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Describing healthcare concerns of adolescents and adults with cerebral palsy

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ABSTRACT

Aim: To identify healthcare concerns of adolescents and adults with cerebral palsy (CP) followed in a multidisciplinary rehabilitation program and identify patient factors associated with the number of concerns raised. *Method:* A retrospective chart review of initial consultations of 241 people with CP (53 % male) aged 14 years or older (mean 27 y 5mo, SD 13 y 2mo), over a three-year period. Descriptive statistics were used to summarize data and explore associations. Poisson's regression was used to predict healthcare concerns from patient demographic factors.

Results: A total of 2237 distinct concerns were raised by the participants, with a median of 9 (range 1–34) concerns per person. Ten healthcare concern categories were reported by more than 25 % of the sample. Only age was associated with the number of healthcare concerns (r = 0.25, p < 0.001). Age and GMFCS significantly predicted total number of healthcare concerns.

Interpretation: Adolescents and adults with CP reported a high number of healthcare concerns at the initial visit to the Transitional and Lifelong Care program and the number of concerns may increase with advancing age. The concerns identified span a variety of biopsychosocial spheres and supports the need for ongoing specialty and multidisciplinary care of this population through their adult years.

1. Introduction

Cerebral palsy (CP) is a disorder of posture and movement¹ occurring in 2.5 per 1000 live births² and the leading cause of physical disability in childhood.³ The disorder encompasses multiple causal pathways, leading to a high degree of individuality in the manifestations of CP, and as a result individuals experience varying severities of disability and associated comorbidities.³ While the underlying brain abnormality in CP is non-progressive, there is broad acceptance that the cumulative impact of aging, musculoskeletal concerns and multimorbidity in CP can result in progressive impairment, activity limitations and/or participation restrictions over time.⁴ As a result, people with CP continue to have special healthcare needs in adulthood, though often struggle to identify and engage with appropriate services and healthcare providers that are knowledgeable about their needs.⁵ There is a significant body of literature regarding the service gap experienced by this population such as a lack of coordination and communication between paediatric and adult care systems contributing to unmet healthcare needs in various health areas,^{6,7} but minimal patient-reported data are available delineating the most common healthcare concerns these patients would identify if given the chance. Thus, it is necessary for those delivering services to adults with CP to use patient-reported data to understand how to best tailor healthcare delivery and contribute to development of best practices for effective transitional care.

The Transitional and Lifelong Care (TLC) program at Parkwood Institute, St. Joseph's Health Care London, is a clinical service that delivers ongoing, coordinated care to adults with complex, childhoodonset disabilities, including CP. In the program, patients have access to physiatry, nurse practitioner (care coordinator), physiotherapy, social work, occupational therapy, speech and language pathology, and

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dietitian consultations and care. The purpose of this study was to gather information about healthcare concerns identified by adolescents/adults with CP (and/or their caregivers) presenting to the TLC program, and to determine whether any demographic factors (age, sex, functional level, topographical distribution of CP) were predictive of the number of concerns identified.

2. Materials and method

A retrospective chart review was conducted to identify healthcare concerns of adolescents and adults with CP in the TLC program. For the purposes of this study "healthcare concerns" were defined as issues raised for discussion by either the patient/caregiver, the TLC healthcare provider or both groups at the time of initial consultation. The initial consultation involves a meeting between patient, caregiver (if appropriate/available) and one of the TLC physiatrists. The sample was composed of patients with CP whose initial consultations occurred between October 2014 and December 2017. All persons aged 14 years or older referred to the TLC during this timeframe were eligible for the study. Ethical approval was obtained through Western University Health Sciences Research Ethics Board with a waiver of consent due to the retrospective chart review methodology and low risk of patient identification using this approach. Data extraction was completed by two trained research assistants using an electronic database system (REDCap) (See Appendix A). Of note, healthcare concerns could be interrelated (i.e., pain medication concerns and increased pain complaints), and this was managed by coding both issues as two separate healthcare concerns when it was expected that more than one management approach would be required (i.e., prescription changes and follow-up or referral to another healthcare provider for intervention). Comorbid conditions that were stable at the time of initial consult, were not considered healthcare concerns for this study. Patient factors that were hypothesized to impact the number of health concerns identified were also extracted, including age, sex, functional ability level as determined by the Gross Motor Function Classification System (GMFCS)⁸ and topographical distribution of impairment. To address reliability and ensure accuracy and consistency of data extraction and coding, the research assistants flagged records that were challenging to extract (i.e., inconsistent, or unfamiliar terminology, different documentation styles between resident physicians) and the research team met frequently to discuss and audit these extractions and/or coding challenges as a quality control mechanism.

2.1. Data analysis

Individual healthcare concerns were assigned to broader concern categories using both deductive and inductive coding approaches. Once all concern category assignments were completed, individual participants were determined to either have "no individual concerns", "one individual concern", or "two or more individual concerns" within each concern category.

Spearman's rho was used to determine whether age, sex, functional ability (GMFCS level), and topographical distribution were associated with number of concerns. A Bonferroni correction factor was applied to account for the multiple comparisons conducted, and thus, an adjusted significance value was used (0.05/4). Spearman's rho correlation coefficients were also used to determine whether patient factors of age, sex, GMFCS and topographical distribution, were associated with the most prevalent healthcare concerns identified. Finally, a Poisson regression was run to determine if the total number of concerns could be predicted based on the patient factors of age, sex, GMFCS and topographical distribution.

