnel.

### Application of Existing Financial Toxicity Framework

The qualitative themes emerging from interviews confirmed the existing framework developed by Witte et al<sup>9</sup> (Fig 1) and identified a novel addition, with supporting exemplary quotes in Table 1.

**Objective burden: direct and indirect costs.** Objective financial burdens experienced by participants included direct and indirect costs. Direct costs included treatment-related costs (such as copays and deductibles) and supportive care costs (such as paying for lotions during radiation or wigs during chemotherapy). Indirect costs included loss of income and employment disruptions such as reduced hours, extended leaves of absences, and loss of employment, experienced by most participants. Other indirect costs were related to an inability to perform unpaid duties that had been previously borne by the participant, such as childcare or domestic duties, requiring paid outside help or volunteers.

**Subjective distress: material, psychosocial, and behavioral.** Subjective aspects of financial toxicity describe consequences of financial concerns including material conditions, psychosocial responses, and coping behaviors. This component describes additional burdens that patients face beyond direct burdens. Material conditions relate to



**FIG 1.** Framework of financial toxicity. The unshaded section demonstrates established framework from Witte et al.<sup>9</sup>; the shaded section demonstrates addition to the framework from current qualitative analysis. Adapted from Witte et al.<sup>9</sup>

changes in spending and use of resources. Respondents took on debt, used savings, or paid bills late. Another material impact was related to property or homes. The most important material concern raised by participants centered around maintaining housing and preventing eviction or foreclosure. Participants additionally expressed concern about making car payments to maintain transportation, which was important to attend treatment visits.

Psychosocial responses were related to individual perceptions of stress, fears, worries, and distress. Participants reflected on the emotional toll of cancer, with almost all participants endorsing significant anxiety, stress, and worry related to not only their diagnosis but also the financial implications of treatment. Participants acknowledged these emotional responses as an integral component of the experience of financial toxicity.

Financial coping behaviors included lifestyle changes and asking for help from family, friends, and social workers (or other ancillary providers). Participants also noted coping behaviors related to maintaining health insurance, such as intermittently going to work specifically to maintain insurance, or seeking other sources of health insurance such as COBRA or disability income. Thus, the themes emerging from this analysis confirm the existing framework.

### Novel Addition to Financial Toxicity Framework

Patient knowledge and expectations related to treatment costs and burden were identified as a novel recurring theme that did not fit into the pre-existing financial toxicity framework and significantly affected participants' experiences. Expectations affected *both* objective financial burden and subjective financial distress and thus patients' experience of financial toxicity.

There was a substantial mismatch between patients' expectations of what would occur during treatment, both in terms of timeline (length of expected treatment) and ancillary costs (such as out-of-pocket costs or costs related to

supportive items) that led to inefficient choices, increasing participants' objective financial burden. This included actions such as not planning to be off from work for an extended period and expecting that work-related income would return to baseline levels sooner than actually occurred, or not expecting that costs from treatment would meet insurance deductibles sooner than expected.

Expectations held by participants affected not only objective burdens as above but also subjective financial distress experienced (Fig 1). The psychosocial component of the subjective domain was frequently noted as affected by emotions, primarily surprise, related to uncertainty of amount of treatment, and ancillary items needed during treatment. The coping behaviors that were needed to get through treatment were also unexpected by many participants, and the material conditions at times represented a stark contrast from daily lifestyle before cancer diagnosis.

Participants explicitly stated that having better managed expectations about financial burdens would have resulted in better preparation, both for the objective burdens of cancer treatment by changing expectations for work and savings needed, and for the subjective distress by preparing patients for the emotional toll and behavioral and material changes in lifestyle during treatment. Better alignment of expectations and reality could improve financial toxicity:

Had I known about the fact that it could get costly [it would have been helpful]. Fortunately for me, I was able to get health insurance, but had I known about the fact that it can be costly—not so much for the medical supplies, but it can be costly because you're going to be laid up for a long period of time, and you're not going to be able to physically do the things that you were able to do prior to the diagnosis and prior to the surgery... I could have prepared better, or at least have had a savings account or had some kind of a cancer plan in place...

