



Children and Youth With Medical Complexity in Canada



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Executive summary

Children and youth with medical complexity represent a diverse group of children with a spectrum of conditions, needs, limitations and medical fragility. Although children and youth with medical complexity are a small proportion of all children, their unique needs result in their substantial use of health care services.^{1,2} This makes it essential to understand

- The landscape of children and youth with medical complexity across Canada, along with variations across provinces and territories;
- The use of health care services and medications by children and youth with medical complexity in Canada, including transfers from pediatric to adult care; and
- The families, the children and youth, and their needs and experience with accessing services.

The main findings from CIHI's first pan-Canadian report on the topic are as follows:

- **Across provinces and territories, there was wide variation in the rates of medical complexity in children and youth. In 2015–2016, the age-adjusted rate for Canada was 948 per 100,000 children and youth, similar to that found in other research.**
- **The unique needs of children and youth with medical complexity required higher use of primary health care services, hospital care and emergency department care.** Rates of hospital care and emergency department (ED) visits were even higher among those with medical technology assistance.
- **Most children and youth with multiple conditions used multiple medications.** Many children and youth with medical complexity used 5 or more drugs in 1 year (39%). The proportion of children and youth prescribed multiple drugs increased with age and varied by the type of medical complexity.
- **Data about children and youth with medical complexity who receive home care is very limited.** On average, children and youth received 44 hours per week of informal care. More than one-third had caregivers who were distressed. Parents and providers often advocate extensively for these children to gain entry to specialized programs.

Children and youth with medical complexity have a wide range of complex chronic conditions

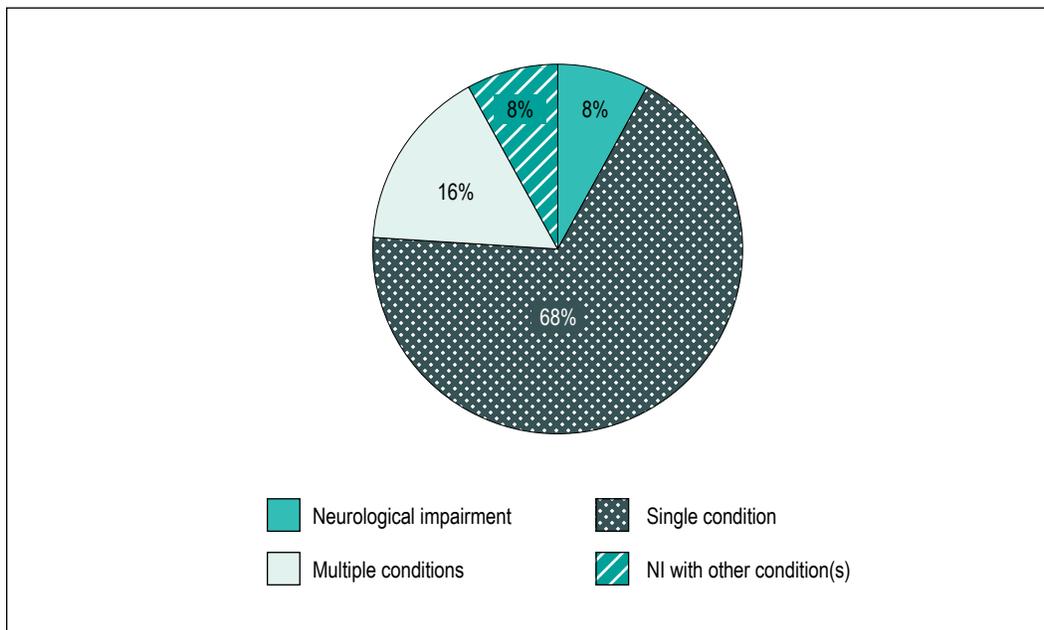
Children and youth with medical complexity have a wide range of conditions. There is no standard definition to identify this population. However, most of these children and youth share 4 characteristics: complex chronic conditions, functional limitations, high health care utilization and a high need for caregiving.^{1,3}

Overall, 97,561 children and youth with medical complexity were identified across Canada for this study. In 2015–2016, the age-adjusted rate of medical complexity was 948 per 100,000 children and youth. Other research reported 670 per 100,000 children and youth in Ontario had medical complexity.²

Most children and youth with medical complexity were younger than 5 years (38%). Almost 1 in 4 were older than 20 (23%). The sex distribution was relatively even (51% male). Similar to the Canadian population,⁴ most of these children lived in urban areas (80%). They were distributed evenly across income groups. Overall, almost 32% of children and youth received medical technology assistance.

Just over two-thirds of these children and youth had a single condition (see Figure 1). In this group, the top 3 conditions were benign and malignant neoplasms (22%), cardiovascular diseases (17%) and gastrointestinal diseases (15%).

Figure 1 Types of medical complexity



Note

NI: Neurological impairment.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, Canadian Institute for Health Information.

