

Key Findings and Conclusions

- This study demonstrates the demanding nature of caregiving for people with DMD, and how these responsibilities impact caregivers' careers and productivity while working
- Caregivers of non-ambulatory recipients experienced a greater impact on their paid work compared to caregivers of ambulatory or transitional recipients



Discussion

- Caregiving responsibilities in DMD require caregivers to make accommodations and changes to their work-life
- Most caregivers experienced at least one work related change due to caregiving
- WPAI scores documented the profound impact of DMD caregiving on work productivity and activities; and all WPAI scores were higher for caregivers of non-ambulatory care recipients, indicating a greater level of impairment with DMD progression
- No other US-based studies have published WPAI scores for caregivers of people with DMD
 - A study with Portuguese caregivers (n=46) noted similar findings to those reported here⁵
- Comparisons between caregivers of one and two person(s) with DMD was limited by the small sample
- Continued research to evaluate the impact of DMD on caregiver employment and work productivity is warranted

ACKNOWLEDGMENTS & DISCLOSURES

SP, IFA, and KLG: Employees of Sarepta Therapeutics, Inc., and may own stock/options in the company. SMS, JSD and AB are employees of Broadstreet HEOR, which received funds from Sarepta Therapeutics, Inc. to conduct this study.

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<https://www.sareptacongresshub.com/ISPO R2024/ISPOR2024/caregiving-dmd>



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The Balancing Act of Paid Work and Caregiving in Duchenne Muscular Dystrophy (DMD): Results From a Cross-Sectional Survey

Patel S¹, Dunne JS², Audhya IF¹, Szabo SM², Bever A², Gooch KL¹

¹Sarepta Therapeutics, Inc., Cambridge, MA, USA

²Broadstreet HEOR, Vancouver, BC, Canada

INTRODUCTION

- Duchenne muscular dystrophy (DMD) is a rare, progressive pediatric neuromuscular disease characterized by diminishing functional ability and loss of independent ambulation
- As DMD progresses, affected individuals rely more heavily on their caregivers,¹⁻² which requires caregivers to make accommodations in their work life (paid employment)²
- While the impact of caring for people with DMD on paid work has been previously described,¹⁻⁵ contemporary US-based analyses on the impact on work experiences are lacking

OBJECTIVES

- As part of a larger survey, the aim of this analysis was to
 - Investigate the extent of paid work accommodations and lost productivity resulting from DMD caregiving
 - Explore the differences in work accommodations and lost productivity between caregivers of one- and two-person(s) with DMD; and between caregivers of those who are non-ambulatory vs. ambulatory

METHODS

- Caregivers of individuals with DMD from a prior study were recruited to complete a web-based survey
 - In the prior study, caregivers were recruited through Parent Project Muscular Dystrophy, a US-based DMD patient group⁶
- Ethics approval was solicited and informed consent obtained prior to participation
- The survey was programmed online (Qualtrics Core XM software) and included both closed- and open-ended questions covering topics relevant to work experience and work accommodations due to caregiving
- The Work Productivity and Activity Impairment for DMD caregivers (WPAI:DMD-CG, v2.0) questionnaire was included for those caring for a single person with DMD
 - Caregivers were asked how their child's DMD impacted their ability to work and perform regular activities in the last seven days
- As the WPAI is not validated for caregivers of multiple care recipients,⁷ caregivers of two were asked about the impact of caregiving on their usual activities and work productivity
- Responses were summarized descriptively and stratified by care recipient ambulatory status and number of care recipients per caregiver

