Health Care Use During Transfer to Adult Care Among Youth With Chronic Conditions

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OBJECTIVE: To compare health care use and costs for youth with chronic health conditions before and after transfer from pediatric to adult health care services.

abstract

METHODS: Youth born in Ontario, Canada, between April 1, 1989, and April 1, 1993, were assigned to 11 mutually exclusive, hierarchically arranged clinical groupings, including "complex" chronic conditions (CCCs), non-complex chronic conditions (N-CCCs), and chronic mental health conditions (CMHCs). Outcomes were compared between 2-year periods before and after transfer of pediatric services, the subjects' 18th birthday.

RESULTS: Among 104 497 youth, mortality was highest in those with CCCs, but did not increase after transfer (1.3% vs 1.5%, P = .55). Costs were highest among youth with CCCs and decreased after transfer (before and after median [interquartile range]: \$4626 [1253–21 435] vs \$3733 [950–16 841], P < .001);Costs increased slightly for N-CCCs (\$569 [263–1246] vs \$589 [262–1333], P < .001), and decreased for CMHCs (\$1774 [659–5977] vs \$1545 [529–5128], P < .001). Emergency department visits increased only among youth with N-CCCs (P < .001). High-acuity emergency department visits increased CCCs (P = .04) and N-CCCs (P < .001), but not for CMHC (P = .59), who had the highest visit rate. Among the 11 individual conditions, costs only increased in youth with asthma (P < .001), and decreased (P < .05) in those with neurologic impairment, lupus, inflammatory bowel disease, and mood/affective disorders.

CONCLUSIONS: Pediatric transfer to adult care is characterized by relatively stable short-term patterns of health service use and costs among youth with chronic conditions.

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Dr Cohen conceptualized and designed the study, interpreted the data, drafted and revised the manuscript; Ms Gandhi and Drs Toulany, Moore, Orkin, Levy, and Stephenson drafted and revised the manuscript and interpreted the data; Mr Fu performed data analysis and interpretation, and reviewed the final manuscript; Dr Guttmann conceptualized and designed the study, obtained funding, interpreted the data, and provided critical revisions to the study; and all authors provided critical revisions of the manuscript and approved the final version.

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WHAT'S KNOWN ON THIS SUBJECT: Growing numbers of youth with chronic conditions are surviving into adulthood. Studies have shown that transfer to adult care is often suboptimally executed with adverse outcomes reported; however, these evaluations are based primarily on small samples and single-disease populations.

WHAT THIS STUDY ADDS: Overall patterns of mortality, health service use, and costs remained relatively stable after pediatric transfer to adult care across cohorts of youth with varied chronic conditions in a universal health care system.

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A growing number of youth with chronic health conditions are surviving into adulthood (\sim 750 000 annually in the United States) who require transfer from a child- to adult-focused health care system.¹⁻³ Transfer of youth with chronic health conditions to adult care is often suboptimal due to factors such as emotional and cognitive developmental challenges, lack of individual and family-centered social supports, communication and coordination challenges between health care sectors, and a lack of appropriately trained adult health care providers.⁴ Decline in health after transfer of care to adult health care providers is well described, possibly due to lapses in adherence, follow-up, and/or insurance coverage⁵; however, most studies reporting this phenomenon have focused on single populations such as those with sickle cell disease,⁶ diabetes mellitus,⁷ or organ transplantation,^{8,9} and relatively little is known about those with chronic mental health¹⁰ and neurodevelopmental conditions. Population-level description of health care use and mortality during transfer may illuminate the pervasiveness of this problem among broad groups of youth transferring to adult care. In Canada, virtually all pediatric primary care, specialist, and hospital care are mandated by provincial funders to transfer by age 18 years, although not all aspects of care are transferred by this age (eg, primary care provided by family physicians); this provides a unique opportunity to assess the impact of this sentinel event on outcomes. The objective of this study was to compare the patterns of health care use and outcomes before and after transfer to adult care among universally insured youth with varied chronic conditions. We hypothesized that transfers are executed poorly and thus lead to increased avoidable health care use, including

emergency department visits and hospitalizations.

METHODS

Study Design and Setting

Data for this longitudinal cohort study were obtained from population-based administrative health datasets at the institute for Clinical Evaluative Sciences (ICES), allowing linkage of individual health records across databases over time, using encoded identifiers for all residents of Ontario, Canada's most populous province (~14 million). Ethical approval was granted by the Sunnybrook Health Sciences Centre Research Ethics Board.

