# The Economic Burden of Caring for a Child with Duchenne Muscular Dystrophy in Canada: A Caregiver Survey

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## INTRODUCTION & OBJECTIVE

- Duchenne muscular dystrophy (DMD) is a rare, severely debilitating, and fatal neuromuscular disease that predominantly affects males and arises in early childhood.[1]
- The value of informal care provided by family caregivers is immense. In addition to assisting older adults with activities of daily living, family caregivers are intimately involved with carrying out complex and wide-ranging healthcare activities. These include coordinating medical care, managing medications, monitoring symptoms, and performing direct patient care tasks.
- As the disease progresses, individuals with DMD require more assistance with activities of daily living. This can significantly impact caregivers' physical, psychological, and financial wellbeing.[2,3] However, there is a paucity of data on the economic burden of DMD incurred by families in Canada.
- The objective of this study was to estimate the economic burden of Canadians caring for a child diagnosed with DMD.

## METHODS & DATA ANALYSIS

- A 37-item electronic, self-administered survey available on Microsoft Forms was created by Pfizer Canada ULC. The survey was validated and revised via feedback from the patient organizations Defeat Duchenne Canada (all provinces except Québec) and La Force DMD (Québec). The survey was then disseminated by these two patient advocacy groups using social media platforms and newsletters.
- The survey targeted adult caregivers living in Canada and caring for at least one individual diagnosed with DMD. The individual did not have to reside with the caregiver. Two or more caregivers caring for the same individual(s) with DMD were allowed to complete the survey independently.
- The survey was available for a 20-day period between July 20 and August 8, 2022.
- Project HERCULES definitions were used to define ambulatory and non-ambulatory health states.[4]
- The self-reported data captured sociodemographic characteristics of caregivers of children with DMD (n=28), caregiver loss of productivity (in employed caregivers only; n=9), and out-of-pocket costs for all caregivers (n=20).
- Costs of car or home adaptation were provided since diagnosis. Other costs were recorded as a monthly or annual expense within the last 12 months.
- Data analysis was descriptive (e.g., median and interquartile range [IQR] for continuous variables, count and proportions for categorical variables).
- Ranges of values (e.g., income, out-of-pocket costs) were represented by their midrange.

## RESULTS

**Table 1. Sociodemographic characteristics of caregivers.** The survey was completed by 20 caregivers living in 5 different Canadian provinces (40% in Québec, 25% in Ontario and 35% in rest of Canada) caring for a total of 28 individuals with DMD.

| Characteristic, n (%) | | Caregivers (N=20) |
|---|---|---|
| Sex | Female | 14 (70) |
| Age, years | 35–54<br>≥55 | 15 (75)<br>5 (25) |
| Highest education level | At least a university certificate or degree at bachelor level | 10 (50) |
| Living with at least one child diagnosed with DMD | | 19 (95) |
| Children with DMD in the household, n | 1<br>2<br>≥3 | 15 (75)<br>2 (10)<br>2 (10) |
| Caregivers per patient | 1<br>2<br>≥3 | 3 (15)<br>13 (65)<br>4 (20) |
| Employment status | Unemployed<br>Employed/self-employed full-time<br>Employed/self-employed part-time<br>Retired | 8 (40)<br>8 (40)<br>1 (5)<br>3 (15) |
| Employment status impacted by DMD diagnosis (n=9)* | | 8 (89) |
| Annual income before DMD diagnosis, median (IQR), $CAD† | Unemployed (n=7)<br>Employed/self-employed part-time (n=1) | 45,000 (50,000)<br>35,000 (NA) |
| Current annual income, median (IQR), $CAD | ***All caregivers (N=20)***<br>Unemployed (n=8)<br>Employed/self-employed full-time (n=8)<br>Employed/self-employed part-time (n=1)<br>Retired (n=3) | ***95,000 (80,000)***<br>17,500 (72,500)<br>105,000 (2,500)<br>95,000 (NA)<br>35,000 (40,000) |

$CAD, Canadian dollars; DMD, Duchenne muscular dystrophy; IQR, Interquartile range; NA, not applicable,

