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Health status and health care utilization profiles of adolescents with disabilities

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ABSTRACT

Background: Adolescents with physical disabilities of childhood often require a transition from pediatric to adult systems as part of life-long, comprehensive health care once they reach 18 years of age. The process of transition can be complex, challenging, and influenced by health-related factors and availability of health care resources.
Objective: To provide a baseline profile of health-related quality of life, health management, social participation, and health care utilization for adolescents 16 years of age with spina bifida (SB), acquired brain injury (ABI), or cerebral palsy (CP) in Toronto, Canada.
Methods: A cross-sectional survey design was used. A sample was drawn from a large, urban pediatric rehabilitation hospital as part of a prospective, longitudinal, observational mixed-methods study. Seven English language, paper-copy standardized measures were completed; measures were organized across the three domains of interest. Health care utilization data were obtained from population-based, health services administrative datasets held by ICES. These data included outpatient physician visits, emergency department visits, and hospitalizations over a 12-month period, beginning at their 16th birthday.
Results: The sample comprised 99 participants: survey measures were completed by 59 participants (12 SB, 19 ABI, and 28 CP) and health care utilization obtained for 92 participants (19 SB, 25 ABI, and 48 CP). Baseline scores across measures and rates of health care utilization are provided. All three groups reported relatively good health-related quality of life. Youth with CP had lower scores on health utility, health management, and social participation, compared with the SB and ABI groups. Youth with SB had slightly higher health care utilization in the 12-month period after their 16th birthday, compared with the ABI and CP groups.
Conclusions: This cross-sectional survey collected comprehensive health status and health care utilization data on 16-year-old youth with SB, ABI, and CP in Toronto, Canada. With few exceptions, the CP group consistently scored lower across measurement domains. These baseline data may be useful for hospital administrators, policy

Abbreviations: ABI, acquired brain injury; CP, cerebral palsy; SB, spina bifida; SD, standard deviation

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makers, and researchers examining changes in health-related quality of life, health management, social participation, and health care utilization among youth with SB, ABI, and CP, particularly in the context of transition planning and evaluation.

1. Introduction

Spina bifida (SB), acquired brain injury (ABI), and cerebral palsy (CP) are complex physical disabilities of childhood that can have significant impact on the health and well-being of children and adolescents.[1] Prevalence estimates in North America are 3.6 per 10,000 live births for SB and 2.9 per 1000 live births for CP.[2,3] Global estimates of the incidence of pediatric traumatic brain injury range from 47 to 280 per 100,000 children per year.[4] Advances in clinical care and medical technologies over the last several decades have resulted in significantly improved survival for children with these conditions, with most individuals with SB, ABI, and CP living well into adulthood.[5,6]

Children and youth with SB, ABI, and CP require ongoing and comprehensive health care.[5,7,8] In Canada, access to pediatric health care systems for childhood-onset physical disabilities and neurodevelopmental disorders often ends at 18 years of age, with provincial mandates for transfer to adult-oriented health care systems between 16 and 19 years of age.[9] This period of health care transition often requires specific supports to ensure "uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive" health care (p. 570).[10] Transition, as defined by Blum et al.,[10] is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" (p. 570). "Preparation for transition," i.e., the period of active preparation for transfer to adult health care for youth with SB, ABI, and CP usually begins around 16 years of age.[11]

The process of health care transition can be complex and challenging, and the needs and transition experiences of youth with disabilities have been described.[12–15] Other authors have reported on the health status and health care utilization of adolescents and young adults with disabilities.[11,14,16–19] A systematic review by Kaehne et al.[20] examined study designs and methods in pediatric health care transition research; however, they cited the lack of baseline data as a significant challenge to advancing evaluative work in this area.

Comprehensive measurement of baseline health status and health care utilization among adolescents with SB, ABI, and CP prior to transition from pediatric to adult health care may be useful to inform policy, programs, services, and health care delivery. Baseline data on health status may also be useful for research, for example, to determine sample size and power for proposed studies, and to determine whether an intervention effect might represent a clinically important difference. The objective of this descriptive cross-sectional survey was to provide a baseline profile of the health status (health-related quality of life, health management, and social participation), and health care utilization among adolescents 16 years of age with SB, ABI, and CP in Toronto, Canada.

