Use of health care among adults with chronic and complex physical disabilities of childhood

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Abstract

Purpose. The purpose of this study was to explore the patterns of health services utilization among adults with chronic and complex physical disabilities of childhood, specifically cerebral palsy, spina bifida, and acquired brain injuries.

Methods. A cohort of 345 young adults who had graduated from the Bloorview MacMillan Children’s Centre was identified. Their health care records were extracted from Ontario Health Insurance Plan (OHIP) and Canadian Institute for Health Information (CIHI) databases, for a four-year period. These data were analysed to estimate the frequency of out-patient physician visits and admissions to hospital.

Results. The mean age of the sample was 21.9 years (range 19.0–26.9 years). The results show that 95% of the sample visited a physician at least once per year, and 24% had a primary care physician. On average, these adults visited physicians 11.5 times per year (approximately once per month) and were admitted to hospital once every 6.8 years.

Conclusions. These results suggest that adults with complex physical disabling conditions from childhood have ongoing health issues that require frequent service. Their admission rate is 9.0 times that of the general population, and few have a primary care physician. A new model of service may be necessary for this high-needs group.

Keywords: Health services research, disability evaluation, cerebral palsy, spina bifida, acquired brain injury

Introduction

Conditions such as cerebral palsy (CP), spina bifida (SB), and acquired brain injury in childhood (ABIc) result in significant disability [1]. Nevertheless, life expectancy is increasing, and now 50–90% of children with these conditions are living to adulthood [2–11]. However, once adulthood is reached (defined in Ontario as the 19th birthday), they are no longer eligible to receive care from paediatric health care institutions. Thus, they must make a transition to the adult health care system.

There are at least four reasons for this transition: (1) adult care providers may be better able to manage adult health issues than paediatric care providers (e.g. screening for hypertension and counselling regarding sexuality/fertility); (2) the change may represent a fresh start with a new provider and stimulate a move towards greater autonomy for health care among young adults; (3) it places them in an age-appropriate setting with their peers; and (4) it protects finite resources in the paediatric health care system so that children are ensured access.

Individuals with CP, SB, and ABIc make a variety of transitions: from school to work; from their parents’ homes to community living; and from health care delivered through children’s treatment centres to adult health care.1 However, it is the transition to adult health services that has been identified as one of the more difficult transitions faced by these groups [12,13] because there is an apparent gap between needs and available health services for adults [14–16].
A detailed review of the literature identified a growing body of discussion papers regarding the transition to adult care for those with chronic and complex physical disabilities of childhood (CCPDC) [12,17–23]. Guidelines based on experience have also been published [24]. The literature suggests that the transition to adult services is difficult for this group, and that integrated multi-disciplinary programmes are important in the care of these individuals [25]. The strongest study to date was conducted by Bottos et al., who studied 27 adults with CP. They reported that the sequelae of CP continue well into adulthood, that ‘contact with health and rehabilitation services was radically reduced’, and that ‘motor performance deteriorated’ once in adulthood [15]. Their need for health care has been reported to increase over time due to a high rate of secondary conditions and complications (e.g. pain, deformities, and bowel/bladder problems) [15,26].

Our collective clinical experience with this population convinces us that this group requires specialized and integrated care. Furthermore, the move to adult services is associated with a disconnection from familiar care providers, yet attempts to establish new connections are difficult for these individuals because of their mobility, social, and communicative challenges. Moreover, there are a very limited number of adult providers who have the necessary expertise. As a result, adults with CP, SB, and ABIc may be unable to access physician services necessary for the maintenance of their health [15], which may place them at an even higher level of risk of adverse health outcomes.

It is time to apply scientific methods to examine the patterns of health services use in this population of adults. This information is essential to understanding the health resources required to support these individuals as they age and may guide clinical practice and health services models in the future.

The purpose of this paper was to begin the process of documenting by exploring patterns of health care utilization, among adults with complex physical disabilities of childhoods, within the Ontario health care system.

Methods

This is a retrospective descriptive study, using a health services analysis approach. The target population was young adults who had graduated from one children’s treatment centre in Ontario, and who had one of the three most common conditions treated at the centre: CP, SB, and ABIc.

Sample

A cohort of recent graduates from the Bloorview MacMillan Children’s Centre (BMCC) was identified through a review of health records. All clients who were at least 19 years of age at the beginning of the study window (1996) were eligible. The age distribution was examined to identify a visual gap in the distribution that could be used as an upper limit on age that would ensure an adequate sample size for the cohort yet limit the sample to a manageable number. This break point was determined to be 26.99 years of age in 1996. Thus, the sample included those born in 1969–1976. Health records were reviewed either in paper or microfiche form to restrict the sample to those who with CP, SB, and ABIc. Those clients whose contact was limited to drivers’ education or the dental clinic were excluded because the focus of the study was on those who had received medical care at the centre.