Data Sources

Cohorts were developed from selected disease registries derived from validated algorithms by using health administrative data, including Pediatric inflammatory Bowel Disease, Ontario Diabetes Database, and the Ontario Asthma Database registries.^{11–13} A clinical registry of all children seen at the 4 provincial pediatric rheumatology clinics was used to define those with systemic lupus erythematosus (SLE).^{14,15} Additional cohorts were defined by using the international Classification of Diseases, Ninth (ICD-9; until 2002) and 10th Revisions (ICD-10), and Diagnostic and Statistical Manual of Mental Disorders, Text Revision (DSM-IV TR) diagnostic codes from inpatient discharge records (Discharge Abstract Database and the Ontario Mental Health Reporting System).

Outpatient physician visit and billing data were obtained from public health insurance data (Ontario Health insurance Plan [OHIP]). Physician specialty was determined from the ICES Physician Database. Primary care delivery by a usual provider of care was determined by using physician claims from OHIP, and the Client Agency Program Enrollment database, assigning enrollment of individuals to a provider in a specific program or group. Home care service visits were captured from the Home Care Database, which records all government-funded home health care. The Ontario Drug Benefit Program data were used to enumerate children whose families are on social support (Ontario Works) and describe outpatient drug use for eligible children. The Registered Persons Database provides demographic information for Ontarians. Postal codes were linked to the 2006 Canadian Census to obtain mean neighborhood income quintile for each dissemination area (population 400–700 inhabitants) that are adjusted for both household size and community size. Immigrant status (nonimmigrant, immigrant, and refugee) was obtained by using the Citizenship and Immigration Canada database, which includes records of permanent residents that applied to land in Ontario since 1985. Other data used included emergency department (ED) visits (National Ambulatory Care Reporting System), and admissions to rehabilitation (National Rehabilitation Reporting System) and continuing care (Continuing Care Reporting System).

Study Population

Youth with at least 1 of 11 chronic conditions, born between April 1, 1989, and April 1, 1993 (last date of follow-up March 31, 2013) were included. Chronic conditions were sorted hierarchically into mutually exclusive condition categories. At the top of the hierarchy was neurologic impairment (NI), defined as diagnoses consistent with static or progressive neurologic, genetic, or other diseases that typically result in functional and/or intellectual impairment,¹⁶ followed by the following chronic conditions: congenital heart disease (CHD), cystic fibrosis (CF), systemic lupus erythematosus (SLE), sickle cell disease (SCD), inflammatory bowel disease (IBD), type 1 diabetes mellitus (DM), and asthma. Last, we explored 3 chronic mental health conditions: eating disorders, schizophrenia and related psychotic disorders (SZ), and mood and affective disorders (MA). For descriptive purposes, the clinical conditions were grouped into (1) complex chronic conditions (CCC; NI, CF, SLE, SCD), which were operationally defined as chronic medical conditions in which multiple morbidities and/or multiorgan manifestations are common,¹⁷ (2) "noncomplex" chronic conditions (N-CCC; CHD, IBD, DM, asthma), defined as chronic conditions typically affecting a single organ system, and (3) chronic mental health conditions (CMHC; eating disorders, SZ, MA).

CHD, CF, and SCD were defined based on hospital discharge records in any field, from birth to age 16. NI and CMHC were defined similarly, but obtained from hospitalization discharges from ages 10 to 16 to try to ensure activity of the underlying conditions necessitating transfer (see Supplemental Table 3 for diagnostic codes used in constructing these cohorts). SLE, IBD, DM, and asthma were defined from records in disease registries. Sensitivity and specificity of these disease definitions using ICES databases are previously reported.11-13

Excluded were youth born before fiscal year 1989 (1991 for the CHD cohort, as CHD categorization requires birth records that were only available at ICES in 1991), those who died before 16 years of age, or those without continuous residency in Ontario from ages 10 to 20 years. To focus the analysis to youth with a high likelihood of ongoing active chronic conditions, for asthma, we excluded those with no asthma-related health care visits (physician, ED, hospitalization) from 10 to 16 years of age. CHD diagnoses were reviewed with a pediatric cardiologist and excluded diagnoses that were very unlikely to have any residual health effects after early

childhood or once repaired (eg, isolated patent ductus arteriosus).