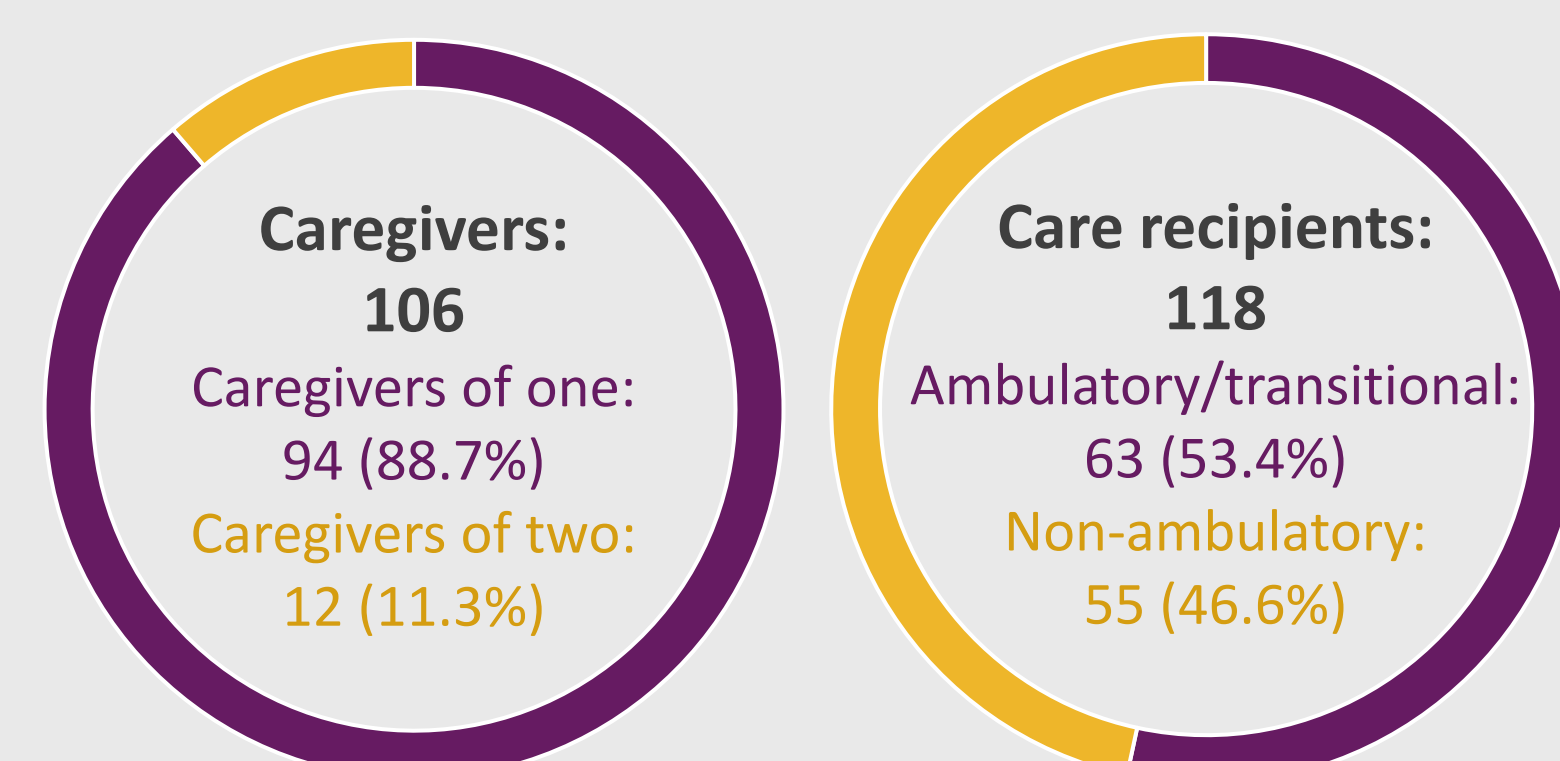
METHODS CONTINUED: WPAI SCORING

- Six questions are asked on the following:
 1. Currently employed (working for pay)
 2. Hours missed due to child's DMD
 3. Hours missed due to other reasons
 4. Hours actually worked
 5. Degree child's DMD affected productivity while working (scale of 0 to 10)
 6. Degree child's DMD affected regular activities (scale of 0 to 10)
- These variables are used to calculate percentage scores (range, 0-100%): overall activity impairment, time missed, impairment while working, and overall work impairment
- Higher WPAI scores indicated greater impairment and less productivity
- See supplemental material (via QR code) for additional information on WPAI scoring

RESULTS

Sample characteristics

- One hundred and six caregivers responded to the survey, representing 118 care recipients



- Sixty-seven percent of caregivers acted as the primary caregivers, and 32.1% provided an equal amount of care as another person
- Mean caregiver age was 46 years; 82.1% were mothers
- Mean age of care recipients was 14.5 years; 27.1% were non-ambulatory and on ventilation

Employment and income

- Sixty-eight percent of caregivers were employed (Table 1)

Table 1 Employment status*

	All	Number of care recipients		Ambulatory status	
		One	Two	Ambulatory/transitional	Non-ambulatory
N	106	94	12	63	55
Employed	72 (67.9)	64 (68.1)	8 (66.7)	45 (71.4)	35 (63.6)
Unemployed or retired	7 (6.6)	7 (7.4)	0	3 (4.8)	4 (7.3)
Homemaker, caregiver, or stay at home parent	29 (27.4)	25 (26.6)	4 (33.3)	16 (25.4)	17 (30.9)
Other	4 (3.8)	4 (4.3)	0	1 (1.6)	3 (5.5)

