Problem

- Anecdotal reports by families and clinicians suggest costs are significant
- Magnitude of costs underestimated
  - Issues related to conceptualizing, measuring, and interpreting
- Costs incurred by families of newly diagnosed children remain relatively unknown
Study Objectives

- **Primary**
  - Identify costs incurred by families of children newly diagnosed with cancer during the first 3 months
- **Secondary**
  - Determine factors that independently influence families’ costs
  - Explore impact of these cancer-related costs on family

Conceptual Framework

- **Predictors**
  - Economic (e.g., income adequacy, drug benefits plan)
  - Social (e.g., foreign born, location of home)
  - Disease (e.g., diagnosis type, age at diagnosis)
- **Cost Components**
  - Direct (e.g., medications, equipment, supplies, and food)
  - Indirect (e.g., lost productivity and care giving time)

Design

- A multi-site, prospective, mixed-methods design with 3 repeated, micro-costing assessments over the 1st 3 months following diagnosis, using a validated costing diary
Quantitative Data Analysis

- Descriptive statistics
  - To describe families 2007 costs stratified by income group
    - Direct
    - Reimbursements subtracted from expenditures
    - Indirect
    - Human Capital Approach
- Multiple regression modeling
  - To determine influential cost factors
    - Direct
    - Indirect

Qualitative Data Analysis

- Guided by cost of illness framework
- Conducted a qualitative content analysis
- Used various examples to highlight particular points within the parents’ discussions of the impact of the cancer-related costs

Sample Characteristics

<table>
<thead>
<tr>
<th>Child</th>
<th>n</th>
<th>Parent</th>
<th>n</th>
<th>Family</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male 0 to 14</td>
<td>43</td>
<td>Mother</td>
<td>71</td>
<td>English</td>
<td>79</td>
</tr>
<tr>
<td>15 to 19</td>
<td>13</td>
<td>Married</td>
<td>89</td>
<td>High Income</td>
<td>45</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>53</td>
<td>Single</td>
<td>2</td>
<td>Low Income</td>
<td>28</td>
</tr>
<tr>
<td>Other Dx</td>
<td>46</td>
<td>Cdn Born</td>
<td>67</td>
<td>Urban</td>
<td>86</td>
</tr>
<tr>
<td>Grade 1-8</td>
<td>42</td>
<td>European</td>
<td>42</td>
<td>Car</td>
<td>90</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mom Post-2nd</td>
<td>54</td>
<td>Support</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dad Post-2nd</td>
<td>41</td>
<td>Drug Plan</td>
<td>81</td>
</tr>
</tbody>
</table>

Note. n = 99
### Direct Costs

<table>
<thead>
<tr>
<th>Type</th>
<th>Use</th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Mdn</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel</td>
<td>99</td>
<td>3068</td>
<td>5820</td>
<td>300</td>
<td>1783</td>
<td>47470</td>
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<tr>
<td>Food</td>
<td>99</td>
<td>978</td>
<td>666</td>
<td>92</td>
<td>849</td>
<td>4054</td>
</tr>
<tr>
<td>Domestic Labour</td>
<td>35</td>
<td>280</td>
<td>565</td>
<td>0</td>
<td>0</td>
<td>2630</td>
</tr>
</tbody>
</table>

Note. n = 99; All expressed in 2007 Canadian dollars; Travel includes car purchase and lease.

### Indirect Costs

<table>
<thead>
<tr>
<th>Type</th>
<th>Use</th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Mdn</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother Work Loss</td>
<td>65</td>
<td>3716</td>
<td>3903</td>
<td>0</td>
<td>2379</td>
<td>11985</td>
</tr>
<tr>
<td>Father Work Loss</td>
<td>63</td>
<td>2552</td>
<td>3623</td>
<td>0</td>
<td>1259</td>
<td>18351</td>
</tr>
<tr>
<td>Mother Leisure Time</td>
<td>96</td>
<td>11373</td>
<td>4995</td>
<td>0</td>
<td>11907</td>
<td>21966</td>
</tr>
<tr>
<td>Father Leisure Time</td>
<td>86</td>
<td>4985</td>
<td>4660</td>
<td>0</td>
<td>3901</td>
<td>18876</td>
</tr>
</tbody>
</table>

Note. n = 99; All expressed in 2007 Canadian dollars.