Health Service Utilization and System Costs

Health service utilization and systems costs were examined by sector. Type of service use included acute care (hospital) admissions, ICU admissions, ED visits, admissions to rehabilitation and complex continuing care (longterm care) facilities, outpatient drugs, primary care and specialist physician visits, and home care service visits. ED visits were subdivided based on the validated, ordinal (5-level) Canadian Triage Acuity Scale (CTAS)¹⁸ into "low" (CTAS 1–3) and "high" acuity (CTAS 4–5).

Service costs were determined from payments to providers using service-specific unit costs. The costs of nonpsychiatric hospitalizations, ED visits, and inpatient rehabilitation were estimated by using case mix methodology, where case cost is determined based on resource weight during an episode of care and applicable unit costs. Complex continuing care and inpatient psychiatric hospitalization case costs were calculated by using measures of resource intensity, length of stay, and per diem costs. Further information on case-costing methodology using administrative data sources in Ontario are available online.19,20

Analysis

The subjects' 18th birthday was defined as the index date, the age of transfer. We compared descriptive patterns of health service utilization and system costs, overall and by sector, calculated over 2-year periods before (age 16–18 years) and after index (age 18–20 years). Differences in demographic characteristics and health service use across cohorts at baseline (age 10–16 years) were examined by using either 1-way analysis of variance (means), Kruskal-Wallis (medians), or χ^2 (categorical) tests. Wilcoxon signed-rank tests

and χ^2 tests were used to compare health service utilization, costs, and mortality within groups, before and after transfer. Paired *t* tests were used to examine the contribution of costs before and after transfer, for each health care sector. Analyses were performed with SAS version 9.4 (SAS institute, inc, Cary, NC). Significance was defined as *P* < .05 (2-tailed).

RESULTS

Clinical and Demographic Characteristics

Among 104 497 youth identified as having chronic conditions, 2520 (2.4%) had CCCs (2118 with NI, 147 with CF, 94 with SLE, and 161 with SCD), 99 433 (95.2%) had N-CCCs (3436 with CHD, 860 with IBD, 2883 with DM, and 92 254 with asthma) and 2544 (2.4%) had a CMHC (374 with an eating disorder, 184 with SZ, and 1986 with MA) (Table 1). Boys made up more than half the study population (56.1%), with a preponderance of girls (71.7%) among mental health conditions (*P* < .001). Across groups, a higher proportion of youth with CCCs were recipients of Ontario Works family financial assistance (44.7%, *P* < .001) and new immigrants or refugees (6.3%, P = .001). Primary care was delivered primarily by family physicians across all 3 groups, with the highest rates of pediatrician-delivered primary care in youth with CCCs (27.1%, P <.001). Disease-specific characteristics showed that low-income status was most common among youth with SCD (45.3%), whereas family financial assistance (Ontario Works) was most common among youth with NI (46.3%). Low-income and financial assistance were least common among those with eating disorders (9.9% and 9.4%, respectively).

