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Describing Healthcare Concerns of Young People and Adults with Cerebral Palsy

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Abstract

The purpose of this study was to identify healthcare concerns of young people and adults with cerebral palsy (CP) in the Transitional and Lifelong Care (TLC) program, and determine whether there were patient factors associated with the number of healthcare concerns. A retrospective chart review of initial TLC consultations was completed (*n* = 241). Descriptive and inferential statistics were used to explore and explain patterns in the sample population. The participants reported a high number of concerns of varied nature that were not easily predicted by condition-specific or demographic variables. This study may better healthcare delivery for young people and adults with CP by raising awareness of the health needs of this population, and potentially leading to the creation of intervention and monitoring guidelines. Furthermore, this research has strong potential to influence priority setting in the development of adult-based clinical programs and contribute to best practices for effective transitional care.

Keywords

Cerebral palsy, young people, adolescents, adults, healthcare concerns, healthcare needs, transitional care, transition of care, transitional care programs, transitional care services.

Summary for Lay Audience

Cerebral palsy (CP) is a motor disorder that is the leading cause of physical disability in children, and the symptoms of CP differ from person to person. Despite the differences in symptoms experienced, people with CP may share similar healthcare needs. The Transitional and Lifelong Care (TLC) program at Parkwood Institute, St. Joseph's Health Care London, is made up of a multidisciplinary team that provides ongoing, coordinated care to persons with complex, childhood-onset disabilities, in particular CP. The main purpose of this study was to identify healthcare concerns of young people and adults with CP in the TLC program and determine whether age, sex, functional ability level, and topographical distribution of impairment were associated with the number of healthcare concerns. Based on the 241 study participants, we found that the most prevalent healthcare concerns were care coordination, medications, and neurologic. Only age was associated with the number of healthcare concerns. These findings may better TLC healthcare delivery for young people and adults with CP by raising awareness of the health needs of this population. This research may also help influence priority setting in the development of adult-based clinical programs and contribute to best practices for effective transitional care.

Co-Authorship Statement

Specific study objectives and research questions were developed by Christina Winger, Dr. Caitlin Cassidy, and Dr. Laura Brunton. Individual study design was aligned with the larger study design, as developed by Dr. Caitlin Cassidy and Dr. Laura Brunton. Data collection was completed by Jessica Starowicz and Christina Winger, with contributions made by the larger study's research team. Data analysis was completed by Christina Winger and Dr. Laura Brunton. All manuscript writing was completed by Christina Winger, with revisions, suggestions, and feedback by Dr. Laura Brunton (all chapters), Dr. Caitlin Cassidy (all chapters), and Dr. Shannon Sibbald (chapters 1, 2, and 3).

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Chapter 1: Introduction and Background

Problem Statement

It has been estimated that up to 18% of young people in North America have a chronic health condition or special healthcare needs, such as musculoskeletal impairments or developmental delays, which affect many facets of their lives (Blum, 1991; Neinstein, 2008; Pinzon et al., 2006). The Ontario Ministry of Education asserts that of the 2.7 million youth under 19 years of age in Ontario, as many as 300,000, or 11%, have special healthcare needs and/or disabilities (Stapleton et al., 2015). Cerebral palsy (CP), a neurodevelopmental disorder, is one of many conditions resulting in these special health care needs. The leading cause of physical disability in childhood (Myers et al., 2020), CP occurs in roughly 2.5 per 1000 live births (Cans, 2000; Oskoui et al., 2013). CP is broadly characterized as a nonprogressive disorder of posture and movement related to an injury to, or an abnormality of, the developing brain (Rosenbaum et al., 2007). The disorder encompasses multiple causal pathways, and as a result, has a heterogenous distribution of severity of disability and associated comorbidities (Hollung, 2020; Myers et al., 2020).

Once considered as an exclusively pediatric condition, survival to adulthood among people with CP has increased dramatically over several decades with advances and improvements in clinical care (Binks et al., 2007). Despite significant heterogeneity in the clinical presentations of people with CP, youth with CP share a variety of challenges when transitioning from pediatric to adult care (Cassidy et al., 2016; Larivière-Bastien et al., 2013), many of which are related to a fragmented healthcare system (Binks et al., 2007). The Canadian Paediatric Society has acknowledged advances in medical treatments and technology that have contributed to the increased lifespan and quality of life of young people with special healthcare needs (Kaufman et al., 2007; Strauss et al., 2008). Moreover, the Society's position statement affirms their support of providing developmentally appropriate care for young people with chronic health conditions as they move into adult care services (Kaufman et al., 2007).

With respect to young people and adults with CP, research has shown that these groups are seven times more likely to require inpatient hospitalizations, and their length of stay averages nine and a half times longer than the hospitalizations for the general population (Young et al., 2007). In comparison to the management offered for children with CP through the holistic pediatric healthcare system, which is family-focused and based on developmentally appropriate care coordinated by a multidisciplinary care team, the adult healthcare system is fragmented with respect to the level and type of support offered, mechanisms for supported decision making, family/parent involvement and consent processes (Kaufman et al., 2007). The adult-oriented system is typically patient-focused and investigational, often with few multidisciplinary services, and reliant on independent, autonomous decisions by the patient (Castillo & Kitsos, 2017; Rosen, 1995). During and after the transition to the adult healthcare system, people with CP continue to have special healthcare needs and struggle to receive services in a beneficial manner (Carroll, 2015). In addition to experiencing changes related to entering a new life stage alongside having a chronic health condition, they also experience changes related to their delivery of care. These and other differences between the pediatric and adult health systems often result in significant barriers to care for patients with special health care needs as they age out of pediatrics, and attempt to access care as adults. The "gap" created between the pediatric and adult systems presents a major challenge to youth with CP, and has resulted in advocacy to develop adult-oriented interdisciplinary health services to fully support the complex healthcare needs of those with CP (Young et al., 2007). This gap in transitional care has been described by young people and adults with CP as being, "lost in transition" (DiFazio et al., 2014, p.22) that may leave them feeling "in a void" related to their healthcare needs (Ko & McEnery, 2004; Morris, 1999).

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 young people and adults with complex, childhood-onset disabilities, including CP. The TLC program is unique and was developed in response to the lack of a comprehensive program prior to 2014, perpetuating challenges in providing suitable care to people with CP after discharge from pediatric rehabilitation centres. Whereas other Canadian transition programs (e.g., LIFEspan Clinic (UHN, 2022)) are a part of pediatric care and focus on developing patient self-management skills, and navigation of healthcare services, the TLC program acts as a "coordination hub" for young people and adults with special healthcare needs, providing lifelong, interdisciplinary medical care (e.g., physiotherapy, dietitian consultation) and social support in areas such as employment and funding. Distinctive and exclusive to Southwestern Ontario, the TLC program delivers exceptional and necessary support to those with varying health and rehabilitative needs related to conditions of childhood-onset. However, despite its strengths, the TLC program still requires the necessary diligent evaluations that are needed, but often lacking, in transition interventions (Prior et al., 2014). To further the program leadership's understanding of how to best tailor healthcare delivery for young people and adults with CP and to contribute to development of best practices for effective transitional care, more information is required about this under-researched population (van der Slot, 2020) – in particular, the most prevalent healthcare issues they experience.

Literature Review

Cerebral Palsy

CP is a lifelong, nonprogressive disorder of childhood-onset, resulting from an injury of the immature brain (Bolger et al., 2017; Rosenbaum et al., 2007). CP is broadly characterized by paresis and incoordination (Rapp & Torres, 2000). As stated in Rosenbaum et al.'s (2007) consensus definition, CP consists of, "a group of permanent disorders of the development of movement and posture causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems" (p. 9). It is important to note that while the brain injury associated with CP is nonprogressive, functional ability level can decline overtime. Due to the heterogeneity that encompasses this disorder, CP was historically categorized into mild, moderate, and severe, or ambulant and non-ambulant status (Wimalasundera & Stevenson, 2016). This language had limited value as it lacked clinical descriptors that were meaningful, valid, and reliable, and as a result produced inconsistencies between an individual's measured motor function and the group to which they had been designated (Rosenbaum et al., 2008).

In today's clinical practice, CP is classified by its distribution, motor type and functional ability level (Wimalasundera & Stevenson, 2016). For distribution of limb involvement, the European Surveillance of Cerebral Palsy Group (SCPE) suggest the terms unilateral or bilateral as the dominant terms for categorization (Cans, 2000); however, terms such as quadriplegia (four limb involvement), diplegia (lower limb involvement) and hemiplegia (unilateral involvement) are often used to describe impairment in more detail. CP motor type can be differentiated as spastic, dyskinetic, ataxic or mixed (Cans, 2000; Johnson, 2002). Lastly, in relation to a patient's functional level, the Gross Motor Function Classification System (GMFCS) describes five functional ability levels – from Level I (most able) to Level V (most limited) (Palisano et al., 1997; Palisano et al., 2007). GMFCS has been found to remain stable through childhood, but may decline in adulthood as comorbidities and their functional consequences accumulate (Frisch & Msall, 2013).

In the Canadian context, CP is the most common physical disability in children (Kawamura et al., 2020). Multiple risk factors are associated with the condition in prenatal, perinatal, and postnatal periods such as premature birth, male sex, stroke prior to two years of age and hypoxic ischemic encephalopathy (Amankwah et al., 2020). Furthermore, research suggests that contextual socio-economic factors such as maternal education and age may also impact the severity of CP (Oskoui et al., 2016). Diagnosis usually occurs within the first two years of life (Lungu et al., 2016), but can occur later in childhood for those with greater functional abilities (Boychuck et al., 2019).

Health and Mobility

Current literature suggests that although the life expectancy of people with CP is approaching near-normal, adults with this childhood-onset disability experience a decline in health and mobility as they age (Andersson & Mattsson, 2001). More specifically, Morgan & McGinley (2014) established that mobility decline occurs in at least 25% of adults with CP who are ambulatory, with factors associated with a higher risk of gait decline including older age, less independence with gait, and higher levels of pain. Similarly, Okumura et al., (2013) found that young adults with special healthcare needs reported worsening health status as they aged into adulthood, which was correlated with their care not being optimized. It is important to note that worsening health status and sub-optimal care frequently occurs around the time of transition from pediatric to adult-oriented services. There is also evidence that individuals with CP are likely to encounter various complications in adulthood in addition to their childhood health issues; for instance, declines in feeding (Krakovsky et al., 2007; Bottos et al., 2001) as well as increased rates of pain and other complications including but not limited to bladder and bowel dysfunction, intensifying spasticity, progressive musculoskeletal deformity (i.e., contractures), cervical spinal arthritis with neurological changes, and gastroesophageal reflux disease (Liptak, 2008). Due to the complex health needs that accompany aging with CP, it is imperative that those transitioning into, and receiving care within, the adult system experience cohesive and coordinated care from a specialized, interdisciplinary healthcare team (Binks et al., 2007; Pinzon et al., 2006).

Transitional Care: Pediatric to Adult

Transitional care, or transition of care, is defined as the purposeful, planned movement of young people with chronic physical and medical conditions from child-centred to adult-oriented healthcare services (Blum, 1991). In recent years, the provision of developmentally- and age-appropriate transitional care has become a priority for researchers, practitioners, and policy makers – primarily due to the substantial number of youth now reporting a chronic medical condition (McDonagh, 2007). Moreover, many federal and provincial organizations (e.g., the Canadian Association of Paediatric Health Centres and the Canadian Paediatric Society) have recognized the importance of having organized transitional care into adult services for children with special healthcare needs, such as CP. Accordingly, these agencies have provided guidelines for transitional care, as internists (who are adult care providers) have reported an increased demand for treatment amongst this population despite a lack of relevant training and/or education (CAPHC, 2016; Peter, 2009).

Physiatrists, or Physical Medicine and Rehabilitation physicians, have extensive training that enables them to treat disabling conditions throughout an individual's lifespan (AAPM&R, n.d.). However, a cohort of Canadian physiatrists identified, "lack of Continuing Medical Education contributing to insufficient expertise in management of CP" and, "inadequate training in medical school contributing to insufficient expertise in management of CP" as barriers to becoming more involved in the care of adults with CP (Cassidy et al., 2016, p. 495). Other major barriers to increased physiatrist involvement in the care of adults with CP identified by Cassidy et al. (2016) include a lack of accessible resources (e.g., social workers and funded therapy programs) and lack of referrals. In the child-centred system, people with CP are eligible for pediatric services that are delivered by multidisciplinary teams, up until the age of 18 (Young et al., 2007). In contrast, within the adult system, people with CP typically receive care from multiple independent providers with the onus placed on the individual to coordinate their own care (Kaufman et al., 2007; Young et al., 2007). Despite some improvement regarding the crucial transition to adult services, many young people with CP still face obstacles and dissatisfaction with the process and the care they receive in the adult setting; this includes a lack of coordination and communication between the healthcare systems, loss of services, feelings of being abandoned in the adult system, and a lack of knowledgeable and attentive adult service providers (Binks et al., 2007; Cassidy et al., 2016; Larivière-Bastien et al., 2013; Reiss & Gibson, 2002).

