Disparities in Access to Healthcare Transition Services for Adolescents with Down Syndrome

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Objective To compare healthcare transition planning in adolescents with Down syndrome with adolescents with other special healthcare needs.

Study design Data were drawn from the 2009-2010 National Survey of Children with Special Health Care Needs, a nationally representative sample with 17 114 adolescents aged 12-17 years. Parents were asked whether providers and the study child had discussed shifting to an adult provider, changing healthcare needs, maintaining health insurance coverage, and taking responsibility for self-care. The transition core outcome was a composite measure based on the results of these 4 questions. Multivariable logistic regression determined the association between Down syndrome and the transition core outcome as well as each of the 4 individual component measures.

Results Although 40% of adolescents with other special healthcare needs met the transition core outcome, 11.0% of adolescents with Down syndrome met this outcome. Adolescents with Down syndrome were less likely to be encouraged to take responsibility for their health (32.2% vs 78.4%). After adjustment for demographic, socioeconomic, and health-related factors, adolescents with Down syndrome had 4 times the odds of not meeting the transition core outcome. For the component measures, Down syndrome adolescents had 4 times the odds of not being encouraged to take responsibility for self-care. Medical home access increased the odds of transition preparation.

Conclusions Adolescents with Down syndrome experience disparities in access to transition services. Provider goals for adolescents with Down syndrome should encourage as much independence as possible in their personal care and social lives. (J Pediatr 2018;[●●●:●●●:●●●].)

More than 90% of children with special healthcare needs (CSHCN) now survive into adulthood and approximately 500 000 CSHCN turn 18 years of age each year.1 Healthcare transition services help adolescents with special healthcare needs prepare for adult-oriented healthcare by encouraging independent management of their medical needs, preventing gaps in insurance coverage, and ensuring continued receipt of care during the transition to adulthood.2,3 The Maternal and Child Health Bureau (MCHB) has identified provision of transition services as 1 of 6 core performance outcomes that define a comprehensive system of care for all CSHCN4; however, only 40% of these children are currently meeting the transition outcome.5

Children with Down syndrome are a particularly vulnerable subgroup of CSHCN, as they have multiple comorbid conditions, incur high medical and social service costs, require frequent outpatient visits, and are more likely to experience unmet healthcare needs yet they are less likely to have a medical home compared with other CSHCN.6,8 The American Academy of Pediatrics has developed health supervision guidelines for children with Down syndrome with specific screening and anticipatory guidance recommendations from birth to early adulthood.9 According to these guidelines, providers should discuss transition planning and self-care at every health maintenance visit starting at age 13 years.9 These discussions also should promote community participation and independent living opportunities, which have both been associated with increased quality of life in young adults with Down syndrome.10,11 Despite the potential benefits of healthcare transition services for adolescents with Down syndrome, adherence to recommendations for transition planning in this population is unknown.

Due to their relative medical complexity, increased comorbidities, and multiple priority items on their health supervision checklist, we hypothesized that adolescents with Down syndrome are not receiving transition services as often as adolescents with other special healthcare needs (OSHCN). The goals of this study were to compare the prevalence of successful healthcare transition planning in adolescents with Down syndrome and adolescents with OSHCN and to examine the effect of different social and demographic factors on transition preparation.

Categorical codes 

CSHCN Children with special healthcare needs
MCHB Maternal and Child Health Bureau
NS-CSHCN National Survey of Children with Special Health Care Needs
OSHCN Other special healthcare needs

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Methods

All data are drawn from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a cross-sectional study sponsored by the MCHB and conducted by the National Center for Health Statistics. The NS-CSHCN is a list-assisted, random-digit-dial, telephone survey of US households in all 50 states and the District of Columbia with at least 1 resident child aged 0 through 17 years at the time of the interview. Since 2001, the NS-CSHCN has been conducted every 5 years to monitor national and state progress on 6 health system performance measures determined by the MCHB, including provision of transition services.\(^5\)\(^,\)\(^12\)\(^,\)\(^13\) For the 2009-2010 NS-CSHCN, data were collected between July 2009 and March 2011.