3. Results

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Table 1

Patient demographics.

Patient Characteristic	n (241)	
	n	%
Age (10-year bands)		
14-23 years	137	56.8
24–33 years	51	21.2
34–43 years	20	8.3
44-55 years 54-63 years	18	7.5
64–72 years	4	1.7
Sex		
Male	128	53.1
Female	113	46.9
Communication	30	124
Other	63	26.1
Not Reported	148	61.4
Type of CP		
Spastic	186	76.6
Dyskinetic	15	7.4
Ataxic	0	0.0
Mixed	32	13.3
Not Reported Topographical Distribution	0	3.3
Unilateral	27	11.2
Right Hemiplegic	12	5.0
Left Hemiplegic	15	6.2
Bilateral	205	85.1
Diplegic	70	29.0
Quadriplegic	135	56.0
Not Reported	9	3.7
GMFCS Level I	30	12.4
GMFCS Level II	33	13.7
GMFCS Level III	26	10.8
GMFCS Level IV	57	23.7
GMFCS Level V	82	34.0
Not Reported	13	5.4
Surgical History	174	70.0
Neurosurgery	1/4	72.2
Bowel or Bladder	3	1.2
Other Non-Orthopedic	121	50.2
None	28	11.6
Not Reported	5	2.1
Epilepsy History	100	
Yes	123	51.0
No Not Reported	3	47.7
Medications	0	1.2
Multi-Use	135	56.0
Antiepileptic	54	22.4
Psychotropic	26	10.8
Tone	23	9.5
Pain Period (CL	44	18.3
Bone Health	98 58	40.7
Sleep	19	7.9
Sialorrhea	18	7.5
Other ^a	84	34.9
None	31	12.9
Not Reported	2	0.8
Physical Exam Results	0.6	05.5
HIP Flexion Contracture	80 122	35.7
Plantar Elexion Contracture	123	51.0 9 1
Scoliosis	31	12.9
Other	2	0.8
None	0	0.0
Not Reported	33	13.7

^a "Other" medication included medications not listed in the data collection instrument (e.g., vitamin B12, naproxen, detrol, multivitamin).

The sample included 241 people with CP in the TLC program (see

Table 1) aged 14–72 years. Most patients (70 %, n = 169) were under the age of 30 at the time of initial consult, and just over half of patients were classified as either GMFCS level IV (24 %, n = 57) or GMFCS level V (34 %, n = 82). A total of 2237 concerns were extracted, once coded, these represented 155 unique healthcare concerns across 17 concern categories (see Appendix B). Ten healthcare concern categories were reported by more than 25 % (n = 64) of the sample (see Fig. 1). Table 2 provides a summary of the most prevalent healthcare concern categories and the specific healthcare concerns contained within them. Table 3 provides a summary of the number of patients who had zero, one, or two or more concerns in each healthcare concern category.

The most prevalent healthcare concern category was need for care coordination, with 84 % (n = 203) of people with CP in the program requiring initiation or coordination of rehabilitation or multidisciplinary care. This category represented 20 % (n = 442) of all concerns raised and included an array of needs such as new referral to specialists, consultation with interdisciplinary medical teams, transition and ongoing care, or a combination of specific concerns requiring significant navigation support. Patients required care in the fields of physiotherapy (28 %, n = 67), social work (21 %, n = 51) and occupational therapy (20 %, n = 49) most frequently. Referrals were also made to seating (12 %, n = 29), speech language pathology (10 %, n = 24), family medicine (10 %, n = 23), and dietetics (9 %, n = 22).

The second most prevalent healthcare concern category related to medications, with 77 % of patients (n = 186) (representing 12 % of all concerns raised, n = 275) having at least one concern related to oral, injectable, or other agents such as starting a new medication, changing medication dose, or stopping medication. More specifically, 61 % (n = 148) of patients had a concern related to individualized medication management, 42 % (n = 100) of patients discussed medications for tone management, and 8 % (n = 18) had a concern related to supplements (e. g., vitamin D, calcium, iron).

In the TLC program, 59 % (n = 142) of adults with CP had neurological concerns (representing 9 % of all concerns raised, n = 192). Within this category, concerns related to spasticity (25 %, n = 61) were most common and encompassed management, control, and/or a noted increase in tone. Seven percent (n = 17) of people with CP in the program had concerns related to abnormal muscular spasms and contractions (i.e., dystonia/dyskinesia/athetosis), and 7 % (n = 17) had concerns related to seizures/epilepsy (e.g., increase in seizure activity, seizure management).

The remaining concern categories identified by at least 25 % of the study sample included: assistive devices (raised by 51 % of participants, n = 123, representing 7 % of all concerns raised, n = 152); social issues/ concerns such as funding, housing and social participation (raised by 43 % of participants, n = 104, representing 9 % of all concerns raised,



Fig. 1. Most prevalent healthcare concerns as a proportion of the sample (n = 241).

Table 2

Most prevalent healthcare concern categories and individual concerns.