2. Methods

A cross-sectional survey – part of a prospective, longitudinal, observational mixed-methods study evaluating a linked model of transition care – collected data on health status and health care utilization among youth with SB, ABI, and CP in Toronto, Canada. The full protocol for the LETS ('Longitudinal Evaluation of Transition Services') study has been published in an open access journal.[21] The LETS study was completed before the onset of the COVID-19 pandemic. The study protocol was reviewed and approved by the Holland Bloorview Research Ethics Board (Approval #09-036).

2.1. Participants

Youth, 16 years of age, with a diagnosis of SB, ABI, or CP were recruited from Holland Bloorview Kids Rehabilitation Hospital located in Toronto, Canada. This large, urban, pediatric academic health sciences center supports the inpatient and outpatient rehabilitation needs of children and youth with physical disabilities and complex medical conditions. Rehabilitative care is delivered by multidisciplinary teams of physicians, nurses, and rehabilitation professionals, within a universal health care model. Prior to recruitment, hospital health data services generated a list of potential participants based on date of birth and diagnosis. In total, 43 youth with SB, 88 youth with ABI, and 128 youth with CP were identified as eligible for the study.[11] Study participants were recruited in person and provided written informed consent or written informed assent with parental/legal guardian consent.

2.2. Data collection

2.2.1. Health-related quality of life, health management, and social participation measures

Participants completed a series of English language, paper-copy questionnaires. In total, seven measures across three domains were selected to generate a comprehensive baseline profile of youth with SB, ABI, and CP prior to the transfer of care to adult services. The three measurement domains were: (i) "health-related quality of life", (ii) "health management", and (iii) "social participation". Table 1 provides a detailed summary of the health status measures, including descriptors, scoring and interpretation, and psychometric properties. All requisite licenses and permissions for use were obtained.

Measures in the "health-related quality of life" domain included the Health Utilities Index® Mark 3 (HUI3)[22] and the Assessment of Health-related Quality of Life (AQoL-6D).[25] Quality of life is an important construct in this context as perceptions of life and health may influence an adolescent's goals and expectations.[34] Given a lack of consensus on the "best" instrument to capture health-related quality of life of adolescents, these two measures were used to generate a breadth of items.[35] The HUI3 includes more functional items, for example, those pertaining to memory, dexterity, and cognition; while the AQoL includes items on mental health and coping (mood, energy, control) and on social issues such as relationships and community involvement.[35] Three measures were used to assess relevant competencies in the "health management" domain: the Autonomy domain of the Arc's Self-determination Scale (ARC),[27,28] the Chronic Disease Self-Efficacy Scales (CDSES),[29] and the Partners in Health Scale (PIH).[30] Managing one's own health, specifically, the skills and confidence needed to monitor symptoms, take charge of medical needs, and seek support when necessary are central aspects of transition preparation. Finally, the "social participation" domain was assessed using the LIFE-Habits General Assessment Tool (LIFE-H), which captures regular day-to-day activities and social roles,[31,32] and the Multi-dimensional Scale of Perceived Social Support (MSPSS),[33] which captures self-care and daily activities, as well as friendships and other social relationships.

2.2.2. Health care utilization data

Health care utilization data were gathered from population-based, health services administrative datasets held by ICES.[7] ICES is an

[7] In 2018, the institute formerly known as the Institute for Clinical Evaluative Sciences formally adopted the initialism ICES as its official name.

Table 1
Overview of health-related quality of life, health management, and social participation measures.

