



# Financial burden of cancer for the caregiver

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# Caregiver burden

- AGENDA
  - Why should we care about caregiver burden?
  - Some data on patient & caregiver burden
  - Other published data & current gaps
  - Ongoing and planned research
  - Future directions
  - Discussion



# Why should we care?

- Cancer creates a burden for the family, not just the patient (Longo, 2006; Guierriere, 2008)
- Caregivers need to manage their own health (Coe & van Houtven, 2009)
- Caregivers quality of life can be aversely impacted (Kim et al, 2008)
- Overburdened caregivers may be providing sub-optimal care to patients and for themselves



# Part of the Financial story

Patient costs by level of burden, INCLUDING travel

Mean 30 day costs (including travel) by level of burden

Burden	N (191)	%	Mean	Standard Deviation	Range
None	57	29.8%	\$374	\$486	\$0-\$2478
Slight	55	28.8%	\$722	\$783	\$12-\$4181
Somewhat	40	20.9%	\$678	\$746	\$50-\$3568
Significant	29	15.2%	\$880	\$1318	\$28-\$5786
Unmanageable	10	5.2%	\$949	\$1015	\$53-\$3089



# Another Part of the Financial Story

## Time off work - Family/friends

Variable	N	% w/ lost time	Mean	Standard Deviation	Range
Family/Friend “time from work”	100	35.5%	7.0	8.2	0.2-30



# Final part of the story

## The informal caregiver

- Absenteeism and Presenteeism
  - Data suggests both are important (Mazanec, 2011)
- Time costs
  - \$6250/month (Guerriere, 2008)
- Health implications including effects on caregiver health (Coe & van Houtven, 2009)



# Some recent Canadian publications on cancer costs

- ◆ Limberg, 2008 (BC – Lost wages, childhood cancers)
  - ◆ Lost wages of parents with children (under 20) with cancer
  - ◆ Sample of 111 families (1990-1996; Data capture 1998-1999)
  - ◆ 64% of mothers, and 16% of father left job after diagnosis
  - ◆ Cancer included: Leukemia (24%), CNS (17%), bone (11%), lymphoma (10%)
  - ◆ Majority left their job for less than 1 year, 89% of males returned, and 80% of females returned to same job
  - ◆ Use of other sources of income:
    - ◆ Employment insurance, social assistance, other financial support
  - ◆ Did NOT report the total loss of income over the 1 year period



# Some recent Canadian publications on cancer costs

- ◆ Guierrier, 2008 (Ontario – Homecare, all cancers)
  - ◆ \$7671 (4 weeks), 85% privately funded or \$6510 (\$2004)
  - ◆ **Includes valuing leisure time lost by patients & caregivers,**
  - ◆ **Recruited from community care centres.**

Table 2 Costs by expenditure category (4-week period) per care recipient

Expenditure category	N*	Mean† (for those reporting costs)	Mean‡ (for total sample)	Median	Lower quartile	Upper quartile
<b>Public</b>						
Home-based healthcare professional appointments	514	696.52	696.52	498.40	249.20	996.80
Ambulatory healthcare professional appointments	425	289.05	239.05	85.50	40.40	173.07
Medication, supplies and equipment	351	328.39	224.25	162.81	41.44	470.03
Total public expenditures	514	1159.77	1159.77	874.78	473.00	1551.83
<b>Private</b>						
Time costs	514	6254.68	6254.68	3718.21	1387.98	8970.78
Out-of-pocket	481	186.84	174.84	89.93	31.23	206.00
Third-party insurance	125	334.63	81.38	107.12	30.00	321.60
Total private expenditures	514	6510.90	6510.90	4063.44	1579.20	9520.34
Total overall	514	7670.67	7670.67	5108.31	2434.00	11 072.56

\* Number of participants reporting in Expenditure category.

† Mean cost for participants who reported costs within each of the relevant categories.

‡ Mean cost within each cost category calculated using the total sample (514).



## Other non-Canadian published data

- Mazanec et al, 2011
  - Work productivity of informal caregivers
    - Absenteeism and Presenteeism evaluated (n=40)
    - Mean loss 22.9%
    - Absenteeism accounted for 9.6% and Presenteeism accounted for 15.4% of lost productivity.
    - Greater loss associated with:
      - Number of caregiver hours, higher cancer stage, married status, greater anxiety, depression and financial burden



# Other non-Canadian published data

- Coe & van Houtven, 2009
  - Caregiver health
    - Negative physical effects on caregivers
    - Delayed onset in many cases
    - Effects may persist for 4 years or longer in some subgroups



# Research Gaps

- In measuring the impact on cancer caregivers we find published data on:
  - Lost income and productivity
  - Lost time (work and leisure)
  - Increased health events (& expenditures)
- No published Canadian data that combines these to present the complete picture for cancer diagnosis and treatment



# Possible solutions

- A comprehensive questionnaire that addresses different dimension of Caregiver burden
- Would include measures of out-of-pocket costs, travel costs, lost income, lost productivity, and health outcomes



# Caregiver Questionnaire (C-SAFE)

- Domains include:
  - Related medical costs (out-of-pocket)
  - Transportations costs
  - Lost work time & productivity
    - Absenteeism and Presenteeism
  - Impact on health care services for the caregiver
  - Applied as a point in time, or as a longitudinal questionnaire (3-4 week intervals)



# Ongoing & planned research

- Caregiver Questionnaire (C-SAFE)
  - Applied in end-of-life care setting (McGill university, Starting summer 2012)
  - Applied in pediatric setting (Toronto Sick-Kids, Forecast start Fall 2012)



# How can this research help?

- Understand better what financial burden is borne by the caregiver
- Understand the impact on work and work productivity for the caregiver
- Understand better what impact caregiver burden has on caregiver & patient care
- Stimulate policy discussions to determine better ways to support caregivers, and ultimately support patients.



# DISCUSSION and QUESTIONS