*Respondents could select multiple options

- Of those, 72.2% (52/72) worked full-time (≥ 35 hours per week), 25.0% (18/72) worked part-time (mean, 22.2 hours per week) and 4.2% (3/72) were self-employed
- Seven percent of caregivers identified as being unemployed/retired
 - Five percent of caregivers were unemployed because of their care recipient's DMD
- Twenty-seven percent of caregivers identified as being a homemaker, caregiver, or stay at home parent
- Employment status and income were similar when stratified by number of care recipients per caregiver and care recipient ambulation status
 - A lower proportion of caregivers of non-ambulatory care recipients (63.6%, 35/55) reported currently working for pay than caregivers of ambulatory or transitional care recipients (71.4%, 45/63)

Work accommodations due to caregiving

- Seventy-seven percent of caregivers experienced ≥ 1 job-related change due to caregiving (Figure 1)
- Twenty-six percent of caregivers took a lower paying job due to caregiving and reported an average reduction of \$25,000 income per year (Figure 1)



Figure 1 Job related change due to caregiving

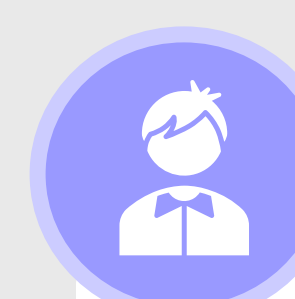
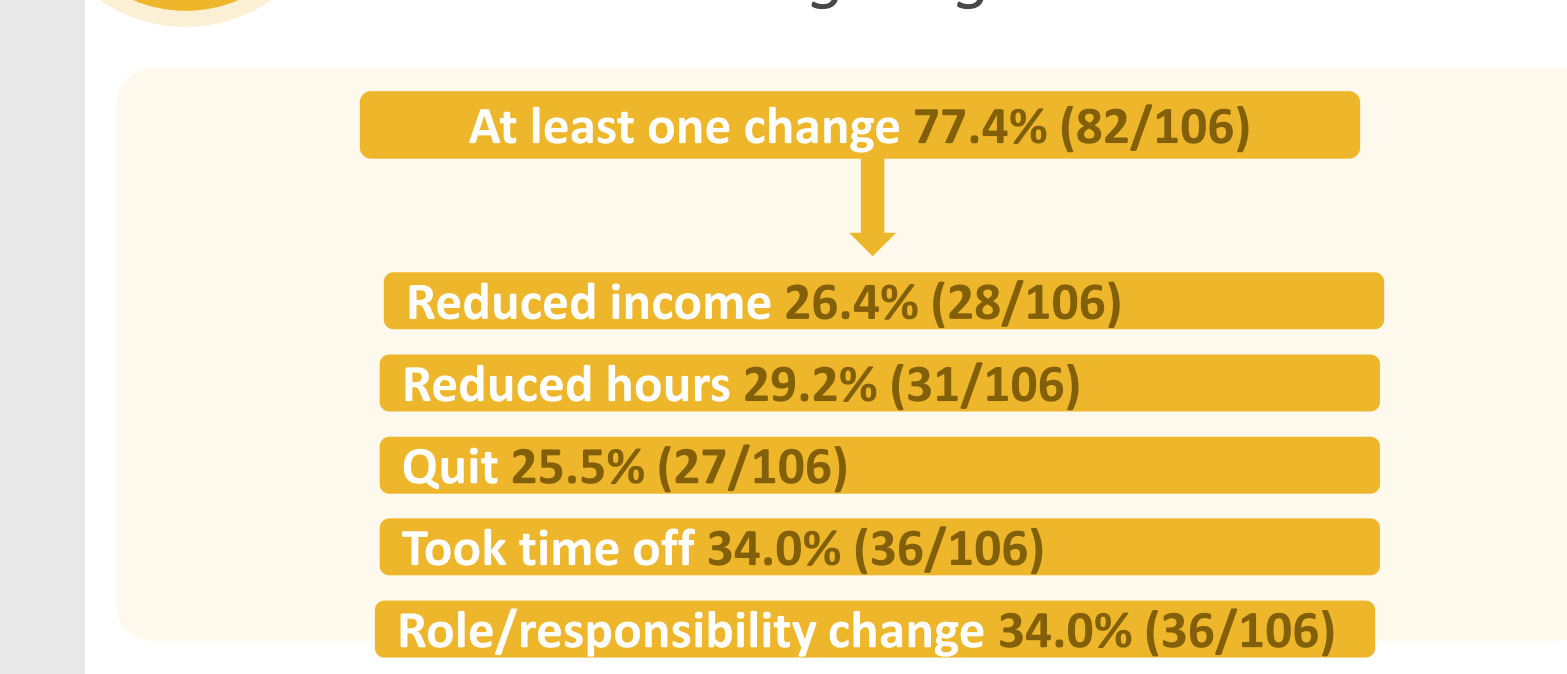
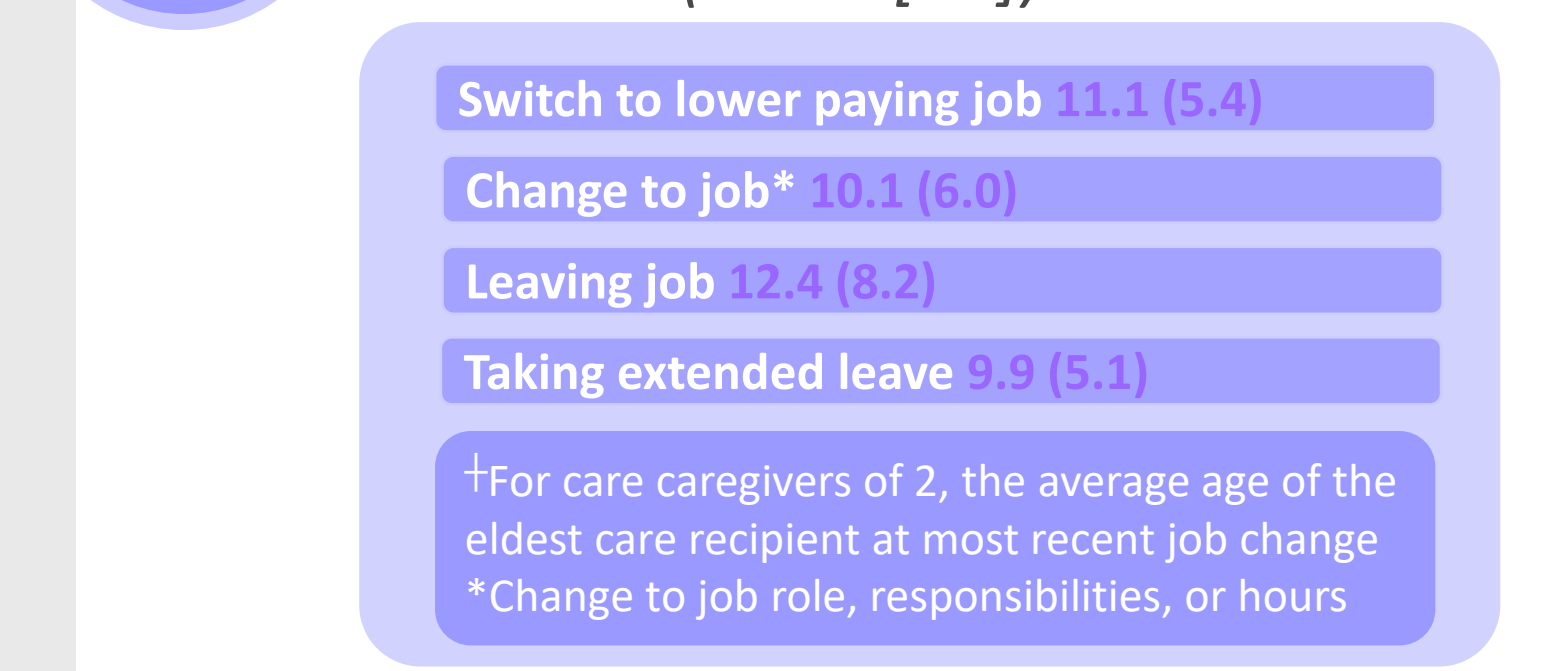