Young people with CP experience this disruption in care due to lack of available health care services at the same time as they experience many “typical” pressures associated with transitioning from childhood to adulthood (Wimalasundera & Stevenson, 2016) (e.g., changes in education and expectations around self-sufficiency (Arnett, 2000)). Furthermore, people with CP may not effectively transition to adult services at the time that coincides with their discharge from pediatric care (particularly if they are unable to find appropriate adult service providers at the time of their discharge), and thus, may present to adult-oriented specialists much later than expected (i.e., when experiencing worsened health issues). In fact, Lam et al (2005) found that of 247 young adults with chronic healthcare conditions, 51% of surgical inpatients and 28% of medical inpatients had no documented plan for transitional care. Considering their vulnerability to interruption in healthcare, Lotstein et al. (2008) have declared a call to action that young people with CP should continue to have, “ongoing access to age- and disease-appropriate healthcare providers; access to uninterrupted, affordable health insurance; development of disease self-management skills; and access to age-appropriate educational and vocational opportunities to allow economic self-sufficiency” (p. 24). There is an ever-growing body of research highlighting the *need* for transitional care for young people with CP; however, there is still limited evidence regarding appropriate *processes* of transitional care and evaluations of transitional care *outcomes* (McDonagh, 2007; Prior et al., 2014) as well as pertinent information that would inform these evaluations.

Transitional and Lifelong Care (TLC) Program

The TLC program at Parkwood Institute, St. Joseph’s Health Care London was developed in 2014 in response to the lack of a comprehensive program in the Southwest Local Health Integration Network (LHIN), exacerbating barriers in the provision of care of people with complex medical conditions after discharge from pediatric rehabilitation centres (e.g., the Thames Valley Children’s Centre). The purpose of the TLC program is two-fold; firstly, it functions to provide suitable and comprehensive long-lasting rehabilitative care services to patients with physical disabilities of childhood, including CP, spina bifida, Rett syndrome and other developmental disabilities, and their families as they leave the child-centred system and enter adult-oriented rehabilitative care (transition service). Secondly, it’s other primary focus is to function as an ongoing clinical service that provides *lifelong* healthcare and support on a regular, and as-needed, basis for patients with

CP and other childhood-onset disabilities (Starowicz et al., 2021), such as those listed above. Thus, the program serves as a “coordination hub” for the provision of multidisciplinary, coordinated lifelong care in a single clinical setting (Starowicz et al., 2021). The TLC program is comprised of a multidisciplinary team that includes nine different health professions: Physiatry, Nurse Practitioner, Social Work, Physiotherapy, Occupational Therapy, Speech Language Pathology, Dietetics, and Rehabilitation Therapy (SJHC, 2020). Transition care program services encompass transitional clinics in the local pediatric rehabilitation centre for young people nearing discharge from pediatric care, and lifelong care program services include outpatient clinic visits at Parkwood Institute for adult, or “post-transition”, patients; system navigation for patients and caregivers; telehealth and telephone support for patients and community partners (e.g., family physicians); access to interdisciplinary rehabilitative services including assessment and treatment within speech and language pathology, physiotherapy, occupational therapy and dietetics; and access to social supports through social work services. Since 2014, the TLC program has delivered services to over 700 patients with childhood-onset chronic health conditions. The population of people with CP within the TLC program is expected to grow as the number of Canadians with CP is expected to increase with longer life expectancy and growth of the Canadian population (Amankwah et al., 2020).

Although young people and adults with CP are a heterogeneous group, and it is acknowledged that they are distinct in a multitude of domains including their experiences in accessing health and rehabilitative care services, for the purposes of this study these groups will be referred to interchangeably as “people with CP”.

Study Purpose

The purpose of this research was to identify healthcare concerns of people with CP in the TLC program and to determine whether specific patient factors were related to, or predictive of the number of healthcare concerns identified. A secondary, exploratory aim was to determine if the most prevalent healthcare concerns were related to specific patient factors. It was hypothesized that the following specific patient factors would be related to, or predictive of, total healthcare concerns:

(1) Age – As people with CP age, they experience increased levels of fatigue (van der Slot et al., 2012), depression (Opheim et al., 2007), pain (Turk, 2009; Turk et al., 2001), falling and worsening gait (Furukawa et al., 2001). Moreover, comorbidities associated with CP and their functional consequences have been found to worsen as a person with CP ages (Frisch & Msall, 2013), despite CP being considered a non-progressive neurodevelopmental disorder (Rosenbaum et al., 2007).

(2) Sex – Research has suggested male sex is a risk factor for CP (Chounti et al., 2013) and sex may be an influential factor in musculoskeletal growth and mobility in ambulant children with CP (Gough et al., 2008). Furthermore, studies have found that there are sex and/or gender differences in pain for the general population (Mckinnon et al., 2019; Mogil, 2012) and people with CP population (van der Slot et al., 2021), such that pain is more prevalent in women than men.

(3) Functional ability level according to the GMFCS (Palisano et al., 1997; Palisano et al., 2007) – Nieuwenhuijsen et al. (2008) found that young people with CP and a higher GMFCS level (or lower functional ability level) have more unmet needs and a higher utilization of healthcare in comparison to those with lower GMFCS levels.

(4) Topographical distribution of impairment – Young people with quadriplegic CP, a sub-type of bilateral topographical distribution of impairment, have previously been found to have more unmet needs (Nieuwenhuijsen et al., 2008).

Overall, it was anticipated that this study would yield invaluable information of the primary challenges experienced by people with CP in the TLC program, as well as a better understanding of their healthcare needs.

Chapter 2: Methodology

Study Design

Design Type

This was a descriptive study using a retrospective chart review to identify healthcare concerns of young people and adults with cerebral palsy (CP) in the Transitional and Lifelong Care (TLC) program. The primary aims of this study were to determine whether specific patient factors were related to, or predictive of, number of healthcare concerns. A third, exploratory aim of this study was to determine if the most prevalent healthcare concerns were related to patient factors such as age, sex, functional ability level, and topographical distribution of impairment. It is important to note that "healthcare concerns" represent issues raised by either the patient/caregiver, the TLC healthcare provider or both groups at the time of initial consultation to the program.

The underlying theoretical basis that informed this work was Bodenheimer & Sinsky's Quadruple Aim Framework (2014). It encompasses the three interdependent goals of the Institute for Health Care Improvement's Triple Aim Framework: "improve the individual experience of care (goal 1), improve the health of populations (goal 2), and reduce the per capita costs of care for populations (goal 3)" (Berwick et al., 2008, p.760), with the addition of a fourth goal: "improve the work life of healthcare clinicians and staff" (Bodenheimer & Sinsky, 2014, p. 573). The specific foci for this work were goals one and two, as it was hypothesized that the results of this study would inform improvements in care delivery for people with CP in the TLC program, and contribute to the evolving understanding of the appropriate standard of care for transitional and lifelong healthcare.

Generally, retrospective research involves the analysis of data that was originally acquired for reasons that do not include research, such as physician notes, emergency room reports, testing reports, and admission and discharge documentation – all of which is contained within the patient chart (Gearing et al., 2006; Jansen et al., 2005). Chart review or clinical record review is the process of obtaining pre-recorded, patient-centred data to answer clinical research questions (Worster & Haines, 2004) and involves surveying the already-collected data, applying statistical analysis, and drawing conclusions (Sarkar & Seshadri, 2014). Retrospective chart review is a popular method in a breadth of different health-related disciplines such as quality assessment, epidemiology, professional education, residency training, and inpatient care (Matt & Matthew, 2013), and is the “gold standard” in identifying clinical data variables, specific aspects of patient treatment, and demographic factors (Cassidy et al., 2002; Gregory & Radovinsky, 2012). In the present research, this retrospective chart review involved extracting and summarizing data recorded as part of the patients’ *initial* consultation in the TLC program (i.e., allergies, surgical history, presence of contractures, etc.).

The advantages of conducting a chart review include accessing large data samples at a relatively low cost; minimal recall bias for events that have occurred in the past; and importantly for the study at-hand, the ability to evaluate hypotheses pertaining to clinical research questions (Gregory & Radovinsky, 2012). Some limitations of using the chart review method include the potential for missing data due to incomplete or missing data within the medical record, difficulty in interpreting jargon or handwriting found in the documentation, possible variability among reviewers and between people who create the data such as residents, program physicians and nurse practitioners, as well as its time-consuming nature (Gearing et al., 2006; Siems et al., 2020). Although researchers have suggested approaches and/or guidelines for a well-conducted chart review (Gilbert et al., 1996; Gregory & Radovinsky, 2012; Siems et al., 2020), there is no singular, universally accepted process (Engel et al., 2009; Jansen et al., 2005). To maintain the reliability and validity of the present study’s chart review, the methodology proposed by Gearing et al. (2006) for conducting retrospective chart review research was adopted, which provides detailed information around the steps of conducting a chart review: (1) conception, (2) literature review, (3) proposal development, (4) data abstraction instrument, (5) development of protocols and guidelines for abstraction, (6) data abstraction, (7) sample, (8) ethics and (9) pilot. Prior to the author’s engagement in the project, components related to the larger scope’s (1) conception, (2) literature review, (3) proposal development, (7) sample, and (8) ethics were already completed (see Figure 1). It is important to note that although a literature review (step 2) was conducted for the larger study, this present study still conducted a separate, more focused literature review. Additionally, for the purposes of this chapter, the term “extraction” will be used from hereafter as the language “abstraction” is synonymous with “extraction”.

Figure 1: Previously Completed Gearing et al. (2006) Steps for Retrospective Chart Review

(1) Conception	• Develop research question(s) (Gearing et al., 2006) • Co-Principal Investigators (Co-PIs) established study purpose
(2) Literature Review	• Review current literature via relevant databases (Gearing et al., 2006) • Co-PIs conducted literature review (for larger study)
(3) Proposal	• Produce research proposal, define study variables (Gearing et al., 2006) • Co-PIs wrote proposals for funding applications
(7) Sample	• Determine sample size, inclusion/exclusion criteria (Gearing et al., 2006) • All TLC patients included age 14 or older
(8) Ethics	• Obtain approval from institutional review board (Gearing et al., 2006) • Co-PIs successfully obtained ethics approval

Participants and Inclusion/Exclusion Criteria

The sample population (*n* = 241) was composed of patients with CP, new to the TLC program, whose initial consultations occurred between October 2014 (the TLC program's establishment) and December 2017. All persons aged 14 years or older that were referred to the TLC program for coordination of care or rehabilitation management during this timeframe were considered eligible for the study. As part of the broader study, "Health Concerns of Adolescents and Adults with Childhood Onset Physical Disabilities", ethics approval was requested and obtained through Western University's Health Sciences Research Ethics Board (HSREB) prior to the current study commencing (HSREB 110893; see Appendix A). The study had waiver of informed consent as per Western University HSREB Standard Operating Policies and Procedures, including but not limited to the study posed no more than minimal risk to the participants and the information would be utilized in an approach that respects patient confidentiality (Western Research, 2016). To promote patient confidentiality, a study identification (ID) number was assigned to each eligible patient record. Furthermore, within the study database, a record ID number was assigned to each new standardized extraction form (see Appendix B).

Ethical Considerations of Retrospective Medical Chart Review

With respect to important ethical considerations of conducting a retrospective chart review, informed consent and patient confidentiality are at the forefront (Allison et al., 2000; Haynes et al., 2007; McCarthy, 2008; Sarkar & Seshadri, 2014). As mentioned above, retrospective research involves the analysis of data that was originally acquired for reasons that do not include research (Gearing et al., 2006; Jansen et al., 2005) – as such, informed consent is not possible in subsequent record reviews. It is common practice for research ethics boards to waive the requirements of informed consent, or "waiver of informed consent", when retrospective chart review studies meet specific, strict criteria as in the current study. It is still possible, however, that confidential patient information may inappropriately or inadvertently misused, which may jeopardize patient safety and/or the healthcare provider-patient relationship (Sarkar & Seshadri, 2014). Thus, there are protocols and procedures established for the handling of data from medical charts.

