Receipt of Services for Transition From Pediatric to Adult Health Care Among Youth With Chronic Medical Conditions: A Cross-Sectional Analysis of the 2022 National Survey of Children's Health

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Introduction: All youth can benefit from health care transition (HCT), the process by which individuals are prepared and supported to leave the family-centered model of pediatric care and enter the autonomous model of adult care. For youth with medical conditions that require enhanced and continuous care (eg, those requiring critical medications, subspecialty care, frequent imaging), HCT services are especially crucial to avoid care disruptions and poor health outcomes. In this cross-sectional study, we sought to explore receipt of HCT services among youth with certain medical conditions, as reported by their caregivers in a nationally representative annual survey.

Methods: Using the 2022 National Survey of Children's Health (NSCH), we examined HCT services received by youth aged 12 to 17 with the following conditions: blood disorders, epilepsy/seizure disorders, asthma, and heart conditions. Additional health conditions will be examined in future steps. Each medical condition group was compared to youth without that condition. Additionally, youth having any special health care need (SHCN) were compared to non-SHCN youth. Sufficient receipt of HCT services was measured as a composite of the following NSCH questionnaire items: (1) whether the youth's doctor discussed the shift to a health care provider (HCP) who treats adults (if the HCP treats only children); (2) whether the HCP actively worked with the youth to make positive choices about their health, gain skills to manage their health and health care, and understand the changes in health care that occur at age 18; and (3) whether the HCP spent time alone with the youth during an appointment in the previous 12 months. Responses to individual transition-related questionnaire items also were explored across health conditions. Data were analyzed using survey procedures in SAS 9.4 to account for the complex survey weights and design variables of the NSCH. Unadjusted bivariate analyses were performed to compare rates of meeting the HCT measure across subgroups of interest, and a design-adjusted Rao-Scott chi square test was applied to assess whether health-condition subgroups differed in receipt of HCT services. Multivariable logistic regression modeling is underway to explore the extent to which having a certain chronic condition was related to receiving HCT services and to evaluate whether a priori–identified covariates confounded or modified the association of interest.

Results: In 2022, HCT services were received by 23% of youth with SHCN and 17% of youth without SHCN. Our preliminary findings (Table 1) suggest no statistically significant difference in HCT service receipt for youth with (vs without) chronic blood disorders (eg, sickle cell disease, thalassemia). Similarly, youth with asthma, epilepsy/seizure disorders, or heart conditions did not significantly differ from youth without these conditions in receipt of HCT services. However,

some potential differences were noted across severity levels of these conditions (data not shown). Specifically, 16% of youth with mild heart conditions received HCT services by the composite criteria, compared with 30% of youth with moderate or severe heart conditions. Similarly, 46% of those with moderate epilepsy/seizure disorders met HCT criteria, compared with only 18% and 14% of those with mild or severe epilepsy/seizure disorders, respectively. Numerous differences also were noted when individual HCT-related questionnaire items were compared for youth with each health condition (vs without) (Table 2). Youth ever diagnosed with asthma had significantly higher rates of working with their doctors to gain skills to manage their own health ($p = 0.002$) and working with the health care provider to make a written plan for HCT ($p < 0.0001$) in comparison to those never diagnosed with asthma. Additionally, youth ever diagnosed with epilepsy/seizure disorders had significantly higher rates of transitioning to a doctor who treats adults ($p = 0.009$) and working with their health care provider to make a written plan for HCT ($p < 0.0001$) as compared to those never diagnosed with epilepsy/seizure disorders.

Conclusion: Preliminary results suggest that youth with SHCN are more likely to receive HCT services than youth without SHCN, but fewer than one-quarter of US youth overall received sufficient preparation to transition to adult medical care in 2022. Various subgroups also show differences in meeting individual transition measures. These will be further analyzed to better understand the reasons for meeting HCT services overall. Additional work is ongoing to explore HCT receipt across groups with similar sociodemographic characteristics and by measures of youth physical functioning, mental health status, and caregiver-reported transition readiness.

Table 1. Weighted percentages of youth with (vs without) certain chronic conditions who received services necessary for health care transition (HCT)[a]

Medical Condition in Youth (Caregiver-reported)	Percentage Receiving HCT Services, Weighted		*p*[b]
Heart Condition (Ever Diagnosed)	**Yes** 18.10	**No** 17.86	0.93
Asthma (Ever Diagnosed)	**Yes** 19.13	**No** 17.62	0.31
Epilepsy/Seizure Disorders (Ever Diagnosed)	**Yes** 23.39	**No** 17.78	0.42
Sickle Cell Disease	**Yes** 48.12	**No** 44.56	0.83
Thalassemia	**Yes** 46.15	**No** 44.00	0.86

[a]Data are from the 2022 National Survey of Children's Health (NSCH).

[b]Statistical significance was assessed using the Rao-Scott chi square test, to account for the complex sampling strategy of the NSCH.

Table 2. Comparison of weighted percentages of youth with (vs without) certain health conditions affirming individual HCT-related items,[a] as reported by caregivers.

Medical Condition in Youth (Caregiver-reported)		Youth discussed seeing a doctor who treats adults	Youth worked with doctor to make positive choices	Youth worked with doctor to gain skills to manage health	Youth worked with doctor to understand health care changes at age 18	Youth received a summary of their medical history	Youth worked with doctor to prepare written plan for HCT	Caregiver knows how the youth will be insured as an adult
Heart Condition (Ever Diagnosed)	**With**	37.68%	74.47%	68.68%	40.57%	74.45%	36.08%	6.12%
	Without	21.95%	75.40%	67.72%	45.82%	73.92%	25.80%	6.33%
	***p*[b]**	0.6	0.8	0.8	0.2	0.9	**0.003**	0.95
Asthma (Ever Diagnosed)	**With**	20.84%	78.47%	73%	45.09%	75.89%	35.66%	6.12%
	Without	22.07%	74.93%	66.90%	45.81%	73.55%	24.50%	6.39%
	p	0.55	0.1	**0.002**	0.7	0.2	**<0.0001**	0.85
Epilepsy/Seizure Disorders (Ever Diagnosed)	**With**	32.19%	79.77%	74.39%	43.27%	81.76%	51.60%	2.80%
	Without	21.75%	75.39%	67.76%	45.64%	73.82%	25.85%	6.34%
	p	**0.009**	0.9	0.2	0.7	0.06	**<0.0001**	0.2
Sickle Cell Disease	**With**	37.68%	91.23%	96.09%	57.10%	96.80%	81.04%	24.90%
	Without	42.32%	93.41%	77.62%	61.81%	76.36%	51.82%	19.24%
	p	0.8	0.8	**0.001**	0.8	**<0.0001**	**0.05**	0.76
Thalassemia	**With**	54.85%	93.30%	80.79%	67.46%	83.70%	43.61%	0
	Without	34.45%	92.27%	80.39%	59.63%	78.12%	55.53%	25.55%
	p	0.08	0.8	1.0	0.6	0.56	0.2	--

[a]Data are from the 2022 National Survey of Children's Health (NSCH).

[b]Statistical significance (was assessed using the Rao-Scott chi square test, to account for the complex sampling strategy of the NSCH; $p \leq 0.05$ was considered a significant between-group difference (values in bold).