Key methods

This study adopted a broad definition of medical complexity using the diagnostic and procedural codes outlined by Feudtner and colleagues.⁵ Consistent with previous literature,² these children were grouped into 4 types of medical complexity:

- **Neurological impairment:** A diverse group of constant and progressive health conditions that involve the central and peripheral nervous systems and result in functional and/or intellectual impairment.
- **Single condition:** A complex chronic condition that affects only a single body system severely enough to require specialty pediatric care and often some time in hospital.
- **Multiple conditions:** Complex chronic conditions that affect more than one body system.
- **Neurological impairment with other condition(s):** Neurological impairment as well as single or multiple conditions.

Some children and youth rely on medical technology assistance to manage or treat a chronic illness, and to maintain essential body functions necessary for sustaining life or overall functional status. Examples include gastrostomy tubes or peripherally inserted central catheters.

This study identified children and youth, newborn to 24 years, who had at least one hospital stay or day surgery in 2015–2016. Children and youth were included in the study if they had a complex chronic condition or neurological impairment recorded in any hospital stay or day surgery between April 2010 and March 2016.

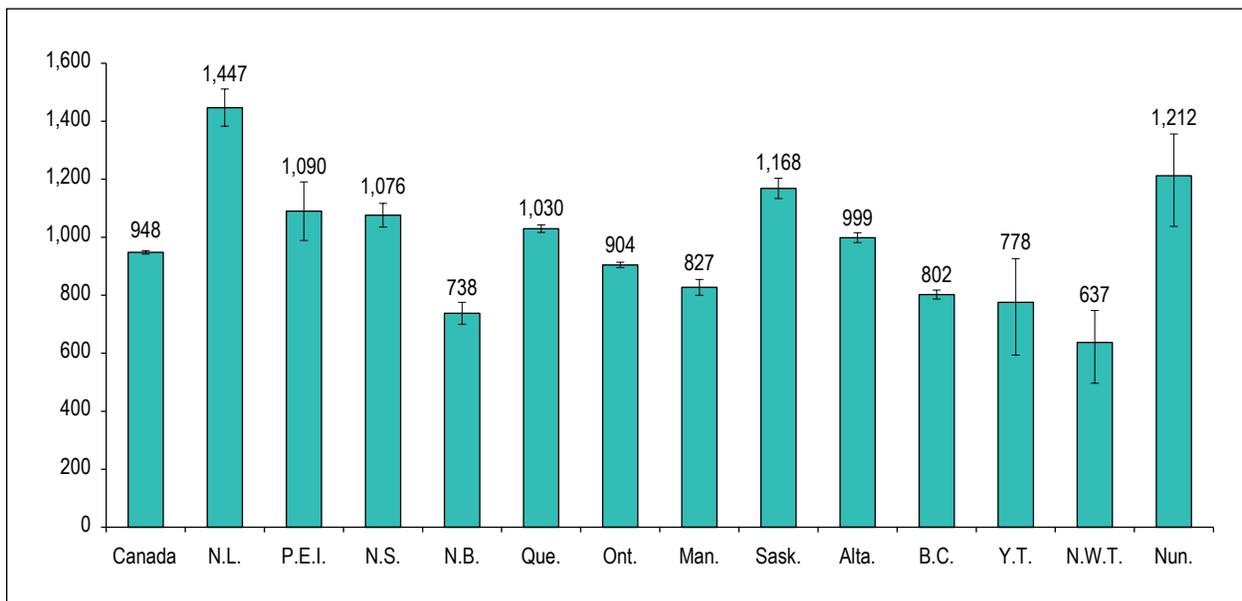
The analyses in this report use Canadian Institute for Health Information (CIHI) data on primary health care, specialty clinic visits, hospital stays, ED care, community drug claims and home care. A 2-year follow-up was applied for most analyses unless otherwise stated. Further information for this report was obtained from standardized interviews with a small number of parents of children and youth with medical complexity in Canada. Unless otherwise stated, the children and youth referenced in this report are children and youth with medical complexity.

Specifics on data and methodology for this report can be found in the companion [methodology notes](#). Companion [data tables](#) provide additional results.

Wide variation in rates of medical complexity across Canada

The age-adjusted rate of medical complexity varied by province and territory (see Figure 2). Variation could be due to differences in service availability (i.e., outpatient and community), the movement of patients across provincial or territorial boundaries and procedures for newborn health care number registration.

Figure 2 Age-adjusted rate of medical complexity per 100,000 children and youth, by province and territory, 2015–2016



Notes

New Brunswick's low rate is partially due to the exclusion of newborns who shared their mother's health care number during their first hospital stay of 2015–2016.

The line at the top of each bar graph shows the confidence interval (CI), which is used to establish whether the age-adjusted rate is statistically different from the average. The width of the CI illustrates the degree of variability associated with the rate. For example, a province or territory might have a wide CI if there is a small number of cases and the results are less stable. Age-adjusted rates are estimated to be accurate within the upper and lower CI 19 times out of 20 (95% CI). Rates with CIs that do not overlap with the Canada result can be considered statistically different.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, Canadian Institute for Health Information; Population estimates, 2011 and 2015, Statistics Canada.

Several provinces had higher rates of specific conditions in comparison with the Canadian average.

- Newfoundland and Labrador's rate of neoplasms was 2 times higher than the Canadian average, driven largely by high rates of benign neoplasms. This province also had the highest rates of respiratory disease and neurological impairment (89% and 53% higher than the Canadian average, respectively).
- Saskatchewan had the highest rates of renal and cardiovascular diseases (50% and 29% higher, respectively).
- Quebec had the highest rates of hematologic and metabolic diseases (60% and 40% higher, respectively).
- The rate of gastrointestinal diseases was highest in Ontario — 24% higher than the Canadian average.