To uphold ethical conduct in a retrospective chart review, the following principles were followed; only information that is required for answering the research question was extracted and coded (Sarkar & Seshadri, 2014); in the current study, only relevant patient information, both demographic and condition-specific, were extracted and used during the data analysis stage. Next, any identifying information within the data was removed prior to the analysis (Sarkar & Seshadri, 2014). For example, although the data element of date of birth was extracted from the patient chart, that information was removed from the downloaded data file, prior to the data analysis stage. Additionally, as mentioned above, a study identification (ID) number was assigned to each eligible patient record, and within the study database, a record ID number was assigned to each new standardized extraction form. It may be ethically questionable whether it is appropriate to include the name of the study program, particularly in publication, as it would disclose where the participants receive CP-specific care. However, the research team deemed the risk to be minimal due to the size of the program and the type of information collected in this study. Furthermore, there is a benefit to disclosing the program name to stimulate program replication and learning for healthcare professionals; as a result, the program name will be disclosed in publications related to this work. Lastly, safeguards must be employed for appropriate and ethical use of data (Sarkar & Seshadri, 2014). Within this study, only authorized members of the TLC program research team had access to the patient medical charts on-site and the standardized extraction form that was stored on a secure database. No study data was stored on personal electronic devices, or removed from institutional network drives. Data analysis documents were accessed via Western University's OneDrive, which is protected by passwords and institutional firewalls.

Data Collection

Data collection occurred at Parkwood Institute through a retrospective chart review of new TLC patient encounters with young people and adults with CP within the abovementioned time frame, and was completed by a research coordinator and the author. See Table 1 for extracted data elements. It is important to note that the data element of "presenting concerns", referred to in this study as "healthcare concerns" or "concerns", included any healthcare or social matter that the patient and/or caregiver felt required the attention of the TLC healthcare provider, or any issue(s) that the TLC healthcare provider felt needed attention at the time of consultation to the TLC program (Starowicz et al., 2021). Consequently, healthcare concerns could be interrelated, such as one could have an issue with their medication dose as a result of a sudden increase in pain, and this would be collected as two separate healthcare concerns. This choice was made to document the clinical actions that were required to resolve each aspect of the healthcare concern reported (for example, the medication dosing change and the follow-up, or additional healthcare providers who were consulted as a result of the pain). Similarly, comorbid conditions that were controlled or stable at the time of initial consult and did not contribute to any active concerns (i.e., were not raised by the patient/caregiver/TLC healthcare provider at the time of initial consult), were not identified as healthcare concerns for this study (Starowicz et al., 2021).

The remaining retrospective review procedures described by Gearing et al. (2006) were applied in the present study to maximize the method's advantages and minimize limitations. More specifically, steps related to (4) refining the data extraction instrument, (5) development of protocols and guidelines for extraction, (6) data extraction, and (9) pilot were implemented. Regarding the extraction instrument (step 4), data extraction was facilitated through a Research Electronic Data Capture (REDCap) database, which is a robust, researcher-controlled data tool that provides secure data collection, storage, and export for researchers (Harris et al., 2009). The project's REDCap database was equipped with the custom standardized extraction form, ensuring consistency throughout data extraction (Matt & Matthew, 2013). For the development of protocols and guidelines for extraction (step 5), including a clear process for making decisions in ambiguous situations (Gearing et al., 2006), a written handbook of instructions outlining conditions and other rules for extracting data was created by the project coordinator. In alignment with data extraction (step 6), including the training and teaching of data collectors, standardized training for data extraction was facilitated by the project coordinator. In addition, to assess for inter-rater reliability (Gearing et al, 2006) and ensure accuracy and consistency amongst the data collected, on-going collaboration and communication with research staff (e.g., project coordinator), and quality control sessions with the study team, were performed. Lastly, to ensure data collection was accurate and feasible, a pilot test of the extraction tool was conducted prior to the beginning of data extraction (step 9).

Table 1: 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 (Palisano et al., 1997; Palisano et al., 2007)
    - 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 data analysis.

Data Analysis

Data Transformation

All extracted raw data elements from REDCap database records were exported into a Microsoft Excel spreadsheet. Subsequently, only raw presenting concerns of TLC patients with CP were copied and pasted into a separate Microsoft Excel spreadsheet to prepare for coding, and a third Microsoft Excel spreadsheet was created for the healthcare concern coding assignments table, with the record ID as the farthest left-hand column and the individual concerns and categories as following right-hand columns. These organizational steps to prepare for coding were completed collaboratively by the author and her supervisor. Individual healthcare concerns were both deductively and inductively coded from the raw data and grouped into broader concern categories, to assist with data analyses and enable healthcare concern categories to be identified (objective 1) and was completed by the author. Coding was deductive as a list of common healthcare concern categories and individual concerns was produced at the outset from a previous TLC program study (Starowicz et al., 2021), and formed the structure for the coding assignments table. For each individual concern in the coding assignments table, the author read each participant's extracted healthcare concerns at the time of initial consult, and assigned either a zero "0" if patient did *not* have this concern and a one "1" if patient did have this concern.

Coding was also inductive as multiple additional descriptors (categorical and individual) were generated to categorize other concerns that were not captured by the previous TLC program study's category structure. The same zero "0" and one "1" assignment legend was used with the inductive coding portion. This process was iterative as decisions were made through discussion with members of the TLC program research team such as between the current study's author and larger study's Co-PIs, and later concern assignments were compared with earlier concerns assignments to ensure accurate and comprehensive coding, as well as inter-rater reliability (Gearing et al., 2006) (e.g., the level of agreement of two or more research team members on a coding assignment). For example, within the broad concern category of Assistive Devices, concerns related to a standing frame were originally coded within the Wheelchair/Seating individual concern category. However, after discussion with the author's supervisor, it was deemed more appropriate to pull the standing frame concerns out of the original concern category assignment (due to clinical differences) and produce a separate Standing Frame individual concern category within Assistive Devices.

Once all concern category assignments were created from individual patient's presenting concerns, the author summarized whether each participant had "no individual concerns", "one individual concern", or "two or more individual concerns" within each broad concern category – for example if a patient had a concern about a standing frame and their wheelchair, they would have been counted in having two or more concerns in the Assistive Devices broad concern category. It is important to note that specific healthcare concern category breakdowns (i.e., individual concerns) were included as the research team was unable to differentiate if reported concerns came from the patient/caregiver, healthcare provider, or both, and thus we sought to honour the words of the patients, caregivers and/or TLC healthcare providers by acknowledging these concern conceptualizations may be distinct.

Description of Variables

Variables of interest included age, sex, functional ability level, and topographical distribution of impairment as these are known factors that are hypothesized to affect the health and wellness people with CP. Total number of healthcare concerns were recorded as mean, median, standard deviation, range, and minimum and maximum. Because age was not normally distributed, it was recoded and reported ordinally rather than continuously, as frequencies in ten-year bands. The remaining variables of sex, functional ability level and topographical distribution were summarized by frequencies and percentages.

Objective 1: identify healthcare concerns of young people and adults with CP in the TLC program

Descriptive statistics were used to characterize the patient demographic variables and healthcare concerns of the sample. Patient factors/characteristics were summarized as mean, median, standard deviation, range, and minimum and maximum, where appropriate. Individual healthcare concerns and healthcare concern categories were reported as frequencies and percentages proportionate to the sample size as well as the concern category. The "most prevalent" healthcare concerns were determined based on concern categories reported by more than 25% of the sample population (*n* = 241). This percentage was not based on a pre-set measure, but rather was deemed large enough to justify clinical consideration and was consistent with other reports in this area (Starowicz et al., 2021). Healthcare concern categories were also summarized based on the number of people with CP who had zero concerns, one concern, or two or more individual concerns in that category.

Objective 2: determine whether specific patient factors were related to, or predicted, number of healthcare concerns

Descriptive statistics were used to demonstrate whether specific patient factors were associated with the number of healthcare concerns. Specifically, Spearman's rho was utilized to determine whether age, sex, topographical distribution and/or functional ability (i.e., Gross Motor Function Classification System (GMFCS) level) was associated with number of concerns. This correlation coefficient was applied as the number of concerns variable was considered ordinal in nature (although differences in total number of concerns could be rank-ordered, there was an inability to assign the same or any meaning to the differences between each level of the variable, i.e. the difference between 2 and 3 concerns could not be considered the same as the difference between 11 and 12 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). This post hoc analysis was applied as it is a popular, yet conservative, method of reducing the chance of committing a Type I error, such that the familywise error rate (the probability of making a Type I error in a series of tests) is controlled among repeated statistical tests (Field, 2018). In addition, both ordinal and nominal crosstabulations were conducted with the determined associated variable(s) and total number of concerns.

Inferential statistical analysis involved conducting an ordinal regression model with the independent variables (predictors) of age, sex, topographical distribution of impairment and GMFCS level, and the dependent variable of total number of concerns. The ordinal regression method was chosen over a linear regression model, such as a one-way ANOVA, as the dependent variable and the majority of predictor variables (sex, topographical distribution and GMFCS level) were ordinal data. Assumptions for ordinal regression were tested including measurement of dependent variable at the ordinal level; measurement of at least one independent variable at the ordinal level, continuous or categorical; no multicollinearity; and proportional odds (Statistics, 2015). The first assumption was tested by looking at the type of variable that was the dependent variable (e.g., ordinal vs. nominal vs. interval/ratio). Next, the second assumption was tested by ensuring the independent variables (one or more) were treated as ordinal, categorical or continuous data. With respect to the assumption of no multicollinearity, this required creating dummy variables of the categorical variables (i.e., sex, topographical distribution and GMFCS level), so there was only one level between them. The final assumption, proportional odds, was tested using the test of parallel lines – this checked whether the independent variable(s) had an identical effect at different locations of the dependent variables (Marquier, 2019; Statistics, 2015).

Objective 3 (Exploratory Aim): determine whether specific patient factors were associated with the most prevalent healthcare concerns

Descriptive statistics were used to determine whether patient factors of age, sex, topographical distribution, and GMFCS level were associated with the most prevalent healthcare concerns identified in objective 1. Specifically, Spearman's rho correlation coefficients were used to determine the association between these ordinal variables. Bivariate analyses were then conducted through crosstabulation tables of prevalent healthcare concerns and variables that were significant in the Spearman's rho correlation coefficients analysis.

Chapter 3: Results

This study utilized a retrospective chart review to identify healthcare concerns of young people and adults with cerebral palsy (CP) in the Transitional and Lifelong Care (TLC) program; determine whether specific patient factors were related to, or predictive of, number of healthcare concerns; and lastly, determine if the most prevalent healthcare concerns were related to patient factors such as age, sex, functional ability level according to the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997; Palisano et al. 2007), and topographical distribution of impairment (exploratory aim).

Patient Factors/Characteristics

Based on the study's inclusion/exclusion criteria, 241 people with CP in the TLC program were eligible (see Table 2). The mean age was 27.4 years (*SD* = 13.2), median age was 23.0 years, and the range was 58.0 – with the youngest person being 14 years of age and the oldest person being 72 years of age. Despite this, most patients (70%) were under the age of 30 at the time of initial consult, and thus, age was not normally distributed. Patient sex was nearly equal between male and female, such that 53% of the sample population (*n* = 241) was male. The person responsible for communication with the program team during the initial consult was commonly not reported (61%). Patients predominantly had spastic cerebral palsy (77%) with a bilateral topographical distribution of impairment (85%). Quadriplegia was the most prevalent topographical distribution (56%) among the sample population (*n* = 241). With respect to functional ability level, distribution was negatively skewed (i.e., less individuals were classified in the lower GMFCS levels and more were classified in the higher GMFCS levels – therefore, the left tail was longer and flatter), as just over half of patients were classified as either GMFCS level IV (24%) or GMFCS level V (34%). The most common surgeries or procedures experienced by the participants (*n* = 241) were orthopedic in nature (72%) including hamstrings lengthening/transfer (40%), plantar flexor lengthening/recession (30%), hip/femoral osteotomy (20%), adductors/hip soft tissue (16%) and scoliosis (13%). A significant portion of the sample population (*n* = 241) also had non-orthopedic surgical history (50%) and of note, only 12% had no surgical history.

Just over half of patients (51%, *n* = 241) had a history of epilepsy. In terms of medication, multi-use medications (e.g., medications that have at least one use such as pain, tone, mood and/or sleep) were most prevalent (56%), followed by bowel/gastrointestinal agents (41%), bone health agents (24%), antiepileptics (22%), pain agents (18%) and tone agents (10%). Specifically, vitamin D (23%), botulinum toxin (20%), peglyte/peg 3350 (21%), and calcium (11%) were the most used medications at the time of initial consult. Thirteen percent of the sample population (*n* = 241) reported taking no medications at the initial consult. In addition to the pre-determined list of medications in the data collection instrument, 65% and 45% of patients (*n* = 241) also reported other medications being used routinely or as-needed, respectively. Based on the physical exam conducted at the initial consult, 51% of patients (*n* = 241) had at least one knee flexion contracture, 36% had at least one hip flexion contracture and 13% of patients (*n* = 241) had scoliosis. Physical exam results were not reported in 14% of the sample population (*n* = 241).

