

Assessing the Socioeconomic Impact of Duchenne Muscular Dystrophy on Carer's Life in Australia: A Cross-Sectional Study



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BACKGROUND

- **Duchenne muscular dystrophy (DMD)** is a severe, progressive neuromuscular disease, typically affecting males, leading to loss of ambulation in adolescence and premature mortality.¹
- **Caregiving** responsibilities place substantial psychological, physical, and financial **burden on families**.²
- Previous Australian studies estimated average household costs of AUD \$46,669 annually (2014) but did not capture the full spectrum of socioeconomic burden.³
- This study provides **updated real-world evidence** on the multidimensional impact of **caregiving** for individuals with DMD in **Australia**.

OBJECTIVES

1. To estimate the **direct, indirect, and non-medical costs of DMD** on households in Australia.
2. To evaluate the impact of caregiving on **quality of life (EQ-5D-5L)**, **psychological health (BDI)**, **caregiving burden (OCBS)**, and **work productivity (WPAI)**.
3. To compare caregiver outcomes by **disease severity** (ventilation vs no ventilation).

METHODS

Design: Retrospective, cross-sectional, multi-site survey (Feb 2025 - Mar 2025).

Recruitment: Through muscular dystrophy advocacy groups; snowball sampling.

Participants: Primary caregivers of DMD patients (n = 86 completed responses).

Instruments:

- Beck Depression Inventory (BDI)
- Oberst Caregiving Burden Scale (OCBS)
- EuroQol EQ-5D-5L
- Work Productivity & Activity Impairment Questionnaire (WPAI)

Severity grouping: Patients were stratified according to a 7-stage Duchenne Muscular Dystrophy (DMD) staging system (Stage 0-6), which reflects progressive functional decline from presymptomatic to full ventilatory support (6).

Analyses: Descriptive statistics and subgroup comparisons. P<0.05 considered significant.

RESULTS

EQ-5D-5L scores declined with increasing caregiver burden and psychological distress:

- Higher OCBS (difficulty) scores associated with lower EQ-5D (Figure 1). OCBS time were similarly correlated with EQ-5D.
- Higher BDI scores strongly correlated with reduced EQ-5D (Figure 2).

WPAI measures (overall impairment) showed weaker but consistent **negative associations** with **EQ-5D** (Figure 3). Other WPAI measures (absenteeism, presenteeism) were similar in their relationship and strength with EQ-5D.

NDIS funding increased with advancing DMD stage, peaking at Stage 5. Only one respondent was classified at Stage 6 (Figure 4).