Other studies have reported higher provincial rates of selected rare conditions among children and youth⁶⁻⁸ and high rates of chronic disease in the general population.^{9, 10} These rates may explain some of the observed differences.

Unique needs of children and youth with medical complexity require higher use of health care services

The unique needs of the small number of children and youth with medical complexity mean that they require ongoing medical support to monitor and maintain their health.³ Consistent with other research,² this small cohort of children and youth consumed a large share of resources in EDs and in hospital care compared with all children and youth age 24 and younger.



Families told us

These children and youth see many types of care providers in different care settings. The challenge of coordinating care often falls to parents or guardians.

While families would prefer to see the same providers for better continuity of care, fragmentation of care is common. This adversely affects the patient and family experience, with families often repeating the same information to each care provider.

Despite the clear need for extensive services, formal coordination of care is not always available. Further, the types of services offered by complex care programs vary by province.

Primary health care visits are twice as high for children and youth with medical complexity

On average, children and youth with medical complexity had approximately 6 primary health care visits in 1 year (see Table 1). Children and youth without medical complexity had an average of 3 visits per year.ⁱ Children and youth had an average of 13 specialty clinic visits over 2 years in Alberta.ⁱⁱ Children with multiple conditions had, on average, 4 times as many visits to specialty clinics compared with those with a single condition.

i. This data includes Nova Scotia and Alberta.

ii. Alberta is the only province that submits full-coverage specialty clinic data to CIHI.

One-third of hospital stays and one-sixth of ED visits are for children and youth with medical complexity

Over 2 years, hospital care costs associated with these children and youth were \$866 million. This accounted for 57% of hospital care costs for all children and youth. Children and youth with medical complexity also accounted for 37% of all hospital admissions and 54% of total hospital days. They had longer stays compared with children and youth without medical complexity.

In Ontario, Alberta and Yukon, where complete ED data was available, these children and youth accounted for 17% of visits and 21% of total costs for all children and youth. In these provinces, the total cost of ED care for these children and youth was more than \$15 million over 2 years.

In a 2-year period, two-thirds of children and youth with medical complexity had at least one ED visit, and one-third had at least one hospital stay. Children and youth without medical complexity were less likely to be admitted to hospital care in the 2 years following their first hospital stay (15%). Children and youth with medical technology assistance had more frequent hospital stays and ED visits compared with those without medical technology assistance.



Families told us

Barriers can prevent children and youth from accessing the care that they need. Publicly covered care may not be able to provide the amount or type of specialized care to best support families in the community. Long wait lists and stringent acceptance criteria hinder access to complex care programs. Such programs offer care coordination, family support and improved communication with health care teams. Parents and providers often advocate extensively for the child to gain entry to programs designed for complex care.

Access to after-hours care is particularly challenging and, apart from some very specialized programs, the only option is to visit an ED. Visits to EDs are complicated for children and youth with medical complexity and their families. Staff may not be familiar with the child's medical history and may not have the experience necessary to treat their conditions.

This can lead to mistakes in care and additional stress for families.

Table 1 Health system use among children and youth with medical complexity, by type of medical complexity, in the 2 years after the first hospital stay in 2015–2016

Health system use	Total	Type of medical complexity			
		Neurological impairment	Single condition	Multiple conditions	NI with other condition(s)
Average number of primary health care physician visits					
Nova Scotia	11	9	10	15	12
Ontario	12	10	12	17	14
Alberta	12	11	11	16	15
Average number of specialty clinic visits					
Alberta	13	10	8	32	23
Hospital stays (Canada)					
Proportion with at least one hospital stay	36%	32%	28%	59%	61%
Average number of hospital stays	2.5	2.0	1.9	3.4	3.3
Average length of stay (days)	21	13	15	33	29
ED visits (Ontario, Alberta, Yukon)					
Proportion with at least one visit	68%	67%	65%	77%	79%
Average number of visits	4.3	4.0	3.9	5.2	5.5

Notes

NI: Neurological impairment.

ED: Emergency department.

The average number of hospital stays and length of stay were calculated for children and youth with at least one acute hospital stay. The average number of ED visits was calculated for children and youth with at least one ED visit in Ontario, Alberta and Yukon. The analysis period begins with the child's or youth's first hospital stay in 2015–2016 and ends after 2 years of follow-up.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018, Canadian Institute for Health Information; Patient-Level Physician Billing Repository (Nova Scotia, Ontario and Alberta data), 2015–2016 to 2017–2018, Canadian Institute for Health Information; Population estimates, 2011 and 2015, Statistics Canada.

