

A PROSPECTIVE MIXED METHODS STUDY TO DETERMINE THE COSTS INCURRED BY FAMILIES OF CHILDREN NEWLY DIAGNOSED WITH CANCER IN ONTARIO

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Purpose: Paediatric cancer may place significant economic burden on families. However, the specific costs and the impact of these costs on families, especially with children newly diagnosed with cancer, remain unknown. The study purposes were to: (a) identify costs incurred by families of children newly diagnosed with cancer, (b) identify the determinants of cost, and (c) explore the impact of costs on families.

Method: A prospective concurrent mixed methods design was utilized to study parents of children newly diagnosed with varying cancer diagnoses from two paediatric hospitals. Parents recorded resources consumed and direct (out-of-pocket expenses) and indirect (productivity losses) costs incurred during one week per month for three consecutive months following diagnosis and listed additional costs incurred since diagnosis. Parents also discussed the impact of these costs in individual interviews. Descriptive statistics and multiple regression were used to describe families' costs (expressed in 2007 Canadian dollars) and to determine influential cost factors. Qualitative content analysis was used to analyze the impact data.

Results: Ninety-nine parents (28 fathers and 71 mothers) completed the study. The majority of children were diagnosed with leukaemia (n = 53), followed by lymphomas (n = 11), and cancers of the central nervous system (n = 10). The mean total three month expenditure was \$28,475 (SD \$12,670; range \$2013 to \$79,249) per family. No statistically significant factors influenced families' direct costs, however, indirect costs were influenced by language spoken at home. Parents described their costs and the coping and management strategies used to lessen the financial impact including managing their expenses and seeking ways to increase their cash flow.

Conclusion: Families are confronted with unavoidable, unexpected, and potentially catastrophic costs following their child's diagnosis. Study implications are geared towards optimally supporting families manage their new financial reality and rendering other childhood cancer costs visible.

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