Posttransfer Mortality, Health Service Use and Costs

The highest mortality rate was in youth with CCCs, pre- (1.3%) and

TABLE T Demographic characteristics and health Service use at Baseline Among Youth with chronic health conditions, i	JY GIINICA	ai Group
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Demographic Characteristics	Overall <i>n</i> = 104 497	CCC <i>n</i> = 2520	N-CCC <i>n</i> = 99 433	CMHC <i>n</i> = 2544	Р
Gender, <i>n</i> (%)					
Girls	45 898 (43.9)	1199 (47.6)	42874 (43.1)	1825 (71.7)	<.001
Boys	58 599 (56.1)	1321 (52.4)	56559 (56.9)	719 (28.3)	
Neighborhood income quintile, n (%)					
1 (lowest)	18654 (17.9)	548 (21.7)	17601 (17.7)	505 (19.9)	<.001
2	19746 (18.9)	493 (19.6)	18783 (18.9)	470 (18.5)	
3	20983 (20.1)	498 (19.8)	20021 (20.1)	464 (18.2)	
4	22077 (21.1)	476 (18.9)	21 068 (21.2)	533 (21.0)	
5 (highest)	22670 (21.7)	495 (19.6)	21 624 (21.7)	551 (21.7)	
Family Financial Assistance (Ontario Works), n	15797 (15.1)	1126 (44.7)	14 149 (14.2)	522 (20.5)	<.001
(%)					
Rurality, n (%)					
Urban	92 401 (88.4)	2187 (86.8)	88011 (88.5)	2203 (86.6)	.002
Rural	12057 (11.5)	331 (13.1)	11 387 (11.5)	339 (13.3)	
Immigrant status, <i>n</i> (%)					
Nonimmigrant	99 581 (95.3)	2360 (93.7)	94794 (95.3)	2427 (95.4)	.001
Immigrant	3702 (3.5)	114 (4.5)	3501 (3.5)	87 (3.4)	
Refugee	1214 (1.2)	46 (1.8)	1138 (1.1)	30 (1.2)	
Usual provider of care, n (%)					
Family physician	85 646 (82.0)	1679 (66.6)	81772 (82.2)	2195 (86.3)	<.001
Pediatrician	12792 (12.2)	684 (27.1)	11846 (11.9)	262 (10.3)	
No provider	6059 (5.8)	157 (6.2)	5815 (5.8)	87 (3.4)	
Health service use at baseline ^a ,median (IQR)					
No. hospitalizations	0 (0-0)	1 (0-2)	0 (0-0)	1 (1-2)	<.001
No. primary care visits	10 (6-17)	13 (7-23	10 (6-17)	14 (8–22)	<.001
No. visits to UPC (family physician)	3 (2-6)	3 (2-6)	3 (2-6)	4 (2–8)	<.001
No. visits to UPC (pediatrician)	3 (2-6)	4 (2-7)	3 (2-6)	4 (2–8)	<.001
Technological dependence (since birth), n (%)	1490 (1.4)	465 (18.5)	1016 (1.0)	9 (0.4)	<.001
UPC = Usual Provider of Care ^a Age 10 to 16 y					

posttransfer (1.5%). Mortality rates did not significantly change in any groups (Table 2). Overall health system costs were highest among youth with CCCs but decreased during transfer (pre- and postmedian [interquartile range (IQR)]: \$4626 [1253–21 435] vs \$3733 [950–16 841], P < .001). Overall costs increased slightly for N-CCCs (median [IQR]: \$569 (263–1246) vs \$589 [262–1333], P < .001), and decreased slightly for CMHCs (median [IQR]: \$1774 [659– 5977] vs \$1545 [529–5128], P < .001).

Across all groups, visits to an adult specialist increased in the 2 years after transfer, whereas both primary care and subspecialty visits to pediatricians decreased. Visits to a family physician increased slightly after transfer only among youth with CCCs (78.3% vs 82.7%, P < .001). The proportion of youth with at least 1 annual primary preventative care visit in the 2 years after transfer decreased across all 3 clinical groups (*P* = .02 for CCCs, *P* < .001 for N-CCCs, *P* < .01 for CMHCs).

Hospitalization rates for both CCCs and CMHCs declined after transfer in both groups (29.1% vs 24.2% for CCCs and 26.8% vs 22.8% for CMHCs, P < .001), as did total number of admissions (P < .001). For N-CCCs, the proportion of patients with a hospital admission increased slightly (5.8% vs 6.3%, P < .001). Hospital ICU admissions did not significantly increase for any of the 3 groups (P =.22 for CCCs, P = .60 for N-CCCs, P =.33 for CMHCs).

The proportion of subjects with ED visits increased among youth with N-CCCs (44.5% vs 45.9%, P < .001, respectively), but not for those with CCCs (P = .28) or those with CMHC (P = .16), with the highest overall rate of ED visits. Increased high-acuity ED visits were noted for CCCs (P = .04) and N-CCCs (P < .001), but not for CMHC (P = .59). Low-acuity visits

remained stable for all 3 groups (P = .60, P = .35, and P = .12, respectively).

Home care service use was highest among youth with CCCs, and decreased after transfer from 39.4% to 33.3% of CCCs (P < .001). The proportion of youth with drug claims increased significantly across claimants in all cohorts (P < .001), as did the number of claims among youth with CCCs (P < .001).

Among the 11 individual conditions (Fig 1), health system costs were highest among youth with CF and SCD. Significant increases in health system costs posttransfer were found for youth with asthma (\$549 (257–1176) vs \$567 (257–1265), P < .001) while significant (P < .05) decreases were found post-transfer for NI, SLE, IBD, eating disorders, and MA (Supplemental Tables 4, 5, and 6).