Table 2: Patient Characteristics

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
44-53 years	18	7.5
54-63 years	11	5.6
64-72 years	4	1.7
Sex		
Male	128	53.1
Female	113	46.9
Communication		
Self	30	12.4
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	8	3.3
Topographical Distribution		
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

Patient Characteristic	*n* (241)	
	n	%
Functional Ability Level		
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		
Orthopedic	174	72.2
Neurosurgery	18	7.5
Bowel or Bladder	3	1.2
Other Non-Orthopedic	121	50.2
None	28	11.6
Not Reported	5	2.1
Epilepsy History		
Yes	123	51.0
No	115	47.7
Not Reported	3	1.2
Medications		
Multi-Use	135	56.0
Antiepileptic	54	22.4
Psychotropic	26	10.8
Tone	23	9.5
Pain	44	18.3
Bowel/GI	98	40.7
Bone Health	58	24.1
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		
Hip Flexion Contracture	86	35.7
Knee Flexion Contracture	123	51.0
Plantar Flexion Contracture	5	2.1
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).

Objective 1: identify healthcare concerns of young people and adults with CP in the TLC program

A total of 2237 distinct concerns were raised by 241 people in the study. Subsequently, 155 specific and different healthcare concerns and 17 concern categories were identified (see Appendix C for the complete table of results). Results related to healthcare concern categories and specific healthcare concerns (see Appendix C) were ordered and presented based on the sample population proportion (*n* = 241), as this was found to be most representative. However, the results are presented in two ways – as proportions relative to both the sample population (*n* = 241) and as total number of distinct concerns (*n* = 2237). Table 3 provides a summary of the most prevalent healthcare concern categories and specific healthcare concerns contained within them. Table 4 provides a summary of the number of patients who had zero concerns, one concern, or two or more concerns in each healthcare concern category. Regarding the most prevalent healthcare concerns among the sample population (*n* = 241), ten were found based upon the aforementioned criterion (i.e., reported by more than 25% of the population sample) (see Figure 2).

The most prevalent healthcare concern category was need for care coordination, with 84% of people with CP in the program (*n* = 241) requiring some degree of multidisciplinary care due to one or more healthcare concerns. This concern category 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. Of the 2237 distinct concerns raised, 20% were related to care coordination (i.e., one person could contribute multiple concerns in this category). Most notably, a significant proportion of patients (*n* = 241) required care in the fields of physiotherapy (28%), social work (21%) and occupational therapy (20%). Examples of concerns that warranted these services include but are not limited to mobility and stretching, acquiring funding for equipment, and home accessibility assessments. Follow-up appointments and/or referrals were also made to seating (12%), speech language pathology (10%), family medicine (10%), and dietetics (9%). The second most prevalent healthcare concern category related to medications, with 77% of patients (*n* = 241) having at least one concern related to oral, injectable, or other agents such as starting a new medication, switching medication dose, or stopping medication. Of the 2237 distinct concerns raised, 12% were related to medications. More specifically, 42% of patients (*n* = 241) had a concern related to botulinum toxin (i.e., an agent often used for muscle tone and/or pain), 8% had a concern related to supplements (e.g., vitamin D, calcium, iron), and 61% (*n* = 241) had a concern related to other medications.

Just over half of the sample population (*n* = 241) had neurologic concerns (57%). Of the 2237 distinct concerns raised, 9% were related to neurologic issues. Concerns related to spasticity (25%) were most common (*n* = 241). Particularly, tone concerns encompassed management, control, improvement, and/or a noted increase in tone. Seven percent of people with CP in the program (*n* = 241) had concerns related to abnormal muscular spasms and contractions (i.e., dystonia/dyskinesia/athetosis), and 7% (*n* = 241) had concerns related to seizures/epilepsy (e.g., increase in seizure activity, seizure management).

Next, 51% of people with CP (*n* = 241) had at least one assistive device concern including orthotics, braces and splints (38%), wheelchair/seating (15%) and gait aids (6%). Of the 2237 distinct concerns raised, 7% were related to this concern category.

The fifth most prevalent category was social concerns (43%); of the 2237 distinct concerns raised, 9% were related to this category. Concerns related to funding, finances or insurance were experienced by 19% of the sample population (*n* = 241), including applying to Developmental Services Ontario funding and Ontario Disability Support Program coverage. In addition, 16% of patients (*n* = 241) had social support/participation concerns and 12% had home accessibility/modification concerns. Other notable social concerns were those related to future care planning (7%), return to/planning for school (5%), driving (e.g., interest in driving, driving rehabilitation needs) (5%), independence (5%), and respite care (3%).

Forty-two percent of the sample population (*n* = 241) had a need to have investigations ordered/completed. Specifically, 19% of patients (*n* = 241) required an X-ray and 10% (*n* = 241) required bloodwork and/or urine testing for assessment of a presenting healthcare concern(s). Other less common investigations needed included magnetic resonance imaging (MRI) (7%) and electromyogram (EMG)/nerve conduction studies (4%). Overall, of the 2237 distinct concerns raised, 7% were related to this category.

Functional mobility concerns were experienced by 40% of the sample population (*n* = 241) and of the 2237 distinct concerns raised, 7% were related to this concern category. Physical activity/fitness/exercise concerns were most prominent as 22% of patients (*n* = 241) had concerns in this area such as stretching and strengthening routines. Concerns related to gait decline (14%) and range of motion (12%) were also notable.

Next, pain concerns were experienced by 39% of people with CP in the program (*n* = 241). Of the 2237 distinct concerns raised, 6% were related to pain. Lower extremity pain (16%) was the most prominent individual concern, alongside pain management (8%) and back pain (8%) concerns. Orthopedic concerns were prevalent, with 30% of the sample population (*n* = 241) expressing at least one concern in this area, representing 4% of the 2237 distinct concerns reported. This category was heterogenous in nature, with some common concerns including upper/lower extremity rotational positioning (7%), flexion contractures (7%), leg length discrepancy (5%), spinal curvatures (i.e., scoliosis) (5%) and joint stability/instability concerns (5%).

Lastly, neurogenic bowel and bladder concerns affected 27% of people with CP in the program (*n* = 241) and accounted for 3% of the 2237 distinct concerns. Neurogenic bowel constituted the majority of concerns in this category (23%) and included constipation, diarrhea, establishing regular bowel movements, and bowel patterns; the remaining concerns in this category pertained to current bladder/kidney functioning and the monitoring of bladder/kidney health (8%) such as bladder urgency, incontinence, and infections.

Although not included in the highlighted list of prevalent healthcare concerns, miscellaneous concerns were quite significant (44%). This concern category was omitted from Figure 2 as it encompassed varied individual concerns that could not be grouped into the broader concern categories. These concerns represented 7% of the 2237 distinct concerns raised. Specifically, concerns related to gastrointestinal (13%), augmentative and alternative communication (8%) and feeding (including enteral feeding tube) (8%) were most common. With respect to the remaining healthcare concern categories, 20% of the sample population (*n* = 241) had concerns in mental health, 17% in diet, 12% related to skin health, and 12% in specific clinical entities (e.g., presentation of new symptoms requiring further investigations). The lowest proportion of concerns were found in the categories of bone health and reproductive and sexual health, with only 6% and 5%, respectively, of people with CP (*n* = 241) affected by these concerns.

Table 3: 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	3.7	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	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	60	24.9	31.3
Dystonia/Dyskinesia	17	7.1	8.9

Concern Category & Individual Concerns	*n*	% of the Sample Size (*n* = 241)	% of the Concerns in Healthcare Category
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	1.6
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		
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 To/Planning for School	13	5.4	6.6
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		
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 Conduction Studies	10	4.1	6.8

Concern Category & Individual Concerns	*n*	% of the Sample Size (*n* = 241)	% of the Concerns in Healthcare Category
Investigations Needed (Continued)			
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 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		
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 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

Concern Category & Individual Concerns	*n*	% of the Sample Size (*n* = 241)	% of the Concerns in Healthcare Category
Orthopedic (Continued)			
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
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 Health	18	7.5	24.7

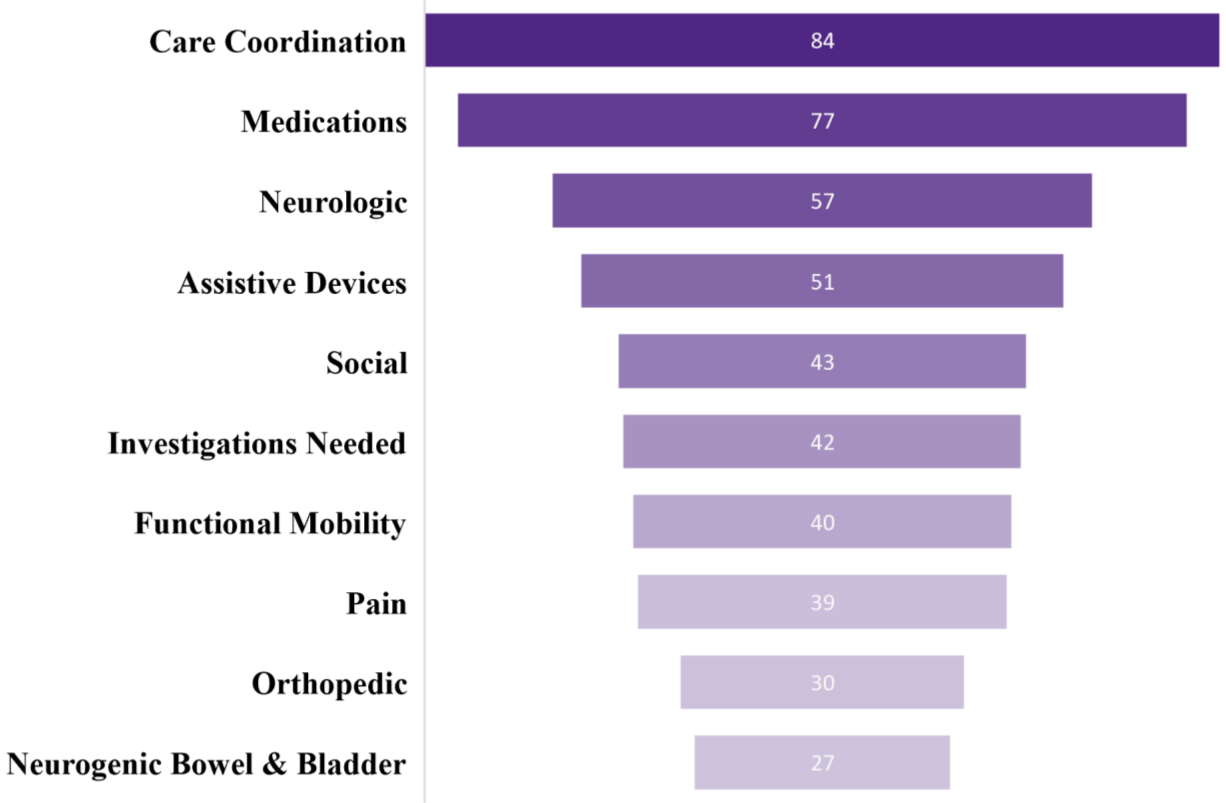
Note. The concerns labelled “___ Other” within certain categories are comprised of individual concerns indicated by only one patient, and therefore were grouped together.

