


# Household Costs and Other Societal Impacts for Individuals With Duchenne Muscular Dystrophy Stratified by Upper Limb Impairment: Results From a Caregiver Survey


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Key Findings

Over a 5-year period:

**~\$73-83K**  
range of mean costs incurred in home and vehicle purchases/modifications per household, irrespective of the level of upper limb (UL) impairment, to accommodate individuals with Duchenne muscular dystrophy (DMD)

**3×**  
increase in medical equipment costs per household for individuals with moderate-to-severe UL impairment vs no UL impairment

**Only 26%**  
of caregivers received compensation from government or non-government entities

**3.4×**  
more likely for households with individuals with moderate-to-severe UL impairment to receive social program payments

DMD, Duchenne muscular dystrophy; UL, upper limb.

## Background

- DMD is a rare genetic disease affecting primarily males and presenting during early childhood<sup>1</sup>
- DMD causes muscle weakness and wasting that diminishes functional capacities, including loss of ambulation between the ages of 10 and 13 years in patients receiving corticosteroid therapy<sup>1,2</sup>
- In non-ambulatory patients especially, preservation of UL function is vital for maintaining independence, given that key activities of daily living, including personal hygiene and feeding, are dependent on arm and shoulder function<sup>3,4</sup>
- Previous studies have shown large economic burdens borne by families of patients with DMD in terms of household expenses and loss of workforce participation, as well as large societal costs, including private insurance and Medicare expenditures<sup>5-9</sup>

## Objective

- To assess the relationship between the severity of UL impairment in patients with DMD and non-medical and recurring household costs, as well as social benefit utilization (eg, financial assistance, disability insurance, public assistance)

## Methods

- An online survey was conducted in September 2023 targeting caregivers who provided care to ≥1 household member with DMD for ≥12 months querying costs and expenditures
- Data were gathered on DMD-related non-medical costs within the past 5 years; other recurring costs, incurred during the previous 3 months, were annualized
- Caregivers were queried regarding out-of-pocket, governmental (eg, Medicaid waiver), and non-governmental (eg, private health insurance, charities, friends) contributions for each expenditure
- Cost and utilization outcomes were stratified by degree of UL impairment of household-dwelling individuals with DMD using 3 categories:
  - No impairment: full use of UL
  - Mild impairment: difficulty raising both arms to shoulder height or eye level at the same time
  - Moderate-to-severe impairment: cannot raise a full glass of water to mouth

## Results

- Ninety caregivers completed the survey, with 74 (82%) providing care for 1 individual with DMD and 16 (18%) providing care for ≥2 individuals, for a total of 106 individuals with DMD
- Caregivers were primarily female (94%) and identified themselves as a primary caregiver (98%)
- Mean age (standard deviation [SD]) of the 106 individuals with DMD was 14.5 (5.3) years
- Of the 106 individuals with DMD, degree of UL impairment was: no impairment, n=40 (38%); mild impairment, n=39 (37%); moderate-to-severe impairment, n=27 (25%)
- Among the 90 caregivers surveyed, the highest level of UL impairment for patients under their care was reported as follows: no impairment, n=27 (30%); mild impairment, n=38 (42%); moderate-to-severe impairment, n=25 (28%)
  - Outcomes (stratified by UL impairment) are reported per the 90 surveyed caregivers and their households

### Home and Vehicle Expenses

- Over the past 5 years, households faced considerable mean expenses for DMD-related home and/or vehicle purchases or modifications, with costs ranging from \$73,057 to \$82,669, irrespective of the level of UL impairment
  - The largest of these costs was related to moving to or building a new home to accommodate the individual(s) with DMD, and costs were inversely associated with the severity of UL impairment: no impairment, \$39,069; mild impairment, \$13,158; moderate-to-severe impairment, \$8,650
  - The second largest cost was purchasing or modifying a handicap-accessible vehicle, which was associated with greater UL impairment: no impairment, \$25,264; mild impairment, \$30,394; moderate-to-severe impairment, \$37,870
  - Other purchase and modification costs included home entrance (eg, ramps), bathrooms, bedrooms, kitchens, and installation of elevators or lifts

### Medical Equipment Expenses

- More severe UL impairment was associated with higher average medical equipment costs over the past 5 years: no impairment, \$7,477; mild impairment, \$13,421; moderate-to-severe impairment, \$22,180 (**Figure 1**)