Inpatient hospitalizations contributed to >30% of overall costs both pre- and post-transfer for all three groups,

		CCC, n = 2520		~	-CCC, $n = 99433$			CMHC, <i>n</i> = 2544	
	Pretransfer	Posttransfer	Ρ	Pretransfer	Posttransfer	Ρ	Pretransfer	Posttransfer	Ρ
Mortality, <i>n</i> (%)	33 (1.3)	38 (1.5)	.55	71 (0.1)	96 (0.1)	.05	6 	7 (0.3)	
Total health system costs (\$CDN), median (IQR)	4626 (1253– 21435)	3733 (950– 16841)	<.001	569 (263–1246)	589 (262-1333)	<.001	1774 (659–5977)	1545 (529–5128)	<.001
		if occurrent to the second	100			Ċ			c T
Any tamily physician visit, n (%)	1972 (78.5) 774 7)	2084 (82.7)	<.001	864/1 (87.0)	86.511 (86.8)	.20	2260 (88.8)	2255 (87.9) 7 /0 10/	8L.
No. larning priysiciari visits, meulari (IQR)	(1-1) C	4 (1-0) rec (cc r)	100.>	(1-2) +	4 (Z-Q)		(11-7) 0	(01-7) Q	10.5
Any primary care pediatrician visit, n (%)	1085 (45.0)	568 (22.5)	<.001	14 5 15 (14.6)	6051 (6.1)	<.001	465 (18.5)	159 (5.5)	<.001
No. primary care pediatrician visits, madian (100)	0 (0–2)	(00) 0	<.001	0-0) 0	(00) 0	<.001	(00) 0	(00) 0	<.001
Any energialist visit in (%)	1889 (74 7)	10/17/01	CU	19831 (121)	17 172 177 21	/ 001	1117 (55 7)	1517 (50 G)	/ 001
	0 0 14.17		- 0Z	42 001 (40.1)	44.0/0 (44.0/ 0 /0 0/	100.2			- 00.~
No. specialist visits, median (IUK)	(c-0) Z	5 (1-1)	<.001	0 (0-2)	0 (0-2)	<.001	1 (0-5)	(q-0) I	<.001
Any pediatric specialist visit, n (%)	1558 (61.8)	902 (35.8)	<.001	17936 (18.0)	7532 (7.6)	<.001	1021 (40.1)	393 (15.4)	<.001
No. pediatric specialist visits, median (IQR)	1 (05)	0 (0-1)	<.001	0 (0-0) 0	0 (0-0) (0	<.001	0 (03)	0-00) 0	<.001
At least one annual primary care	397 (15.8)	347 (13.8)	.02	17722 (17.8)	16643 (16.7)	<.001	493 (19.4)	423 (16.6)	<.01
preventative visit, n (%)									
Physician costs (\$CDN), median (IQR)	797 (352–1629)	874 (311–2049)	<.001	286 (105–631)	264 (81–644)	<.001	730 (252–1886)	628 (182–1806)	<.001
Hospitalizations									
Any hospitalization, <i>n</i> (%)	734 (29.1)	610 (24.2)	<.001	5796 (5.8)	6261 (6.3)	<.001	683 (26.8)	581 (22.8)	<.001
No. hospitalizations, median (IQR)	0 (0-1)	0-0) 0	<.001	0-0) 0	0-0) 0	<.01	0 (0-1)	0-0) 0	<.001
Hospital costs (\$CDN), median (IQR)	0 (0-3123)	0 (0-0) 0	<.001	0 (0-0)	0 (0-0)	.30	0 (0-1749)	0-0) 0	<.001
ICU admissions									
Anv ICU admission. <i>n</i> (%)	156 (6.2)	137 (5.4)	.22	537 (0.5)	521 (0.5)	.60	30 (1.2)	23 (0.9)	.33
Total ICU LOS, median (SD)	0-0) 0	0 (0-0)	.19	0 (0-0)	0 (0-0)	.15	0 (0-0)	0 (0-0)	.20
ED visits									
Any ED visit, n (%)	1408 (55.9)	1376 (54.6)	.28	44 268 (44.5)	45686 (45.9)	<.001	1649 (64.8)	1609 (63.2)	.16
No. ED visits. median (IOR)	1 (0-2)	1 (0-2)	.14	0 (0-1)	0 (0-1)	<.001	1 (0-3)	1 (0-3)	.27
No high acuitva FD visits median (IOR)	0 (0-1)	0 (0-1)	04	0 (0-1)	0 (0-1)	< 001	1 (0-2)	0 (0—2)	59
No Tow actuitv ^b ED visits median (IDR)	0 (0—1)	0 (0-1)	. O.	0 (0-1)	0 (0-1)	35	0 (0-1)	0 (0-1)	00: C1
ED costs (\$CDN) madian (IDR)	1.43 (D-619)	1 ZA (D_663)	10	0 (0-020)		. 001 100 /	930 (0-798)	919 (D-755)	31
Home care visits		0000	- ?			-	61		2
Any home care service visit. n (%)	994 (39.4)	839 (33.3)	<.001	1491 (1.5)	1502 (1.5)	.81	42 (1.7)	50 (2.0)	.37
No home care service visits median	0 (0-16)	(6-0) 0	< 01	(0-0) 0	0 (0-0)	92	0-0) 0	0 (0-0)	28
(IQR)									
Home care costs (\$CDN), median (IOR)	0 (0-2132)	0 (0-1398)	<.001	0 (0-0)	0 (0-0)	.15	0 (0-0)	0-0) 0	.10
Drug use									
Any drug claim, <i>n</i> (%)	866 (34.4)	1234 (49.0)	<.001	9796 (9.9)	11677 (11.7)	<:001	460 (18.1)	713 (28.0)	<.001
No. drug claims, median (10R)	5 (3-10)	6 (3-10)	<.001	4 (2–7)	3 (1–6)	<.01	4 (2–6)	4 (2–8)	<.001
Drug costs (\$CDN), median (IQR)	0 (0-293)	0 (0-1321)	<.001	0 (0-0)	0 (0-0)	<.001	0 (0-0)	0 (0-26)	<.001
Other health service costs ^c (\$CDN), median	784 (209–2932)	334 (128-1165)	<.001	117 (42–247)	150 (56-290)	<.001	235 (93-464)	247 (108-445)	.54
IQR									
LOS, length of stay.									
^a High-acuity ED visits = Canadian Triage and Acuity ((CTAS) 13.								