Data abstraction

The records of eligible clients were reviewed in detail. Information on diagnosis, date of birth, and health card number was recorded on a chart abstraction form. The level of severity of their condition was recorded for those with cerebral palsy using the Gross Motor Function Classification System (GMFCS) [27] and for those with spina bifida using the level of motor function recorded in their health record during childhood. An accurate surrogate for severity in the ABIc population was not available. This information was securely transported to the Institute for Clinical Evaluative Sciences (ICES) under institutional consent from the BMCC and with the approval of the Research Ethics Boards at the Bloorview MacMillan Centre and the Hospital for Sick Children.

Measures

This study focused on three components of the health care pattern: the frequency of outpatient physician visits (OPPVs), the number of in-patient episodes of care (IPECs), and the prevalence of a primary care physician (PCP). The frequency of OPPVs is an indicator of community-based care and was sub-divided into office appointments and emergency department visits. The number of IPECs is a surrogate measure of serious complications requiring hospital level care. The presence of a PCP is believed to be an indicator of an adequate level of health maintenance and promotion provided by a single physician, thus indicating some continuity of care.

While these indicators do have limitations, they are expected to provide a reasonable estimate of patterns of health care and are a logical starting point in the effort to explore patterns of health care utilization in these populations. A more detailed level of information may be available by other methods but may
not cover all providers or all patients consistently. The use of these administrative data has the advantage of ensuring consistent access to data from all providers for all patients for the full 4-year period.

Data linkage

The records from the BMCC were linked to data from the Ontario Health Insurance Plan (OHIP) at ICES to assess the frequency of OPPVs and the proportion seeing a PCP, and to data from the Canadian Institute for Health Information (CIHI) to assess the number of IPECs. To minimize the effect of year to year variability in patterns of health care, data from a 4-year period were used: 1996–1999 inclusive.

Analysis

Information from OHIP billing data was aggregated to identify OPPVs. The number of OPPVs was defined as the number of unique days on which physician services were billed to OHIP. This strategy has the benefit of ensuring that if several physicians saw a patient on the same day, it was not counted multiple times, since this often represents consultations within one visit.

Information from CIHI data was aggregated to identify IPECs. An IPEC was defined as all care between admission and separation (discharge) dates as recorded in the CIHI data.

The number of OPPVs to each different physician were analysed to determine whether or not the client had a PCP during the 4-year period. Patients were classified as having a PCP if greater than 50% of their OPPVs were to one physician. This definition is based on modification of a primary care rule previously described by Jaakkimainen [28] and Menec et al. [29].

Frequencies of OPPVs and IPECs were calculated for the total group over the 4-year period. In addition, rates per 100 were estimated by diagnostic group. Proportions were used to summarize the numbers with a PCP. Note that rules to ensure patient confidentiality were carefully followed, and no information on groups less than five in number were reported. Accordingly, we have suppressed some of the sub-group results from this study.

Results

The list of previous clients who met the inclusion and exclusion criteria for this study contained 1079 potential subjects born in the years 1969–1976. The chart review process further limited the cohort to those clients who had CP, SB or ABIc ($n = 382$). Of these, 359 had a valid OHIP number confirmed using the Registered Persons Database at ICES, and 349 were found to have at least one OHIP and/or CIHI record during the period of 1 January 1996 to 31 December 1999. The patterns of health care use for the remaining four individuals suggested that they had not remained users of the Ontario health care system for the duration of the 4-year period of interest (had either moved or died), leaving a total sample of 345 adults.

Description of sample

The sample of 345 adults with chronic and complex physical disabilities of childhood origin comprised 199 adults with CP (58%), 87 adults with SB (25%), and 59 adults with ABIc (17%). The mean age as of 1 January 1996 (the time of the first administrative record included in the analysis) was 21.9 years and ranged from 19.0 to 26.9 years. The mean age in each diagnostic group was very similar (22.0, 21.4, and 22.3 years for CP, SB and ABIc, respectively), and the mean ages for men and women were 21.6 and 21.8 years, respectively.

Due to small numbers in each of the severity groups, the severity scores were aggregated into mild and severe categories. We were able to classify 82.4% of the CP group, of whom 42.1% had mild CP, and 57.9% had severe CP (severe was defined as GMFCS $\geq 3$). In the SB group, we were able to classify 85.1%, of whom 33.8% had mild SB, and 66.2% had severe SB (severe was defined as functional level L2 or higher).