Readmissions, high users and long stays in hospital

The **30-day readmission rate** after discharge from hospital was 5% over 2 years. Notably, this readmission rate was lower than that for the general pediatric population (6.9%) reported in CIHI's Your Health System web tool.¹¹ Children and youth with medical complexity may use hospital care differently than the general pediatric population. For example, given their complex needs, the children and youth in this study may have had better discharge planning before they leave the hospital. An Ontario study of children and youth with medical complexity reported a higher rate of 30-day readmission (13.2%).²

Over 2 years, approximately 1% of children and youth in this study were **high users**. High users were defined as individuals with an average of 3 or more hospital stays and 30 days in the hospital, per year. Children and youth with multiple conditions were the largest proportion of high users (51%). 1 in 7 hospital stays among high users included an intensive care unit (ICU) stay.

Long stays in hospital (60 or more days) represented approximately 2% of hospital stays over 2 years. Most long stays in hospital (76%) included an ICU stay. Children and youth with multiple conditions accounted for approximately 41% of long stays in hospital.

Out-of-province and out-of-territory specialized care is required for those who live in smaller regions

Canadians access hospital care outside their home province or territory for a variety of reasons. In total, 3% of children and youth in this study (2,464) were hospitalized outside their home province or territory for their first hospital stay of 2015–2016. Compared with those in larger jurisdictions, more children and youth from Prince Edward Island, New Brunswick and the territories travelled out of jurisdiction for care. Nova Scotia, Ontario and Alberta provided care to the most children and youth with medical complexity from out of province/territory.ⁱⁱⁱ 3 hospitals (the IWK Health Centre in Nova Scotia, the Children's Hospital of Eastern Ontario and the University of Alberta Hospital) cared for almost half of these out-of-province/-territory children and youth.

iii. Quebec facilities do not report the province or territory associated with the health care number to CIHI's Hospital Morbidity Database, meaning it is not possible to track the inflow of patients to Quebec.



Families told us

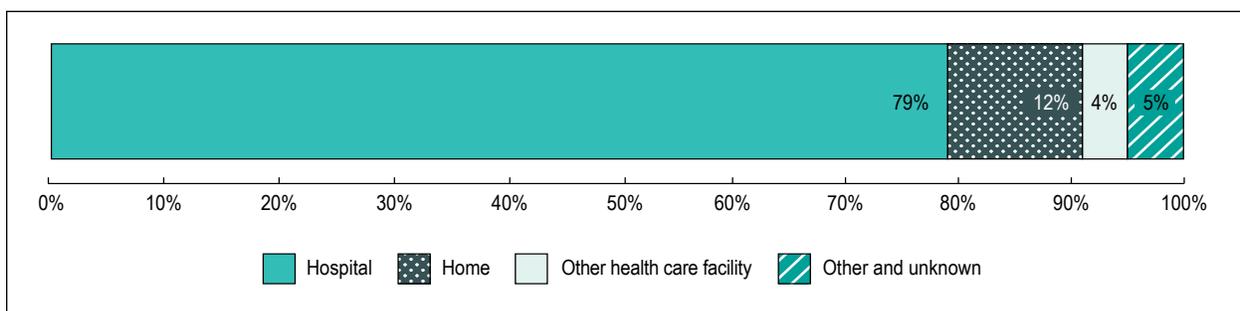
Families had often travelled to access care for their child, including specialty programs and therapies at major pediatric centres. Specialty programs, as well as services that provide families with a home away from home, help support families travelling for care.

While families may consider moving closer to specialist care, the informal support found in their community, often by extended family, may be of greater importance.

Most deaths of these children and youth occur in hospital

Overall, within the 2-year study period, 2% of children and youth died. Other research showed a similar 2-year rate among Ontario children with medical complexity (2.5%).² The proportion of in-hospital deaths among children and youth (see Figure 3) was greater than that of both the general population¹² and the pediatric population, which were approximately 60%.

Figure 3 Percentage of children and youth with medical complexity who died in the 2 years after the first hospital stay in 2015–2016, by location of death



Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, Canadian Institute for Health Information; Canadian Vital Statistics Death Database (linked to the Discharge Abstract Database, National Ambulatory Care Reporting System and Ontario Mental Health Reporting System), 2015 to 2017, Statistics Canada.

Few children and youth with medical complexity receive palliative care in hospital

Palliative care is an important component of care for patients and their families.¹³ The *Framework on Palliative Care in Canada*¹⁴ has identified children and youth as a priority area for improvement of access. Patients can receive pediatric palliative care in hospitals, hospices, outpatient clinics and community health centres, and at home.



Families told us

Palliative care for children and youth goes beyond managing care at the end of life. It encompasses pain and symptom management, transition support from hospital to home and respite care. Services are sometimes available around the clock, helping these children and youth remain out of the hospital. It is possible for children and youth to become ineligible for these programs as their health stabilizes.

In this study, palliative care was identified during a hospital stay if a child or youth had a diagnosis of palliative care, saw a palliative medicine service provider, or received palliative medicine interventions or services. Palliative care was provided by multiple physician specialties, but most often by pediatricians.^{iv} Fewer than 1% of children and youth had palliative care in hospital in 2015–2016.^v Infants were twice as likely to have palliative care, compared with children and youth age 1 to 24 years, and made up one-third of those with palliative care (34%). Children and youth with neurological impairment and other condition(s) were more than 13 times as likely to have palliative care in hospital compared with those with a single condition.