TABLE 2 Health Care Use, Costs, and Mortality, Before and After Transfer to Adult Care, Among Youth With Chronic Health Conditions

• high-acting to Visitis = canadian image and actury (ULAS) I=-3.
• Low acting= CTAS 4, 5.
• Other health service costs include ambulatory visits to cancer and dialysis clinics; nonphysician OHIP billings; laboratory claims; admissions to rehabilitation, continuing care, and long-term care facilities; capitation payments; and assisted devices program. and were the largest contributor of overall costs in the CMHC group both pre- and posttransfer (Fig 2). During both periods, among CCCs, home care was the largest contributor of costs, whereas outpatient physician claims accounted for the largest costs among N-CCCs.

DISCUSSION

Among youth with varied chronic medical and psychiatric conditions, we found relatively stable patterns of mortality, overall health care use, and costs after transfer from pediatric to adult care. After transfer, overall annual preventive care visits declined while specialist visits increased. High-acuity ED use increased slightly for youth with CCCs and N-CCCs, but hospitalizations declined for those youth at highest risk of these outcomes (CCCs and CMHCs).

We used a population-level longitudinal study with a robust sample size across multiple conditions. Only 1 of the 11 conditions we studied (asthma) demonstrated an increase in health care use after age 18, but the absolute amount (median difference of \$18) is of questionable clinical significance. Even among conditions with potential for disease progression (eg, CF, SCD, SZ), we did not find significant increases in health care use.

Some changes observed, such as a decline in preventive care visits, could be due to a lack of access to services posttransfer, but may also reflect changes in patterns of health-seeking behavior in young adulthood, such as delays in obtaining primary care services after moving to new communities for education or vocational purposes. Others, such as the decline in admission for CCCs and CMHCs, combined with an increase in high-acuity ED use for those with N-CCCs and CCCs suggest that thresholds for admission and discharge from hospital may differ between the adult and child health care systems. Use of outpatient



FIGURE 1

Median health system costs by Ontario youth with chronic conditions, before and after transfer from pediatric to adult care. ***P < .001; **P < .01; *P < .05.



FIGURE 2

Proportion of total health system cost by sector, among children and youth with chronic conditions, before and after transfer to adult care. ***P < .001; **P < .001; *P < .05.

services and the ED account for a proportionately smaller amount of cost in children and youth with CCCs,^{21,22} so these changes may not be reflected in changes to overall costs.