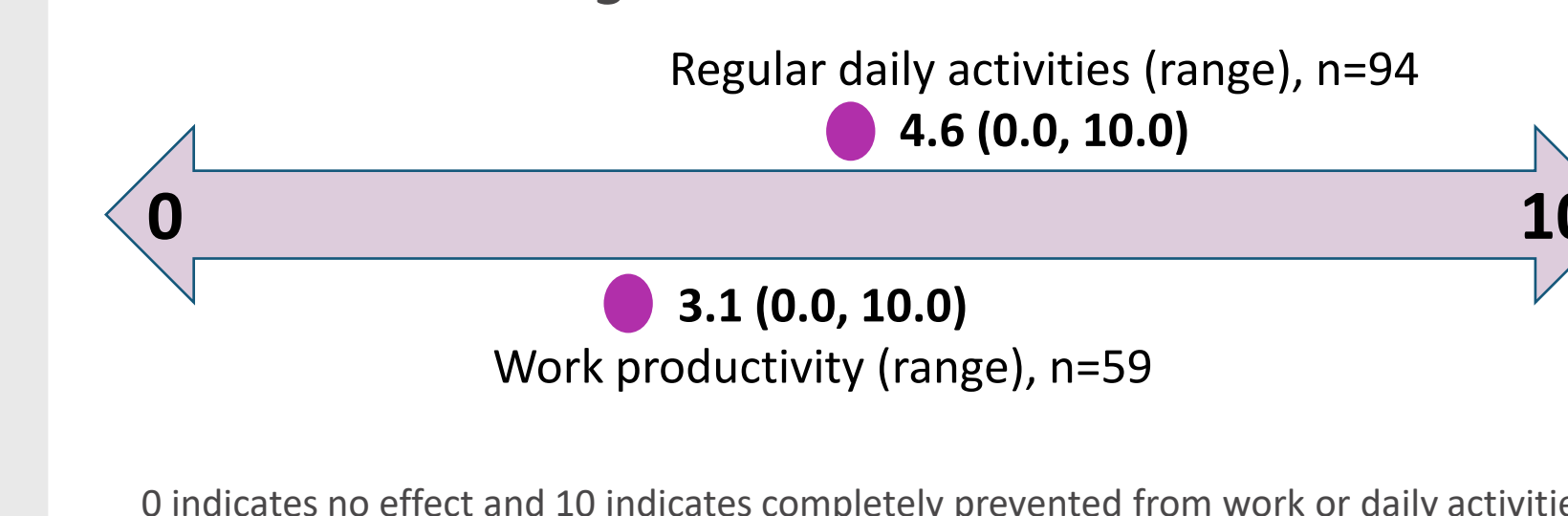
Figure 2 Care recipients age[†] (mean [SD]) at most recent...



- Additionally, 27.4% and 34.9% of caregivers reported they would work more hours or get a different job, respectively, were it not for their caregiving responsibilities
- These findings were similar when stratified by number of care recipients per caregiver and care recipient ambulation status

Impact of caregiving on productivity while working: WPAI:DMD-CG Caregivers of one care recipient (n=94)

Figure 3 Average effect of care recipient(s)'s DMD on caregivers':



- Caregivers of non-ambulatory care recipients (n=46) reported a higher effect of care recipients' DMD on regular daily activities than caregivers of ambulatory or transitional care recipients (n=48) (6.0/10 vs. 3.3/10)

Table 2 WPAI percentage scores

	All	Ambulatory status	
		Ambulatory/transitional	Non-ambulatory
Caregiver of one, N	94	48	60
Average overall activity impairment (SD)	40.7% (22.9%)	33.1% (19.1%)	60.2% (22.1%)
Employed, N	58*	34	24
Average work time missed (SD)	8.4% (13.4%)	6.5% (10.1%)	11.2% (17.1%)
Average impairment while working (SD)	30.5% (25.9%)	22.4% (18.9%)	42.1% (30.6%)
Average overall work impairment (SD)	34.8% (28.5%)	26.5% (21.7%)	46.6% (33.5%)

*One record removed as caregiver had not worked in previous 7 days

- On the WPAI, 62.8% (59/94) reported currently working for pay; 7 caregivers provided inconsistent responses to the employment status question earlier in the survey (Table 1)
- Caregivers reporting to be working for pay (n=59), on average worked 37.9 hours per week and missed 3.7 hours per week due to DMD
- On average, caregivers of non-ambulatory care recipients (n=24) missed more time from work due to DMD than caregivers of ambulatory or transitional care recipients (n=35) (4.5 vs. 3.1 hours); and caregivers of non-ambulatory care recipients also reported a higher affect of care recipients' DMD on work productivity (4.2/10 vs. 2.2/10)
- All WPAI percentage scores were higher for caregivers of non-ambulatory care recipients (Table 2)

Impact of caregiving on work and usual activities for caregivers of two care recipients (n=12)

- Sixty-seven percent (8/12) reported their usual activities were affected by DMD
- Employed caregivers (n=8) worked 40.3 hours/week, and missed 8.5 hours/week, on average, due to DMD
 - Five of these reported their work productivity was affected by DMD