Measure	Acronym	Source	Assessment domain and interpretation	Psychometric properties
Health-related quality of life domain				
Health Utilities Index® Mark 3 [15Q version]	HUI3	**Development paper:** [22] Feeny D, Furlong W, Torrance GW, Goldsmith CH, Zhu Z, DePauw S, Denton M, Boyle M. Multi-Attribute and Single-Attribute Utility Functions for the Health Utilities Index Mark 3 System. *Med Care* 2002;40:113–128. **Tool website:** http://www.healthutilities.com	Self-rated 15-item measure of 8 health attributes [vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain or discomfort] over a 4-week period. Combinations of attributes and levels create utility scores representing health status and health-related quality of life. The 15Q version is for individuals over 12 years of age. A generic scale is used for scores with 0.00 (dead) and 1.00 (perfect health); negative scores can be obtained. **Higher scores indicate greater health state and health related quality of life.**	Internal consistency: Not available Test-retest reliability: 0.77 (subscales 0.14–0.073)[23] Construct validity: Extensive studies have been conducted
Assessment of Health-related Quality of Life-6D Simplified	AQoL-6D	**Development paper:** [24] Hawthorne G, Richardson J, & Osbourne R. (1999). The Assessment of Quality of life (AQoL) instrument: a psychometric measure of Health-Related Quality of Life. *Qual Life Res* 1999;8(3):209–224. **Tool website:** https://www.aqol.com.au	Self-rated 20-item measure of health-related quality of life with 5 dimensions [independent living, mental health, coping, relationships, pain, senses]. Responses are combined into dimension scores and a single utility score. Utility scores are scaled from − 0.04 (worst health state) and 1.0 (best health state). **Higher scores represent higher health-related quality of life.**	Internal consistency: 0.81(subscales: 0.86–0.052)[24] Test-retest reliability: 0.80[25] Construct validity: Adequate[26]
Health management domain				
The Arc's Self-determination Scale - Adolescent Version	ARC	**Development paper:** [27] Wehmeyer ML. *The Arc's Self-determination Scale: Procedural Guidelines*. The Arc, 1995. [28] Wehmeyer ML, & Kelchner K. *The Arc's Self-determination Scale Adolescent Version*, 1995. **Tool website:** https://www.thearc.org	Self-rated 72-item measure of self-determination assessing four domains: autonomy, self-regulation, self-realization and psychological empowerment. Questions include case-based open-ended questions and questions with binary choices or Likert scale. Standard scores yielded for total self-determination score and four domain scores ranging from 1 to 100. Raw scores are converted to percentile scores. **Higher scores indicate greater self-determination.**	Internal consistency: 0.90 (0.62–0.090 for subscales)[27] Test-retest reliability: Not available Construct validity: Adequate[27]
Chronic Disease Self-Efficacy Scales	CDSES	**Development paper:** [29] Lorig K, Stewart A, Ritter P, González V, Laurent D, Lynch J. *Conceptual Basis for the Chronic Disease Self-Management Study*. In: *Outcome Measures for Health Education and other Health Care Interventions.* Thousand Oaks CA: Sage Publications, Inc., 1996, p.24–25,41–45. **Tool website:** Https://selfmanagementresource.com	Self-report 33-item measure of level of confidence in engaging in activities across 10 domains that will influence health and well-being. Response options range from "1 – not all confident" to "10 – totally confident. **Higher scores indicate higher self-efficacy.** Domains include: (i) Exercise Regularly Scale, (ii) Get Information about Disease Item, (iii) Obtain Help from Community, Family, Friends Scale, (iv) Communication with Physician Scale, (v) Manage Disease in General Scale, (vi) Do Chores Scale, (vii) Social/Recreational Activities Scale, (viii) Manage Symptoms Scale, (ix) Manage Shortness of Breath Item, and (x) Control/Manage Depression Scale.	Internal consistency: 0.77–0.91 for subscales[29] Test-retest reliability: 0.72–0.89 for subscales[29] Construct validity: Not available
Partners in Health Scale	PIH	**Development paper:** [30] Battersby MW, Ask A, Reece MM, Markwick MJ, Collins JP. The Partners in Health Scale: the development and psychometric properties of a generic assessment scale for chronic condition self-management. *Aus J Prim Health* 2003;9(2–3):41–52. **Tool website:** https://www.flindersprogram.com.au	Self-report 13-item measure assessing perceptions of current self-management knowledge, attitudes and behaviors and impact of their chronic condition. Questions are scored on a 0–8 Likert scale ranging from 'very little or never' to 'always or well' and yield 4 subscale scores and a total mean score. **Lower scores represent better self-management practice.**	Internal consistency: 0.88 [0.88 on subscales][30] Test-retest reliability: Not available[30] Construct validity: Not available