Of the 1,070 children and youth who died in hospital in 2015–2016, 35% had a record of palliative care in the 2 years prior to death. In contrast, among adults age 19 and older who died in hospital in 2015, 66% had palliative care in the last year of life.¹⁵

iv. Physician specialties for palliative care claims were determined using physician billing data from Nova Scotia, Ontario and Alberta.
v. The palliative designation in hospital could not be captured in Quebec due to differences in palliative care coding practices.

Most children and youth with multiple chronic conditions use multiple medications

Given their medical complexity, appropriate treatment for these children and youth often includes taking multiple medications. This study examined the use of medications over 1 year. Prescriptions dispensed from community pharmacies in 3 provinces^{vi} were analyzed. Many children and youth used 5 or more drug classes in 1 year (39%), and 14% used 10 or more different drug classes (see Figure 4). Half of the patients age 18 and older used 5 or more drug classes in 1 year (50%), while only 29% of children age 9 and younger used 5 or more drug classes.



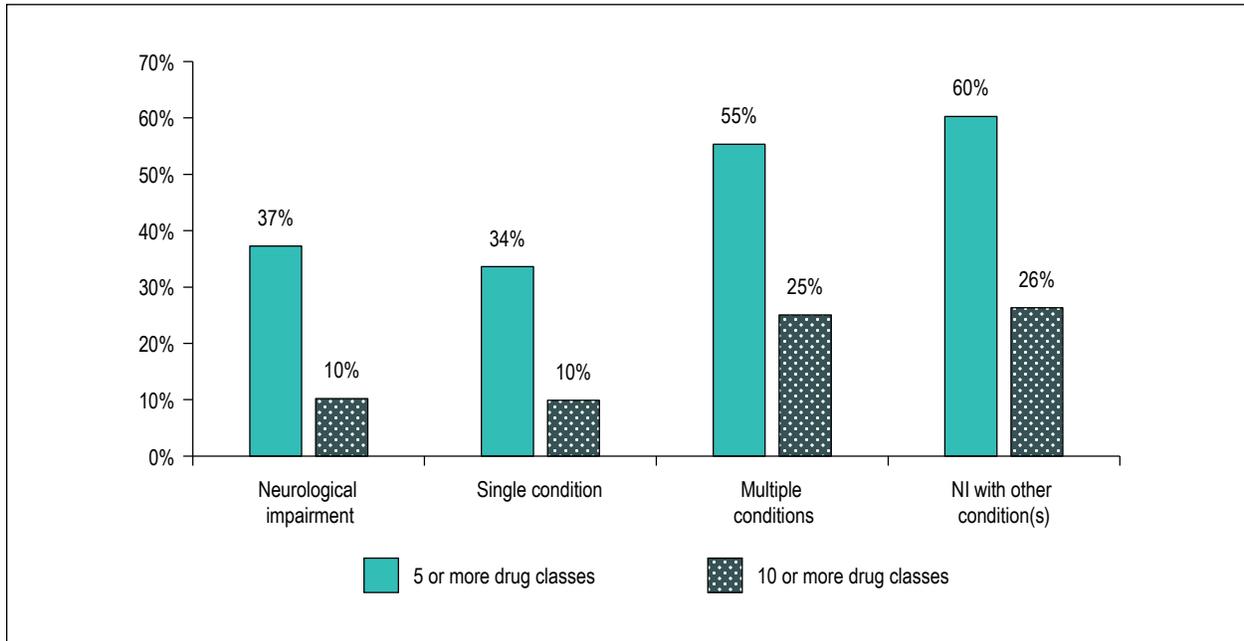
Families told us

Children and youth often need rare and expensive medications. Accessing these medications can be challenging for families, often requiring private insurance plans and out-of-pocket costs once maximum coverage is reached.

Rare or specialized medications may not be available in community pharmacies in small towns, leaving families to travel longer distances for access.

vi. Manitoba, Saskatchewan and British Columbia provide data for the study population.

Figure 4 Percentage of children and youth who used multiple medications in the year after the first hospital stay in 2015–2016, by type of medical complexity



Note

NI: Neurological impairment.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, and National Prescription Drug Utilization Information System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

2 measures determined which types of drugs were most common. The rate of use describes the proportion of children and youth who used a specific drug class at least once (see Table 2).

Table 2 Most common drug classes, by rate of use among children and youth with medical complexity

Drug class	Rate of use (%)
Penicillins with extended-spectrum	25%
Opioids in combination with non-opioid analgesics	16%
Selective beta-2-adrenoreceptor agonists	13%
First-generation cephalosporins	12%
Proton pump inhibitors	11%

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, and National Prescription Drug Utilization Information System, 2015–2016 to 2017–2018, Canadian Institute for Health Information.

The proportion of total claims reflects the drugs with the most claims dispensed. Drugs frequently prescribed to a small proportion of children and youth would have a low rate of use but represent a high proportion of total claims. Psycholeptics, such as antipsychotics, accounted for the highest proportion of total claims (14%), followed by antiepileptics (11%).

Home care data on children with medical complexity is limited

Children and youth with medical complexity depend heavily on informal and unpaid caregiving by family members. When informal care cannot meet their needs, many children and their caregivers require home care or respite care services. This study examined the use of home care over 2 years for 6 jurisdictions^{vii} with the limited home care data available at CIHI. The first home care assessment with the Resident Assessment Instrument–Home Care (RAI-HC) after their first hospital stay of 2015–2016 was included.^{viii} Most home care data for this cohort was from Ontario (74%) for youth age 18 and older. A home care record was found for approximately 1% of the children and youth in this study.