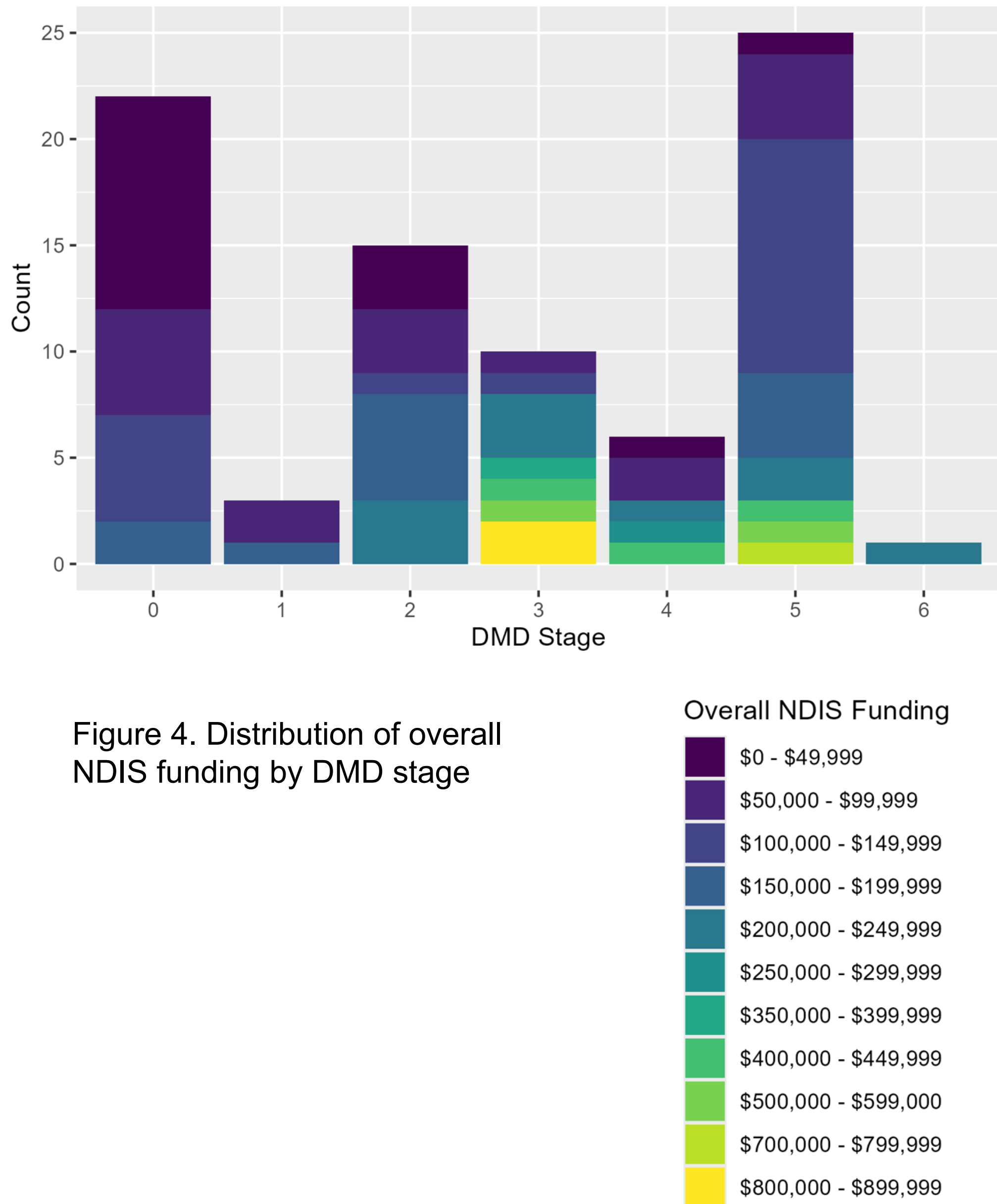


Figure 4. Distribution of overall NDIS funding by DMD stage

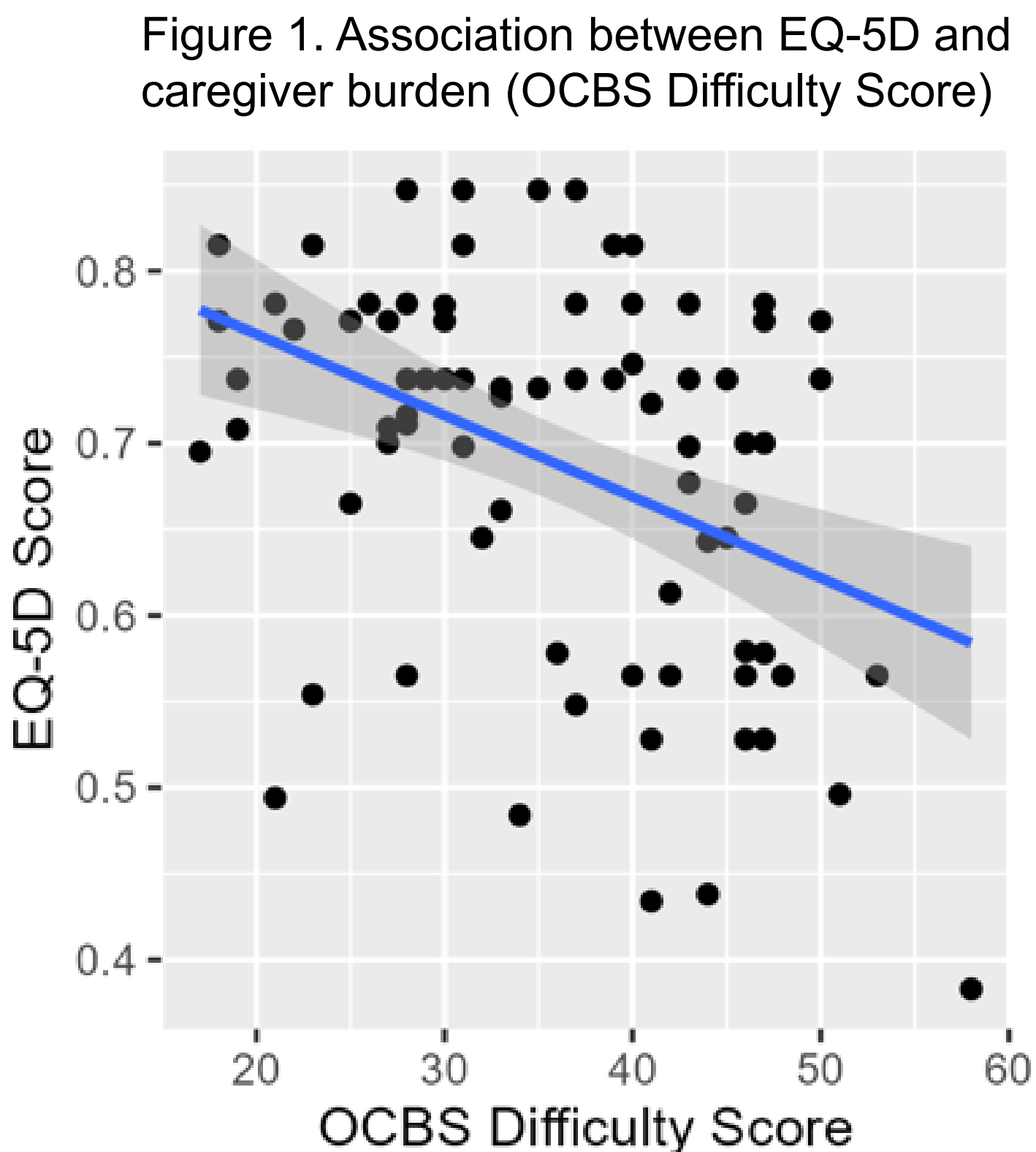


Figure 1. Association between EQ-5D and caregiver burden (OCBS Difficulty Score)