(*continued on next page*)

Table 1 (*continued*)

Measure	Acronym	Source	Assessment domain and interpretation	Psychometric properties
Social participation domain				
LIFE-Habits: General Assessment Tool [Short Form LIFE-H 3.0]	LIFE-H	**Development paper:** [31] Noreau L, Fougeyrollas P, Vincent C. The LIFE-H: Assessment of the quality of social participation. *Tech Disab* 2002;14:113–118. [32] Fougeyrollas P, Noreau, L, Beaulieu M, Dion SA, Lepage C, Sévigny M, St Michel G, Tremblay J. *Assessment of Life Habits (LIFE-H 3.1) General Short Form* (Ed. 2003). Lac-Saint-Charles: QC, 2003. ISBN 2-922213-25-0. **Tool website:** https://www.mhavie.ca	Self-report measure assessing 77 day to day life habits across 12 domains (Daily activities: 6 and Social roles: 6). Life habits are assessed across 2 dimensions: the level of accomplishment and type of assistance required; using a 9-point scale from "0 – not accomplished' to '9 – accomplished with no difficulty and no assistance'; 'not applicable' is also a response option. In the version employed, **higher scores indicate optimal participation.**	Internal consistency: Short form 0.67 (children) and 0.83 (adults)[31] Test-retest reliability: > 0.60[31] Construct validity: Adequate[31]
Multi-dimensional Scale of Perceived Social Support	MSPSS	**Development paper:** [33] Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Perceived Social Support. J Pers Assess 1988;52:30–41.	Self-report 12-item measure assessing perceptions of adequacy of support received with 3 subscales: 'Significant Other', 'Friends' and 'Family'. Response options range from 'very strongly disagree' to 'very strongly agree' on a 7-point scale (0–6) with a maximum score of 72 divided by 12 for mean score. **Higher scores indicate greater perceived social support.** Scale scores ranging from 1 to 2.9: low support; 3–5: moderate support; and 5.1–7: high support.	Internal consistency: 0.88 [0.91–0.85 for subscales][33] Test-retest reliability: 0.85 [0.85–0.72 on subscales[33] Construct validity: Adequate[33]

independent, non-profit research institute funded by an annual grant from the Ontario Ministry of Health (MOH) and the Ministry of Long-Term Care (MLTC). As a prescribed entity under Ontario's privacy legislation, ICES is authorized to collect and use health care data for the purposes of health system analysis, evaluation, and decision support. Secure access to these data is governed by policies and procedures approved by the Information and Privacy Commissioner of Ontario.

Participants' unique Ontario Health Insurance Plan numbers were used to capture outpatient physician visits, emergency department visits, and hospitalizations over the 12-month period starting on their 16th birthday (determined based on date of birth). Both planned and unplanned outpatient physician visits and hospitalizations were included. These datasets were linked using unique encoded identifiers and analyzed at ICES.

2.2.3. Scoring and analyses

Scoring guidelines for the questionnaires were followed. Rules for handling missing responses on the Chronic Disease Self-Efficacy Scales, Assessment of Health-related Quality of Life, and LIFE-Habits General Assessment Tool were applied. Participants with missing responses on the Partners in Health scale and the Multi-dimensional Scale of Perceived Social Support were removed from analysis as rules for missing data are not defined. The HUI3 and the ARC autonomy scales had very few missing data. Code was written (based on scoring guidelines) for R statistical software, except for the AQoL-6D measure as a Statistical Package for Social Sciences (SPSS) algorithm was available. For the health care utilization data, SAS statistical software was used as per institutional requirements at ICES.