Table 4: Summary of Concerns Per Category

Concern Category	Summary	*n*	% of the Sample Size (*n* = 241)
Care Coordination			
	No Concerns	38	15.8
	One Concern	74	30.7
	Two+ Concerns	129	53.5
Medications			
	No Concerns	55	22.8
	One Concern	110	45.6
	Two+ Concerns	76	31.5
Neurology			
	No Concerns	99	41.8
	One Concern	93	38.6
	Two+ Concerns	49	20.3
Assistive Devices			
	No Concerns	118	49.0
	One Concern	99	41.1
	Two+ Concerns	24	10.0
Social			
	No Concerns	137	56.8
	One Concern	49	20.3
	Two+ Concerns	55	22.8
Investigations Needed			
	No Concerns	140	58.1
	One Concern	66	27.4
	Two+ Concerns	35	14.5
Functional Mobility			
	No Concerns	144	59.8
	One Concern	66	27.4
	Two+ Concerns	31	12.7
Miscellaneous			
	No Concerns	146	60.6
	One Concern	69	24.5
	Two+ Concerns	36	14.9
Pain			
	No Concerns	148	61.4
	One Concern	62	25.7
	Two+ Concerns	31	12.9
Orthopedic			
	No Concerns	168	69.7
	One Concern	61	25.3
	Two+ Concerns	12	5.0

Concern Category	Summary	*n*	% of the Sample Size (*n* = 241)
Neurogenic Bowel and Bladder			
	No Concerns	177	73.4
	One Concern	55	22.8
	Two+ Concerns	9	3.7
Mental Health			
	No Concerns	192	79.7
	One Concern	35	14.5
	Two+ Concerns	14	5.8
Diet			
	No Concerns	201	83.4
	One Concern	31	12.9
	Two+ Concerns	9	3.7
Skin Health			
	No Concerns	211	87.6
	One Concern	28	11.6
	Two+ Concerns	2	0.8
Specific Clinical Entities			
	No Concerns	212	88.0
	One Concern	27	11.2
	Two+ Concerns	2	0.8
Bone Health			
	No Concerns	227	94.2
	One Concern	8	3.3
	Two+ Concerns	6	2.5
Reproductive & Sexual Health			
	No Concerns	229	95.0
	One Concern	12	5.0
	Two+ Concerns	0	0

Figure 2: Most Prevalent Healthcare Concerns as a Proportion of the Sample (*n* = 241)



Objective 2: determine whether specific patient factors were related to, or predicted, number of healthcare concerns

The first three assumptions of the ordinal regression model related to measurement of the dependent variable at the ordinal level (measurement of at least one independent variable at the ordinal level, continuous or categorical, and no multicollinearity) were tested and met. More specifically, the dependent variable (total concerns) was measured at the ordinal level; three of four predictor (independent) variables were categorical variables and the remaining predictor variable (age) was treated both continuously and categorically depending on the analysis; no multicollinearity was determined by creating dummy variables of the predictor variables (excluding age) using “1” for did have the variable level, and “0” for did not have (e.g., for topographical distribution, all individuals who had unilateral distribution were assigned a “1”, and the remaining who did not have unilateral (or had bilateral distribution) were assigned a “0”). Despite meeting the previous assumptions, the ordinal regression model violated the final assumption of proportional odds. The test of parallel lines should produce a significance level greater than 0.05 (Marquier, 2019), which did not occur ($p < .001$). As a result of this violation, regression was not completed.

The median number of concerns per person in the sample population was 9.0 and the range was 33.0, with the minimum number of concerns reported being 1, and the maximum number of concerns reported being 34. In applying the Bonferroni correction factor (0.05 significance level/4 comparisons), an adjusted significance threshold of 0.0125 was set. Of the four patient variables, only age was significantly associated with the number of healthcare concerns ($r = 0.245$, $p < 0.001$); sex, topographical distribution and GMFCS level were not correlated with the number of concerns (see Table 5). Investigating age further using 10-year bands revealed that in the higher age bands there were fewer people with CP (see Table 2). Post-hoc re-defining of age as an ordinal variable (using 10-year age bands) and providing a range of number of total healthcare concerns, allowed for visual analysis of the distribution of age and number of concerns via crosstabulation. For example, individuals over the age of 30, despite not being the largest age band, still contributed a significant number of concerns at the time of initial consult (see Table 6).

Table 5: Correlations Between Patient Factors and Number of Healthcare Concerns

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

*p < .01 (2-tailed).

Table 6: Nominal Crosstabulation of Age (in bands) and Total Healthcare Concerns

Age	Total Healthcare Concerns per Person (% of Age Band with Number of Concerns)					
	1-6	7-11	13-18	19-24	25-30	31-34
14-23 (*n* = 137)	26 (19)	75 (55)	31 (23)	5 (4)	0 (0)	0 (0)
24-33 (*n* = 51)	10 (20)	13 (25)	25 (49)	3 (6)	0 (0)	0 (0)
34-43 (*n* = 20)	3 (15)	10 (50)	5 (25)	0 (0)	1 (5)	1 (5)
44-53 (*n* = 18)	3 (17)	7 (39)	7 (39)	1 (6)	0 (0)	0 (0)
54-63 (*n* = 11)	0 (0)	2 (18)	8 (73)	1 (9)	0 (0)	0 (0)
64-72 (*n* = 4)	0 (0)	3 (75)	1 (25)	0 (0)	0 (0)	0 (0)

Objective 3 (Exploratory Aim): determine whether specific patient factors were associated with the most prevalent healthcare concerns

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 7). There was a very weak correlation between medication concerns and GMFCS level; weak correlation between medication concerns and age; weak correlation between neurologic concerns and age; weak correlation between investigations needed and age; weak correlation between functional mobility and age; weak inverse correlation between functional mobility and topographical distribution; moderate inverse correlation between functional mobility and GMFCS level; weak correlation between pain and age; very weak inverse correlation between pain and GMFCS level very weak inverse correlation between pain and topographical distribution; and lastly, a very weak correlation between neurogenic bowel and bladder and topographical distribution. Healthcare concerns related to care coordination, assistive devices, social, and orthopedic were not associated with any patient factors of age, sex, topographical distribution and/or GMFCS level.

Post-hoc crosstabulation of functional mobility and age suggested that older age may be correlated with more functional mobility concerns. Secondly, crosstabulation of functional mobility and topographical distribution found that a unilateral distribution was associated with more functional mobility concerns (i.e., 74% of people with unilaterally distributed CP had at least one functional mobility concern, whereas only 36% of people with bilaterally distributed CP had at least one functional mobility concern). Similarly, crosstabulation of functional mobility and GMFCS level revealed that a lower GMFCS level, or better functional ability level, was correlated with more functional mobility concerns (see Table 8).

Table 7: Significant Correlations between Patient Factors and Most Prevalent Healthcare Concerns

Health Concern (Category)	Age			GMFCS Level			Topographical Distribution		
	r_s	Strength	p	r_s	Strength	p	r_s	Strength	p
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

*p < .01 (2-tailed).

Note. The abbreviated phrase “v. weak” represents “very weak”.

Table 8: Crosstabulation of Functional Mobility Healthcare Concerns and GMFCS Level

GMFCS Level	Functional Mobility Concerns		
	Zero concerns	One concern	Two or more concerns
I	11	14	5
II	8	10	15
III	10	12	4
IV	39	12	6
V	69	13	0
Not reported/unknown	7	4	2

Overall, this chapter summarized the results of the current study including patient characteristics, healthcare concerns of young people and adults with CP in the TLC program, specific patient factors that were related to number of healthcare concerns, and associations between specific patient factors and most prevalent healthcare concerns. The next chapter will discuss this study’s findings.

Chapter 4: Discussion

This descriptive study used a retrospective chart review to identify healthcare concerns of young people and adults with cerebral palsy (CP) in the Transitional and Lifelong Care (TLC) program; determine whether specific patient factors were related to, or predictive of, number of healthcare concerns; and determine if the most prevalent healthcare concerns were related to patient factors of age, sex, functional ability level according to the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997; Palisano et al., 2007), and topographical distribution of impairment.

Healthcare Concerns

A large number (*n* = 2237) of distinct concerns were identified for patients presenting to the TLC program at the time of initial consultation, providing further evidence that adults with complex, childhood-onset physical disabilities, including CP, experience persistent health issues from childhood and would benefit from ongoing coordinated care in adulthood (Frisch & Msall, 2013; Yi et al., 2019; Young, 2007). It is important to recognize that participants were able to contribute multiple concerns to each healthcare concern category, to be reflective of the fact that sometimes a single comorbidity or secondary impairment can generate multiple healthcare concerns or actions. Notably, this speaks to why the coordinated approach of the TLC program may be extremely useful as to reduce duplication of services and burden of visiting multiple providers.

Of the ten most prevalent healthcare concern categories identified, the top concern category was care coordination – with 84% of people with CP in the program requiring some degree of multidisciplinary care due to one or more healthcare concerns. This finding is consistent with literature that has demonstrated that young people and adults with chronic health conditions (specifically CP) encounter challenges with continuity and coordination of care (Björquist et al., 2015; Kroll & Neri, 2003; Larivière-Bastien et al., 2013; Larivière-Bastien et al., 2007). For example, a recent study by Bagatell et al. (2017) explored the transition experiences of young adults with CP and found that navigating systems and services, such as those related to healthcare, was a fragmented and difficult part of adulthood for this population. Similarly, a study of young adults with CP from the Netherlands revealed that the available level of healthcare services and utilization was not sufficient, and they continued to experience unmet healthcare service needs (e.g., the need for *more* physiotherapy) (Nieuwenhuijsen et al., 2008). Blackman & Conaway

(2014) also found that caregivers reported a lack of discussion with physicians surrounding the transition (of their young family member with CP) from the pediatric to adult healthcare systems. These findings emphasize the value of a program such as the TLC program, where appropriate, comprehensive, and lifelong care is at the forefront of care delivery. Moreover, the participants of the current study were able to be referred to various healthcare providers at the time of initial consultation, including physiotherapy, social work, occupational therapy, speech language pathology, and dietetics – all of which are available services through the TLC program's multidisciplinary team. Although it is likely that specialist referrals would decline in subsequent follow-up appointments, 54% of the sample population were referred to two or more speciality providers during the initial clinical encounter, further underscoring the necessity for coordinated and multidisciplinary care for people with CP across the lifespan. The significant proportion of care coordination concerns reported in this study, alongside the TLC program's collaborative and dedicated rehabilitative team, indicates the program fills a gap in the Canadian healthcare system by serving as a "coordination hub" for the provision of multidisciplinary, coordinated care in a single clinical setting (Starowicz et al., 2021). Moreover, a qualitative study by Kroll & Neri (2003) identified that a barrier to effective care coordination for people with CP, multiple sclerosis and spinal cord injury was healthcare provider lack of condition-specific knowledge and understanding – further highlighting the potential for programs similar to the TLC program to be expanded to other jurisdictions.

The second most prevalent healthcare concern category was medications, with 77% of patients having at least one concern related to oral, injectable, or other agents such as starting a new medication, switching medication dose, or stopping medication. Almost half of the sample population (42%) had a concern related to botulinum toxin, often used to manage muscle tone (spasticity and dystonia) and/or pain in children (Gibson et al., 2007). Moreover, 61% of patients in the current study had concerns related to medications other than those used to treat spasticity and other types of muscle tone. This is in line with findings by Roquet and colleagues (2018), which revealed that medication use for multiple indications in a cohort of children, adolescents, and adults with CP, specifically analgesic (pain) and psychotropic drugs, increased significantly with age. In addition, systematic reviews of the literature have established that pain prevalence in people with CP increases with age (Harvey et al., 2021; Mckinnon et al., 2019) and GMFCS level (Harvey et al., 2021; Mckinnon et al., 2019; van Gorp, 2021). There is limited evidence regarding the effectiveness and use of pain medications in CP, however, which could contribute to the small proportion of patients in the current study taking pain agents (18%). Moreover, the mean age of young people and adults with CP in the TLC program was 27 years, and many of the 18% of patients were GMFCS level IV (24%) or V (34%) at the time of initial consult. Combined, these findings suggest that there is value in continuing to monitor medication management in the TLC program longitudinally, as we expect that there may be an increase in use of pain agents overtime as the population ages.

A little over half of the sample population had neurologic concerns (59%), with concerns related to spasticity (25%) being the most common – this was expected as spasticity (a type of muscle tone) is a coexisting neurologic symptom associated CP (Smith et al., 2021). Furthermore, spasticity, which is generally characterized by muscle tightness, is the most common motor disorder associated with CP (Johnson, 2002). Remarkably, all remaining neurologic concerns were reported by less than 10% of patients with CP, including issues with seizures/epilepsy and fatigue. This may be explained by well-established awareness and management of long-standing issues from childhood such as epilepsy (Fortuna et al., 2018; Young et al., 2011). The low rates of concerns related to fatigue are interesting as it has been identified as a common secondary condition associated with CP in adulthood (Brunton & Bartlett, 2017; McPhee et al., 2017). Due to the retrospective nature of this study, it is unclear whether the fatigue concerns that were present were reported by the healthcare provider and/or the patient/caregiver(s). The small proportion of fatigue concerns in this study may be attributed to a lack of fatigue screening measures/tools at the time of initial consultation, or because discussions of more urgent concerns were prioritized at the initial consultation. Future studies with the sample population should explore this in more detail.