Families told us

Families receive a variety of services at home or in the community, including nurses, support workers, dietitians and therapists. Parents reported that receiving sufficient support at home is challenging.

Home care staff with pediatric expertise are not always available for families. Families often face long wait times to qualify for, or to receive, home care services. Some families do not qualify unless their child uses multiple medical technologies or has severe impairment.

Children and youth with neurological impairment and other condition(s) represented 43% of the individuals receiving home care. Almost one-third of those receiving home care had severe or very severe cognitive impairment (32%), and almost a quarter had the highest level of impairment in their activities of daily living (e.g., personal hygiene, eating, toileting) (23%).

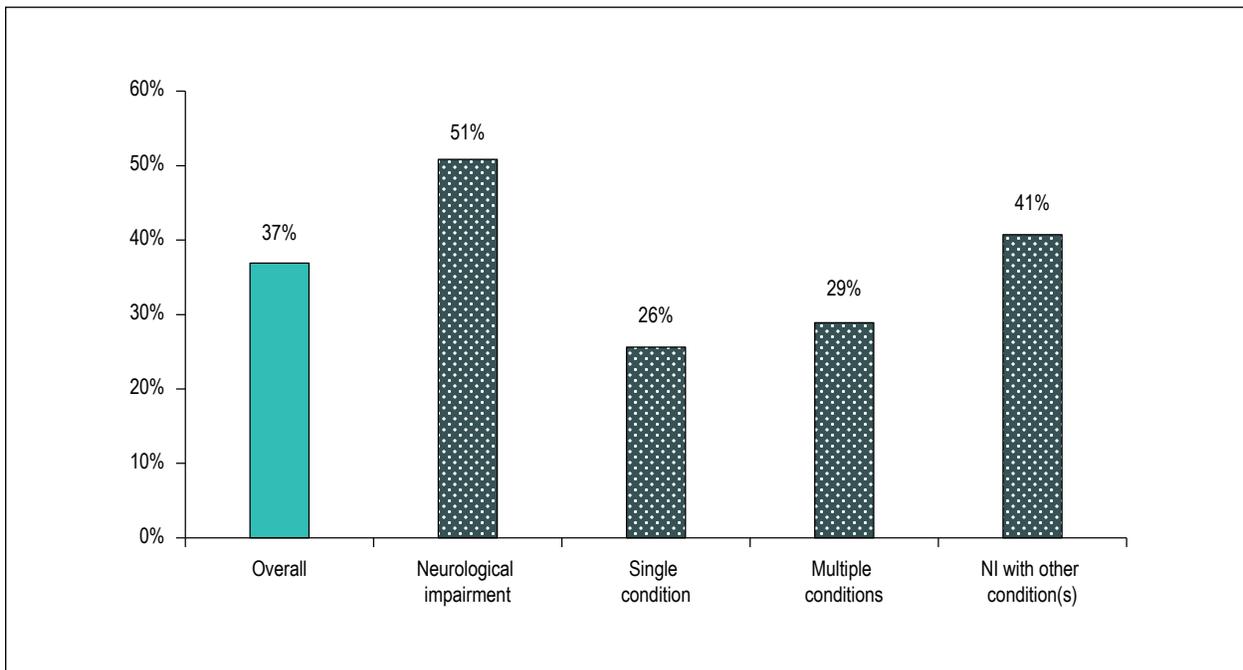
vii. The 6 jurisdictions were Newfoundland and Labrador, Ontario, Saskatchewan, Alberta, British Columbia and Yukon.

viii. Although provinces are providing home care services to children and youth under 18, they cannot use the current RAI-HC tool, which provides insight on patient function, to report their data to CIHI's Home Care Reporting System.

Over one-third of primary caregivers expressed distress

In addition to formal care, children and youth with home care received, on average, 44 hours per week of informal care from family and friends. Almost all children and youth receiving home care had a primary caregiver (97%), most of whom lived with them (88%). Of these primary caregivers, 37% expressed feelings of anger, distress or depression, or felt they were unable to continue in their caring activities (see Figure 5). This percentage was similar for the caregivers of general recipients of home care.¹⁶ However, caregiver distress increased in those caring for children and youth with neurological impairment.

Figure 5 Distress among caregivers of children and youth with medical complexity receiving home care in the 2 years after the first hospital stay in 2015–2016, by type of medical complexity



Note

NI: Neurological impairment.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018, and Home Care Reporting System, 2015–2016 to 2017–2018, Canadian Institute for Health Information; Population estimates, 2011 and 2015, Statistics Canada.



Families told us

Being a parent of a child or youth with medical complexity is highly demanding. Parents often experience distress from the traumatic experiences associated with their child's health status and their interactions with the health care system. The uncertainty of their child's future can weigh heavily on families.

Parents struggle with the dual role of being a parent while also providing elements of their child's medical care. The latter role can be distressing to the child.

Options for full respite care are limited and even when available, parents are always on call. Parents indicate that their informal support is constant, including during the night.

