

Financial Toxicity of Breast Cancer Care: The Patient Perspective through Surveys and Interviews

Background

- Economic burden of cancer care is an emerging concern in the United States
- The potential financial toxicity of breast cancer care at the patient level remains poorly understood.
- As much as 47% of people with cancer in the United States report “catastrophic” levels of financial hardship
- Patients with financial hardships are four times less likely to rate their quality of life as excellent or very good

This study aims to:

Characterize the scope of the contributors to financial distress on breast cancer patients and the resources utilized to address them

Methods

- Retrospectively evaluated adult female patients diagnosed with invasive breast cancer or ductal carcinoma in situ between 2014 and 2019 at a single institution.
- Those who enrolled in copay assistance or indicated financial concerns on an intake distress screen were provided a web-based survey assessing financial changes, resources used, and financial engagement with providers.
- A mixed methods design was used to investigate financial distress patients faced
- For the quantitative component, a web-based surveys were delivered to patients meeting criteria via Research Electronic Data Capture.
- For the qualitative portion we performed semi-structured interviews to further explore sources of financial distress which were analyzed by two researchers using grounded-theory methodology.

Results

Fig 1. Distribution of Financial Distress Scores.

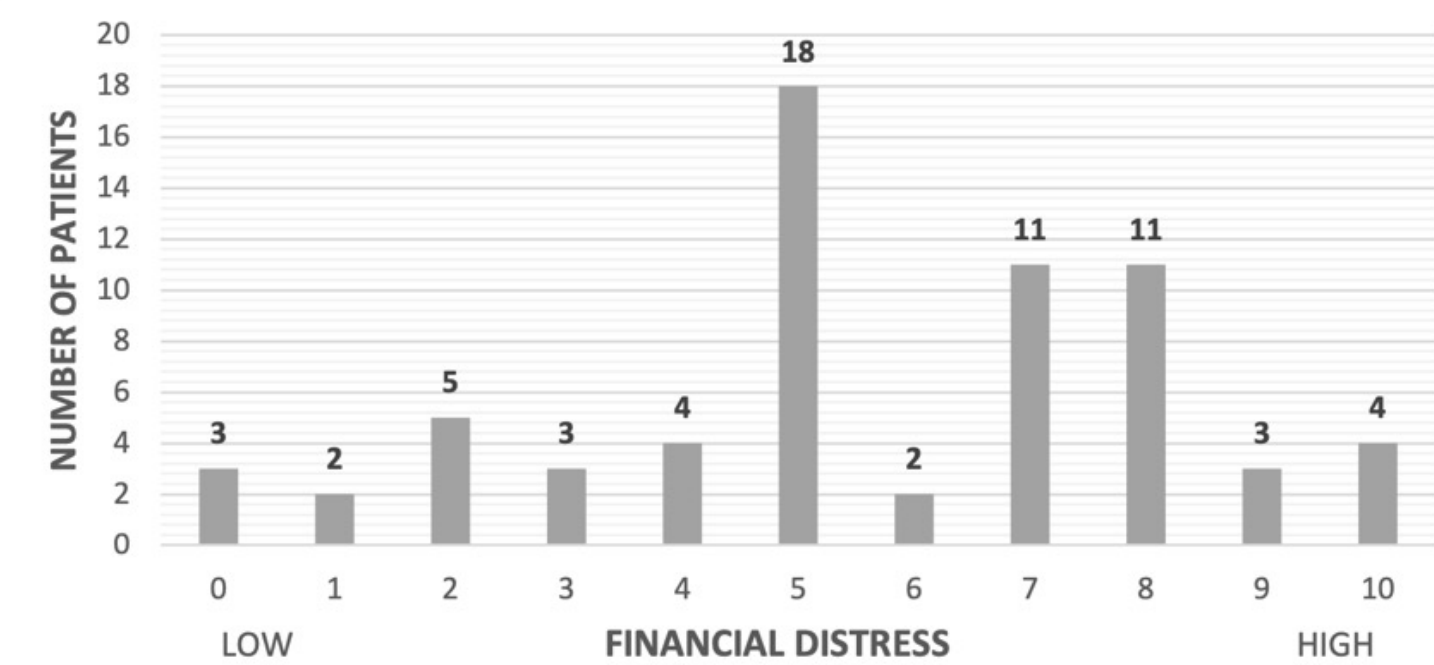
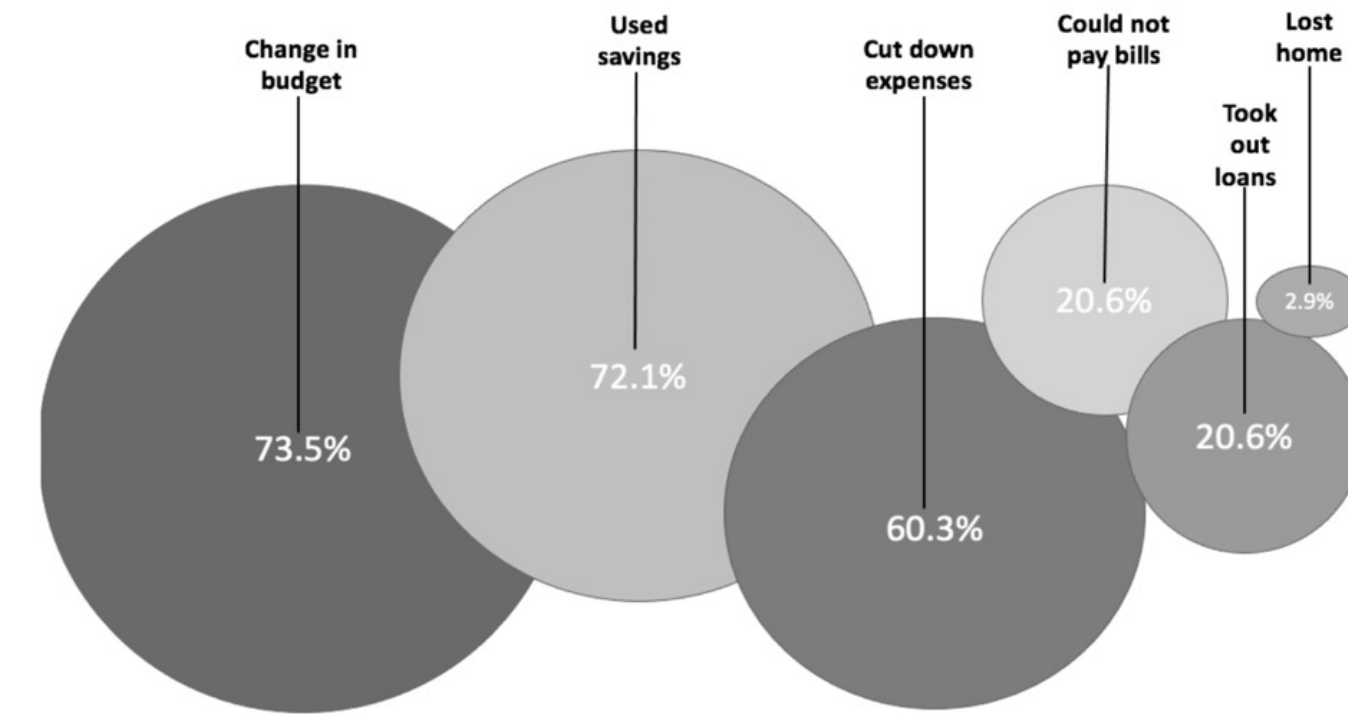