### Total 3-month Cost of Illness

<table>
<thead>
<tr>
<th>Type</th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Mdn</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct</td>
<td>5446</td>
<td>6659</td>
<td>754</td>
<td>3503</td>
<td>51906</td>
</tr>
<tr>
<td>Indirect</td>
<td>22873</td>
<td>9594</td>
<td>1259</td>
<td>23130</td>
<td>49236</td>
</tr>
<tr>
<td>Total</td>
<td>28475</td>
<td>12670</td>
<td>2013</td>
<td>27157</td>
<td>79249</td>
</tr>
</tbody>
</table>

Note. n = 99; All expressed in 2007 Canadian dollars.
Cost Predictors

- No significant direct cost predictors
- Language spoken at home produced an $R^2$ of 0.06 for a model of unadjusted time costs at a significance level of 0.05

Impact of Cancer Costs

Direct Costs

- Ensure child had access to treatment
- Cope with clinical side effects
- Maintain family household
Coping with Clinical Side Effects

Sometimes, he’ll say, “I feel like having this kind of food”. And I’m thinking, “We don’t have it”. There are times where I haven’t had the money to buy what he’s wanted. I feel really bad if he’s hungry and I don’t have the money to get what he wants. He needs to eat. So, I try and substitute, but he’s so picky. When he wants something, he wants it, and there’s nothing that can replace what he wants. Mother, Child 4 years, Low Income

Parental Employment Status

• But I do it because I have no choice… It hurts… Because I cannot take time off from work. If I do, I’m going to lose a day’s pay, and then, I can’t pay my bills and everything will be just piling up. So, I have to go to work in the day, and then, stay here at night. It hurts. It hurts. Yes. You want to be here. But you can’t. What can I do? Mother, Child 15 years, Low Income

Care giving Activities

• Attending hospital appointments
• Administering medications and watching for side effects
• Providing emotional support to their child
• Protecting their child from infection
• Adopting new roles as teachers and playmates
• Shouldering the organizational burden

Labels for the care giving activities were borrowed from Clarke, Fletcher, & Schneider (2005) who described the home health care work of mothers of children with cancer.
Care Giving Activities

• ... you've got to keep going back and forth to your room, make sure your kid doesn't vomit, your kid is not in pain, your kid didn't jump out of the bed, or the IV doesn't go on ... or the CVL [central venous line] has not been pulled. And then you go to bed ... and then you got to change diapers every hour, hour and 15 minutes ... and you got to do that, that's your job. So you don't sleep. *Mother, Child 2 years, High Income*

Strategies Utilized to Manage Costs

• Managing expenses
• Increasing debt
• Relying on savings or assets
• Seeking support

Managing Expenses

• I buy what we need as opposed to buying a whole bunch of groceries and stocking up. I find I just buy what we need. Same with the kids, if they need clothes or shoes, if they need it, we buy it. I just find that it's not, you know ... it's not a good time to ask right now. And if it's needed then we buy it. But if it's not, we just keep putting it off. *Mother, Child 13 years, High Income*
Cost Interpretation

• Expenses reflect only those of the 1st 3 months following a childhood cancer diagnosis and already exceed 37% of the families’ annual after tax income (Statistics Canada, 2010)
• Expenses exceed previous estimate of 1/3 the family after-tax income and suggests families are bearing a catastrophic burden (Barr et al, 1996)

Implications

• Determine costs associated with childhood cancer across all treatment phases, institutions, and health care systems
• Develop and test interventions to ease the care giving demands and to lessen the financial impact
• Adopt key multi-stakeholder knowledge translation strategies

Conclusions

• Significant costs are incurred by families of children newly diagnosed with cancer
• Limited knowledge exists regarding variables that influence families’ costs
• Families adopted various strategies to manage increased out-of-pocket expenses combined with reduced household income
• Implications are geared towards optimally supporting families faced with significant costs related to their child being diagnosed with cancer
PhD References


https://tspace.library.utoronto.ca/bitstream/1807/24897/6/Argerie_Tsimicalis_201006_PhD_thesis.pdf

POGO's Contribution

- Monetary Support
  - Research Fellowship ($50,000)
  - Grant ($55,000 - declined $32,890)
  - Outstanding Poster Award ($250)
- POGONIS
  - Creation of database
  - Data entry, storage (physical and electronic), analysis
  - Statistical expertise
- Feedback
  - Fellowship and grant competition
  - Privacy review
- Formal (Dr. Mark Greenberg, Thesis committee member)
- Informal
- Career Development
  - Seed Grant Review Panel
  - SIOP nomination
  - Reference letters
  - Networking
  - Telepractice guidelines
  - Guest speaker
- Space/Facilities
  - Personnel
- Knowledge Translation
  - Annual POGO Symposium
  - National Post interview
  - Fundraising