The financial impacts on families of these children and youth are large. Often, 1 parent is out of the workforce to provide care to the child or youth. Many parents pay out of pocket for therapies, home care and drugs.

Transferring out of pediatric care results in more visits to family doctors

In Canada, provincial and territorial governments mandate that at age 18, youth transfer from the pediatric health system to the adult care system.¹⁷ Youth with medical complexity and their families often face a break in the delivery of care as patients leave the pediatric system.¹⁸



Families told us

A smooth transition out of pediatric care requires extensive planning. Families find it helpful to start discussions with care providers as early as possible.

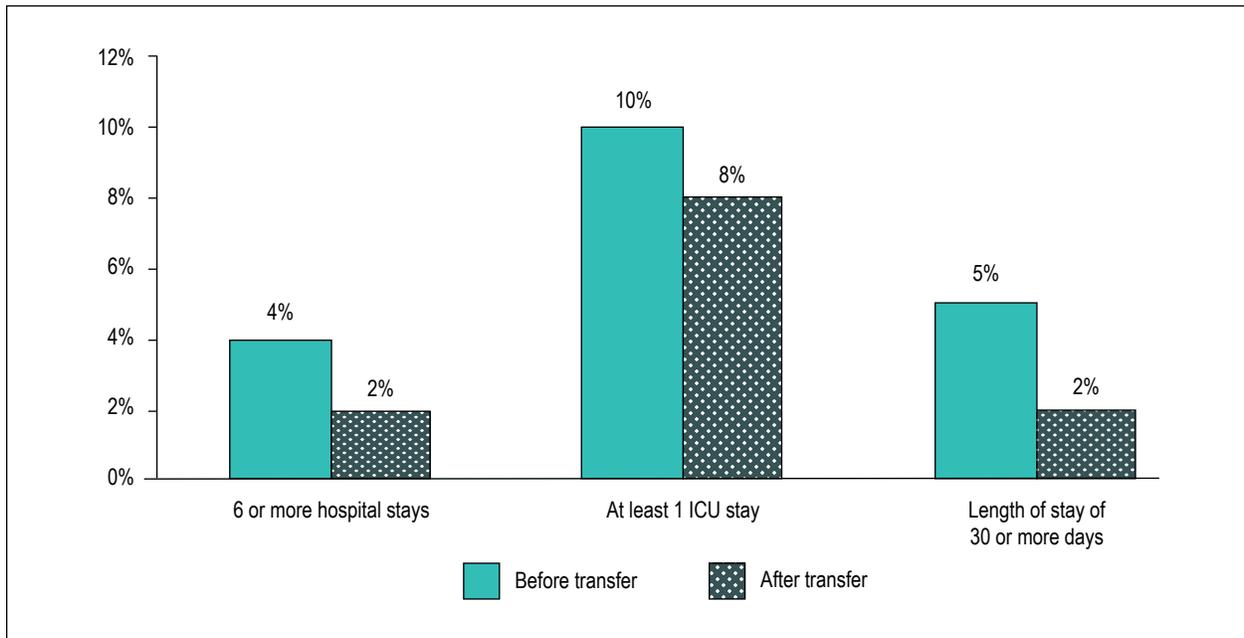
To plan for a transfer, families can identify the appropriate adult-focused care providers and gradually incorporate their services as the youth ages out of the pediatric care system.

Families indicate that pediatric services for their children are far more extensive compared with the services available in adulthood.

This study defined the 18th birthday as the transfer point and examined health system use in the 2 years before the transfer and the 2 years after. In 2015–2016, 2,700 youth in the study turned 18 years of age.^{ix} Youth with medical complexity had more visits to general practitioners after transferring.^x The proportion of youth with at least one hospital stay dropped from 51% to 40% before and after the transfer (see Figure 6). Across all provinces and all types of medical complexity, youth had fewer hospital stays after the transfer. Some provincial variations were observed.

Interestingly, the proportion of youth with an average of 4 or more ED visits in a year did not change (12%). It may be that the adult health care system has a higher threshold for admission to hospitals relative to pediatric care.¹⁹ Meanwhile, visits to the ED are patient-driven and do not change once youth become adults.

Figure 6 Changes in hospital and ICU stays among youth with medical complexity who transferred to adult care in 2015–2016, 2 years before and after transfer



Note

ICU: Intensive care unit.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018, Canadian Institute for Health Information.

^{ix.} Quebec was excluded as birthdates were not reported.

^{x.} This includes Nova Scotia, Ontario and Alberta.

Conclusions

This report illustrates how children and youth with medical complexity use Canada's health care systems. While these children and youth represent less than 1% of the pediatric population, their extensive medical needs correspond to a higher required use of health care services and medications. In this study, they used a large proportion of primary health care services, hospital care and ED visits. While these children and youth had long stays in hospital, they had fewer readmissions than the general population of children and youth. Accessing specialized care outside major cities can be challenging, and travel may be required. Records of home care and palliative care were found for a small proportion of children and youth.