Descriptive statistics were used to summarize the data; means and standard deviations were reported by measure and by clinical group (SB, ABI, and CP). Formal statistical testing was not conducted. First, the survey measures – health-related quality of life, health management, social participation, and health care utilization – were identified as secondary outcomes in the original protocol (with no power calculations). Second, the sample sizes in the groups were small. Last, there was caution around conducting multiple comparisons across the three groups as formal testing would have increased the likelihood of a spurious "statistically significant finding."

3. Results

In total, the LETS study prospectively recruited 99 participants 16 years of age; 21 adolescents with SB (49 % of eligible), 30 with ABI (34 % of eligible), and 48 with CP (38 % of eligible), representing an overall recruitment rate of 38 % of eligible participants.[11] Of the 99 recruited participants, 59 (60 %) completed the survey self-report measures: 12 (57 %) SB, 19 (63 %) ABI, and 28 (58 %) CP. Population-based data on health care utilization were collected for 92 (93 % of total sample) recruited participants; 2 SB and 5 ABI participants did not consent to providing their unique Ontario Health Insurance Plan numbers required to access the ICES databases.

Demographic and clinical characteristics of the LETS study sample have previously been reported.[11] Most study participants were born in Canada (88 %), and almost two thirds of participants were male (64 %).[11] Of the SB sample, 81 % were diagnosed with lipomyelomeningocele and 9.5 % with myelomeningocele (9.5 % missing diagnostic details).[11] Of the CP sample, severity was classified using the Gross Motor Function Classification System; a five-level classification system for CP based on self-initiated movement.[36] The Gross Motor Function Classification levels for the CP participants were as follows: 35 % mild (I–II), 17 % moderate (III), and 29 % severe (IV–V) (19 % missing details).[11] Last, of the ABI sample, 67 % reported an injury-related cause, while 33 % reported a medical event as the cause.[11] In keeping with the sample age range, most of the adolescents reported living at home with one or both parents.

3.1. Measures

Aggregate data for the health-related quality of life, health management, social participation, and health care utilization measures are presented by clinical diagnostic group in Table 2.

3.1.1. Health-related quality of life

Applying a categorical approach to interpreting overall health utility scores,[37] HUI3 scores for the SB and ABI group were just within the moderate disability class (range: 0.70 to0.88); scores for the CP group were in the severe disability class (range: < 0.70). Of note, HUI3 scores for the CP participants were considerably lower overall and closer to the 0.00 anchor. All three groups reported relatively good health-related quality of life with similar AQoL2–6D utility scores across the groups ranging from 0.7 to 0.8.

3.1.2. Health management

There was variability across groups in the percentile scores relative to sample norms on the ARC autonomy subscale (higher percentiles indicate higher positive scores in the domain).[27] The SB group scored highest (~ 70th) followed by the ABI group (~ 60th) and CP group (~ 45th). While clinical cut-points are not available, the scores of the

Table 2
Profile of health-related quality of life, health management, social participation, and health care utilization among 16-year-old youth with SB, ABI, and CP in Toronto, Canada.

