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 ² Broadstreet HEOR, Vancouver, BC, Canada

Supplemental material

WPAI questionnaire: Scoring

- > The WPAI questionnaire assesses the impact of health conditions on ability to work and perform regular activities
- > The WPAI:DMD CAREGIVER is adapted for caregivers of people with DMD
- > Caregivers are asked how their child's DMD impacted their ability to work and perform regular activities in the last seven days

6 questions are asked on the following variables:

- Q1 = currently employed or working for pay (Y/N)
- Q2 = hours missed due to health problems (continuous)
- Q3 = hours missed due to other reasons (continuous)
- Q4 = hours actually worked (continuous)
- Q5 = degree child's DMD affected productivity while working (scale of 0 to 10)
- Q6 = degree child's DMD affected regular activities (scale of 0 to 10)

Scores are then calculated as follows:

- 1. Percent work time missed (absenteeism): Q2/(Q2+Q4)
- 2. Percent impairment while working (presenteeism): Q5/10
- Percent overall work impairment (absenteeism plus presenteeism*): Q2/(Q2+Q4)+[(1-(Q2/(Q2+Q4))x(Q5/10)]
- 4. Percent activity impairment: Q6/10
- Scores are multiplied by 100 to express in percentages
- > Higher WPAI scores indicate greater impairment and less productivity

*Overall work impairment is described as absenteeism + presenteeism, but the equation is an 'or' calculation: absenteeism + [(1-absenteeism) x presenteeism]