Concern Category & Individual Concerns	n	% of the Sample Size $(n = 241)$	% of the Concerns in Healthcare Category
Care Coordination	442		
Physiotherapy	67	27.8	15.2
Social Work	51	21.2	11.5
Occupational Therapy	49	20.3	11.1
Seating	29	12.0	6.6
Speech Language Pathology	24	10.0	5.4
Family Physician	23	9.5	5.2
Dietetics	22	9.1	5.0
Transition/Ongoing Care	18	7.5	4.1
Interdisciplinary Medical Team	17	7.1	3.8
Neurology	16	6.6	3.6
Recreational Therapy	15	6.2	3.4
Unspecified Care Referral/Follow-up	15	6.2	3.4
Optometry/Ophthalmology	10	4.1	2.3
Care Coordination Other	10	4.1	2.3
Gastroenterology	9	3./	2.0
Failing Physician/Care Provider	0	3.3	1.8
Orthopedics	0	3.3	1.9
Rehabilitation Therapy	7	2.9	1.0
Developmentation incrapy	6	2.9	1.0
Psychology/Counselling/Therapy	6	2.5	1.4
Orthotics	5	2.1	1.1
Respirology	5	2.1	1.1
Dentistry/Orthodontics	4	1.7	0.9
Personal Support Worker (PSW)	4	1.7	0.9
Declined/Not Interested in Referral	3	1.2	0.7
Feeding Clinic	3	1.2	0.7
Gynaecology	3	1.2	0.7
Urology	3	1.2	0.7
Wound Clinic	2	0.8	0.5
Medications	275		
Medications Other	148	61.4	53.8
Botulinum Toxin/Botox	100	41.5	36.4
Supplements	18	7.5	7.5
Neurologic	192		
Spasticity	61	25.3	31.8
Tone Generally	60	24.9	31.3
Dystonia/Dyskinesia	17	7.1	8.9
Vision	10	7.1 4.1	5.9
Snasms	10	33	4.2
Neurology Other	6	2.5	3.1
Cognition	4	1.7	2.1
Peripheral Neuropathy/Paresthesia	4	1.7	2.1
Tremors	3	1.3	1.6
Speech/Articulation Clarity	3	1.2	1.6
Fatigue	2	0.8	1.0
Numbness/Sensory Loss	2	0.8	1.0
Shunt Function	2	0.8	1.0
Assistive Devices	152		
Orthotics, Braces and Splints	91	37.8	59.9
Wheelchair/Seating	35	14.5	23.0
Gait Aids	14	5.8	9.2
Therapeutic Devices	7	2.9	4.6
Standing Frame	4	1.7	2.6
Social	198	10.1	00.0
Financial/Funding/Insurance	46	19.1	23.2
Social Support/Participation	38	15.8	19.2
Future Core (Living Planning	29 16	12.0	0 1
Return To/Planning for School	10	5.4	6.1
Driving	11	4.6	5.6
Independence	11	4.6	5.6
Employment/Volunteering	8	3.3	4.0
Respite Support Services	8	3.3	4.0
Transportation	8	3.3	4.0
Social Other	5	2.1	2.5
Advocacy	2	0.8	1.0
Accessible Driving/Parking Permit	2	0.8	1.0
School Accommodations	1	0.4	0.5
Investigations Needed	146		

(continued on next page)

Table 2 (continued)

Concern Category & Individual Concerns	n	% of the Sample Size $(n = 241)$	% of the Concerns in Healthcare Category
X-ray	45	18.7	30.8
Bloodwork/Urinalysis Culture	23	9.5	15.8
Magnetic Resonance Imaging (MRI)	16	6.6	11.0
Electromyogram (EMG)/Nerve	10	4.1	6.8
Conduction Studies			
Unspecified Imaging	9	3.7	6.2
Bone Mineral Density Test	8	3.3	5.5
Ultrasound	8	3.3	5.5
Investigations Needed Other	7	2.9	4.8
Electroencephalogram (EEG)	6	2.5	4.1
Swallowing/Modified Barium	4	1.7	2.7
Assessment			
Bone Scan	3	1.2	2.1
Sleep Study	3	1.2	2.1
Genetic Testing	2	0.8	1.4
Functional Mobility	164		
Physical Activity/Fitness/Exercise	53	22.0	32.3
Gait Decline	36	14.9	22.0
Maintain/Improve/Limited Range of Motion	28	11.6	17.1
Improve/Decline in Functional Ability	16	6.6	9.8
Increase/Maintain/Decrease in Functional Mobility	14	5.8	8.5
Improve/Limited Ambulation	10	4.1	6.1
Falls/Fall Prevention	7	2.9	4.3
Pain	132		
Lower Extremity Pain	38	15.8	28.8
Pain Management	19	7.9	14.4
Back Pain	18	7.5	13.6
Upper Extremity Pain	11	4.6	8.3
Inflammatory and Pain Conditions	9	3.7	6.8
Unspecified Pain	9	3.7	6.8
Headaches	8	3.3	6.1
Musculoskeletal Pain	8	3.3	6.1
Pain Other	5	2.1	3.8
Generalized/Diffuse Pain	3	1.2	2.3
Neuropathic Pain	3	1.2	2.3
Orthopedic	92		
Upper/Lower Extremity Rotational	17	7.1	18.5
Positioning			
Contractures/Flexion Contractures	13	5.4	14.1
Leg Length Discrepancy	12	5.0	13.0
Spinal Curvature	12	5.0	13.0
Joint Stability/Instability	11	4.6	12.0
Hip Concerns	6	2.5	6.5
Joint Management	5	2.1	5.4
Foot Concerns	4	1.7	4.3
Ankle Concerns	3	1.2	3.3
Back Concerns	3	1.2	3.3
Hardware Concerns	3	1.2	3.3
Neurogenia Rowel and Pladdar	د 79	1.2	3.3
Neurogenic Bowel/Device Concerns	/3 55	22.8	75.3
Current Bladder/Kidney Status/	18	22.0	73.3 94 7
Function and Monitoring Bladder/ Kidney HealthStatus/Function	10	7.5	47./
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Note. The concerns labelled "___Other" within certain categories are comprised of individual concerns indicated by only one patient, and therefore were grouped together.

