Financial Toxicity and Cost-Management Behaviors Among Patients with Myelodysplastic Syndromes

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BACKGROUND

- Financial toxicity (FT) refers to the objective monetary burden and subjective psychological distress that cancer patients face as a result of their care.
- Myelodysplastic syndromes (MDS) are particularly costly, with patients facing an estimated burden of nearly $130,000 in the first two years following diagnosis.

AIMS

To better understand the degree to which MDS patients report:
1) financial toxicity
2) finance-related worries and behaviors, and
3) cost-related medication scrimping

METHODS

- Observational, cross-sectional study
- From Oct 2021-Jun 2022, 112 participants with MDS from the Cancer Support Community’s Cancer Experience Registry® provided sociodemographic and clinical history information and completed:
  – Comprehensive Score for financial toxicity (COST; scores range from 0 to 44, with lower indicating worse financial well-being)
  – Questions regarding finance-related worries, behaviors, and medication scrimping

PARTICIPANTS

112 individuals with MDS

Mean/n SD/%

Age (years) (range 14-93)
M=69.8 SD=11.0 73%

Employment Status

- Employed Full-Time, Part-Time, or Temp.
- Unemployed due to disability or other reason
- Currently in Treatment
- History of Transplant

Race & Ethnicity

- Non-Hispanic White
- Non-Hispanic Asian/Asian American
- Non-Hispanic Black
- Non-Hispanic American Indian/Alaska Native
- Hispanic
- Non-Hispanic other/Multiracial

Gender

- Woman
- Man

Household Income <$40,000

- 22 20%

RESULTS

Level of Financial Toxicity

The mean COST score was 28.9 (SD=10.5)
32% of participants indicated at least mild levels of financial toxicity
9% reported moderate to severe toxicity

13% of participants indicated that they were moderately to severely concerned about health insurance or money worries.

Actions Taken to Manage Cost

- 31% utilized co-pay cards (e.g., pharmacy cards)
- 22% used retirement funds
- 19% received cash gifts or gift cards from others
- 12% borrowed money or went into debt
- 11% used up or depleted savings
- 7% sold or liquidated assets
- 1% filed for bankruptcy

Medication Scrimping

- 6% of participants indicated that in the past 12 months, there were times when they needed some kind of prescription medication but did not get it because of the cost.

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Comprehensive Score for Financial Toxicity (COST) Item Ratings

- I have enough money in savings, retirement, etc. to cover costs.*
- I am satisfied with my current financial situation.*
- I am frustrated that I cannot work or contribute as much as usual.
- I feel I have no choice about the amount of money spent on care.
- I worry about the financial problems I will have in the future.
- I feel in control of my financial situation.*
- I feel financially stressed.
- My out-of-pocket medical expenses are more than I expected.
- My treatment has reduced my satisfaction with my finances.
- I am able to meet my monthly expenses.*
- My illness has been a financial hardship to my family and me.
- I am concerned about keeping my job and income.

CONCLUSIONS AND IMPLICATIONS

- MDS patients report significant cost-related worries, frustrations, and fears related to treatment, with almost 1 in 10 noting moderate/severe financial toxicity.
- MDS patients engage in a variety of strategies to mitigate the financial burden of treatment, including tapping into personal assets and scrimping on prescription medication.
- Future research should examine how maladaptive coping strategies for dealing with financial toxicity (e.g., medication scrimping) impacts patient outcomes.
- MDS healthcare teams should consider engaging in timely conversations about the cost and value of MDS treatments, conducting periodic assessments of financial toxicity, and offering access to financial and work-related resources for patients who may be at risk for financial toxicity.

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Note: Data for “I don’t know” and “Prefer not to share” response options omitted from table.

9 (8%) participants reported an IPSS-R score of very low risk, 50 (45%) low risk, 19 (17%) intermediate risk, 6 (5%) high risk, and 5 (5%) very high risk, and 19% did not know.

Please contact melissa@cancersupportcommunity.org with questions or for additional information.