**TABLE 1.** Confirmation of Financial Toxicity Framework by Witte et al and Addition to the Framework Identified by This Study

| Theme                         | Domain                | Definition  | Exemplary Quotations <sup>a</sup>  |
|-------------------------------|-----------------------|---|--|
| Financial toxicity            | NA                    | The synergistic stress of the impact of a cancer diagnosis on objective financial burden along with subjective financial distress that creates the experience of financial toxicity | <p>I think that's the hardest thing for a cancer patient—for me, wasn't the treatments themselves. It was the stress and the burden of the financial hardship that you go through, the loss of losing your hair and losing your breasts and your eyelashes, and feeling like you've lost your identity. Then the financial burden on top of all of it is unbelievably stressful. You feel like it's never going to end or that you see the light at the end of the tunnel. (52-year-old, White, non-college-educated woman)</p> <p>...to have that stress all while you're trying to just to get through and survive, it really hinders the healing process. You lay awake at night and you're like, How am I going to do this? How am I going to feed myself? How am I going to make sure that I have what I need and that I get the treatments I need and see the doctors I need and get the medications I need and things like that? (31-year-old, White, non-college-educated woman)</p> |
| Objective financial burden    | Direct costs          | Direct, measurable costs related to cancer treatment  | <p>I was totally naive about it. I didn't even really think about the cost of care as far as my cancer care goes with copays. [...] They're a specialty for my insurance, so they're even more than regular copays. Each ultrasound, doctor's visit, chemo visit, nurse practitioner visit, and nonstress tests, those were all \$30 each. It just didn't even dawn on me how quickly all of that adds up when you're going into [redacted] on a weekly. I would have like two or three appointments a week. That's 90 bucks. Then on top of it, it's gas. You're there all day, so you need food to eat and parking. (40-year-old, White, college-educated woman)</p>   |
|                               | Indirect costs        | Indirect costs related to cancer treatment, such as income loss   | <p>I was put on six months leave of absence from my job, which really hurt me—devastated me financially. (50-year-old, race unknown, some college)</p> <p>My mother-in-law and my father-in-law are both retired. They actually care for our little one. They didn't have to take any time off from that. I know some of the other family members had to help out, juggle around schedules to make sure that we had childcare and somebody to help me out... (39-year-old, Asian, college-educated woman)</p>  |
| Subjective financial distress | Material conditions   | Material goods important to patients' day to day lives that were affected by cancer treatment and increased subjective distress. Specific areas included housing and transportation | <p>I was too sick to get out of bed most days so it was hard to—I think my biggest stress was making the mortgage payment and the car and the car insurance because those were top priority but still have enough to be able to get groceries and gas in the cars and that sort of thing. (43-year-old, White, college-educated woman)</p>   |
|                               | Psychosocial response | Psychosocial manifestations of financial distress   | <p>I wanted to stress the emotional and physical toll that it has a person's body. Again, like I said, the professionals can tell you what the side effects are. That's physical. They don't really know about the emotional part, and of course, that depends on the individual and how they handle things. (68-year-old, Black, college-educated woman)</p>  |
|                               | Coping behaviors      | The behaviors and coping strategies used to mitigate financial distress, which include support seeking, coping lifestyle, and coping care   | <p>We had to ask for help a lot. My mom really helped and really had to pull family in to help as best I could. My mom's job, they were so nice. They did a fundraiser for me. That helped us get through a bit. Yeah, people brought us groceries and food. By other people helping bring some of those things in and having that community around to help is what enabled us to take care of some of the things. Some of those other basic needs. (28-year-old, Black, college-educated woman)</p>   |

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**TABLE 1.** Confirmation of Financial Toxicity Framework by Witte et al and Addition to the Framework Identified by This Study (continued)

| Theme                  | Domain       | Definition  | Exemplary Quotations <sup>a</sup>  |
|------------------------|--------------|---|--|
| Novel theme identified | Expectations | Patients endorsed uncertainty related to treatment that affected financial planning and subsequently increased both objective and subjective financial distress | <p>Had I known about the fact that it could get costly [it would have been helpful]. Fortunately for me, I was able to get health insurance, but had I known about the fact that it can be costly—not so much for the medical supplies, but it can be costly because you’re going to be laid up for a long period of time, and you’re not going to be able to physically do the things that you were able to do prior to the diagnosis and prior to the surgery... I could have prepared better, or at least have had a savings account or had some kind of a cancer plan in place... (51-year-old, Black, college-educated woman)</p> <p>You know, honestly, I had no idea. I think I had sticker shock every time I saw, though. Every time I saw how much anything was. Yeah, I think honestly, I didn’t really know how much things were going to cost. (28-year-old, Black, college-educated woman)</p> <p>I honestly thought this would be really quick. I didn’t think anything. I knew I would be off work. I figured I’d probably only be off work for may be three or four months. [...] it’s like a domino effect. One thing happens, another thing happens, another thing happens. What really turned out is this, me going back to work since 2017 twice a year. It’s been three years of me just going back to work for a week or two just to reinstate my insurance. (31-year-old, Black, non-college-educated woman)</p> <p>They’re just more miscellaneous expenses that one doesn’t expect when you get diagnosed with cancer that later you realize, oh, I need this. (49-year-old, Hispanic, non-college-educated woman)</p> |

Abbreviation: NA, not available.