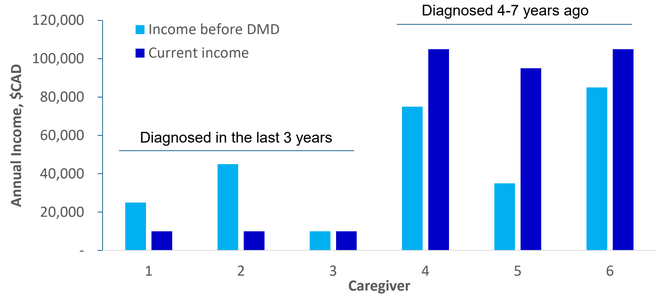
References: 1. Emery. Lancet. 2002;359(9307):687-695. 2. Landfeldt et al. J Neurol. 2016;263(5):906-915. 3. Schwartz et al. J Patient Rep Outcomes. 2021;5(1):124. 4. Broomfield J et al. Abstract presented at the European Conference on Rare Diseases and Orphan Products (ECRD) 2020; 14-15 May, 2020; Virtual

**Table 2. Clinical Characteristics of Individuals with DMD at the Time of Survey.** Eleven individuals (39%) were diagnosed with DMD in the first 3 years of their life and the remainder between 4 and 7 years of age.

| Characteristic, n (%) | | Individuals with DMD (N=28) |
|---|---|---|
| Age at survey completion, years | 0–3<br>4–7<br>8–17<br>≥18 | 1 (4)<br>3 (7)<br>16 (57)<br>9 (32) |
| Health status* | Stands from supine, and walks (early ambulatory)<br>Cannot stand from supine but can walk (late ambulatory)<br>Cannot stand from supine but can stand assisted (transfer)<br>Cannot stand or walk (non-ambulatory) | 10 (36)<br>3 (11)<br>1 (4)<br>11 (39) |

*Walk was defined as can walk for 10 meters. Stand from supine (i.e., laying on the floor face upward) was defined as getting up from the floor using as little support as possible. Stand was defined as standing up tall. Three patients aged ≥28 years had missing data regarding their ambulatory health state; these patients were assumed to be non-ambulatory, given their age. DMD, Duchenne muscular dystrophy

**Figure 1. Annual Income in Caregivers Whose Employment Status Was Impacted by a DMD Diagnosis.**



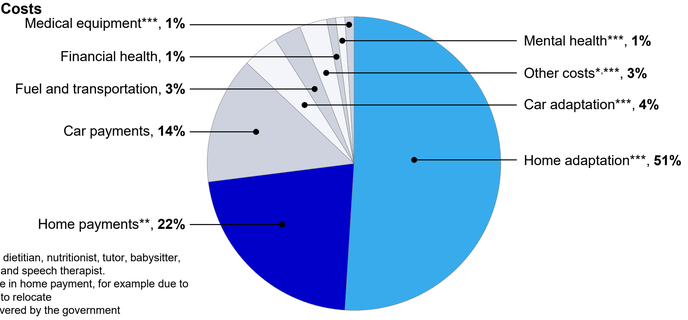

Caregivers 4 and 6 care for ambulatory individuals (aged 8–13 years); caregivers 1 and 3 care for non-ambulatory individuals (aged 8–13 years); caregivers 2 and 5 care for non-ambulatory individuals (aged 14–17 years). Two participants, out of the 8 whose employment status was impacted, did not report before and after incomes. $CAD, Canadian dollars; DMD, Duchenne muscular dystrophy.

**Table 3. Working Habits Among Caregivers.** Employed caregivers did not report a significant shift in their working habits due to DMD. However, caregivers were absent for a median (IQR) of 2 (2) days per month or 7 (14) hours per month due to caregiving responsibilities.

| | | Prior to DMD diagnosis, n (%) | At survey completion, n (%) |
|---|---|---|---|
| Days worked per week, n | 4<br>5 | 0<br>9 (100) | 2 (22)<br>7 (78) |
| Hours worked per week, n | <8<br>25–32<br>33–40<br>>40 | 0<br>1 (11)<br>5 (56)<br>3 (33) | 1 (11)<br>1 (11)<br>6 (67)<br>1 (11) |