Patterns of health services utilization

Initial review of the OHIP and CIHI data revealed that over 95% of the patients in each diagnostic group were seen by a physician each year.

Out-patient physician visits (OPPVs). Among the group of 345 individuals, there was a total of 15,895 OPPVs. These were evenly distributed over the 4-year period. Thus, on average, there were 11.5 visits per person per year or one visit per person every 1.0 months. Among the OPPVs, 96.5% were office appointments and 3.5% were classified as emergency department visits. The number of visits by diagnostic group is shown in Table I.

In-patient episodes of care (IPECs). There were 204 IPECs for the cohort. These were also evenly distributed over the 4-year period. Thus, on average, there were 14.8 admissions per 100 patients per year, or one admission for each patient every 6.8 years. The number of admissions per patient per year in each of the diagnostic groups is shown in Table II. Note that because of the small sample sizes, these estimates are not considered precise.
Primary care physician (PCP) pattern. When the data on which individual physicians were providing OPPVs to each patient were reviewed across the 4-year period, 11.0% of patients were found to have fewer than 10 physician visits and were not considered to have a PCP according to the algorithm previously reported [28,29]. In addition, 65.5% had less than 50% of their visits to one physician and thus were added to the 11.0% without a PCP. Only 23.5% clearly demonstrated a PCP pattern of care. The rate was slightly higher for those with CP, at 31.2%.

Although the intent of this study was descriptive, we did explore the data to identify trends that may guide future study. Women appeared to have slightly higher rates of health care use, but no trends related to aging were observed. We also explored the relationship between having a primary care physician and the rate of emergency visits. The results show that there was no substantial association between having a PCP and the number of IPECs. However, emergency visits appeared to be slightly less common in those with a PCP. More detail is provided in Tables III and IV.

In order to determine whether IPECs were related to their underlying condition of CP, SB, or ABI, we had a physician familiar with these populations manually review the diagnostic codes for each IPEC. For many, there were no codes available. However, for those on which there were codes, the physician rated the IPEC as either ‘attributable’ to the underlying condition, ‘not-attributable’, or ‘uncertain’. Analysis of these data indicated that across the three groups, 81.2% of admissions were attributable to the underlying condition.

Discussion

This study shows that adults with CP, SB, and ABIC access physician services frequently: on average, they see a physician on a monthly basis. This may be interpreted as excellent access to care. However, most did not have a primary care physician. They were seeing many different physicians. While it is difficult to determine the importance of this finding without additional information regarding their health status, our exploratory analyses suggest that having a primary care physician is important because it may potentially reduce the number of emergency visits. This hypothesis must be tested in future studies.
We also compared the annual admission rate observed in this study (rate = 14,783 per 100,000) to that reported for the general population by Statistics Canada (rate = 1,641 per 100,000 Canadians between the age of 25 and 44 years in 1997–1998).\(^2\) Note that we excluded pre-natal and obstetrical records from our analysis due to low numbers and the sensitive nature of these data. Therefore, these have also been excluded from the population data. The resulting comparison shows that the admission rate among adults with chronic and complex physical disabilities of childhood was 9.0 times that of the general population.

There are several potential limitations in this study. The study was completed on a small sample from a single children’s treatment centre in Ontario. The data used were limited to those available from OHIP and CIHI, and are therefore focused on physician services. Much of the rehabilitation care provided to these populations is delivered by therapists and is not recorded by OHIP. Finally, our definition of OPPVs and IPECs used an aggregation algorithm that may underestimate the true number.

Conclusions

This study provides the first estimates of the frequency of physician visits, admissions to hospital, and patterns of primary care for adults with CP, SB, and ABIc. It appears that most individuals are connected to the adult health care system but that there is much room for optimization of the patterns of care. Out-patient physician visit rates and admission rates are both high. This study also identified the need to study the relationship between having a primary care physician and rates of emergency department usage in the future. If multi-disciplinary programmes were available to adults (similar to those provided in paediatric centres), it is possible that better care would be provided. This care may also prove more efficient and cost-effective for the health care system.

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Notes

1. The restriction of services delivered by children’s treatment centres in Ontario (and elsewhere in Canada) to exclude young adults became policy at different centres at different times (e.g. some treatment centres followed adults to age 21 until 2000), but all now have a policy of exclusion at 19 years of age to protect the limited resources for children.

2. Reference information from Statistics Canada website: Canadian Statistics—Hospital Separation (www.statcan.ca/english/Pgdb/health18b.htm).

References