<sup>a</sup>Demographic information presented at the end of each quote. Age indicates age at the time of application for philanthropic assistance.

### Gaps Identified

Participants identified four areas of concern (or gaps in support) that led to subjective or objective financial distress: incorrect treatment expectations, lack of provider conversation, inability to identify resources, and lack of social support. Participant comments and suggestions also pointed to ways to mitigate financial toxicity (Table 2).

As mentioned above, participants wished they had been better prepared for the timing and financial implications of treatment. They highlighted the importance of exploring ways to manage cancer treatment expectations such as through decision aids or access to allied health professions (eg, social workers and financial advisors) to help mitigate financial toxicity.

Participants indicated that they had few or no conversations with their doctors regarding the impact of treatment on finances or the financial burdens patients faced from treatment: "...I can't remember any of my oncologists saying, 'Hey, are you financially stable?' They just wanted to know the physical and mental part..." Participants largely noted that they wished that the potential financial implications of treatment had been discussed early on in their treatment course to better plan for the financial burdens. A

small number of participants did note that this could be overwhelming early on when patients are first diagnosed with breast cancer.

Participants noted a significant challenge with identifying resources for financial assistance during treatment, with many participants turning to sources of information outside of the health care system (such as internet searches and charitable organizations). Participants desired more access to allied health providers, such as social workers or nurse navigators, for assistance in identifying resources. However, participants also noted that allied health providers in many health systems are overwhelmed with the number of patients that require assistance, identifying a key area of need: "The social workers at those cancer places, they're so bombarded by different people that they don't have that time they need with a individual sometimes."

Finally, participants noted challenges in navigating the health care system and identified support groups as an important source of emotional assistance during treatment, advising patients to seek similar sources of support. Many participants reached out to various nonprofit and charitable organizations for support, but many noted difficulties in



**TABLE 2.** Gaps Identified and Correlation With Patient Advice for Mitigating Financial Toxicity

| Gaps Identified  | Participant Advice for Patients   | Exemplary Quotations <sup>a</sup>   | Possible Strategies for Mitigation That Merit Future Research   |
|--|---|---|---|
| Incorrect expectations about how treatment would affect finances | Request clarity, as much as possible, on expected costs and timeline                              | <p>I wish I would have known what kind of money I would have been expected to pay. With that, that could have been something I could have been saving for. If I would have known something like that and had savings for medical expenses, then that's something that would have been a big help. (41-year-old, Black, college-educated woman)</p> <p>I definitely wish they let me know what I was in for, what to expect... (48-year-old, White, non-college-educated woman)</p>  | Explore ways to manage cancer treatment expectations through decision aids or recruitment of allied health professionals to better prepare patients                         |
| Lack of provider conversations about finances                    | Discuss early that finances can be an issue during treatment                                      | <p>With my general providers, I don't think it was ever really brought up at all. When I first was diagnosed, I would go in and see my breast surgeon and my team, and they would talk to me about the treatment aspects of it. I don't really think that anything was really mentioned about the cost. (39-year-old, Asian, college-educated woman)</p> <p>Right from the very beginning, absolutely, [is the right time to mention financial strain related to treatment]. As soon as you're diagnosed and you go in there and they give you that packet saying this is what you have, this is what we're going to be doing next, they should give you the information to say, 'I know this is overwhelming, but here's some other information just for you to have. You may not need it, but just in case. We give it to everybody.' Let them have it because it's better to have it early than too late. The sooner the better, I think. (43-year-old, White, college-educated woman)</p> | Investigate ways to optimize provider conversations and identify value-concordant ways to better inform patients of financial implications of treatment at the optimal time |
| Inability to identify financial resources                        | Seek out allied health provider to find resources for assistance                                  | <p>The nurse navigator helped so much. I was so glad that he actually—because I was prideful and didn't want to say anything, but I was glad that he pushed me [to get help]. (41-year-old, White, college-educated woman)</p> <p>Well, I wish I had known about [the financial advisor] from the beginning because I didn't find about her until—I probably was halfway through treatment when I found out about her. (31-year-old, Black, non-college-educated)</p>   | Investigate optimal means to deploy allied health professionals, recognizing their important impact on the patient experience   |
|  | Seek out assistance outside of medicine through friends and family or philanthropic organizations | <p>We had to ask for help a lot. My mom really helped and really had to pull family in to help as best I could. (28-year-old, Black, college-educated woman)</p> <p>There's a bunch of different organizations, and they would help with little things. Like one might help with a car insurance bill. I did research for hours on the computer trying to find what organizations were available for me. That's kind of how I made it through the second time [I was diagnosed with cancer]. I even got help from my church. My church was able to help me make mortgage payments for two months so just kind of reaching out. (42-year-old, White, college-educated woman)</p>   | Explore methods to better identify and allocate resources to match patients in need with resources in the community   |