About half of people with CP in the TLC program had at least one assistive device concern including orthotics, braces and splints (38%), wheelchair/seating (15%) and/or gait aids (6%). This aligns with current research that demonstrates mobility decline occurs in at least 25% of adults with CP who are ambulatory. The risk of gait decline is also higher in those who are older (Himuro et al., 2018) and those who have higher levels of pain (Morgan & McGinley, 2014) – however, the mean age of the sample population was under 30 years, and pain concerns were lower in prevalence (i.e., only 39% of the sample population had one or more concerns in this area in comparison to more prevalent concern categories) – suggesting there was another factor influencing the significant percentage of TLC patients with an assistive device concern. In particular, the risk of gait decline is higher in those who are less independent with gait (Morgan & McGinley, 2014), and almost two-thirds of patients were GMFCS level IV or V; due to this population being largely non-ambulatory, and thus less independent with gait, they likely required an assistive device for mobility. While Roquet et al. (2018) found that during the care transition process for people with CP there was a decrease in use of equipment, research by Posłuszny et al. (2017) indicates that environmental adaptations are an influential factor in determining functional independence for this population – and independence has been identified by adults with CP as a key pillar of success in adulthood (Gannotti et al., 2021). Additionally, in people with CP who are already largely non-ambulatory (e.g., GMFCS level V), it is less likely to see declines in ambulation, which may explain the high number of concerns for splints (e.g., used for passive positioning) and wheelchairs, but the relatively lower concerns for gait aids. The healthcare providers responsible for the coordination and/or assessment of assistive devices for patients include physical and occupational therapists, and the process can occur either in their independent practice as part of the TLC program, or as part of a specialized seating clinic that would be an outside referral. In either case, the TLC program provides imperative access to services that address ongoing needs related to assistive devices for adults with CP. It is also important to consider how many people with CP are not a part of the TLC program, and as a result, are unable to access these vital services.

The next most prevalent healthcare concern category was social, as 43% of young people and adults with CP in the TLC program had one or more concerns in this area (e.g., concerns related to social support/participation). Current research across developed countries demonstrates that adults with CP have lower levels of social inclusion, economic independence and educational achievement when compared to adults with other disabilities (Huang et al., 2013; Törnbom et al., 2015). In fact, 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 (Bagatell et al., 2017). The current study finding of 43% of the sample population having concerns related to funding, finances or insurance is consistent with previously published research, highlighting the difficulties associated with eligibility for and accessing funding for people with CP (Burkhard et al., 2013; Davis et al., 2010). The knowledge that young adults with CP are socially disadvantaged (Reddihough et al., 2013), coupled with the volume of social concerns reported by patients of the TLC in the current study, indicates that this population may benefit from increased social support or targeted social services to enhance quality of life.

Forty-two percent of the sample population had concerns that prompted new investigations to be ordered/completed. X-ray, bloodwork, and urine testing were most common investigations needed. As people with CP age, there is evidence that they encounter various complications in addition to their childhood health issues; for instance, progressive musculoskeletal deformity (i.e., contractures), cervical spinal arthritis with neurological changes, and gastroesophageal reflux disease (Liptak, 2008). Moreover, young people with CP experience an increased risk of musculoskeletal impairments, limiting and restricting their participation (Rosenbaum et al., 2007) – suggesting that frequent check-ups and diagnostic interventions are required for people with CP with respect to their current or emerging comorbidities (e.g., hip dislocation status, spinal curvatures such as scoliosis, and the possibility of cervical spinal stenosis causing neurologic deterioration). The significant proportion of investigations needed at the time of initial TLC program consultation suggests an important role of health monitoring in the lifelong care of people with CP.

Functional mobility concerns were experienced by 40% of the sample population. This is consistent with the current literature, which suggests that although life expectancy of people with CP is approaching near-normal, adults with childhood-onset disability experience an early decline in health and mobility (Andersson & Mattsson, 2001; Himuro et al., 2018). In particular, one third of adults with CP experience a decline in walking ability before 35 years of age (Day et al., 2007). Throughout adult life, a progressive decline in functional ability has been reported across all GMFCS levels (Bottos et al., 2001; Verschuren et al., 2018). Of note, children with CP spend more time in sedentary behaviours, less time engaged in moderate physical activity (Capio et al., 2012), and tend to have higher body fat percentages than their peers (Williams et al., 2020) – indicating the need for special attention to physical activity in childhood, and the importance of promoting lifelong physical activity and participation. The current study revealed that physical activity/fitness/exercise concerns were prominent as 22% of patients with CP in the program had concerns in this area. Moreover, the benefits of encouraging adults with CP to be active is imperative as a recent Canadian study found that increased physical fitness in young adults with CP was effective in improving social participation, mental health, and fatigue – even without a significant change in functional ability status (i.e., GMFCS level) (McPhee et al., 2017). Another study conducted in Sweden also found that severity of fatigue decreased with an increased level of physical activity (Jacobson et al., 2020). Overall, physical activity, fitness and exercise concerns were often identified alongside physiotherapy concerns, as relevant stretching or strengthening exercises were sought to assist with other challenges (e.g., improvements in mobility, pain, balance, strength). Due to the known positive outcomes of physical activity on health and well-being, the TLC program should continue promotion of physical activity as an intervention and preventative strategy for people with CP.

Pain concerns were experienced by 39% of people with CP in the program, and lower extremity pain (16%) was the most common individual concern. This is in accordance with the literature as a systematic review by Mckinnon et al. (2019) revealed that pain was most frequent in lower limbs for people with CP. Moreover, emerging research indicates that pain is highly prevalent in young adults with CP (specifically GMFCS levels II-V), and thus, comprehensive and longitudinal pain monitoring is imperative for well-being and quality of life for adults with CP (van Gorp et al., 2021). Notably, despite the high proportion of participants under the age of 30 (i.e., in the young adult range), the present study did not find as high proportion of pain concerns in comparison to other work – van Gorp et al. (2021) found that 53% of people with CP with GMFCS level II, and 56% with GMFCS levels III-V, reported pain; Engel et al. (2003) found that 67% of adults with CP reported one or more chronic pain problem; and Schwartz et al. (1999) found that 67% of adults with CP reported one or more areas of pain. This discrepancy may be due to pain being reported indirectly as associated comorbidities and conditions, such as contractures, orthopedic deformities, and spasticity (Tosi et al., 2009), and therefore not coded as a pain concern. Or it could perhaps be attributed, like fatigue, to underreporting related to being prioritized lower than other concerns in the initial consult (recalling that the high number of concerns reported at the time of initial consult, i.e., median number of concerns per person was 9, may have limited the discussion of pain). Another consideration may be given to the long-standing nature of pain, such that the individuals that experience pain may not prioritize their concerns related to it, given how long they have lived with it.

Next, orthopedic concerns were reported by 30% of the sample population. Individual concerns were heterogenous (e.g., flexion contractures and spinal curvatures), such that no one concern had a significantly larger proportion. Research has established musculoskeletal deformities are common secondary conditions of CP, including contractures at various joints (Klenø et al., 2021), subluxations and dislocations of the hip, abnormalities of the foot, degenerative joint disease, and scoliosis (Gajdosik & Cicirello, 2002). Due to reporting inconsistencies in TLC patient medical charts, hip status (e.g., in joint, partially, or fully dislocated – from consult physical examination) was omitted from data analysis. However, over 90% of TLC patients with CP presented with at least one lower extremity contracture during the physical exam at the initial consultation, further exemplifying the prevalence of contractures in people with CP. Although less reported, concerns related to the hip, foot, joint management, and spinal curvature were nonetheless discussed at the time of initial encounter – warranting the coordinated, continuous care provided by the TLC program for patient orthopedic concerns (e.g., referral to orthopedic specialist if needed, botulinum toxin prescription provided for management of pain associated with contractures or tone).

Lastly, neurogenic bowel and bladder concerns, which affected 27% of participants, have been identified as prevalent comorbid conditions experienced by people with CP (Klingbeil et al., 2004; Turk et al., 2001). Since adults with CP experience an increased prevalence of pain such as that associated with bladder/bowel dysfunction or abdominal pain (Smith et al., 2021; van der Slot et al., 2021), symptoms associated with these concerns may have been captured elsewhere (e.g., pain) – potentially under-emphasizing this concern category. Future research within the TLC program should consider the interconnectedness of healthcare concerns for people with CP in how they are followed, acted, and reported on.

Although not included in the highlighted list of prevalent healthcare concerns, due to its composition of varied individual concerns (that could not be grouped into broader concern categories), miscellaneous concerns were quite significant (40%) in the sample population. This emphasizes the importance of a flexible and individualized approach to care, such as the one offered by the TLC program, so that these lower prevalence needs can still be met effectively. Of particular interest are patient concerns related to the gastrointestinal (GI) system as people with CP experience a higher incidence of gastroesophageal reflux disease, the most reported GI concern for participants, when compared to the general population (Liptak, 2008; Svien et al., 2008; Turk, 2009). It is unclear whether GI concerns came from the TLC healthcare provider or the patient/caregiver(s) – future research is required to determine whether this could be a contributing factor to the small proportion of GI concerns reported (13%) in the present study.

Two remaining healthcare concern categories that were not included in the most prevalent healthcare concerns, but will be discussed due to their clinical significance, are mental health and bone health. With respect to mental health, a recent Canadian study found that adults with CP are at an increased risk for experiencing psychiatric disorders as compared to the general population (McMorris et al., 2021). In fact, 1 in 3 adults with CP will have a psychiatric disorder and are approximately 1.5 times more likely to have an anxiety or mood disorder when compared to adults in the general population (Eres et al., 2021; McMorris et al., 2021). This literature is partially reflected in the finding that 11% of the sample population reported psychotropic medication use at the time of initial consultation. In addition, medication use in this population is complicated by prescription of multi-use medications, which includes medications that may have been used for pain, tone or other indications but that also have at least one use in the treatment of mental health-related issues, and may therefore have also been impacting upon mental health. For example, gabapentin (sleep), cymbalta (mood), effexor (mood), nitrazepam (sleep), clonazepam (anxiety, sleep), chloral hydrate (sleep), amitriptyline (sleep) and lorazepam (behaviour, anxiety, sleep) all have multiple indications, which suggests that the actual proportion of psychotropic medication use in the sample population could be much higher, and thus, more reconcilable with the finding of 20% of patients in this sample reporting concerns with mental health. It is also important to consider that mental health concerns may have been under-reported due to the need to develop rapport between healthcare provider and client before these are revealed, which is unlikely to be achieved in initial clinic encounters upon which this study was based. At the very least, healthcare providers in the TLC program should make a continued effort to proactively address possible mental health concerns with new and existing patients.

Regarding bone health, this was one of the lowest proportions of healthcare concerns with only 6% of people with CP affected by these concerns. This finding is not consistent with other research, as skeletal fragility is an identified major issue for people with CP across the lifespan (French et al., 2019; French et al., 2019; Whitney et al., 2018) such that people with CP experience insufficient development and preservation of the musculoskeletal system; and are therefore at increased risk for fractures (Whitney et al., 2020; Whitney et al., 2019; Wort et al., 2013). This discrepancy may be explained by bone health concerns being overlooked due to the high number of concerns reported, or because there were more pressing concerns that dominated the initial consultation encounter. TLC program providers should be cognizant of this possibility and set out to discuss this area of concern in future patient encounters.

Related Patient Factors

This study found that the median number of concerns reported per person was 9 and that the maximum number of concerns reported at the initial (single-visit) consultation was 34. This considerable range of number of concerns reported emphasises the importance of continuous, multidisciplinary medical care and social support for people with CP. A study by Solanke et al. (2018) found that a large proportion of young people with CP had continuing healthcare needs into early adulthood, confirming the results of the current study.

As expected, the patient factor of age was significantly associated with number of healthcare concerns reported by patients of the TLC program. Although CP is considered a non-progressive neurodevelopmental disorder (Rosenbaum et al., 2007), comorbidities and their functional consequences have been found to worsen as a person with CP ages (Frisch & Msall, 2013). Particularly, people aging with CP experience increased levels of pain (Turk, 2009; Turk et al., 2001), depression (Opheim et al., 2007), fatigue (van der Slot et al., 2012), falling and worsening gait (Furukawa et al., 2001). Visual analysis of distribution of age and total number of healthcare concerns revealed that a significant proportion of older adults with CP (81%) presented with a high number of concerns (e.g., at least 13), whereas a much lower proportion of young adults with CP (23%) presented with a high number of concerns. Although only a relatively small proportion of the oldest adults with CP (25%) had a high number of concerns during the initial consultation, this may be explained by the small subgroup sample sizes. Nonetheless, these findings indicate that older age may increase the number of healthcare concerns an individual has. This also may be explained, in part, by the TLC program being a relatively new program, such that an adult with CP presenting to the clinic may not have had comprehensive care from a knowledgeable provider since their early/young adulthood, and thus, have been without care for a longer period and have more concerns at the time of initial consult. This should be considered in future TLC program studies as well as incorporated in future clinical programs, as age may act as a proxy for how long an individual has gone without adequate care.

