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The financial costs of metastatic breast cancer and the decisions patients make to cope with costs: Findings from the Cancer Experience Registry

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Introduction

- The Cancer Support Community (CSC) represents a global network of nonprofit, community-based organizations that provide professionally led support and education to cancer patients and their families.
- An estimated 155,000 people are living with metastatic breast cancer (MBC) in the United States.
- With new developments in treatment, people are living longer with MBC and have to manage greater financial burden related to care, including copays and out of pocket costs.
- This research sought to explore the MBC patient experience in managing the costs of care.

Methods

- The CSC's Cancer Experience Registry is an online initiative designed to collect patient reported data and raise awareness about the psychosocial impact of cancer.
- Currently, over 7,400 cancer patients and survivors have enrolled in the Cancer Experience Registry.
- Since March 2013, 968 people living with MBC registered with the Cancer Experience Registry and 599 of these MBC registrants completed the questionnaire about the financial costs of MBC.
- The present analysis includes 496 US based registrants with completed data.

CANCER EXPERIENCE REGISTRY
METASTATIC BREAST CANCER

- CSC established the Cancer Experience Registry to track the immediate, ongoing and changing social and emotional experiences of cancer survivors.
- The Registry reaches cancer patients and survivors across the country and engages them to share their voices about issues that matter to them.
- Through the Cancer Experience Registry we are able to:
  - Collect, analyze and disseminate insights and knowledge toward the goal of improving the lives of those experiencing cancer.
  - Help the nation's health care systems to be more responsive to the needs of cancer survivors.
  - Accelerate and enhance the productivity of research to improve quality outcomes.
- Currently, there are over 7,400 cancer patients and survivors in the Cancer Experience Registry from over 35 countries and representing more than 40 cancer diagnoses.

Anyone who has ever been diagnosed with cancer of any type can join the Cancer Experience Registry at:

www.CancerExperienceRegistry.org

Results

- 38% of registrants report being seriously or very seriously concerned about health insurance or money worries. 46% reported clinically significant levels of stress-related intrusive ideation about the financial cost of care (Impact of Events Scale. Horowitz et al., 1979).
- Registrants reported experiencing a significant burden from MBC related expenses, as shown in Table 1.
- Because of these expenses, registrants have (*list not inclusive*):
  - Foregone vacations, celebrations, and social events (54%)
  - Refinanced their house (13%)
  - Filed for bankruptcy (6%)
  - Downsized their living accommodations (17%)
  - Liquidated their assets (19%)
  - Depleted their savings (41%)
  - Borrowed against or used money from a retirement plan (28%)
  - Cut their grocery expenses (43%)
  - Applied for or used public assistance (15%)
  - Chosen a treatment that is not as effective but costs less (9%)
  - Asked their doctor if there was a less expensive treatment (19%)
  - Tried to negotiate payments with credit companies (24%)
  - Negotiated with service providers to reduce costs (22%)
  - Used pharmaceutical assistance programs (26%)
  - Accepted money from friends or family (40%)
  - Cashed in a life insurance policy early (8%)
- In order to reduce the cost of treating MBC, registrants *often* or *always* postpone seeking psychological counseling or support (34%) and delay follow up on recommendations for complementary treatment such as physical or occupational therapy and nutrition counseling (31%).

Table 1. Patient reported areas of financial burden

Please tell us how much of a burden the following additional expenses cause you. **(0=not at all to 4=very much)**	**n**	**≥ 3 (%)**
Copays for medical treatments (e.g., surgery, chemotherapy, radiation, etc.)	492	46.1
Prescription drugs and over the counter medication (including copays)	492	40.9
Copays for medical appointments or visits	492	39.3
Diagnostics or treatment not covered by insurance	492	39.7
Complementary medicine or alternative therapy (e.g., vitamins, homeopathy)	491	37.9
Travel (e.g., parking, gas)	489	20.6
Medical supplies	489	21.3
Late fees on bills	492	19.6
Counseling and/or therapy	488	19.9

Sample Characteristics *(n=599)*

Characteristic	Proportion
Female	99%
Caucasian	91%
Education ≥ College Degree	69%

Characteristic	Median
Age	56
Time Since MBC Diagnosis	3 years

Conclusions and Future Directions

- MBC places a significant financial burden on patients, which can result in significant distress and in patients taking measures that can significantly impact their quality of life and health outcomes.
- Future implications for research include the development and evaluation of interventions designed to enhance doctor-patient communication and support (e.g., financial counseling) to ensure that the financial cost of MBC does not negatively impact the patient's quality of life, course of cancer care, and health outcomes.

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