	Spina Bifida (SB) Eligible sample N = 43 Recruited sample N = 21		**Acquired Brain Injury (ABI)** Eligible sample N = 88 Recruited sample N = 30		**Cerebral Palsy (CP)** Eligible sample N = 128 Recruited sample N = 48	
	Measures sample N = 12		**Measures sample N = 19**		**Measures sample N = 28**	
Standardized measures	**Responses (n)**	**Mean (SD)**	**Responses (n)**	**Mean (SD)**	**Responses (n)**	**Mean (SD)**
Health-related quality of life domain						
HUI3	12	0.7 (0.26)	17	0.7 (0.34)	27	0.3 (0.46)
AQoL2-6D	12	0.8 (0.25)	13	0.8 (0.16)	27	0.7 (0.22)
Health management domain						
ARC						
Autonomy (Percentile)	11	73.4 (13.78)	19	59.9 (22.67)	26	44.9 (26.16)
CDSES						
Exercise	11	7.4 (2.26)	17	7.5 (2.58)	28	6.1 (2.95)
Get information on disease	11	7.8 (2.71)	17	5.9 (3.27)	28	5.2 (3.15)
Obtain help	11	7.9 (1.71)	17	7.9 (1.54)	28	7.2 (2.54)
Communication with physician	11	7.4 (2.21)	16	7.7 (2.57)	28	6.5 (3.73)
Manage disease in general	11	8.0 (1.86)	14	7.6 (1.85)	28	5.8 (3.11)
Chores	11	8.4 (2.01)	15	7.7 (2.83)	28	5.3 (3.83)
Social/recreational activities	11	8.7 (1.47)	15	8.8 (1.58)	28	6.6 (3.61)
Manage symptoms	11	7.7 (2.03)	14	7.2 (1.76)	28	5.9 (3.21)
Manage shortness of breath	11	7.9 (3.08)	17	6.9 (3.87)	28	5.4 (4.01)
Manage depression	11	7.9 (1.62)	15	7.7 (1.44)	28	6.4 (2.74)
PIH	9	33.0 (13.19)	15	36.1 (24.38)	17	61.1 (33.97)
Social participation domain						
LIFE-H						
Nutrition	10	9.4 (1.05)	16	8.8 (2.00)	24	5.3 (3.86)
Fitness	10	9.2 (1.25)	16	9.1 (1.35)	24	6.1 (3.54)
Personal care	10	9.3 (1.47)	16	8.8 (2.28)	24	4.7 (3.55)
Communication	10	9.5 (0.97)	16	8.9 (2.29)	22	6.3 (3.33)
Housing	10	8.6 (2.46)	16	9.6 (0.87)	23	5.4 (3.75)
Mobility	10	7.3 (3.36)	16	8.9 (1.90)	23	5.7 (3.30)
Responsibilities	10	9.4 (0.80)	16	8.3 (3.37)	20	5.9 (3.86)
Interpersonal Relationships	10	9.4 (1.44)	16	9.7 (0.61)	24	7.8 (2.99)
Community life	10	8.3 (2.87)	16	9.1 (2.13)	24	5.6 (3.75)
Education	10	7.3 (3.29)	16	7.1 (3.89)	22	6.0 (3.80)
Employment	10	6.0 (3.33)	16	7.8 (2.88)	19	5.8 (3.08)
Recreation	10	7.9 (3.03)	16	8.6 (2.28)	22	5.3 (3.62)
LIFE-H TOTAL	10	8.5 (1.70)	16	8.7 (1.73)	24	7.4 (2.78)
MSPSS						
Significant other	11	6.1 (1.30)	17	5.9 (1.44)	25	6.1 (1.20)
Friends	11	5.7 (1.19)	18	5.5 (1.38)	25	5.3 (1.76)
Family	11	5.7 (1.83)	18	6.2 (1.04)	25	6.3 (0.77)
MSPSS TOTAL	11	5.8 (1.31)	17	5.8 (1.13)	25	5.9 (0.90)
Healthcare utilization data						
	Utilization sample N = 19		**Utilization sample N = 25**		**Utilization sample N = 48**	
Type of visit	**Data (n)**	**Number of events per person-year Mean (range)**	**Data (n)**	**Number of events per person-year Mean (range)**	**Data (n)**	**Number of events per person-year Mean (range)**
Outpatient physician visits	19	6.4 (0–25)	25	3.9 (0–10)	48	5.1 (0–17)
Emergency department visits	19	0.7 (0–5)	25	0.2 (0–4)	48	0.2 (0–2)
Hospitalizations	19	0.4 (0–3)	25	0 (0–0)	48	0.1 (0–1)

CP group would be considered "below average" (< 50th percentile).

On the Chronic Disease Self-Efficacy Scales, all three groups ranked themselves as moderately confident or higher on measure domains, with means in the range of 5 to 9. All three groups clustered around or above published means of chronic disease populations.[29] Item scores for the CP group were generally lower than those for the SB and ABI groups; more marked differences were noted for domains related to chores and social/recreational activities.