Contrastingly, sex, topographical distribution and GMFCS level were not found to have any correlational relationship with number of concerns. These findings are remarkable as they go against the current study's initial hypothesis, which was that these four selected patient variables would be related to number of concerns. Research has established that young people with CP with higher GMFCS level (or lower functional ability level) and bilateral topographical distribution have more unmet needs and a higher utilization of healthcare than those with lower GMFCS level (or higher functional ability level) and unilateral distribution (Nieuwenhuijsen et al., 2008). This illustrates associations between GMFCS level, topographical distribution and unmet needs – which informed the rationale behind the current study's initial hypothesis. With respect to sex, studies have suggested male sex as a risk factor for CP (Chounti et al., 2013) and sex as an influential factor in musculoskeletal growth and mobility in ambulant children with CP (Gough et al., 2008). Furthermore, research has found that there are sex and/or gender differences in pain for the general population (Mckinnon et al., 2019; Mogil, 2012) and people with CP population (van der Slot et al., 2021), such that pain is more prevalent in women than men. Overall, despite the null findings, the substantial range of concerns reported, may speak to the individualized care required for people with CP – particularly during the transitional care period (CAPHC, 2016) – due to the complexity of healthcare concerns experienced by this heterogenous population (Harvey et al., 2021). Future research should explore whether this finding is consistent or can be disputed with different samples (i.e., more distributed age; perhaps age mediates the relationship between sex and number of concerns).

In addition, it has been universally recognized that a biopsychosocial approach based on the International Classification of Functioning, Disability and Health (ICF) is recommended for the treatment and rehabilitation of people with developmental disabilities, including CP (Officer & Posarac, 2011; World Health Organization, 2001). This model reflects the interaction between health conditions and contextual factors (Rosenbaum & Stewart, 2004), and therefore highlights the impact of personal factors on the care and rehabilitation processes of people with CP. Moreover, studies have found relationships between CP and low socioeconomic status (Sundrum et al., 2005; Wu et al., 2011), birthweight (Spencer et al., 1999) and maternal education (Oskoui et al., 2016). These additional environmental and personal factors may help to explain participants' high number of concerns of varied nature that were not easily predicted by condition-specific or demographic variables.

Healthcare Concern Associations

Of the 10 healthcare concern categories that were most prevalent among the sample population, six had weak but significant associations with at least one patient factor. However, it is important to note that due to the exploratory nature of this objective, the Bonferroni correction factor was not applied to account for multiple comparisons – and it is possible that there is an increased risk of type I error. Accordingly, researchers and readers alike should use caution when interpretating these results.

None of the healthcare concerns were related to the patient factor of sex, despite research that has indicated there may be important sex differences for people with CP related to their healthcare experiences (Chounti et al., 2013; Gough et al., 2008; Romeo et al., 2016). For example, a review by Romeo et al. (2016), found that although males with CP have may have greater vulnerability to lesions and injuries associated with CP, the severity of impairment does not appear to be affected by sex. This exploratory analysis of the association of healthcare concerns and sex is a first step in understanding the role sex may play in the healthcare experience of adults with CP.

A weak correlation was found between pain concerns and age. This finding is supported by literature that reports older adults with CP have been found to experience higher levels of pain (Turk, 2009; Turk et al., 2001). Moreover, pain in individuals with CP often begins at a young age and can develop into a lifelong condition (i.e., chronic pain) (Creavin et al., 2010). However, a Dutch study by van der Slot et al. (2012) revealed that pain experience in a cohort of adults with CP was not age-specific – these conflicting reports and the exploratory nature of this association suggests that researchers and healthcare providers should be aware of this potential relationship and consider it in future studies and practice.

Post-hoc examination of the weak association between functional mobility and age suggested that older age may be linked to more functional mobility concerns. This finding aligns with research by Andersson & Mattsson (2001) and Himuro et al. (2018) who found that adults with childhood-onset disabilities, in particular CP, experience a decline in health and mobility that can happen early in adulthood, often before 35 years of age (Day et al., 2007). In the current study, further exploration of the association between functional mobility and topographical distribution of impairment also revealed that a unilateral distribution was associated with more functional mobility concerns, such that 74% of people with unilaterally distributed CP had at one or more functional mobility concerns, whereas only 36% of people with bilaterally distributed CP had at one or more concerns in this category. It is well established that topographical distributions do not equate to certain activity or participation levels (Wimalasundera & Stevenson, 2016); however, people with unilateral CP experience affected muscle tone and movement on (predominantly) one side of the body (Steenbergen & Gordon, 2006); whereas people with bilateral CP experience these issues on both sides of the body (Andersson & Mattsson, 2001). Perhaps people with CP who have unilateral topographical distribution have more functional ability to begin with (as less limbs are affected), and due to having more functional ability to lose, present with more concerns than their peers with bilateral distribution of impairments. A similar thought can be applied to the association between functional mobility and GMFCS level, as the current study revealed that a lower GMFCS level, or higher functional ability level, was correlated with more functional mobility concerns. Despite the fact that CP is a non-progressive disorder, in adulthood researchers have reported a progressive decline in functional ability level, regardless of GMFCS level (Bottos et al., 2001; Verschuren et al., 2018). It is likely that people with CP who were able once able to ambulate (e.g., GMFCS level I-III), in comparison to people with CP who were never able to ambulate (e.g., GMFCS level IV-V) may have had more functional abilities susceptible to decline – which may explain the relationship identified in this study.

Implications

Clinical and Other Implications

The TLC program serves an expansive and diverse patient population from a wide area of southwestern Ontario. As such, the research gained from this study will provide insightful, generalizable information regarding how to best serve this under-researched population (van der Slot, 2020). More specifically, the findings from this research will inform quality improvement processes within the TLC program (e.g., introducing mental health screening and bone health consultation during initial encounter, as discussed above), ensuring it meets the health and rehabilitative needs of people with CP and enhancing not only their transition from pediatric to adult care services, but lifelong care as well. In terms of other programs that serve adults with CP, the list of most common healthcare concerns may contribute to best practices for effective care during the transitional period and beyond. For example, healthcare providers can use this information to structure and prioritize which concerns should be assessed to make the most effective use of their (often time-constrained) resources during appointments. Beyond CP, the healthcare concerns reported in this study may also assist with the history-obtaining process during initial consultation in other clinical settings, as healthcare providers could incorporate condition-tailored inquiries that are in-line with the findings (e.g., ask about care coordination history if working with individuals with childhood-onset conditions). Additionally, the current study's discussion pertaining to healthcare concerns that were under-reported, or not expected, may help to prompt other healthcare providers in other fields to engage in thoughtful conversations with their clients and colleagues about widespread areas of interest such as mental health, or even areas that one would assume would be a top concern category in their patient population (e.g., to confirm what is known in existing literature with their sample population). At the systems-level, this study also has strong potential to influence priority setting in the development of similar programs, such as transition and lifelong care programs. Furthermore, the findings from this study undoubtedly have implications on the healthcare resource allocation and funding at both the provincial and federal levels – as they contribute an understanding of the prevalence and needs of a cohort of Canadians with CP in relation to assistive devices (Ontario Assistive Devices Program), driving (Ontario Ministry of Transportation) and funding/financial concerns (Ontario Disability Support Program), among other areas (namely rehabilitation care). This knowledge may aid policy makers and other relevant stakeholders in decisions surrounding eligibility criteria, the development of additional social programs, and information dissemination.

Research Implications

Due to the retrospective nature of this study, concerns of young people and adults with CP were only captured at the initial consultation encounter with respect to their transition (or re-introduction for many older adults) and ongoing care in the TLC program. Future prospective 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 *how* and *what* individual experiences are like (Carpenter & Suto, 2008) – further illuminating the healthcare experiences and concerns of people with CP. Other research inquires could include evaluating the continuity of care received by TLC patients (e.g., including those with CP and other complex rehabilitative needs). If subsequent descriptive studies with other TLC program populations are pursued in the future, researchers should ensure differentiation between reported healthcare provider concerns, patient/caregiver concerns, and concerns of both groups. Finally, since this study did not address goals 3 and 4 of the "Quadruple Aim" framework (Bodenheimer & Sinsky, 2014), which aim to reduce the per capita costs of care for populations and improve the work environment of healthcare professionals (Bodenheimer & Sinsky, 2014), future studies should be aligned with these objectives to inform TLC program development and related research.

Limitations

The primary limitations of this study were due its retrospective nature. More specifically, the data extracted and summarized came from medical charts as part of patients' initial consultation in the TLC program. Medical charts are intended primarily for patient care and are not typically sufficiently complete or fit for all research purposes (Jansen et al., 2004). During the data collection stage, the author encountered incomplete documentation and handwriting discrepancies within some patient charts, which are well-known challenges associated with conducting retrospective chart reviews (Siems et al., 2020). To remedy this, the author discussed the issue with the program's physiatrist and/or administrative assistant to ensure alternative sources of information were provided (e.g., printing off e-record of initial consult dictation notes). Additionally, recording of information in the patient medical chart was done by various TLC program healthcare providers (e.g., physiatrist, nurse practitioner, resident physicians) – thus, affecting the consistency of specific data elements recorded and potentially compromised the extraction of those elements. For example, communication status (i.e., who reported concerns at initial consult), and hip status were not consistently reported; this affected the standardized data collection of these variables and resulted in their omission during the data analysis stages. Another common challenge in relation to the flow of information from the initial consultation encounter to patient medical chart was experienced (Jansen et al., 2004). In this case, the source(s) of the healthcare concerns were not consistently reported and not captured by a standardized method (e.g., chart form designating patient/caregiver concerns versus provider concerns). The research team was unable to differentiate if reported concerns came from the patient/caregiver, healthcare provider, or both, which is an important limitation of this study.

The study data was also collected by more than one research team member, increasing the potential for human error, as the author joined the team after data collection had already begun. To minimize this risk and maintain reliability of validity of the present study, a written handbook of instructions outlining conditions and other rules for extracting data was created by the project coordinator and followed by all data collectors, in alignment with Gearing et al.’s (2006) procedures for retrospective review.

Age was not normally distributed in the sample population, such that despite the large age range and adequate sample size, over two-thirds of patients were under 30 years of age at the time of initial consult. This brings into question the study findings’ representativeness, and whether the most prevalent healthcare concerns are accurate reflections of both adults’ and older adults’ healthcare concerns. Over half of the sample population were between the ages of 14 and 23 years at the initial encounter, perhaps suggesting the results are more representative of people with CP during the transitional care period. Lastly, this study was unable to complete the ordinal regression analysis due to violation of the test of proportional odds (final assumption of the regression model) and therefore, variance in the total number of concerns, as predicted by the patient variables, could not be determined. Subsequent related research should prioritize this analysis stage to determine whether the regression model can be completed appropriately.

Chapter 5: Conclusion

This study outlined the most prevalent healthcare concerns of people with cerebral palsy (CP) in the Transitional and Lifelong Care (TLC) program, such as those related to care coordination, medications, and neurologic concerns – with the goal of bettering healthcare delivery for young people and adults with CP. 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 (e.g., age, sex, functional ability level, and topographical distribution of impairment). Despite this, these findings provide insight into the resources and structure required for adequate care in transition and beyond, and the need for lifelong care of patients served by the TLC program. Healthcare professionals in the program, and those treating adults with CP in other communities, should continue to address well-established areas of concern for people with CP, including care coordination, medications, functional mobility, social and assistive devices; but should also give consideration to less commonly reported concerns that have been frequently identified in the literature as common challenges for this population, such as mental health and bone health. The results of this study will inform future TLC program evaluation, as they align with the first two goals of Bodenheimer & Sinsky's (2014) "Quadruple Aim" Framework of improving the individual experience of care and improving the health of populations – which situates transitional and lifelong care alongside system-wide healthcare improvements (Prior et al., 2014). Overall, this research provided an opportunity to gain a deeper knowledge of pressing healthcare concerns of a Canadian cohort of young people and adults with CP, which have future implications on healthcare resource allocation and funding at both provincial and federal levels.

