



Caregiver-Reported Quality of Life in Youth with Down Syndrome

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Objectives To describe caregiver-reported quality of life (QOL) in youth with Down syndrome (DS) and to examine the role of obesity on QOL.

Study design Caregivers of youth with and without DS aged 10 through 20 years completed questionnaires examining QOL (Pediatric Quality of Life Questionnaire) and weight-related QOL (Impact of Weight on Quality of Life – Kids). Age- and sex-specific z scores were generated for body mass index. Obesity was defined as a body mass index ≥ 95 th percentile for age and sex.

Results Caregiver-reported Total QOL, Physical Health, and Psychosocial Health summary scores were all lower in the DS group compared with the non-DS controls ($P < .001$). Social and School Functioning were also lower ($P < .001$), but Emotional Functioning did not differ between DS and non-DS groups ($P = .31$). Physical Functioning ($P = .003$) and Total scores ($P = .03$) differed between youth without DS with and without obesity, but no differences were reported between youth with DS with and without obesity. On the Impact of Weight on Quality of Life – Kids, caregivers of youth with DS reported greater Body Esteem ($P = .020$) and Social Life scores ($P = .03$) than caregivers of non-DS youth. Caregivers of youth with obesity, regardless of DS status, reported significantly lower weight-specific QOL scores than caregivers of youth without obesity.

Conclusion Caregivers reported lower QOL in youth with DS compared with youth without DS with the exception of emotional functioning. Obesity influences most domains of weight-related QOL in youth with and without DS; therefore, providers should address weight concerns in youth with obesity even in the presence of DS. (*J Pediatr* 2017;189:98-104).

Clinical Trial Registration NCT01821300.

The World Health Organization defines quality of life (QOL) as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live in relation to goals, expectations, standards, and concerns.”¹ Measurements of QOL attempt to quantify a person’s or caregiver’s subjective evaluation of well-being across a variety of domains, each of which comprises the interaction of personal and environmental factors.

These domains include physical (eg, health, functional ability to work and/or attend school, and participation in leisure activities), emotional, and social well-being. This conceptual model is applicable to all persons, of all ages, with and without developmental disabilities.

Affecting 1 in approximately 700 live births,^{2,3} Down syndrome (DS) is one of the most common causes of developmental disability in the US. Moreover, with advances in medical management and care, 20-year survival probability of individuals born with DS is 88%.⁴ Life expectancy for DS has increased significantly from an average age of 9 years in 1900 to an estimated median survival of 58 years, with 25% of individuals with DS living to 62 years of age.^{5,6} QOL in individuals with DS, however, has received limited attention.

Individuals with DS are at greater risk for various medical conditions, including congenital cardiac defects, leukemia, thyroid dysfunction, hearing loss, visual disturbances, and obstructive sleep apnea, all of which, if left untreated, adversely can affect QOL.⁷⁻⁹ Individuals with DS are also at high risk for neurodevelopmental and behavioral disorders, such as intellectual disability (ID), speech and language disorders, autism spectrum disorder (ASD), and mood and anxiety disorders, which also can affect QOL.^{10,11}

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ABAS-II	Adaptive Behavior Assessment System-Second Edition
ASD	Autism spectrum disorder
BMI	Body mass index
DS	Down syndrome
ID	Intellectual disability
IWQOL-Kids	Impact of Weight on Quality of Life Questionnaire Kids
PedsQL	Pediatric Quality of Life Questionnaire
QOL	Quality of Life

DS also is associated with an increased risk for obesity,^{7,12} with an estimated prevalence of 47%-48% in adults¹³ and 30%-50% in children.¹⁴⁻¹⁶ Highlighting the potential implications for youth with DS, research in typically developing youth has found QOL among children with obesity to be lower than peers without obesity.^{17,18} The extent to which obesity influences QOL in youth with DS has yet to be established.

The investigation of QOL in youth with DS is essential to support the well-being of the individual throughout their lifespan. The purpose of this study was to examine and describe caregiver-reported QOL in children and adolescents 10-20 years old with DS. We also examined the role of obesity on QOL in this cohort.