The Partners in Health Scale ranges from 0 to 104: a score of 0 reflects excellent partnership in health management while a score of 104 reflects no partnership.[30] Both the SB and ABI groups had means in the low to mid 30 s suggesting strong partnerships and management behaviors. In contrast, the score of the CP group was in the low 60 s suggesting less strong partnerships and management behaviors.

3.1.3. Social participation

Total mean scores for the LIFE-Habits General Assessment Tool were similar for SB and ABI with item scores ranging from 6.0 to 9.7. The total mean score for the CP group was lower, reflected in a range of item scores from 5.3 to 7.8, indicating greater difficulty or assistance required in daily activities.[32] Last, all three groups reported consistent Multi-dimensional Scale of Perceived Social Support total mean scores reflecting high perceived support (range: 5.1 to7.0).[33]

3.2. Health care utilization

Outpatient physician visits ranged from 4 to 6 visits/per person-year across the three groups. Emergency department visits and hospitalizations were much less frequent, ranging from 0.2 to 0.7/per person-year for emergency department visits and from 0 to 0.4/per person-year for hospitalizations across the three groups. With the caveat that the frequency of events was relatively low, the SB group had the highest rates of health care utilization.

4. Discussion

Our cross-sectional survey collected comprehensive baseline information on 16-year-old Canadian youth with a diagnosis of SB, ABI, or CP across a range of health status domains as well as data on health care utilization. Youth with CP had consistently lower scores on health utility, health management, and social participation, compared to youth with SB and ABI. Almost half of all CP participants, however, were considered moderately to severely disabled (Gross Motor Function Classification System levels III–V). Such youth require greater physical assistance and more adaptations to address mobility and participation needs.[36] Therefore, this may explain why the CP group had lower health utility scores, and lower scores on items related to autonomy, self-efficacy, and self-management, compared to the SB and ABI groups. Youth with SB had slightly higher health care utilization rates in the 12-month period after their 16th birthday, compared to the ABI and CP groups.

Our survey findings are generally consistent with previously published research. For example, Young et al. studied Ontario youth 13–17 years of age with CP and SB.[17–19,38] Addressing the CP cohort, their study sample also had a mean health utility (HUI) score of 0.3.[18] Mean AQoL scores in the Young et al. study, however, were lower (0.3),[18] compared to our survey (0.7). The wider participant age range (13–17 years) in the Young et al. study,[18] compared to the narrow age range in our survey (16 years), may explain this discrepancy; given that expectations of competence in developmental tasks captured by the adolescent quality of life measure, such as responsibilities for household tasks, relationships, and emotional maturity, vary by chronological age. Last, Young et al.[17] reported slightly higher outpatient physician visits at 6 per person- year.

Donkervoort et al.[39] and Smits et al.[40] independently measured social participation of youth and young adults with CP using the LIFE-Habits General Assessment Tool. Both studies had higher participation scores, particularly around personal care, mobility, and recreation, compared to our survey; however, both studies had a much higher proportion of participants with mild CP (Gross Motor Function Classification System levels I–II), compared with our survey.

One limitation is that our cross-sectional survey sample was recruited from a single children's treatment center in Ontario. The modest response rate was also a limitation. The use of English-only measures may have limited participation from marginalized and under-represented groups. The time commitment to complete the paper/pencil measures may also have been a deterrent to participation. Last, while our survey captured outpatient physician visits, we were unable to capture services provided by other rehabilitation professionals commonly used by these clinical groups such as nurses, therapists, and social workers. Therefore, caution is required when interpreting health care utilization rates. A general strength of our study was the collection of comprehensive data across a range of health and well-being measures for three prevalent and complex conditions, commonly grouped together in studies of childhood disability and rehabilitation.[1,41,42] Another strength of our survey was the use of population-based, health services administrative datasets. Such health utilization data are free from recall bias as data capture is system-based.[19] Given the single center design, however, it is unknown whether our data are generalizable to other pediatric centers or geographic locations.