n = 198); need for work-up/investigation of medical issues (raised by 42 % of participants, n = 101, representing 7 % of all concerns raised, n = 146); needs related to functional mobility (raised by 40 % of participants, n = 97, representing 7 % of all concerns raised, n = 164); pain (raised by 39 % of participants, n = 93, representing 6 % of all concerns, n = 132); orthopedic issues such as contractures and scoliosis (raised by 30 % of participants, n = 73, representing 4 % of all concerns raised, n = 92); and neurogenic bowel and bladder issues (raised by 27 % of participants, n = 64, representing 3 % of all concerns, n = 73). Miscellaneous concerns that couldn't be coded in other concern categories

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Summary of concerns per category.

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Concern Category	Summary	n	% of the Sample Size (<i>n</i> = 241)
Care Coordination			
	No Concerns	38	15.8
	One Concern	74	30.7
	Two+	129	53.5
Madiantiana	Concerns		
Medications	No Concerns	55	22.8
	One Concern	110	45.6
	Two+	76	31.5
	Concerns		
Neurology			
	No Concerns	99	41.8
	One Concern	93	38.6
	1w0+	49	20.3
Assistive Devices	Concerns		
	No Concerns	118	49.0
	One Concern	99	41.1
	Two+	24	10.0
	Concerns		
Social			
	No Concerns	137	56.8 20.2
	Two	49	20.3
	Concerns	55	22.0
Investigations Needed	Goneerins		
0	No Concerns	140	58.1
	One Concern	66	27.4
	Two+	35	14.5
	Concerns		
Functional Mobility	No Concorro	144	50.0
	No Concerns	144	59.8 97.4
	Two+	31	127.4
	Concerns	01	101/
Miscellaneous			
	No Concerns	146	60.6
	One Concern	69	24.5
	Two+	36	14.9
Dain	Concerns		
raiii	No Concerns	148	61.4
	One Concern	62	25.7
	Two+	31	12.9
	Concerns		
Orthopedic			
	No Concerns	168	69.7
	One Concern	61 10	25.3
	Concerns	12	5.0
Neurogenic Bowel and	Goncerns		
Bladder			
	No Concerns	177	73.4
	One Concern	55	22.8
	Two+	9	3.7
Mental Health	Concerns		
Melital Fleatur	No Concerns	192	79 7
	One Concern	35	14.5
	Two+	14	5.8
	Concerns		
Diet			
	No Concerns	201	83.4
	One Concern	31	12.9
	1 w0+ Concerns	9	3./
Skin Health	Concerns		
	No Concerns	211	87.6
	One Concern	28	11.6
	Two+	2	0.8
Creating Officiant Partici	Concerns		
Specific Clinical Entities	No Concerns	21.2	88.0
	no concerns	212	(continued on next new)
			(communed on next page)

Table 3 (continued)

Concern Category	Summary	n	% of the Sample Size ($n = 241$)
	One Concern	27	11.2
	Two+	2	0.8
	Concerns		
Bone Health			
	No Concerns	227	94.2
	One Concern	8	3.3
	Two+	6	2.5
	Concerns		
Reproductive & Sexual			
Health			
	No Concerns	229	95.0
	One Concern	12	5.0
	Two+	0	0
	Concerns		

were identified in 44 % (n = 105) of participants, and encompassed issues such as gastrointestinal complaints, augmentative communication needs and enteral feeding considerations. The remaining concern categories included mental health (20 % of participants, n = 49), diet (17 % of participants, n = 40), skin health (12 % of participants, n = 30), bone health (6 % of participants, n = 14) and sexual health (5 % of participants, n = 12).

The median number of concerns in the sample population was 9.0 (minimum 1, maximum 34). Of the four patient variables analyzed, only age was significantly associated with the number of healthcare concerns (r = 0.245, p < 0.001; see Table 4). A small significant predictive effect of age was found for total number of concerns. For every extra year of age, 1.009 (95 % CI, 1.005–1.012) times more concerns were reported, a statistically significant result, p < .001. Similarly, a predictive effect was found for GMFCS level such that individuals classified as GMFCS levels II had 1.153 (95 % CI, 1.006–1.323; p = 0.041) and individuals classified as GMFCS level III had 0.824 (95 % CI 0.707–0.961; p = 0.013) times the concerns reported compared to individuals classified as GMFCS level V. Concerns reported by individuals with GMFCS I and IV were not significantly different than those in GMFCS level V.

Of the ten healthcare concern categories that were most prevalent among the sample population, six had very weak to moderate, but significant, associations with at least one patient factor (see Table 5). Posthoc crosstabulation suggested that older age, lower GMFCS level, and a unilateral distribution were correlated with more functional mobility concerns. Healthcare concerns related to care coordination, assistive devices, social issues, and orthopedic needs were not associated with any patient factors of age, sex, GMFCS level and/or topographical distribution.

