Three Studies Reveal Cancer Patients Face Serious Financial Hardship, Do Not Discuss Treatment Costs With Physicians

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ASCO Perspective

“As oncologists, we see the burden of high treatment costs on our patients every day. Many of them are skimping on needed medication, liquidating their savings, and taking other extreme measures to control costs,” said Timothy D. Gilligan, MD, MSc, FASCO, ASCO expert and chair of the Quality Care Symposium News Planning Team. “These studies reaffirm the important role we can play in initiating and guiding conversations about cost of cancer care with our patients so that together we can make the best possible treatment decisions.”

ALEXANDRIA, Va. – New studies released today reveal the financial difficulties that people living with cancer currently face. The research looks at financial distress, also known as “financial toxicity,” among patients with metastatic breast cancer and older patients, as well as conversations about cost of care that women with breast cancer are having with their physicians. Authors will present their findings at the American Society of Clinical Oncology’s (ASCO) upcoming Quality Care Symposium, taking place September 28–29, in at the JW Marriott Phoenix Desert Ridge in Phoenix.

Following is a summary of each of the three major studies on financial toxicity.

Nationwide Survey Reveals Metastatic Breast Cancer Patients Face Major Financial Stress due to Treatment Costs

This summary includes updated data not in the abstract.

A new nationwide analysis of more than 1,000 people living with metastatic breast cancer from 41 states reveals significant cancer-related financial burden known as “financial toxicity,” particularly for
uninsured patients.

“While providers have little control over the cost of treatment, they should monitor the burden and stress that it can impose on their patients as a component of the care they provide,” said lead author Stephanie B. Wheeler, PhD, MPH, member of the University of North Carolina (UNC) Lineberger Comprehensive Cancer Center and an associate professor in the UNC Gillings School of Global Public Health. “Clinicians should be attentive to how financial toxicity may be differentially experienced by patients with metastatic disease where treatment failure and rapidly changing treatment plans may add complexity and stress. Initiating conversations about treatment costs can be an important way for providers to help monitor how patients are faring and discuss solutions to mitigate financial distress.”

The survey found that of the 1,054 study participants, approximately one-third were uninsured. Uninsured patients with metastatic cancer were more likely to identify as a racial/ethnic minority, have lower income, and work full time. Compared to insured respondents, uninsured respondents more often reported refusing or delaying treatment due to cost (96% vs. 36%) and more often reported that they were contacted by a collections agency (92% vs. 30%). In addition, uninsured patients more often reported not being able to meet monthly expenses, not being satisfied with their financial situation, and not being in control of their financial situation.

Despite these very real cancer-related financial hardships experienced by uninsured patients, insured respondents reported having higher cost-related emotional distress, including being “quite a bit” or “very” stressed about not knowing cancer costs (41% vs. 24%), and a greater amount of financial stress on their families due to their cancer (36% vs. 19%).

“Our study shows that the financial toxicity of cancer is alarmingly high in many metastatic breast cancer patients and that having health insurance doesn’t protect patients from the psychosocial impact of high cancer costs,” said Dr. Wheeler. “High co-insurance and deductibles mean that many patients are still shouldering an enormous financial burden out-of-pocket and feeling anxious about what it will mean for their own and their families’ finances and financial legacy.”

Researchers fielded an online survey to metastatic breast cancer patients over a 14-day period by partnering with the Metastatic Breast Cancer Network and using the software tool Qualtrics. The national survey took approximately 20 minutes to complete and included questions related to sociodemographics, health insurance status, cost-related communication with providers, post-treatment financial burden, financial coping strategies, and emotional well-being. Patients were offered a $10 Amazon gift card for participating.

This study suggests that people with metastatic cancer potentially face a substantial financial
burden, and it can help to guide future interventions to screen for, monitor, and alleviate the financial burden associated with cancer care. Health insurance expansion is a necessary but insufficient strategy to address this financial burden; additional interventions are needed, as well as serious consideration of the value of some high-priced, low-yield therapies in the metastatic setting.

**Nearly One in Five Older Patients With Advanced Cancer Face Serious Financial Hardship**

*This summary includes updated data not in the abstract.*

According to new research from the University of Rochester, 18% of older patients with advanced cancer are experiencing financial difficulties due to the cost of their treatment that are negatively affecting their care, quality of life, and mental health. The multi-center study of 542 patients ages 70-96 from across the United States examined this under-studied population and the impact of “financial toxicity” on anxiety, depression, and other factors related to quality of life.

“The majority of patients with cancer are older, which means they’re living on restricted incomes and often don’t want to burden either their caregivers or kids,” said senior author Supriya Gupta Mohile, MD, MS, the Wehrheim Professor in the University of Rochester Medical Center’s Wilmot Cancer Institute. “Their spouses may also have their own health care needs, and their finances have to cover many expenses other than cancer care, including food, medications, and housing. This is a vulnerable group we haven’t paid enough attention to as a society but really need to, especially as the older population continues to grow.”