Methods

The data for this secondary analysis of caregiver-reported QOL were derived from a cross-sectional study aimed at examining body composition and cardiometabolic risk in youth with DS vs typically developing youth of comparable age, sex, race, ethnicity, and body mass index (BMI) *z* score. The institutional review boards of the Children's Hospital of Philadelphia and Children's National Health System approved all procedures. Parental consent and participant consent or assent, when appropriate, were obtained.

Participants were male and female subjects aged 10-20 years and at least 1 caregiver. Exclusion criteria included major organ system illness not related to DS (except diabetes mellitus), current or previous oncologic process, cyanotic or unstable congenital heart disease, current pulmonary hypertension, pregnancy, genetic syndrome known to affect glucose tolerance, familial hypercholesterolemia, or current treatment with medications known to affect insulin sensitivity or lipids (other than diabetes agents in known diabetes mellitus). Given the primary aim of the larger study was examining cardiometabolic risk factors in DS, and ASD is more common in children with DS, children and adolescents with ASD were not excluded from the parent study. For this substudy, youth with DS and ASD (*n* = 16) were included, but non-DS participants whose caregiver reported a diagnosis of ASD were excluded (*n* = 2) to capture a typically developing cohort.

Questionnaires and Measures

Caregiver-perception of his/her child's health-related QOL was assessed with the use of the parent-proxy report of the Pediatric Quality of Life Inventory (PedsQL) Version 4.0. Versions of the PedsQL for 8-12 years old (child), 13-18 years old (adolescent), and 18-25 years old (young adult) were used. Caregivers completed the version that corresponded to the chronological age of their child. The instructions ask how much of a problem each item has been during the past 1 month. A 5-point response scale is used (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0-100 scale

(0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that greater scores indicate better QOL. Scale scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). If more than 50% of the items in the scale are missing, the scale score is not computed. The Physical Health Summary Score (8 items) is the same as the Physical Functioning Scale. To create the Psychosocial Health Summary Score (15 items), the mean is computed as the sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning Scales.¹⁹ The parent-proxy of the PedsQL has been used previously with caregivers of children, adolescents, and young adults with intellectual and developmental disabilities and has shown sound psychometric properties.²⁰

Parent perception of the effects of weight on his/her child's QOL was assessed with a caregiver-proxy version of the Impact of Weight on Quality of Life – Kids (IWQOL-Kids) questionnaire. The IWQOL-Kids is a validated, 27-item, self-report measure of weight-related QOL for youth ages 11-19 years. It yields 4 subscales (Physical Comfort, Body Esteem, Social Life, and Family Relations) and a Total score, which have strong psychometric properties, discriminate among weight status groups, and are responsive to weight change.^{21,22} Scaled scores are standardized and range from 0 to 100, with greater scores representing better weight-related QOL.

The Adaptive Behavior Assessment System-Second Edition (ABAS-II) Parent Form²³ is a widely used, caregiver-completed questionnaire that assesses adaptive behavior in individuals aged 5-21 years. Caregivers rate their child's ability to perform daily tasks correctly when needed. It consists of 9 subscales that form a Conceptual composite, a Social composite, and a Practical composite. The Conceptual composite comprises Communication, Self-direction, and Functional Academics subscales and is used to assess skills such as conversational turns, the ability to work independently, and keeping lists or reminders. The Social composite comprises the Leisure and Social subscales and is used to assess skills such as waiting turns and listening to others. The Practical composite comprises the Self-Care, Home Living, Health/Safety, and Community Use subscales and is used to assess skills such as rules for community safety, maintaining household duties, and finding public restrooms. The ABAS-II also yields a Global composite of overall adaptive functioning, the Global Adaptive Composite. The ABAS-II has demonstrated high internal consistency (*r* values range from 0.85 to 0.99) and high test-retest reliability (*r* values range from 0.80 to 0.90).²³

Weight (kilograms) was measured by digital electronic scale (Scale-Tronix; Welch Allyn Inc, Skaneateles Falls, New York), calibrated daily, and stature (centimeters) was measured on a wall-mounted stadiometer (Holtain Ltd, Crymych, United Kingdom) with the participant wearing light clothing without shoes by trained research anthropometrists using standard techniques. Age- and sex-specific *z* scores were generated based on Centers for Disease Control and Prevention 2000 growth charts²⁴ for BMI so that DS and non-DS groups were compared by the same reference. Obesity was defined as a BMI \geq 95th percentile for age and sex.

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