Respondents were the parents or guardians who knew the most about the health status of the children in the household. Households were screened for CSHCN using the Child and Adolescent Health Measurement Initiative CSHCN Screener.\(^14\) A total of 372,698 children residing in 196,159 households were screened for special healthcare needs. In households with multiple CSHCN, one child was selected randomly to be the subject of the detailed interview. Detailed interviews were completed for 40,242 CSHCN. Children with Down syndrome were identified by the parents’ response to the question: “Does (study child) currently have Down syndrome?” Because access to healthcare transition services for adolescents was the outcome variable in this study, only children ages 12 through 17 years were included in the analysis (n = 17,114).

Outcome Measure

The transition core outcome is a composite measure based on the results of 4 individual component measures. These component measures evaluated whether providers had discussed the following transition issues with the study child: (1) shifting to an adult provider, (2) adult healthcare needs, (3) maintaining health insurance coverage, and (4) increasing responsibility for self-care. The first component measure was assessed only if the child currently sees a provider who does not treat adults. For the first 3 component measures, if the parent indicated that a discussion on the topic did not occur, the parent was asked a follow-up question about whether a discussion on the topic would have been helpful. To meet the transition core outcome, the parent must indicate that each of the first 3 discussions either occurred or would not have been helpful and that the provider “always” or “usually” encourages the adolescent to take increased responsibility for healthcare needs.

Covariates

Ten variables that have been associated with transition planning in adolescents with special healthcare needs were included in the multivariable model. These covariates were age, sex, race/ethnicity, primary language at home, 3 disease severity variables, type of insurance coverage, household income, and access to a medical home.\(^7\) Age was dichotomized at 12-14 years and 15-17 years. Disease severity was captured by the presence of functional limitations, the number of comorbid conditions, and the number of qualifying screening criteria on the CSHCN Screener, a 5-item tool that identifies children as having special healthcare needs if they experience at least 1 of 5 health consequences due to their health condition.\(^14\) CSHCN who qualify on more screener items or experience functional limitations have more complex healthcare needs.\(^5\)\(^,\)\(^12\)\(^,\)\(^13\)\(^,\)\(^16\) The presence of comorbidities, which have been associated with unmet healthcare needs in children with Down syndrome,\(^7\) was determined by the parents’ response to whether or not the study child had any of 19 other conditions: attention deficit/hyperactivity disorder, depression, anxiety, behavioral or conduct problems, autism spectrum disorder, developmental delay, intellectual disability, asthma, diabetes, epilepsy, migraines, traumatic brain injury, heart problems, blood problems, cystic fibrosis, cerebral palsy, muscular dystrophy, arthritis, or allergies. The American Academy of Pediatrics medical home definition was operationalized through a series of questions designed to measure the 5 key subcomponents of the medical home—whether the child has a personal doctor or nurse, has a usual source of care for sick and well-child visits, receives family-centered care, receives effective care coordination, and is able to obtain needed referrals.\(^17\)\(^,\)\(^18\)

Statistical Analyses

Statistical analyses were conducted via StataSE 12.0 software (StataCorp LP, College Station, Texas). All analyses accounted for the complex sampling design according to National Center for Health Statistics guidelines.\(^19\) With the exception of household income, all survey responses recorded as “don’t know” or “refused” were coded as missing. Poverty-level estimates incorporated imputed household income values for missing data by using a single-imputation approach described in the survey procedures.\(^20\)

Descriptive characteristics of adolescents with Down syndrome and adolescents with OSHCN were compared with the \(\chi^2\) test for proportions and \(t\) test for means. The proportion of adolescents who met the core transition outcome and each individual component measure also were compared between those with Down syndrome and those with OSHCN via the \(\chi^2\) test. Logistic regression was performed to estimate crude OR and aOR and 95% CI for the association between a Down syndrome diagnosis and transition preparation. In adjusted logistic regression, the dependent variable was defined as not meeting the transition core outcome and its component measures, which is consistent with previous publications using the NS-CSHCN.\(^5\)\(^,\)\(^12\) The Walter Reed National Military Medical Center Institutional Review Board determined that this study was exempt from human subjects review.

Results

Our study determined that an estimated 0.9% of adolescents with special healthcare needs had Down syndrome. Demographic characteristics of adolescents with Down syndrome (n = 151) and adolescents with OSHCN (n = 16,963) are shown in Table I. Adolescents with Down syndrome qualified as

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