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**TABLE 2.** Gaps Identified and Correlation With Patient Advice for Mitigating Financial Toxicity (continued)

| Gaps Identified                                      | Participant Advice for Patients                              | Exemplary Quotations <sup>a</sup>   | Possible Strategies for Mitigation That Merit Future Research   |
|--|--|---|---|
| Lack of support in navigating the health care system | Find a support group, get help of allied health professional | <p>I think I would...definitely [advise] a group or a Facebook page, a website, or something where they can go to talk with other women who've been through it. I think you learn more when you connect with other women that are going through it or have been through it. [...]<br/>Mainly just let them know there's people out there to help them. (43-year-old, White, college-educated woman)</p> <p>I wish I would have had a buddy system to be matched up with a fellow, another—I mean, like multiple battle buddies that were going through it. With now going through it, I wish it would have been able to where they could have helped with getting a lot of information out with other resources, and just really understanding the process more... (37-year-old, Black, college-educated woman)</p> | Identify, promote, and improve key sources of community support during cancer treatment, as well as investigate optimal means to deploy allied health professionals |

<sup>a</sup>Demographic information presented at the end of each quote. Age indicates age at the time of application for philanthropic assistance.

finding such sources of assistance and used support groups to identify philanthropic organizations.

## DISCUSSION

This unique study of patients who sought financial support from a fund intended to support women experiencing financial toxicity after breast cancer diagnosis enhances previous understanding. It complements an existing framework of financial toxicity by suggesting the addition of treatment expectations as an important novel theme affecting financial toxicity in participants we interviewed. We identify four qualitative gaps: treatment expectations, provider conversations, identification of resources, and support-finding.

Strategies for mitigation of the gaps identified are provided in Table 2. Ensuring alignment of patient expectations with experiences may allow patients to prepare materially or psychologically for the financial implications of treatment. Improving patient-provider conversations by identifying values-concordant ways to inform patients of financial implications at the optimal time appears needed, especially as a minority of participants endorsed that information too early could be overwhelming. To help patients identify assistance, optimizing resource identification and allocation is needed, such as providing more funding for and hiring of allied health professionals, or training and providing protected time for doctors to discuss finances. Resources will need to be focused to ensure that utilization of additional providers does not inadvertently increase financial toxicity. Challenges in navigating the health care system may be mitigated through identifying key sources of community support during treatment.

Financial toxicity is a complex and multifactorial phenomenon. Establishment of a framework to understand the

multiple factors involved, such as the one devised by Witte et al,<sup>9</sup> offers a means to navigate this complexity and attempt to minimize the impact of financial toxicity. Strengths of this framework include its acknowledgment of the multitude of factors that affect financial toxicity, including not only measurable objective burdens of direct and indirect costs but also subjective components that affect the experience. We confirm the applicability of this framework through the qualitative findings described here. Further investigation of the applicability of this framework may assess correlations between components, such as how objective and subjective costs may each amplify each other; for example, greater psychosocial distress may increase the likelihood of missing work.

As financial toxicity has been increasingly recognized as a complication of treatment, efforts to characterize and measure it have emerged. Patient-reported outcomes such as the COmprehensive Score for financial Toxicity,<sup>14</sup> Incharge Financial Distress/Financial Well-Being scale,<sup>15</sup> or Economic Strain and Resilience in Cancer<sup>16,17</sup> explore financial worries and offer a means to quantitatively measure financial experiences. Further development and deployment of such measures will promote better understanding of the prevalence of financial toxicity, and measures can be informed by the updated framework in this study. Future efforts may include identifying how managing expectations may benefit both patients who are better able to financially prepare for impending crisis and those who would benefit from reduction in ambiguity, which may lessen psychosocial distress.