Discussions with families showed the extent of services they must access, although these services can be disjointed without a coordinated plan. Parents and providers often must advocate extensively for entry into complex care programs. These complex care programs with navigators to help families coordinate and access care are valued, but too often the programs are pilots, are not well resourced by health services and are not scaled up to reach most children and their families. More data on home care and palliative care services provided to these children and their families will be of benefit in planning better integrated care.

Moving forward

Children and youth with medical complexity are a diverse group, with uncommon diagnoses, unique needs and varying access to supports. This report offers a population-based overview to understand how these children and youth use the health systems across Canada.

There is a demand from families and health care providers for better data to describe this population, to encourage advocacy and to improve service delivery and planning.

In this study, the data coverage for home care for pediatric clients and outpatient specialty clinics was very limited. Many children and their families use a wide range of health-related services, including school-based programs, social and community services, and specialized therapies. Although this type of information could provide a more fulsome picture of the needs of children and youth, it is currently not available.

Additionally, care providers and policy planners may benefit from ongoing monitoring and surveillance efforts for this population. Trends over time, as well as detailed resource data, would further support policy planning. Future research might further explore the role of mental health disorders among children and youth with medical complexity.

Families and service providers aim to reduce hospital stays for these children and youth as much as possible. Integrated care coordination may be one way to optimize care delivery and decrease hospital stays. Experts advocate for enhanced care delivery in hospitals and communities, which includes care coordination, integration and specialty clinics, to empower both families and service providers to promote proactive care rather than reactive care for children and youth with medical complexity.²⁰

Appendix: Text alternative for figures

Text alternative for Figure 1

Table: Types of medical complexity

Type of medical complexity	Proportion of children and youth with medical complexity
Neurological impairment	8%
Single condition	68%
Multiple conditions	16%
NI with other condition(s)	8%

Note

NI: Neurological impairment.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, Canadian Institute for Health Information.

Text alternative for Figure 2

Table: Age-adjusted rate of medical complexity per 100,000 children and youth, by province and territory, 2015–2016

Jurisdiction	Adjusted rate per 100,000 children and youth	Lower limit of confidence interval for rate	Upper limit of confidence interval for rate
Canada	948	942	954
N.L.	1,447	1,383	1,511
P.E.I.	1,090	989	1,191
N.S.	1,076	1,035	1,117
N.B.	738	700	776
Que.	1,030	1,016	1,043
Ont.	904	895	914
Man.	827	800	854
Sask.	1,168	1,133	1,203
Alta.	999	982	1,016
B.C.	802	787	818
Y.T.	778	611	944

Jurisdiction	Adjusted rate per 100,000 children and youth	Lower limit of confidence interval for rate	Upper limit of confidence interval for rate
N.W.T.	637	512	763
Nun.	1,212	1,053	1,371

Notes

New Brunswick's low rate is partially due to the exclusion of newborns who shared their mother's health care number during their first hospital stay of 2015–2016.

The confidence interval (CI) is used to establish whether the age-adjusted rate is statistically different from the average. The width of the CI illustrates the degree of variability associated with the rate. For example, a province or territory might have a wide CI if there is a small number of cases and the results are less stable. Age-adjusted rates are estimated to be accurate within the upper and lower CI 19 times out of 20 (95% CI). Rates with CIs that do not overlap with the Canada result can be considered statistically different.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, Canadian Institute for Health Information; Population estimates, 2011 and 2015, Statistics Canada.

Text alternative for Figure 3

Table: Percentage of children and youth with medical complexity who died in the 2 years after the first hospital stay in 2015–2016, by location of death

Location of death	Percentage of children and youth with medical complexity who died
Hospital	79%
Home	12%
Other health care facility	4%
Other and unknown	5%

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, Canadian Institute for Health Information; Canadian Vital Statistics Death Database (linked to the Discharge Abstract Database, National Ambulatory Care Reporting System and Ontario Mental Health Reporting System), 2015 to 2017, Statistics Canada.

Text alternative for Figure 4

Table: Percentage of children and youth who used multiple medications in the year after the first hospital stay in 2015–2016, by type of medical complexity

Number of drug classes	Neurological impairment	Single condition	Multiple conditions	NI with other condition(s)
5 or more drug classes	37%	34%	55%	60%
10 or more drug classes	10%	10%	25%	26%

Note

NI: Neurological impairment.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2015–2016, and National Prescription Drug Utilization Information System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

Text alternative for Figure 5

Table: Distress among caregivers of children and youth with medical complexity receiving home care in the 2 years after the first hospital stay in 2015–2016, by type of medical complexity

Type of medical complexity	Percentage of caregivers with distress
Overall	37%
Neurological impairment	51%
Single condition	26%
Multiple conditions	29%
NI with other condition(s)	41%

Note

NI: Neurological impairment.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018, and Home Care Reporting System, 2015–2016 to 2017–2018, Canadian Institute for Health Information; Population estimates, 2011 and 2015, Statistics Canada.

Text alternative for Figure 6**Table: Changes in hospital and ICU stays among youth with medical complexity who transferred to adult care in 2015–2016, 2 years before and after transfer**

Hospital and ICU stays	Before transfer	After transfer
6 or more hospital stays	4%	2%
At least 1 ICU stay	10%	8%
Length of stay of 30 or more days	5%	2%

Note

ICU: Intensive care unit.

Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018, Canadian Institute for Health Information.

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