Our findings differ from those of many studies. Most studies have

focused on patient- (or parent-) reported outcomes, and have consistently reported inadequate support in transfers.³ One large study of acute care utilization in SCD used population-level administrative data across 8 states, describing a peak in utilization for both ED use and inpatient use among 18- to 30-yearolds, with lower rates reported in the 10- to 17-year-old age group.²³ Differences between these findings and ours may be due to design issues (cross-sectional versus longitudinal), our relatively small SCD sample (n =155) and/or differences in access, as the US findings varied by insurance status. Another explanation could be the difference in primary care, as 82% of youth in our study had a family physician as a primary care provider; pediatrician primary care may create a "double hit" in transfer.

Another explanation for the lack of changes during transfer was that our study did not allow for a sufficient observation period posttransfer to observe deleterious effects, which may only occur after a lag period of suboptimal care. This is supported by data from Western Australia on type 1 DM that demonstrate peaks in increased standardized mortality ratios in the 25- to 29-yearold age bracket for both men and women.²⁴ However, in a single-center longitudinal cohort of children with SCD (n = 940), 6 of 7 reported deaths occurred after 18 years of age; median time to death after transfer of 1.2 years (range, 0.2–5.3 years).²⁵

There are a number of important limitations to our study. We lack complete data on private drug and home care coverage, and care from a small number of providers (eg, primary care nurse practitioners in rural areas). Indirect health costs, including those from private insurers and, in particular, those borne by patients and families were not captured. We were unable to assess outcomes of those youth with onset of their chronic medical or psychiatric conditions between the ages 16 and 18 years. Our inclusion criteria for some cohorts (NI, SCD, CHD, and all 3 CMHC groups) were limited to ICD-10 and DSM-IV-TR codes from hospitalizations, missing youth not hospitalized with these conditions.

The sensitivity and specificity of diagnostic codes for these conditions have not been formally assessed. We characterized "complexity" of medical conditions by using 1 framework (multiorgan involvement); an alternative classification system (eg, based on baseline costs), may have placed youth with IBD into the "complex" grouping, although given the relatively small sample size of this group, would have likely not changed our overall findings. We analyzed a variety of relatively high-prevalence chronic conditions, but our list was not exhaustive. We developed mutually exclusive disease categories, but, in the process, may have missed the effects of important comorbidities such as medical and mental health conditions (eg, SLE and MA).²⁶ Subgroups with small sample sizes may have been underpowered to detect differences, and small differences reported with larger groups (eg, asthma) may be of limited clinical importance. Children who died in the pretransfer period (n = 109) were unable to contribute to posttransfer data, and the overall period of observation included vulnerable periods of transition both before and after age 18. Some subjects may have maintained Ontario residency while obtaining some health services out-of-province as post-secondary students (eg, from university health services), which may have possibly underestimated health care use after transfer. It has been estimated that among the 62% of Canadians who attend post-secondary institutions by age 19, 27 only ~10% attend out-of-province,²⁸ and many may still access health care in their home province. Given the stability of health care use across varied sectors of care, it is unlikely that this phenomenon had a substantial effect on outcomes. Last, some youth (eg, those whose care was delivered by a family physician without a pediatric specialist) may not have transferred care to a new provider.

CONCLUSIONS

Patterns of health care use of young adults with childhood-onset chronic conditions may look very similar to the patterns these people exhibited as youth, at least in the short-term. The implication is that quality metrics focused on transfers may need longer observation periods to detect meaningful differences in health system use and that patterns of health service utilization may not accurately reflect the overall health status of this population. Future work with longer time horizons and replication of our study design in other jurisdictions will further illuminate the trajectories of youth with chronic conditions as they traverse into the adult health care system.

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ABBREVIATIONS

CCC: complex chronic conditions
CF: cystic fibrosis
CHD: congenital heart disease
CMHC: chronic mental health
conditions
DM: diabetes mellitus
DSM: Diagnostic and Statistical
Manual
ED: emergency department
IBD: inflammatory bowel disease
ICD: international Classification of
Diseases
ICES: Institute for Clinical
Evaluative Sciences
IQR: interquartile range
MA: mood and affective disorders
N-CCC: non-complex chronic
conditions
OHIP: Ontario Health insurance Plan
SCD: sickle cell disease
SLE: systemic lupus
erythematosus
SZ: schizophrenia

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