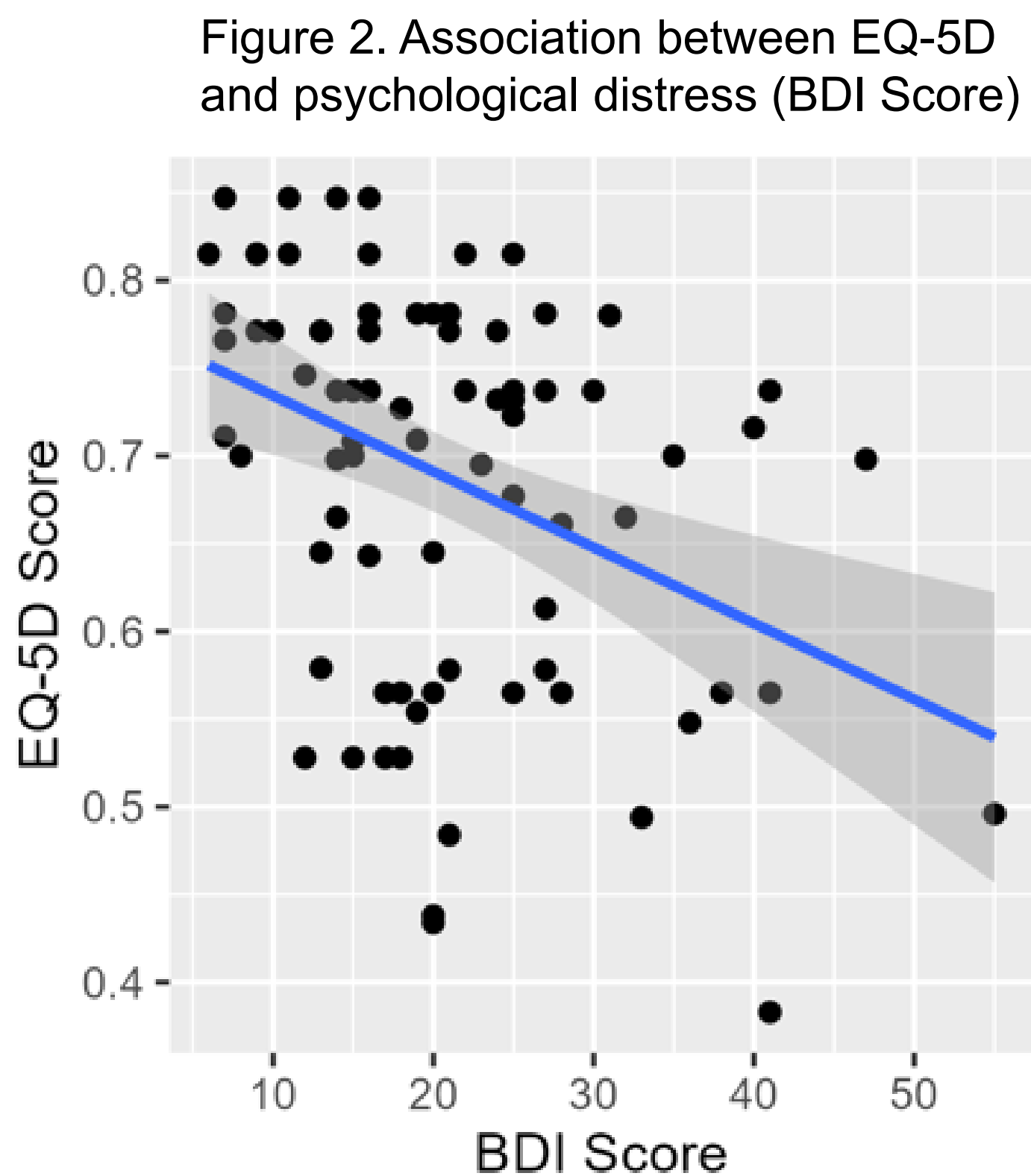


Figure 2. Association between EQ-5D and psychological distress (BDI Score)



Figure 3. Association between EQ-5D and work productivity impairment (WPAI)

CONCLUSION

- **Caregivers of DMD patients** experience substantial emotional, financial, and productivity burden.
- Burden increases with disease severity, particularly in terms of **depression risk** and **caregiving difficulty**.
- Findings support the need for policy and health system interventions to provide targeted mental health support and financial assistance for DMD families.

DISCLOSURES

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