4. Discussion

This study found that adolescents and adults (aged 14–72 years) with CP present with a high number of healthcare concerns when given the opportunity to voice (personally or via proxy) their concerns in a dedicated clinic environment. Moreover, 2237 *distinct* concerns were identified for patients presenting to the TLC program at the time of initial consultation, suggesting that not only are concerns abundant in this population, but that they represent a broad spectrum of issues rather than being confined to one medical sphere. This high level of need

Table 4

Correlations between patient factors and number of healthcare concerns.

Patient Factor	r_s	р
Age	.245*	.000
Sex	031	.635
Topographical Distribution	.088	.173
Functional Ability Level (GMFCS)	.038	.555

* *p* < .01 (2-tailed).

supports the conclusions of previous work^{4,9} that adults with CP require continuous access to coordinated care by providers with experience navigating the variety of challenges that arise with aging with CP. As expected, patient age was significantly associated with number of healthcare concerns reported by patients of the TLC program. Although CP is a non-progressive neurodevelopmental disorder,¹ comorbidities and their functional consequences have been found to worsen as a person with CP ages.⁹ Particularly, people aging with CP have been shown to experience increased levels of pain,¹⁰ depression,^{11,12} fatigue,¹³ falls and worsening gait.¹⁴ In the current study, a significant proportion of older adults with CP (81 %, n = 9) in the 54–63 age band (n = 11) presented with a high number of concerns (e.g., at least 13), whereas a much lower proportion of young adults with CP (23 %, n = 31) in the 14–23 age band (n = 137) presented with a high number of concerns. None of the healthcare concerns were related to the sex of participants, despite research that has indicated there may be important sex differences in healthcare experiences amongst people with CP.¹⁵

4.1. Considerations Regarding Common Concerns

The most frequently identified concern was care coordination. This finding is consistent with previous literature that detailed the challenges adults with CP encounter with continuity and coordination of medical and rehabilitative care,¹⁶⁻¹⁸ and that they often experience unmet healthcare needs.⁷ This may be accentuated during the transition from pediatric to adult services,¹⁹ particularly as people with CP often struggle to find appropriate services staffed by providers with condition-specific knowledge.¹⁷ These findings emphasize the value of a program such as the TLC, where appropriate, comprehensive, and lifelong care is available from an interdisciplinary team of providers with extensive experience in management of this patient population across the lifespan. A notable strength of the in-depth exploration of care coordination in this study is the ability to consider care needs by discipline. Specifically, this study identified considerable ongoing needs for physical therapy and occupational therapy that are not reported in other studies of adult outcomes. This may be due to use and reliance on health administrative data in past reports, which provide information on needs based on services used/accessed; however, if there are no available services or providers for patients to access, the need cannot be demonstrated with that type of data.

The second most prevalent healthcare concern category pertained to medication use (dose changes, new medication initiation, side effects, etc.). This was an expected finding given the wide variety of medical challenges and multimorbidity faced by adults with CP.^{20,21} Often, medications are prescribed to adults with CP based on data extrapolated from studies that did not include those with CP among their sample populations, which may or may not be appropriate. Importantly, recent work by Whitney et al.²² has highlighted the risks of polypharmacy for this population. Considering the frequency of medication concerns presented in this patient cohort, and the risks inherent to polypharmacy, much more work is needed to establish appropriate prescribing practices in this population to minimize risk while maximizing symptom control and appropriate management of comorbidities.

A little over half of the sample population had neurological concerns, with spasticity being the most raised issue. Of note, all other neurologic concerns were reported by less than 10 % of patients with CP, including issues with seizures/epilepsy and fatigue. This may be due to well-established awareness and management of long-standing issues from childhood such as epilepsy.²³ The low rates of concerns related to fatigue conflict with literature^{24,25} which could reflect the lack of fatigue screening at the time of initial consultation, a prioritization of more urgent concerns, or resignation and acceptance of fatigue as part of daily life and aging. Future studies should continue to explore this issue in more detail and over time.

Forty-two percent (n = 101) of the sample population had concerns that prompted new investigations (i.e., tests/procedures) to be ordered/

Table 5

Significant correlations between patient factors and most prevalent healthcare concerns.

Health Concern (Category)	Age		GMFCS Level	GMFCS Level			Topographical Distribution		
	rs	Strength	р	rs	Strength	р	rs	Strength	р
Medications	.219*	weak	.001	.164*	v. weak	.012	_	_	_
Neurologic	.208*	weak	.001	_	_	_	_	_	_
Investigations Needed	.293*	weak	.000	_	_	_	_	_	_
Functional Mobility	.210*	weak	.001	.471*	moderate	.000	.258*	weak	.000
Pain	.307*	weak	.000	.144*	v. weak	.029	.139*	v. weak	.033
Neurogenic Bowel & Bladder	—	—	—	—	—	—	.138*	v. weak	.035

Note. The abbreviated phrase "v. weak" represents "very weak".

p < .01 (2-tailed).