Financial toxicity can occur across all income and education levels, as evidenced by this study, which included 44% of participants earning over \$50,000 USD per year and 66% with a bachelor's degree or higher. However,

previous studies have shown that some groups experience financial toxicity at a higher rate than others. Patients in lower socioeconomic strata and racial and/or ethnic minorities are more likely to report financial toxicity.<sup>18</sup> One of the strengths of this study was its purposeful inclusion of a diverse population. Understanding the synergistic impacts of financial toxicity in conjunction with wider issues of systemic racism is needed to optimize mitigation efforts.

The complexity of financial toxicity creates challenges in knowing how to intervene and where to direct research efforts. Strategies for mitigation may span from organizational efforts that aim at the health care system, to interpersonal efforts aimed at patient-provider interactions, to individual efforts seeking to arm patients with knowledge that can mitigate financial toxicity.<sup>19</sup> Prior research at the interpersonal level has suggested that patients have preferences regarding when they would like to have cost-of-care conversations,<sup>20</sup> and improving patient-provider communication may be a mitigation target.<sup>21</sup>

We add to the existing literature with explicit advice from the perspective of patients themselves on what they wish had been done differently while they were experiencing financial toxicity. This provides a unique lens to identify gaps to direct future research efforts. These gaps direct attention toward improving interpersonal efforts, optimizing conversations with providers and other allied health professionals. They also identify targets at the individual level, including methods to better allocate resources for patients to identify assistance and support. Additional research into mitigating financial toxicity at the organizational is needed as well. This may include efforts to optimize treatment such as hypofractionated radiotherapy, reducing the length of treatment needed, or identifying optimal ways to omit chemotherapy without compromising care or treatment efficacy<sup>22</sup> as the receipt of chemotherapy is associated with higher rates of being unable to work after treatment,<sup>23</sup> although it is unclear if this association is because of chemotherapy side effects or

due to lack of the ability to fully control for disease severity in studies demonstrating that association.

Limitations of this study include its small sample size, although offset by the rich narrative evidence collected. Data were collected from a purposefully diverse sample following rigorous qualitative methods and interviews continued until thematic saturation. Thus, this work provides hypothesis-generating data that may be validated in future studies using complementary quantitative analyses. It is important to note that the findings may not generalize to all patients experiencing financial toxicity after breast cancer diagnosis. Our participants were those who identified an organization to provide assistance, and it is unclear how populations who were unable to identify resources for aid might be different. Further identification and exploration of marginalized groups, who may lack even the resources necessary to identify organizations such as the Pink Fund, should be the focus of future work. Participants self-reported all demographic and oncologic information without verification by medical professionals. Participants received a small monetary incentive, which may have potentially influenced the decision to participate. Finally, participants in this study were interviewed up to 3 years after undergoing cancer treatment, which increases potential recall bias, and these findings need to be validated in patients actively experiencing financial toxicity.

In conclusion, this qualitative study confirms an existing framework for understanding financial toxicity that incorporates both objective burdens and subjective distress. We identify treatment expectations as a novel theme affecting both of these components of financial toxicity. Four gaps are identified that illuminate specific aspects of financial toxicity: treatment expectations, provider conversations, identification of resources, and support-finding. Mitigating patients' financial toxicity is an important unmet need in optimizing cancer treatment, and future research focusing on these areas is needed.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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**AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST****Financial Toxicity During Breast Cancer Treatment: A Qualitative Analysis to Inform Strategies for Mitigation**

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**Susan Goold**

**Patents, Royalties, Other Intellectual Property:** A simulation exercise (CHAT) I coinvented, when others pay to use it, results in royalties to me, my coinventor, and our institutions. My own royalty receipts in the past 2 years have been less than \$1,000 US dollars

