PATIENT SURVEY: FINANCIAL HARDSHIP ASSOCIATED WITH CANCER

SUMMARY OF FINDINGS

Cancer-related costs cause financial hardship among a majority of cancer patients, which can take an enormous toll on quality-of-life. Identifying solutions to address this issue requires an accurate understanding of patients’ cancer-related medical and non-medical costs, including loss of income. The situation is further complicated by patients’ lack of information regarding out-of-pocket charges and network coverage, resulting in unanticipated expenses and an inability to plan for future financial needs.

KEY FINDINGS

For people with cancer, financial hardship is widespread and related to both medical and non-medical expenses.

- Financial hardship from cancer-related expenses was reported by 70 percent of respondents, 86 percent of whom characterized it as moderate or severe.
- Nearly half (40 percent) of respondents reported that medical and non-medical expenses contribute equally to their financial difficulties (approximately $200 to $500 per month for each). A similar proportion (42 percent) said that medical expenses were the major source of their financial hardship and the remaining 18 percent said that non-medical expenses were most responsible.
- The most commonly mentioned out-of-pocket medical expenses were diagnostic tests and scans (53 percent), prescription medications (43 percent), outpatient treatments including radiation (37 percent), surgery (36 percent), and physician office visits (39 percent).
- The most commonly mentioned out-of-pocket non-medical expenses were gasoline (37 percent), food (40 percent), non-prescription medicines (30 percent), and special clothing and wigs (27 percent).

"All I can say is that I am appalled at the cost. There were tons of "hidden" costs for the specialists’ visits and primary care visits also." - SURVEY RESPONDENT

"I have to travel to Portland, ME from NH for treatment. I have over $3,000 in out-of-pocket expenses. Don’t have any idea how I will pay." - SURVEY RESPONDENT

Patients and family members often need to alter their employment status, resulting in decline in income and a potential loss of insurance coverage.

- Among those working full-time when diagnosed, two-thirds (66 percent) reported quitting, reducing their hours, or taking a leave of absence.
- Almost half (46 percent) said a household member reduced their work hours to provide caregiving services.

"My husband had to retire to take care of me and the house." - SURVEY RESPONDENT

MOST COMMONLY MENTIONED OUT-OF-POCKET MEDICAL EXPENSES

<table>
<thead>
<tr>
<th>Medical Expense</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic tests and scans</td>
<td>56%</td>
</tr>
<tr>
<td>Prescription medications</td>
<td>43%</td>
</tr>
<tr>
<td>Outpatient treatments including radiation</td>
<td>37%</td>
</tr>
<tr>
<td>Surgery</td>
<td>36%</td>
</tr>
<tr>
<td>Physician office visits</td>
<td>39%</td>
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</tbody>
</table>

MOST COMMONLY MENTIONED OUT-OF-POCKET NON-MEDICAL EXPENSES

<table>
<thead>
<tr>
<th>Expense</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gasoline</td>
<td>37%</td>
</tr>
<tr>
<td>Food</td>
<td>40%</td>
</tr>
<tr>
<td>Non-prescription medicines</td>
<td>30%</td>
</tr>
<tr>
<td>Special Clothing and Wigs</td>
<td>27%</td>
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</tbody>
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Financial hardship is often exacerbated because patients do not receive information on the costs of care or resources to help them manage these costs.

- Before treatment began, only one-quarter of patients said they had a full understanding of the out-of-pocket costs they would incur.
  - More than two thirds of patients did not have costs explained or did not remember having costs explained to them either before (69 percent) or during (71 percent) treatment.
- One-third (32 percent) received a bill from a provider they mistakenly thought was in network; of those, more than half (56 percent) could not afford to pay the bill.
- Key information gaps identified by patients were:
  - Information about organizations that provide financial assistance and/or navigation
  - Information on costs of treatment before beginning treatment

"There was never a breakdown of costs explained when treatment started...there is more counseling needed in all areas of what to expect." - SURVEY RESPONDENT

"Wanted the insurance company to answer our questions about exactly what would be covered. Instead, we received conflicting answers from different insurance representatives." - SURVEY RESPONDENT

The financial consequences of cancer treatment can take an enormous toll on quality-of-life for patients and families.

- In order to pay cancer-related expenses:
  - 1/2 cut back on groceries, transportation, clothing and tuition
  - 1/3 applied for financial assistance
  - 1/3 borrowed from family or friends
  - Nearly 1/3 missed paying bills such as rent, utilities and phone

"For about a year and half, I was homeless living from a hotel or family/church member’s home during radiation." - SURVEY RESPONDENT

"Reduced all non-essential expenses, including giving. A friend organized a fund raiser for my family, so my expenses were covered (eventually). Meals were provided by a circle of friends/neighbors and church, so grocery bills were reduced." - SURVEY RESPONDENT

Methodology

3,000 CancerCare clients with email addresses, who had been diagnosed with cancer in the past five years and had not received financial assistance through this organization, were identified randomly and sent invitations to participate in this survey.

The questionnaire was completed by 110 respondents through Survey Monkey in April 2017.

Research supported by the Pharmaceutical Researchers and Manufacturers of America