completed. Despite a perception that CP is non-progressive (and agreement that, by definition, the underlying brain abnormality of CP is static), the findings of this study add to the growing recognition amongst researchers and clinicians that people with CP face ever-changing medical challenges as they age. These changes may include progressive musculoskeletal impairments or deformities (i.e., contractures, joint subluxation or arthrosis), cervical spinal arthritis with neurological compromise, and gastroesophageal reflux disease, among others.¹ Adults with CP are also at significant risk of multimorbidity implicating the cardiorespiratory, renal and other body systems.²⁰ The significant proportion of investigations needed at the time of initial TLC program consultation further suggests an important role for health monitoring in the lifelong care of people with CP that is currently unmet for adults with CP who do not have access to specialized, coordinated care. Many adults with CP who have transitioned out of pediatric services are expected to manage their own healthcare needs, ideally with support from a general practitioner. However, many patients cannot find a general practitioner or may not find one with an accessible office or knowledge of the particularities of aging with CP. The findings of the current study highlight the challenges, inadequacies, and inequities of that model of care. In addition, the volume of new investigations required upon presentation to the TLC program coupled with numerous medication concerns likely indicates significant lack of access to specialists who care for adults with CP. This finding aligns with existing research that highlights the inadequate medical school training and consequently insufficient expertise of physicians caring for people with CP.²¹

Social concerns, including those related to funding, finances, insurance, schooling, housing, work/volunteerism and relationships were prevalent. This is in line with research demonstrating that adults with CP have lower levels of social inclusion, economic independence and educational achievement when compared to adults with other disabilities,²⁷ and experience difficulties accessing funding.²⁸ Access to support and services for post-secondary education and employment has been identified as a barrier in the transition experience of young adults with CP.¹⁹ Taken together, this data forms a strong argument for increased social supports for adults with CP.

Functional mobility concerns were also common. Post-hoc examination revealed a weak correlation between older age and an increased number of functional mobility concerns. This is consistent with previous reports, which suggest that adults with CP often experience an early decline in health and mobility, with one third experiencing a decline in walking ability before 35 years of age.^{29,30} Interestingly, in the current study, unilateral distribution of CP impairments was also associated with more functional mobility concerns, such that 74 % (n = 20) of people with unilaterally distributed CP (n = 27) had one or more functional mobility concerns, whereas only 36 % (n = 74) of people with bilaterally distributed CP (n = 205) had one or more concerns in this category. Additionally, a lower GMFCS level (higher functional ability level) was correlated with more functional mobility concerns. Though the literature clearly shows that all people with CP, regardless of GMFCS level, are susceptible to functional decline with age,^{29,30} this study demonstrates that it may be that those with higher gross motor abilities

early in life (i.e., hemiplegia or GMFCS I-III) are more likely to raise functional changes as a concern in adulthood.

Other frequent concerns identified in this study included pain, orthopedic issues, and neurogenic bowel/bladder challenges. It was notable that mental health and bone health were relatively less reported areas of concern, particularly given the prevalence of these issues in previously studies.^{31–34} It is postulated that the low rates of mental health and bone health concerns may be related to the high overall volume of concerns already identified in initial consultations and that these issues were discussed more fulsomely in follow up visits after other concern categories had already been addressed. It is also important to consider that mental health concerns may have been under-reported due to the need to develop some rapport between the physiatrist and client before exploring sensitive issues more deeply in subsequent visits. Due to the clinic model, patients do not meet with a social worker during the initial consultation, rather this is a team member they are able to access, and receive support from, following the initial consultation.

A strength of this study is that the data resulted from conversations between patients, caregivers, and healthcare providers, and did not rely on administrative or survey data. This allowed for in-depth exploration of healthcare concerns from all parties. However, due to the retrospective nature of this study, concerns were only captured at the initial consultation encounter with respect to their transition (or reintroduction to care for many older adults) to the TLC program. Future prospective and longitudinal research should be conducted to determine whether and how the healthcare concerns of this population have been addressed, and whether concerns in specific categories have persisted, evolved, or emerged over time. Consideration should also be given to the integration of qualitative methods in future program studies, as qualitative research seeks to understand the *how* and *what* of individual experiences.

The findings from this research will inform quality improvement processes within the TLC program, ensuring it meets the health and rehabilitative needs of people with CP and enhancing their transition from pediatric to adult care services and ongoing lifelong care. The data presented here can also be used to help develop and expand programs to serve adults with CP worldwide. Interested providers or policy makers can use the list of most common healthcare concerns to advocate for funding to create or expand additional healthcare services for adults with CP. Additionally, these findings may contribute to creating standards or guidelines for best practices to effectively care for adults with CP during the transitional period and throughout adulthood. Finally, where comprehensive health services for adults with CP do not exist and care coordination falls to the patients, caregivers or general practitioners, the results of this study can provide a "roadmap" of areas to assess, monitor and intervene upon throughout adult care.

4.2. Limitations

Age was not normally distributed in this sample population, such that despite the large age range and adequate sample size, over two-thirds of patients (n = 169) were under 30 years of age at the time of

initial consult. This suggests that the results are likely quite representative of concerns amongst transitional aged youth and young adults with CP but raises a question about whether the results can be generalized to older adults with CP, and the accuracy of the prediction of healthcare concern numbers from age.

This study was completed retrospectively, and as such it was impossible to determine if concerns raised were identified by patients/ caregivers or healthcare providers, future research should endeavor to differentiate between concerns reported by patients, caregivers, and healthcare providers. In addition, the sample population consisted of adolescents and adults with CP who voluntarily sought care in the TLC program, and thus had healthcare concerns that required clinical services and thus may not represent the entire population of people with CP.

