Measuring Caregiver Health Spillover Effects Associated with Autism Spectrum Disorder:
A Comparison of the EQ-5D-3L and SF-6D

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Measures and data collected on children with Autism Spectrum Disorder (ASD) (manuscript section 2.2.1)

A number of clinical and health-related quality of life (HRQL) measures for children with ASD were selected from the Autism Treatment Network (ATN) site assessments including: autism severity scores, adaptive behavior scales, cognitive ability, a pediatric quality of life measure, and measures of emotional and behavioral problems.

Severity of autism was assessed with the Autism Diagnostic Observation Schedule (ADOS) score. The ADOS severity score assesses the severity of autism on communication and behavior of the child and ranges from 1 to 10 [1]. An ASD classification is related to an ADOS severity score of 4 and above.

HRQL of the child was assessed with two measures: the Pediatric Quality of Life Inventory 4.0 (PedsQL) and the Health Utilities Index Mark 3 (HUI-3). The PedsQL measures HRQL of the child using 23 questions on four domains: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items) [2]. The total scale score of the PedsQL ranges from 0 to 100, where higher numbers representing better HRQL. The HUI-3 measure includes eight dimensions (vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain), and its score ranges from -0.36 to 1, with -0.36 representing "worst possible health" and 1 representing "best possible health" [3].

The child's adaptive behavior (i.e., daily living and social skills) was measured with the Vineland Adaptive Behavior Scales Second Edition (Vineland-II) [4]. This instrument measures adaptive behavior according to four domains: communication, socialization, daily living skills, and motor skills. A higher Vineland-II score is indicative of better child adaptive functioning. Cognitive ability (IQ) of the child was measured with the Stanford-Binet Intelligence Scales, 5th Edition (SB-5), Abbreviated Battery [5]. This is an individually administered, standardized cognitive assessment that could be used with individuals aged 2 years and older, and scores

can range from 40 to 160. If the child could not be evaluated on the SB-5, the Mullen Scales of Early Learning, American Guidance Service Edition (range 50 to 150) [6] or the Bayley Scales of Infant and Toddler Development, 3rd Edition (range 49 to 155) [7] were used to assess cognitive ability. All three cognitive ability measures provide and age-standardized score with a mean of 100 and standard deviation of 15.

Behavior and emotional problems of the child were measured with the Child Behavior Checklist (CBCL). The CBCL uses age- and gender-standardized percentile scoring with an average of 50 and standard deviation of 10, where higher percentile ranking represents increased behavioral problems [8]. Furthermore, sleep behaviors of the children were assessed with the Children's Sleep Habits Questionnaire (CSHQ) [9]. The CSHQ includes 33 unique items that can be grouped into eight sleep domains (bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, sleep disordered breathing, and daytime sleepiness). A total score was calculated by summing the responses to all items (range 33 to 99). A higher total score indicates more disturbed sleep, and a score above 41 indicates clinically significant pediatric sleep problems.

Responses for the PedsQL, HUI-3, Vineland-II, CBCL, and CSHQ were reported by the caregiver; other child data came from clinical assessment.

We obtained information on the child's age and gender. Child's age was included in the analysis given the evidence that maladaptive behaviors among individuals with ASD improve with age, suggesting that younger children with ASD may require increased caregiving relative to older children with ASD [10, 11].

Measures and data collected on caregivers children with ASD (manuscript section 2.2.2)

Among caregivers, HRQL data was collected with two generic preference-weighted HRQL instruments: the three-level EuroQoL-5 Dimension (EQ-5D-3L) and the 12-item Short Form survey version 2.0 (SF-12 v2.0). The EQ-5D-3L (range -0.109 to 1) measures health utility using five dimensions (mobility, self-care, usual activities, pain/discomfort, and

anxiety/depression) with three response options each [12, 13]. The SF-12 v2.0 was used to derive the SF-6D (range 0.3 to 1), which contains six dimensions of health (physical functioning, role limitations, social functioning, pain, energy, and mental health) [14]. Both the EQ-5D-3L and the SF-6D measures provide a health utility score where 0 equals the score related to the state of death, and 1 represents the state of perfect health, and scores less than 0 represent states worse than death. Caregivers also responded to the EuroQol Visual Analogue Scale (EQ-VAS). The EQ-VAS measures general health on a visual analogue scale ranging from 0 (worst imaginable health state) to 100 (best imaginable health state).

The survey also collected information on the caregivers' age, gender, educational level, marital status, hours of sleep per night, depressive feelings and behaviors, care-related quality of life, and family-related quality of life.

Depressive symptoms of caregivers were assessed with the Center for Epidemiologic Studies Depression Scale (CES-D) (range 0 to 60) [15]. A total score was calculated with higher scores reflecting more depressive symptoms and a cut-off point of 16 indicating a high level of depressive symptoms.

Care-related quality of life was measured with the CarerQol-7D [16]. The CarerQol-7D indirectly measures care-related quality of life using seven dimensions related to informal caregiving, which can be described as care provided by family or friends: relational problems, mental health problems, problems with daily activities, financial problems, physical health problems, fulfillment, and support [17]. Using a tariff for the US, an index score of the CarerQol-7D was calculated ranging from 0 (worst informal caregiving situation) to 100 (best informal caregiving situation) [18].

Quality of life of families with children was assessed with the Family Quality of Life Scale (FQLS) according to five domains: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support [19]. The FQLS ranges from 25 to 125 with higher scores representing higher family quality of life.

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