It is unclear whether the consistently lower scores across the health status domains for the CP group, compared with the SB and ABI groups represents a true difference between the groups, a chance finding, or because of bias. As stated earlier, statistical testing was not conducted, given that these were secondary outcomes, sample sizes were small, and caution around multiple testing. In addition, the response rate for the CP group for the paper-based measures was only 22 % of eligible participants. Given this low response rate, it is possible that the CP sample may not be representative. For example, if families with more severely disabled children were more likely to complete the measures, specifically for the CP group, compared with the SB and ABI groups, this would explain the lower scores for the CP group across all domains.

Comprehensive baseline data on health status and health care utilization for youth with SB, ABI, and CP can help inform health care policy and delivery. Such data can also help tailor the development of specific interventions - based on the needs of adolescents - to manage their health and health care transition.[43] Improving the quality of health care transition for youth with disabilities requires addressing gaps in care that may lead to adverse health and health-related quality of life outcomes. In Ontario, quality standards have been identified to address variations in how transition care is delivered across the province. The standards include quality statements about what high-quality transition care should look like, e.g., early identification and transition readiness, information-sharing and support, transition plan, coordinated transition, introduction to adult services, and transfer completion.[9] The aim of the quality standards is to promote consistent and evidence-informed transitions care.

Baseline data, such as those collected in our survey, also provide a foundation for evaluation, an activity that is central to intervention and service delivery planning. Too often requests to assess the impact of a new service or intervention are made after changes in practice have been implemented, thereby missing the window for baseline data capture.[20] Changes in service delivery ought to be supported by data-driven quality improvement efforts.[43]

Baseline cohort profiles can also help identify measurement gaps and standardize the use of key outcome measures.[20,44] For example, a systematic review by Levy et al.[44] reported that only five of 52 studies evaluating health care transition interventions employed quality of life measures as the primary outcome, and each of these five studies used a different measure. Comprehensive baseline datasets, increased standardization of measures, and rigorous evaluation studies can enhance the understanding of "clinically meaningful change" and the sensitivity of available measures to capture such a change.[45]

5. Conclusions

This cross-sectional survey collected comprehensive health status and health care utilization data on a cohort of 16-year-old youth with SB, ABI, and CP in Toronto, Canada, on the cusp of active transition preparation. With few exceptions, the CP group consistently scored lower across measurement domains, compared with the SB and ABI groups. These data may be useful for hospital administrators, policy makers, and researchers examining changes in health-related quality of life, health management, social participation, and health care utilization among youth with SB, ABI, and CP, particularly in the context of transition planning and evaluation.

CRediT authorship contribution statement

Shauna Kingsnorth: Conceptualization, Methodology, Funding acquisition, Project administration, Formal analysis, Writing - original draft, Writing - review & editing. **Yani Hamdani:** Conceptualization, Methodology, Funding acquisition, Writing – original draft, Writing – review & editing. **Clare Cheng:** Data curation, Formal analysis, Writing – review & editing. **Sally Lindsay:** Conceptualization, Methodology, Funding acquisition, Writing – review & editing. **Joanne Maxwell:** Conceptualization, Methodology, Funding acquisition, Writing – review & editing. **Angela Colantonio:** Conceptualization, Methodology, Funding acquisition, Writing – review & editing. **Mark Bayley:** Conceptualization, Methodology, Funding acquisition, Supervision, Project administration, Writing – review & editing. **Colin Macarthur:** Conceptualization, Funding acquisition, Supervision, Project administration, Formal analysis, Writing - original draft, Writing - review & editing.

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Ethics Statement

The study protocol was reviewed and approved by the Holland Bloorview Research Ethics Board (Approval #09-036). Study participants were recruited in person and provided written informed consent or written informed assent with parental/legal guardian consent.

Data Availability

The authors do not have permission to share data.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Trial Registration

The LETS Study is registered as a clinical trial: ID NCT00975338 with information available at www.clinicaltrials.gov.

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