5. Conclusions

This study outlined the most prevalent healthcare concerns of youth and adults with CP presenting to a multidisciplinary, comprehensive lifelong care program. Exploratory findings suggest there may be associations between some specific patient factors and most prevalent healthcare concerns (e.g., age and functional mobility). Ultimately, participants reported a high number of concerns of varied nature that were not easily predicted by condition-specific or demographic variables. These findings provide insight into the resources and structure required to provide adequate care during the transition to adult care and beyond and underscore the need for lifelong care of adults with CP. Healthcare professionals treating adults with CP should continue to offer opportunities to address the wide-ranging needs in this population, including care coordination, medication use, functional mobility, pain, bowel and bladder challenges, mental health, and bone health.

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CRediT authorship contribution statement

CC and LB conceptualized, designed and initiated the study. JS and CW collected the data. CW performed the analysis of the data and drafted the manuscript. CC and LB supported data analysis and provided critical feedback to the manuscript. CW, CC, and LB edited the manuscript. All authors contributed to the article and approved the submitted version.

Ethical statement

Informed consent was not obtained due to the retrospective nature of this chart review. The privacy rights of human subjects was observed through restricted access to records by authorized study personnel only, and the use of a robust, secure, hospital approved data management platform.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Caitlin Cassidy reports financial support was provided by Academic Medical Organization of Southwestern Ontario (AMOSO).

Data Availability

Data will be made available on request.

Appendix A: Table of patient factors and concerns extracted

Data Elements Extracted
Age (in years, at the time of initial consult)
Date of birth (mm/dd/yyyy)
Sex
Communication (person reporting concerns at initial consult)
Self, other or not reported
Type of CP
Spastic, dyskinetic, ataxic, mixed or not reported
Topographical distribution
Unilateral, bilateral or not reported
Topographical distribution – unilateral
Right hemiplegic or left hemiplegic
Topographical distribution – bilateral
Diplegic or quadriplegic
Functional ability level according to the Gross Motor Function Classification System
I, II, III, IV, V or not reported
Surgical history
Hip status ^a – in joint, partially or fully dislocated
Epilepsy history
Medications (at the time of initial consult)
Presenting concerns (at the time of initial consult)
Physical exam results
Hip flexion contracture, knee flexion contracture, plantar flexion contracture, and/or scoliosis
^a Due to reporting inconsistencies in patient medical charts, "hip status" was eventually omitted from dat

analysis.

Appendix B: Complete table of healthcare concern categories and individual concerns

Concern Category & Individual Concerns	n	% of the Sample Size ($n = 241$)	% of the Concerns in Healthcare Category
Care Coordination	442		
Physiotherapy	67	27.8	15.2
Social Work	51	21.2	11.5
Occupational Therapy	49	20.3	11.1
Seating	29	12.0	6.6
Speech Language Pathology	24	10.0	5.4
Family Physician	23	9.5	5.2
Dietetics	22	9.1	5.0
Transition/Ongoing Care	18	7.5	4.1
Interdisciplinary Medical Team	17	7.1	3.8
Neurology Regrestional Therapy	10	6.0	3.0
Unspecified Care Referral/Follow-up	15	6.2	3.4
Ontometry/Onbthalmology	10	4 1	2.3
Care Coordination Other	10	4.1	2.3
Gastroenterology	9	3.7	2.0
Family Physician/Care Provider Search/Transfer	8	3.3	1.8
Orthopedics	8	3.3	1.8
Rehabilitation Therapy	7	2.9	1.6
Psychiatry	6	2.5	1.4
Psychology/Counselling/Therapy	6	2.5	1.4
Orthotics	5	2.1	1.1
Respirology	5	2.1	1.1
Dentistry/Orthodontics	4	1.7	0.9
Personal Support Worker (PSW)	4	1.7	0.9
Declined/Not Interested in Referral	3	1.2	0.7
Feeding Clinic	3	1.2	0.7
Gynaecology	3	1.2	0.7
Urology Wound Clinic	3	1.2	0.7
Wound Clinic Mediantiana	2	0.8	0.5
Medications Other	2/5	61.4	53.9
Botulinum Toxin/Botox	140	41 5	36.4
Supplements	18	7.5	75
Neurologic	192	,10	, 10
Spasticity	61	25.3	31.8
Tone	60	24.9	31.3
Dystonia/Dyskinesia	17	7.1	8.9
Neurologic (Continued)			
Seizures/Epilepsy	17	7.1	8.9
Vision	10	4.1	5.2
Spasms	8	3.3	4.2
Neurology Other	6	2.5	3.1
Cognition	4	1.7	2.1
Peripheral Neuropathy/Paresthesia	4	1.7	2.1
Tremors	3	1.3	1.6
Speech/Articulation Clarity	3	1.2	1.0
raugue Numbrass /Sensory Loss	2	0.8	1.0
Shunt Function	2	0.8	1.0
Assistive Devices	152	0.0	1.0
Orthotics. Braces and Splints	91	37.8	59.9
Wheelchair/Seating	35	14.5	23.0
Gait Aids	14	5.8	9.2
Therapeutic Devices	7	2.9	4.6
Standing Frame	4	1.7	2.6
Social	198		
Financial/Funding/Insurance	46	19.1	23.2
Social Support/Participation	38	15.8	19.2
Home Accessibility/Modifications	29	12.0	14.6
Future Care/Living Planning	16	6.6	8.1
Return 10/Planning for School	13	5.4	5.5
Drivilig	11	4.0	5.0
Fundovment /Volunteering	21 Q	т. 0 3 3	4.0
Respite Support Services	8	3.3	4.0
Transportation	8	3.3	4.0
Social Other	5	2.1	2.5
Advocacy	2	0.8	1.0
Accessible Driving/Parking Permit	2	0.8	1.0
School Accommodations	1	0.4	0.5
Investigations Needed	146		
X-ray	45	18.7	30.8
Bloodwork/Urinalysis Culture	23	9.5	15.8
Magnetic Resonance Imaging (MRI)	16	6.6	11.0