Fig 2. Financial Adaptations Due to Breast Cancer Diagnosis.



- 68 patients completed the online survey, 15 of the 68 also participated in semi-structured phone interviews.
- On the online survey 74% of participants endorsed a financial distress score ≥ 5 on a scale of 0-10. 74% changed their budget, 72% used their savings, and 60% cut down on spending.
- 40% used resources such as financial counseling or financial assistance.
- Interviews revealed three major contributors to financial distress: [1] unexpected medical and non-medical expenses, [2] lost revenue from missed work, and [3] altered budgeting.

Table 3. Semi-Structured Interview Codes and Sample Quotes

Code	Subcode	Patient example:
Unexpected Costs	Insurance	<ul style="list-style-type: none"> • “We had to meet different deductibles, so there’s just been a lot of outgoing money to medical bills that was not able to be used for anything else.” • “The surgeon used a certain anesthesiologist, and they suddenly were out of my network like two days before surgery.” • “I see an out-of-pocket psychiatrist... I’m paying like \$200 to \$300 per session and then during chemo I was going maybe like every two weeks.”
	High Deductibles	
	Billing Errors	
	Out of Network Providers	
	Out-of-Pocket Medical Costs	
Lost Revenue	Physical Therapy	<ul style="list-style-type: none"> • “As far as financials go, the effects of the hole that I dug, because of not getting my full income...it’s going to take a long time to get out of it. So I still have that to face. It’s going to take years.” • “So you’re sort of damned if you do, damned if you don’t. If you don’t work during your treatment, you know, you don’t have resources, and if you earn too much or there’s another source of income, then you’re penalized for it.”
	Mental Health	
	Pain Management	
	Out-of-Pocket Non-medical Costs	
	Travel and Parking	
Altered Budget	Lodging	<ul style="list-style-type: none"> • “You minimize expenses entirely because you have to prioritize your health...treatments and going to doctor’s appointments instead of working.” • In order to pay the bills... to pay the deductible and the out of pocket, I had to take money out of my retirement fund. • “I had to miss life. I had to miss things with my kids and events.”
	Use of Savings	
	Early Retirement Withdrawal	
Patient Recommendations	Limited Spending on Leisure Activities	<ul style="list-style-type: none"> • “It would be helpful to have somebody check-in...wouldn’t it be amazing if every patient had...like the equivalent of a project manager?” • “There are a lot of resources, but when you have insurance you just feel like you don’t qualify for anything. And it would be nice...to get a packet upfront of resources.” • “I think cancer patients get bombarded with information in the beginning.”
	Check-ins	
	Easier to navigate/ Package resources	

Conclusions

- Many breast cancer patients experience significant financial distress, and do not have access to the resources they need.
- Patients expressed that they would best be served by having access to easy-to-navigate financial resources made available near the time of diagnosis with additional follow up as needed.
- This study highlights the need for financial transparency, supportive financial services, and counseling at the time of diagnosis, throughout treatment and beyond.

Future Directions

- We plan to evaluate distress longitudinally in order to be able to provide resources as needed throughout treatment.
- We aim to utilize our nurse navigators to administer the distress screening tool throughout breast cancer treatment to better identify patients with worsening or new distress so we can provide proactive, individualized supportive services

Selected References

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 Fenn, K.M., et al., Impact of financial burden of cancer on survivors’ quality of life. *J Oncol Pract*, 2014. 10(5): p. 332-8.

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