The costs of cancer to the patient and carers

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National Cancer Registry Ireland

The socio-economic implications of cancer as a chronic disease for patients and carers.
The Association of European Cancer Leagues.
World Cancer Congress, Montreal, August 2012
Where the costs of cancer fall

- Society
  - Employers
  - Patients and their families
Key questions

1. What are the costs of cancer for patients and carers?
2. How does cancer impact on work and income?
3. What do families do to cope financially?
4. What are the financial consequences?
5. What are the other costs?
Methods

Breast, prostate, lung cancer
- In-depth interviews with Oncology Social Workers (n=21)
- In-depth interviews with survivors (n=20)
- Postal survey of survivors (n=724 participated)

Colorectal cancer
- Focus group with Bowel Cancer Support Group
- In-depth interviews with survivors (+/- family members; n=22)
- Postal survey of survivors (n=495)
- Postal survey of family caregivers (n=154)
1. What are the costs of cancer for patients and carers?
Direct and indirect costs of cancer for patients & carers

**Treatment-related out-of-pocket costs**
- Consultant fees
- GP fees
- Tests & treatment
- Inpatient hospital stay
- Hospital parking
- Meals

**Additional health-related and medical costs**
- Prescription medicines
- Over-the-counter medicines
- Other medical therapies (e.g. counselling, physiotherapy)
- Alternative therapies (e.g. reflexology)
- Dietary supplements
- Childcare
- Home-help
- Nursing care
- House modifications
- Medical supplies (e.g. stoma bags)
- Personal items (e.g. wigs, clothes)
Direct and indirect costs of cancer for patients & carers

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Timeforgone
Quantifying the costs

Out-of-pocket costs

Time and travel costs
## Out-of-pocket costs: breast, prostate and lung patients

<table>
<thead>
<tr>
<th>Service</th>
<th>% of respondents who paid for</th>
<th>median amount (€2007-2008)</th>
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<tbody>
<tr>
<td>consultants</td>
<td>45%</td>
<td>€465</td>
</tr>
<tr>
<td>primary care doctors</td>
<td>36%</td>
<td>€250</td>
</tr>
<tr>
<td>counselling</td>
<td>6%</td>
<td>€360</td>
</tr>
<tr>
<td>physiotherapy</td>
<td>9%</td>
<td>€320</td>
</tr>
<tr>
<td>other therapies (e.g. occupational)</td>
<td>2%</td>
<td>€400</td>
</tr>
<tr>
<td>complementary therapies</td>
<td>15%</td>
<td>€300</td>
</tr>
<tr>
<td>prescription medications</td>
<td>29%</td>
<td>€300</td>
</tr>
<tr>
<td>over-the-counter medications</td>
<td>39%</td>
<td>€100</td>
</tr>
<tr>
<td>dietary supplements</td>
<td>13%</td>
<td>€200</td>
</tr>
<tr>
<td>wigs/hairpieces</td>
<td>40%*</td>
<td>€400</td>
</tr>
<tr>
<td>lymph drainage</td>
<td>5%*</td>
<td>€140</td>
</tr>
<tr>
<td>travel/parking (for hospital appts)</td>
<td>79%</td>
<td>€425</td>
</tr>
<tr>
<td>increased household bills</td>
<td>59%</td>
<td>_#</td>
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</tbody>
</table>

* of women with breast cancer; # amount not assessed
Informal carer costs
Carers’ costs: colorectal cancer

Diagnosis and initial treatment period

**Hospital-based costs**
- Mean cost: €5,085 per carer

- Time costs: 70%
- OOP: 16%
- Travel: 14%

**Domestic-based costs**
- Mean cost: €8,795 per carer

- Time costs: 90%
- OOP: 10%

OOP = out-of-pocket costs
Carers’ costs: colorectal cancer

Diagnosis and initial treatment period

**Hospital-based costs**
- Mean cost: €5,085 per carer

**Domestic-based costs**
- Mean cost: €8,795 per carer

First year after diagnosis

€29,207 per carer

- 70% Time costs
- 16% OOP
- 14% Travel

- 90% Time costs
- 10% OOP
Key questions

- How does cancer impact on work and income?
Work and income: breast and prostate patients

Continued working: 18% of those working at diagnosis

Time off work post-diagnosis: 82%

Received any sick pay: 53%

Permanently left workforce: 18%

Resumed working: 66%

Planned to resume working: 16%

Average absence: 30 weeks

Average reduction in working hours: 8 pw
Work and income: breast and prostate patients

Continued working: 18% of those working at diagnosis

Time off work post-diagnosis: 82%

Received any sick pay: 53%

Permanently left workforce: 18%

Resumed working: 66%

Planned to resume working: 16%

Average absence: 30 weeks

Average reduction in working hours: 8 pw

52% of those working at diagnosis experienced a drop in income
Key questions

3. What do families do to cope financially?
Making financial adjustments

Out-of-pocket costs + lost income

- Use savings
- Borrow money
- Cut back spending
Making financial adjustments

Out-of-pocket costs + lost income

Use savings
Borrow money
Cut back spending

- Used savings 54%
- Borrowed money 11%
- Cut spending on:
  - leisure activities 12%
  - holidays 20%
  - regular items 21%
Key questions

4. What are the financial consequences?
What are the financial consequences?

- Drop in income
- Out of pocket costs
- Financial adjustments
What are the financial consequences?

- Drop in income
- Out of pocket costs
- Financial adjustments

financial worries +/- cancer-related financial difficulties/burden
Objective cancer-related financial stress

Cancer diagnosis has made household’s ability to make ends meet....

Subjective cancer-related financial strain

Feelings about household’s financial situation since cancer diagnosis....

- less difficult
- no change
- more difficult

- less concerned
- no change
- more concerned

7% 44% 49%
30% 38% 32%
Importance of employment status at diagnosis

Cancer-related financial stress
more difficult to make ends meet

- employed: 63%
- self-employed: 58%
- not working: 47%
- retired: 23%

Overall = 49%
Key questions

5. What are the other costs?
Cancer-related financial stress and strain are related to lower quality-of-life in colorectal cancer

% survivors reporting low health-related quality-of-life*

Cancer-related financial stress:
impact of cancer on ability to make ends meet

- Improved: 14%
- No change: 23%
- Worsened: 34%

Cancer-related financial strain:
feelings about financial situation since cancer diagnosis

- Less concerned: 10%
- No change: 19%
- More concerned: 38%

* EORTC QLQ30 HRQoL score <33
Summary: economic and financial costs of cancer

- Direct medical costs
- Emotional/QoL impact
- Financial worries/difficulties
- Financial adjustments
- Workforce participation & lost income
- Other out-of-pocket costs
- “Lost” time costs
- “Lost” time costs

patients + carers
Conclusion

- Cancer imposes a significant financial and economic burden on patients and their families.
- There are many dimensions to that burden - and it is not always straightforward to identify who is at risk.
- There is an urgent need to develop
  - strategies to identify patients and carers who are financially (and, hence, may be emotionally) vulnerable
  - services and supports to aid patients and their families

Identify | Intervene | Improve outcomes
Acknowledgements

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“And it’s a time in your life when you are most vulnerable. It’s at a time of your life when worry should be, if possible, taken off you. Even if it’s only for a short period of time….. the time of your treatment is a time when you most need to have your mind focused. And your mind needs to be focused on making yourself better, not worrying about finances.”