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Concern Category & Individual Concerns	n	% of the Sample Size ($n = 241$)	% of the Concerns in Healthcare Category
Electromyogram (EMG)/Nerve Conduction Studies Investigations Needed (Continued)	10	4.1	6.8
Inspecified Imaging	9	37	62
Bone Mineral Density Test	8	3.3	5.5
Ultrasound	8	3.3	5.5
Investigations Needed Other	7	2.9	4.8
Electroencephalogram (EEG)	6	2.5	4.1
Swallowing/Modified Barium Assessment	4	1.7	2.7
Bone Scan	3	1.2	2.1
Sleep Study	3	1.2	2.1
Genetic Testing	2	0.8	1.4
Functional Mobility	164	22.0	20.0
Physical Activity/Fitness/Exercise	53	22.0	32.3
Maintain/Improve/Limited Bange of Motion	28	14.9	22:0 17 1
Improve/Decline in Functional Ability	16	6.6	9.8
Increase/Maintain/Decrease in Functional Mobility	14	5.8	8.5
Improve/Limited Ambulation	10	4.1	6.1
Falls/Fall Prevention	7	2.9	4.3
Miscellaneous	165		
Gastrointestinal	32	13.3	19.4
Augmentative Communication/Communication	19	7.9	11.5
Feeding/Enteral Feeding Tube	19	7.9	11.5
Cardiology/Respiratory	12	5.0	7.3
Miscellaneous Other	12	5.0	7.3
Statorrhea/Oral Secretions	12	5.0	7.3
Surgical Consideration/Inquiry	10	4.1	0.1
Fundorinopathies	0 5	5.5 2 1	4.0
Dental/Oral Health	4	17	2.4
Posture	4	1.7	2.4
Blood Pressure	3	1.2	1.8
Twitching/Cramping	3	1.2	1.8
Hyperhidrosis	2	0.8	1.2
Inpatient Stay (Care Coordination)	2	0.8	1.2
Pain	132		
Lower Extremity Pain	38	15.8	28.8
Pain Management	19	7.9	14.4
Back Pain	18	7.5	13.6
Upper Extremity Pain	11	4.0	8.3
Inspecified Pain	9	3.7	6.8
Headaches	8	3.3	61
Musculoskeletal Pain	8	3.3	6.1
Pain Other	5	2.1	3.8
Generalized/Diffuse Pain	3	1.2	2.3
Neuropathic Pain	3	1.2	2.3
Orthopedic	92		
Upper/Lower Extremity Rotational Positioning	17	7.1	18.5
Contractures/Flexion Contractures	13	5.4	14.1
Leg Length Discrepancy	12	5.0	13.0
Spinal Curvature	12	5.0	13.0
Joint Stability/Instability	11	4.0	12.0 6 E
Inip Concerns Joint Management	5	2.5	5.4
Foot Concerns	4	1.7	4.3
Ankle Concerns	3	1.2	3.3
Back Concerns	3	1.2	3.3
Hardware Concerns	3	1.2	3.3
Knee Concerns	3	1.2	3.3
Neurogenic Bowel and Bladder	73		
Neurogenic Bowel/Device Concerns	55	22.8	75.3
Current Bladder/Kidney Status/Function and Monitoring Bladder/Kidney HealthStatus/	18	7.5	24.7
Function			
Mental Health	62	11.6	45.0
Anecuve Disorder Concerns Rehaviourel Concerns	28	11.0	45.Z
Denavioural Concerns	10	5.0	20.0 19.4
Siccy Mental Health Other	12	2.0 2.1	17. 1 81
Diet	49	<u>2,1</u>	0.1
Diet/Nutrition	22	9.1	44.9
Weight Loss/Gain/Management	15	6.2	30.6
Diet (Continued)			
Dietary Management of Health Concern	12	5.0	24.5
Skin Health	32		

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Concern Category & Individual Concerns	n	% of the Sample Size ($n = 241$)	% of the Concerns in Healthcare
			Category
Wound/Skin Management	24	10.0	75.0
Edema/Swelling/Lymphedema Management	5	2.1	15.6
Pressure Management	3	1.2	9.4
Specific Clinical Entities	31		
Query Neurologic	14	5.8	45.2
Query Medical	9	3.7	29.0
Query Orthopedic	6	2.5	19.4
Query Neurogenic Bowel/Bladder	2	0.8	6.5
Bone Health	20		
Treatment/Management of Osteoporosis/Bone Health	8	3.3	40.0
Bone Health/Fractures	7	2.9	35.0
Osteoporosis/Osteoporosis Risk	5	2.1	25.0
Reproductive & Sexual Health	12		
Menstruation/Menorrhagia/ Amenorrhea/Pre-Menstruation	10	4.1	83.3
Sexual Function	1	0.4	8.3
Women's Health Issues	1	0.4	8.3

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