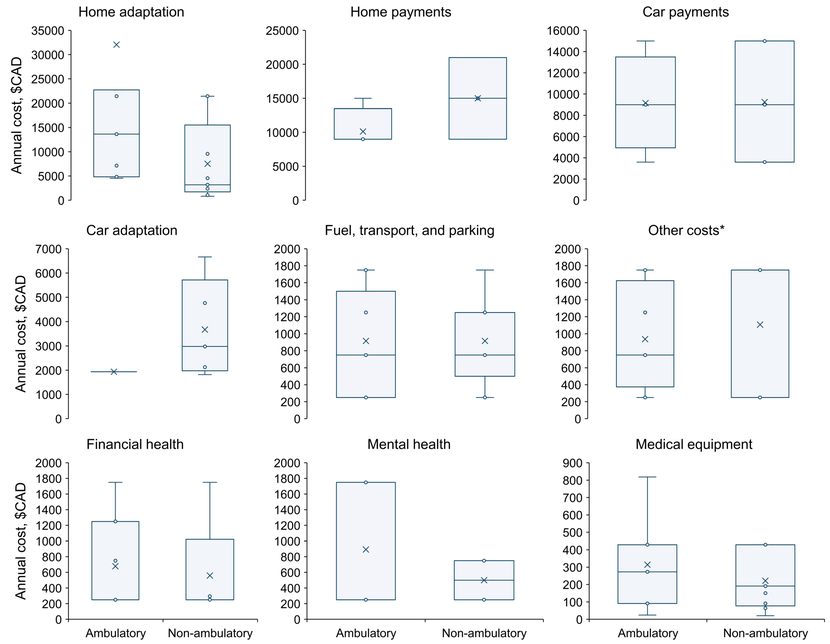
Responses among the 9 caregivers who were employed or self-employed when their child received a diagnosis of DMD. DMD, Duchenne muscular dystrophy; IQR, interquartile range.

**Figure 2. Median Annual Out-of-pocket Costs for Each Category of Expenses as a Percentage of Total Annual Costs**




* Includes dietitian, nutritionist, tutor, babysitter, guardian, and speech therapist.
** Increase in home payment, for example due to necessity to relocate
*** Not covered by the government

**Figure 3. Median Annual Out-of-pocket Costs Based on Health Status of Persons with DMD.**




* Includes dietitian, nutritionist, tutor, babysitter, guardian, and speech therapist. $CAD, Canadian dollars; DMD, Duchenne muscular dystrophy.

## RESULTS (continued)

- Most individuals with DMD aged ≤18 years were ambulatory (13/19 [68%]), while most individuals with DMD aged ≥18 years were non-ambulatory (8/9 [89%]).
- Median (IQR) annual income was $40,000 ($40,000) prior to diagnosis. It dropped to $10,000 ($0) within 3 years of the diagnosis and increased to $105,000 ($5,000) 4 to 7 years after diagnosis **(Figure 1)**. Seven caregivers (35%) became unemployed following the DMD diagnosis.
- Five caregivers (63%) reported they lost or refused a promotion (valued between $1,000 and $20,000) due to their caregiving responsibilities.
- Median (IQR) annual out-of-pocket costs related to DMD were $23,446 ($22,312) with 91% of these expenses due to home and car adaptations and payments **(Figure 2)**.
- Out-of-pocket costs associated with home adaptation, home payments, and car adaptation differed the greatest between ambulatory and non-ambulatory health states **(Figure 3)**.

## LIMITATIONS

- Only descriptive statistics were used due to the sample size and within-group variability.
- More data are needed to better understand the socioeconomical burden experienced by caregivers, including unpaid labor related to caregiving, especially for those who exited the workforce, and effect on quality of life.
- Economic benefits of new medical products and cost offsets arising from alleviating caregiver strain, such as reduced productivity losses or decreased healthcare spending for the informal caregiver, were not considered in this study.

## DISCUSSION & CONCLUSIONS

- **This study describes the societal impact of DMD in Canada and provides a pivotal and unique perspective on the economic burden of Canadians caring for a child diagnosed with DMD.**
- **Caregivers in this population experienced a considerable financial burden, especially in the first three years following the diagnosis of DMD. They also experienced limited professional growth or had to exit the workforce.**

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