

## **Financial and family burden associated with cancer treatment in Ontario, Canada.**

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### **Abstract:**

**GOALS OF WORK:** To determine the financial and family resources burden associated with the treatment of cancer. A questionnaire was developed to determine the direct monthly "out-of-pocket costs" (OOPC), the indirect costs, and the associated perceived family burden.

**MATERIALS AND METHODS:** A self-administered questionnaire using a quota sample from five cancer clinics in Ontario, Canada was given to 282 cancer patients (74 breast, 70 colorectal, 68 lung, and 70 prostate). Monthly OOPC were obtained for: drugs, home care, homemaking, complementary and alternative medicines, vitamins and supplements, family care, travel, parking, accommodations, devices, and others. The questionnaire asked if OOPC for treatment were a burden, and if others took time from work to provide caregiving.

**MAIN RESULTS:** The mean monthly OOPC was \$213, with an additional \$372 related to imputed travel costs. For those patients who responded that the burden was "significant" (16.5%), their OOPC was \$452. In the case of patients responding that their burden was "unmanageable" (3.9%), their OOPC was \$544. The survey showed that 35.6% of patients required others to take time from work and this was higher in the under-65 category. The mean number of days lost from work in the previous 30 days for these caregivers was 7 days.

**CONCLUSIONS:** These results suggest the financial burden is problematic for 20% of this sample. The caregivers' lost time from work influence this burden, and for 36% of this sample, it amounts to one third of their working days in any given month. Policies and programs to address these gaps are needed.

### **Comments:**

Strengths/uniqueness: This paper describes the financial and time related burden by the patient and family associated with the treatment of cancer. It is one of the few studies which have reported out-of-pocket and time-related work losses of patients and family caregivers. It is one of the first which correlates these costs with self perceived measures of burden. Burden is reported as perceived burden, absolute out-of-pocket costs, days lost from work and percent out-of-pocket of income. Finally, the paper is unique in providing evidence that patients and their families experience significant burden despite the fact that several provincial and federal plans are in place to address this issue.

Weakness: The primary weakness relates to the conceptualization of burden. Perceived burden for example includes not only out-of-pocket but all time and intangible costs. Analysis however was conducted with out-of-pocket costs and excluded the work related losses. To be fair however, there is no consensus of assigning value to non-work related time losses and capturing intangible costs. This study does not address unmet needs. In other words, the costs are biased downward in that compliance with treatments maybe low when personal costs are high. Perceived burden also do not take into account differences in culture or accumulated burden.

It is unclear whether the measurement of family income is before/after tax. As well, it is not clear whether alternative sources of income (eg. reverse mortgages) have been captured.

An acknowledged limitation is that these costs have not been correlated with the illness severity or trajectory.

Finally, a 30-day recall period is generally assumed to be sufficient to accurately measure direct medical costs but is questionable for out-of-pocket costs. It is also not known how self-reported resource use compares to resources collected with interviewer-assist interviews.

Relevance to Palliative Care: Of primary importance to palliative care medicine is raising the awareness that 20% of cancer patients describe the burden as significant or unmanageable. This finding suggests that all clinicians take into account the personal costs when developing a treatment plan. It is now know that financial burden correlates with psychological distress which means that programs need to allocate resources for counseling. In particular, it is hoped that this research will lead to the development of early referral mechanisms for psychologists and social workers. Finally, this work is important in helping develop policies which provide subsidies to patients experiencing high burden.