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**APPENDIX**

**TABLE A1.** Participant Characteristics<sup>a</sup>

| Characteristic                        | All Available <sup>b</sup> |       | Interviewed <sup>c</sup> |       | P    |
|---------------------------------------|----------------------------|-------|--------------------------|-------|------|
|                                       | n                          | %     | n                        | %     |      |
| Total                                 | 78                         | 100.0 | 32                       | 100.0 |      |
| Age (mean in years, SD)               | 46.9<br>(9.9)              |       | 45.9<br>(11.8)           |       | .650 |
| Race                                  |                            |       |                          |       | .369 |
| White                                 | 54                         | 69.2  | 18                       | 58.1  |      |
| Black                                 | 11                         | 14.1  | 8                        | 25.8  |      |
| Hispanic                              | 5                          | 6.4   | 3                        | 9.7   |      |
| Asian                                 | 2                          | 2.6   | 2                        | 6.5   |      |
| Not reported                          | 6                          | 7.7   | 1                        | 3.1   |      |
| Education level                       |                            |       |                          |       | .871 |
| Less than bachelor's degree           | 23                         | 29.5  | 11                       | 34.3  |      |
| Bachelor's degree                     | 45                         | 57.7  | 18                       | 56.3  |      |
| More than bachelor's degree           | 9                          | 11.5  | 3                        | 9.4   |      |
| Not reported                          | 1                          | 1.3   | 0                        | 0.0   |      |
| Adjusted gross income, USD            |                            |       |                          |       | .979 |
| < \$25,000                            | 18                         | 23.1  | 8                        | 25.0  |      |
| > \$25,000-\$50,000                   | 23                         | 29.5  | 10                       | 31.3  |      |
| > \$50,000-\$75,000                   | 17                         | 21.8  | 7                        | 21.9  |      |
| > \$75,000                            | 20                         | 25.6  | 7                        | 21.9  |      |
| Sole breadwinner                      |                            |       |                          |       | .528 |
| Yes                                   | 47                         | 60.3  | 17                       | 53.1  |      |
| No                                    | 31                         | 39.7  | 15                       | 46.9  |      |
| Dependents                            |                            |       |                          |       | .292 |
| Yes                                   | 50                         | 64.1  | 17                       | 53.1  |      |
| No                                    | 28                         | 35.9  | 15                       | 46.9  |      |
| Employment status before <sup>d</sup> |                            |       |                          |       | .567 |
| Full-time                             | 60                         | 76.9  | 24                       | 75.0  |      |
| Part-time                             | 16                         | 20.5  | 5                        | 18.8  |      |
| Self-employed                         | 2                          | 2.6   | 2                        | 6.3   |      |
| Employment status after               |                            |       |                          |       | .472 |
| Full-time                             | 3                          | 3.8   | 1                        | 3.1   |      |
| Part-time                             | 18                         | 23.1  | 6                        | 18.8  |      |
| Self-employed                         | 1                          | 1.3   | 1                        | 3.1   |      |
| Disability                            | 21                         | 26.9  | 8                        | 25.0  |      |
| FMLA or sick leave                    | 22                         | 28.2  | 19                       | 31.3  |      |
| Unemployment                          | 13                         | 16.7  | 6                        | 18.8  |      |
| Health insurance status               |                            |       |                          |       | .939 |
| Employer                              | 22                         | 28.2  | 11                       | 34.4  |      |

(continued in next column)

**TABLE A1.** Participant Characteristics<sup>a</sup> (continued)

| Characteristic            | All Available <sup>b</sup> |      | Interviewed <sup>c</sup> |      | P |
|---------------------------|----------------------------|------|--------------------------|------|---|
|                           | n                          | %    | n                        | %    |   |
| Private                   | 3                          | 3.8  | 1                        | 3.1  |   |
| Medicaid or Medicare      | 9                          | 11.5 | 4                        | 12.5 |   |
| Not reported <sup>e</sup> | 44                         | 56.4 | 16                       | 50.0 |   |

Abbreviations: FMLA, Family and Medical Leave Act; SD, standard deviation; USD, US dollars.

<sup>a</sup>Information was collected at the time of application for philanthropic assistance while experiencing financial toxicity, not at the time of interview.

<sup>b</sup>A total of 116 consents were received; 38 of these had online accounts that were not accessed as those participants were not needed to achieve the interview sample. Characteristics of the 78 individuals who consented to participate and whose paper charts were reviewed to select interviewees are provided to demonstrate broader characteristics of those receiving funding from the Pink Fund.

<sup>c</sup>Participants were purposefully sampled for the selection of qualitative interviews, including deliberate oversampling of racial and ethnic minorities.

<sup>d</sup>Employment status self-reported as before and after diagnosis.

<sup>e</sup>Insurance categories were designated at the time of application for philanthropic assistance; no designation for uninsured was provided, and those who are uninsured assumed to be included in this not reported section.