Because financial toxicity is a subjective measure without a standard definition, the authors developed an easy-to-use screening measure for patients with a cancer diagnosis based on the current literature and comprised of three basic questions. Patients were categorized as experiencing financial toxicity if they answered yes to any one of the following questions: (1) Have you ever delayed medications due to cost?; (2) Have you ever had insufficient income in a typical month for food or housing?; and (3) Have you ever had insufficient income in a typical month for other basic needs?

“We wanted to create a screening tool that wasn’t too time consuming or difficult for patients to fill out so that we could identify as many patients who are financially distressed as possible,” said lead author Asad Arastu, MSc, a medical student at the University of Rochester. “This study shows that an alarming number of older cancer patients report delaying taking their medications or are unable to afford basic needs such as food and housing.”

Patients experiencing financial toxicity had a higher prevalence of severe anxiety (18% vs. 7%), a higher prevalence of depression (27% vs. 21%), and a higher prevalence of poor quality of life
(41% vs. 22%) than patients who do not report financial hardship. On average, patients experiencing financial toxicity scored higher on the Generalized Anxiety Disorder Scale-7—a widely used standard measurement tool for generalized anxiety disorder—higher on the Geriatric Depression Scale (indicating greater depression severity), and lower on the Functional Assessment of Cancer Therapy Scale-General (indicating lower quality of life).

Through baseline visits, the authors found that for patients who met the criteria for experiencing financial toxicity, cost issues were only brought up about half the time by the oncologists. The authors developed this screening tool as a way to prompt oncologists to ask their patients questions, which would create an opening to connect the ones who are experiencing financial hardship with a social worker or financial specialist.

The authors see the next step as increasing interventions to help patients and caregivers through standardized support to help older patients with cancer find all the available resources that can help them allay costs.

**Few Women With Breast Cancer Discuss Costs With Physicians Before Beginning Treatment**

*This summary includes updated data not in the abstract*

Findings from a new study reveal that while many women with breast cancer experience significant financial burden and most prefer to discuss the cost of their cancer care before beginning treatment, few are having conversations about treatment costs with their cancer care teams.

"In an era of rising cancer treatment costs, we don’t routinely discuss the financial implications of cancer care with women embarking on treatment," said lead study author Rachel Adams Greenup, MD, MPH, Director of the Breast Fellowship and Associate Professor of Surgery and Population Health Sciences at Duke University Medical Center. “Many treatment options for breast cancer are comparable in their effectiveness, but their costs can vary. As women consider various cancer treatment options, information about costs could help them make more informed decisions about which therapies are best for them."

In the study, 607 women with a history of breast cancer (stage 0-III) completed an 88-question electronic survey on their experiences with breast cancer treatment costs and their preferences for cost transparency. The majority of women in the study had either private insurance (70%) or Medicare (25%) and reported a higher annual household income (>$74,000) than the general U.S. population. The survey found that 43% of women reported considering costs when making treatment decisions, and 40% preferred that their doctors consider costs when providing medical
recommendations. Though 79% of women surveyed preferred to understand costs prior to starting treatment, 78% of them never discussed costs with their cancer care teams.

The survey also asked women to characterize their financial burden using one of five categories: none, slight, somewhat, significant, and catastrophic. Approximately 15% of women reported significant to catastrophic financial burden. Patients’ median out-of-pocket (OOP) costs were $3,500; 25% of women reported OOP costs greater than or equal to $8,000; 10% reported OOP costs greater than or equal to $18,000; and 5% reported OOP costs greater than or equal to $30,000.

Women who had more extensive surgery or were diagnosed with more advanced stages of breast cancer were more likely to report financial harm. Women who were older, further out from breast cancer diagnosis, had higher household income, or had a greater percentage of their care covered by insurance were less likely to experience financial harm. Women who discussed costs during their medical visit were also more likely to report financial harm, which, according to the study’s authors, may be because patients who proactively raised the issue with their providers faced greater financial vulnerability. The 16% of women who reported discussing costs with their cancer care teams were more likely to have stage II or III breast cancer (56% vs. 40%), were less likely to be depressed (24% vs. 30%), and had less insurance coverage compared to those who did not have discussions about treatment costs.

One limitation of the study is that the majority of women who participated in the survey were well-insured, well-educated, and white. According to the study’s authors, this suggests that women with breast cancer in the United States may experience even greater risk of financial harm than the study participants.

This year’s symposium will include more than 340 abstracts focusing on efforts to improve the quality of care for patients with cancer. On-site facilities for reporters will include a working newsroom and access to leading experts in quality care.

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- Financial Considerations
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