**Figure 1** Medical Equipment Costs Over the Past 5 Years by Impairment Severity

Upper limb impairment severity	Costs in dollars (US)
No impairment (n=27)	\$7,477
Mild impairment (n=38)	\$13,421
Moderate-to-severe impairment (n=25)	\$22,180

### Professional Caregiving and Supportive Therapy Expenses

- Annualized costs for in-home professional caregiving over the past 12 months were similar for no impairment (\$2,504) and mild impairment (\$1,579) but considerably higher for moderate-to-severe impairment (\$11,199; **Figure 2**)

**Figure 2** In-home Professional Caregiving Costs Over the Past 12 Months by Impairment Severity

Upper limb impairment severity	Costs in dollars (US)
No impairment (n=27)	\$2,504
Mild impairment (n=38)	\$1,579
Moderate-to-severe impairment (n=25)	\$11,199

- Annualized costs for supportive therapy (ie, physical therapy, occupational therapy, mental health counseling) over the past 12 months were comparable between the impairment groups: \$988 for no impairment, \$802 for mild impairment, and \$1,060 for moderate-to-severe impairment

### Social Benefit Utilization and Governmental and Non-governmental Contributions

- The proportion of caregivers compensated by government and other entities increased with greater impairment: 7% (2/27) for no impairment, 21% (8/38) for mild impairment, and 52% (13/25) for moderate-to-severe impairment (**Figure 3**)

**Figure 3** Proportion of Caregivers Compensated by Government and Other Public Sources

Upper limb impairment severity	Proportion (%)
No impairment	7%
Mild impairment	21%
Moderate-to-severe impairment	52%

- The proportion of families that received benefit payments from social programs also increased with greater severity: 19% (5/27) for no impairment; 26% (10/38) for mild impairment, and 64% (16/25) for moderate-to-severe impairment (**Figure 4**)

**Figure 4** Benefit Payments Received From Social Programs

Upper limb impairment severity	Proportion (%)
No impairment	19%
Mild impairment	26%
Moderate-to-severe impairment	64%

- In most cases, a majority of non-medical costs were paid out of pocket by households, while governmental and non-governmental sources paid a minority of these costs (**Table 1**)

**Table 1** Proportions of Non-medical Expenses Paid Out of Pocket, by Government Sources, and by Non-governmental Sources

	No impairment n=27	Mild impairment n=38	Moderate-to-severe impairment n=25
Mean (SD) proportion of expenses paid out of pocket by households (%)			
Home and vehicle expenses (past 5 years)	85 (31)	70 (38)	78 (29)
Medical equipment expenses (past 5 years)	80 (37)	64 (44)	65 (42)
In-home professional caregiving (past 12 months)	63 (48)	10 (17)	24 (33)
Supportive therapy (past 12 months)	63 (52)	79 (39)	40 (55)
Mean (SD) proportion of expenses paid by governmental sources (%)			
Home and vehicle expenses (past 5 years)	3 (15)	6 (19)	7 (17)
Medical equipment expenses (past 5 years)	14 (35)	13 (29)	20 (32)
In-home professional caregiving (past 12 months)	38 (48)	90 (17)	76 (33)
Supportive therapy (past 12 months)	38 (52)	7 (19)	60 (55)
Mean (SD) proportion of expenses paid by non-household, non-governmental sources (%)			
Home and vehicle expenses (past 5 years)	12 (29)	25 (36)	15 (23)
Medical equipment expenses (past 5 years)	6 (19)	23 (39)	15 (24)
In-home professional caregiving (past 12 months)	0 (0)	0 (0)	0 (0)
Supportive therapy (past 12 months)	0 (0)	14 (38)	0 (0)

SD, standard deviation.

## Conclusions

- Households caring for individuals with DMD incur considerable non-medical expenses as UL impairment progresses
- Adaptations and modifications to homes and vehicles impose a large economic burden on the families of individuals with DMD regardless of their UL impairment
- Medical equipment expenses are also high for these families and escalate as UL impairment becomes more severe to accommodate disease progression
- Moderate-to-severe UL impairment is associated with considerably higher caregiving costs compared with less severe impairment
- Overall governmental and non-governmental financial contributions are substantial and represent a large societal economic burden

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