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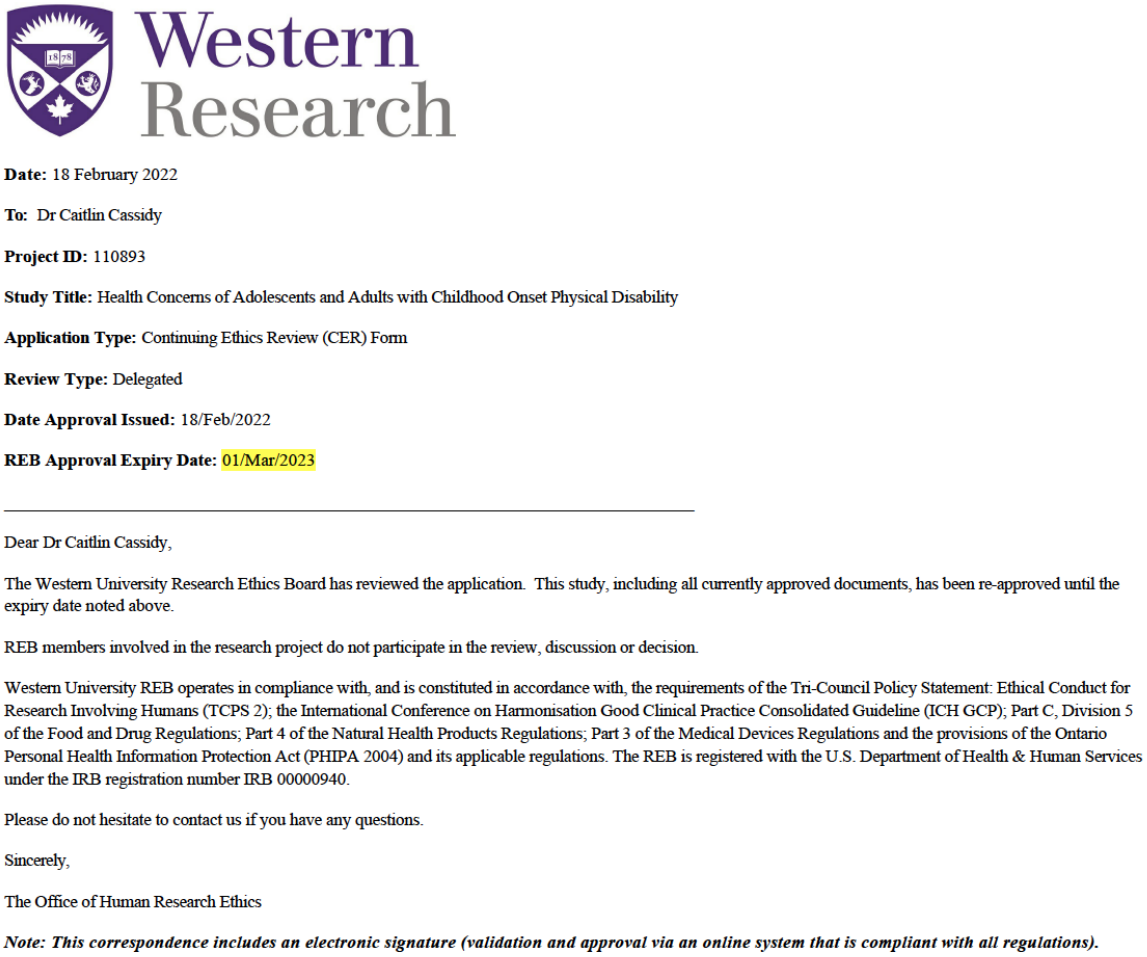
Appendices

Appendix A: Ethics Approval



Western Research

Date: 18 February 2022

To: Dr Caitlin Cassidy

Project ID: 110893

Study Title: Health Concerns of Adolescents and Adults with Childhood Onset Physical Disability

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Date Approval Issued: 18/Feb/2022

REB Approval Expiry Date: 01/Mar/2023

Dear Dr Caitlin Cassidy,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

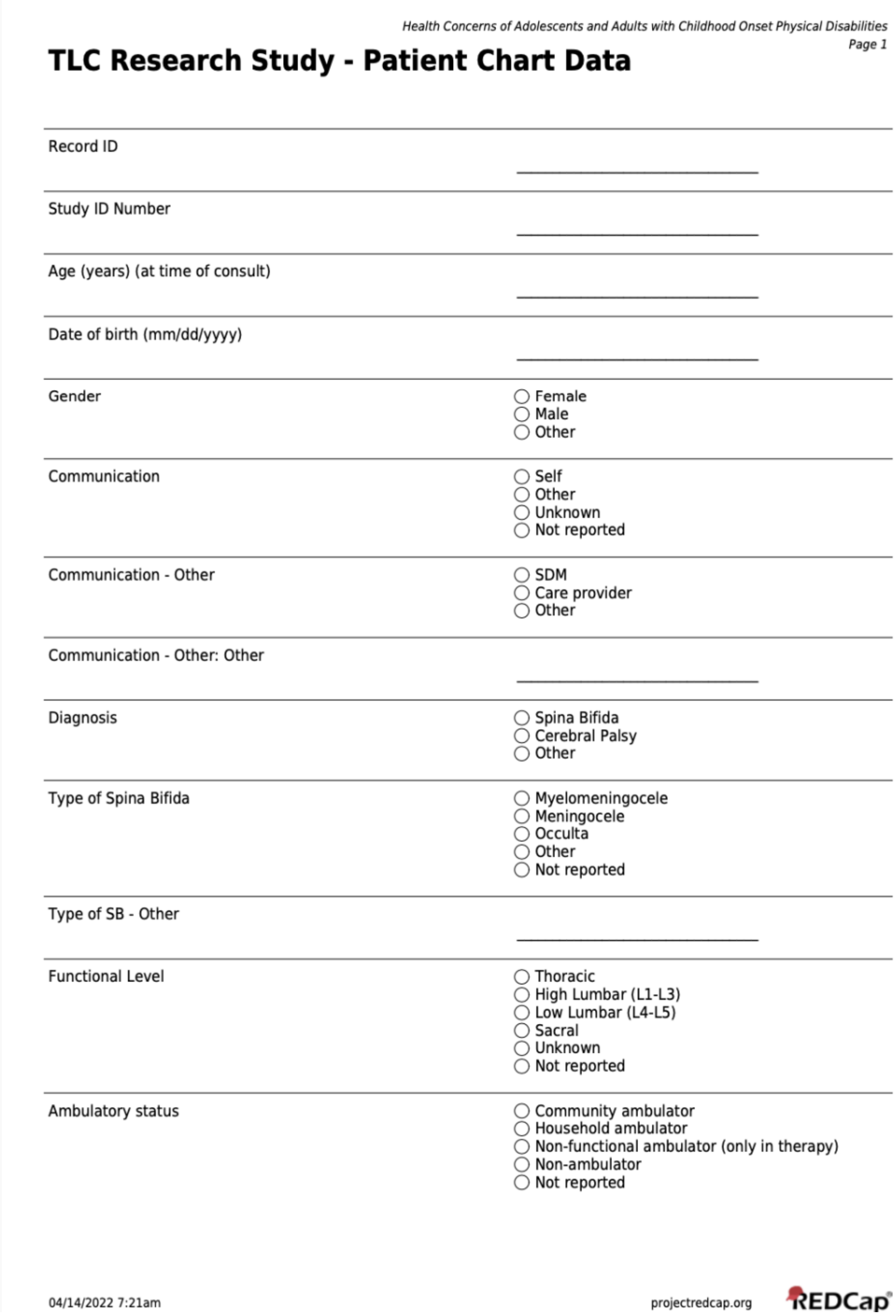
Please do not hesitate to contact us if you have any questions.

Sincerely,

The Office of Human Research Ethics

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B: REDCap Data Extraction Tool



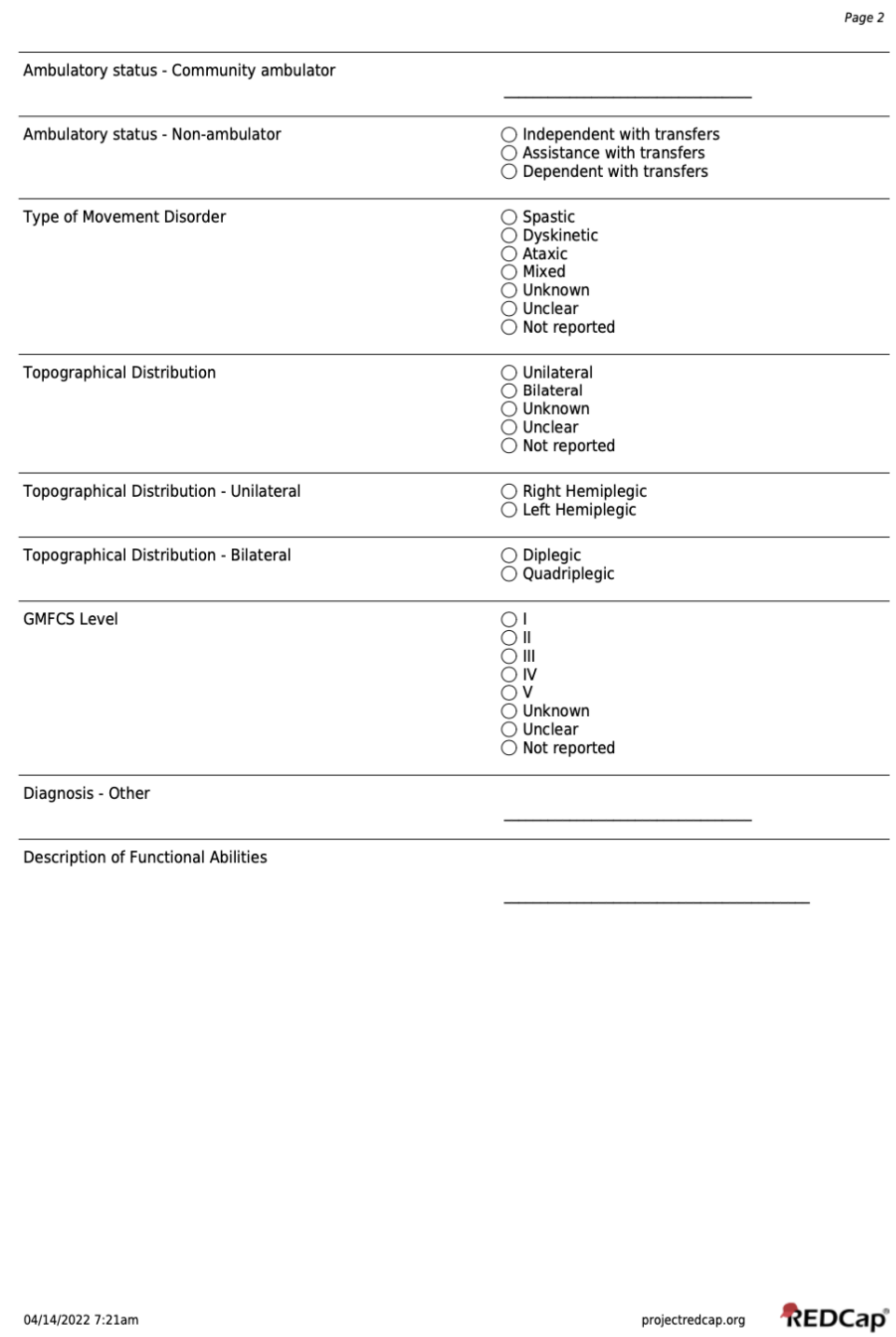
Health Concerns of Adolescents and Adults with Childhood Onset Physical Disabilities
Page 1

TLC Research Study - Patient Chart Data

Record ID	______________________________
Study ID Number	______________________________
Age (years) (at time of consult)	______________________________
Date of birth (mm/dd/yyyy)	______________________________
Gender	○ Female ○ Male ○ Other
Communication	○ Self ○ Other ○ Unknown ○ Not reported
Communication - Other	○ SDM ○ Care provider ○ Other
Communication - Other: Other	______________________________
Diagnosis	○ Spina Bifida ○ Cerebral Palsy ○ Other
Type of Spina Bifida	○ Myelomeningocele ○ Meningocele ○ Occulta ○ Other ○ Not reported
Type of SB - Other	______________________________
Functional Level	○ Thoracic ○ High Lumbar (L1-L3) ○ Low Lumbar (L4-L5) ○ Sacral ○ Unknown ○ Not reported
Ambulatory status	○ Community ambulator ○ Household ambulator ○ Non-functional ambulator (only in therapy) ○ Non-ambulator ○ Not reported

04/14/2022 7:21am projectredcap.org REDCap®

Note. Although the term “gender” was used here rather than “sex”, people with CP were not asked of their gender identity at the time of initial consult, and thus, this demographic characteristic is a reflection of patient sex.



Page 2

Ambulatory status - Community ambulator	______________________
Ambulatory status - Non-ambulator	○ Independent with transfers ○ Assistance with transfers ○ Dependent with transfers
Type of Movement Disorder	○ Spastic ○ Dyskinetic ○ Ataxic ○ Mixed ○ Unknown ○ Unclear ○ Not reported
Topographical Distribution	○ Unilateral ○ Bilateral ○ Unknown ○ Unclear ○ Not reported
Topographical Distribution - Unilateral	○ Right Hemiplegic ○ Left Hemiplegic
Topographical Distribution - Bilateral	○ Diplegic ○ Quadriplegic
GMFCS Level	○ I ○ II ○ III ○ IV ○ V ○ Unknown ○ Unclear ○ Not reported
Diagnosis - Other	______________________
Description of Functional Abilities	____________________________

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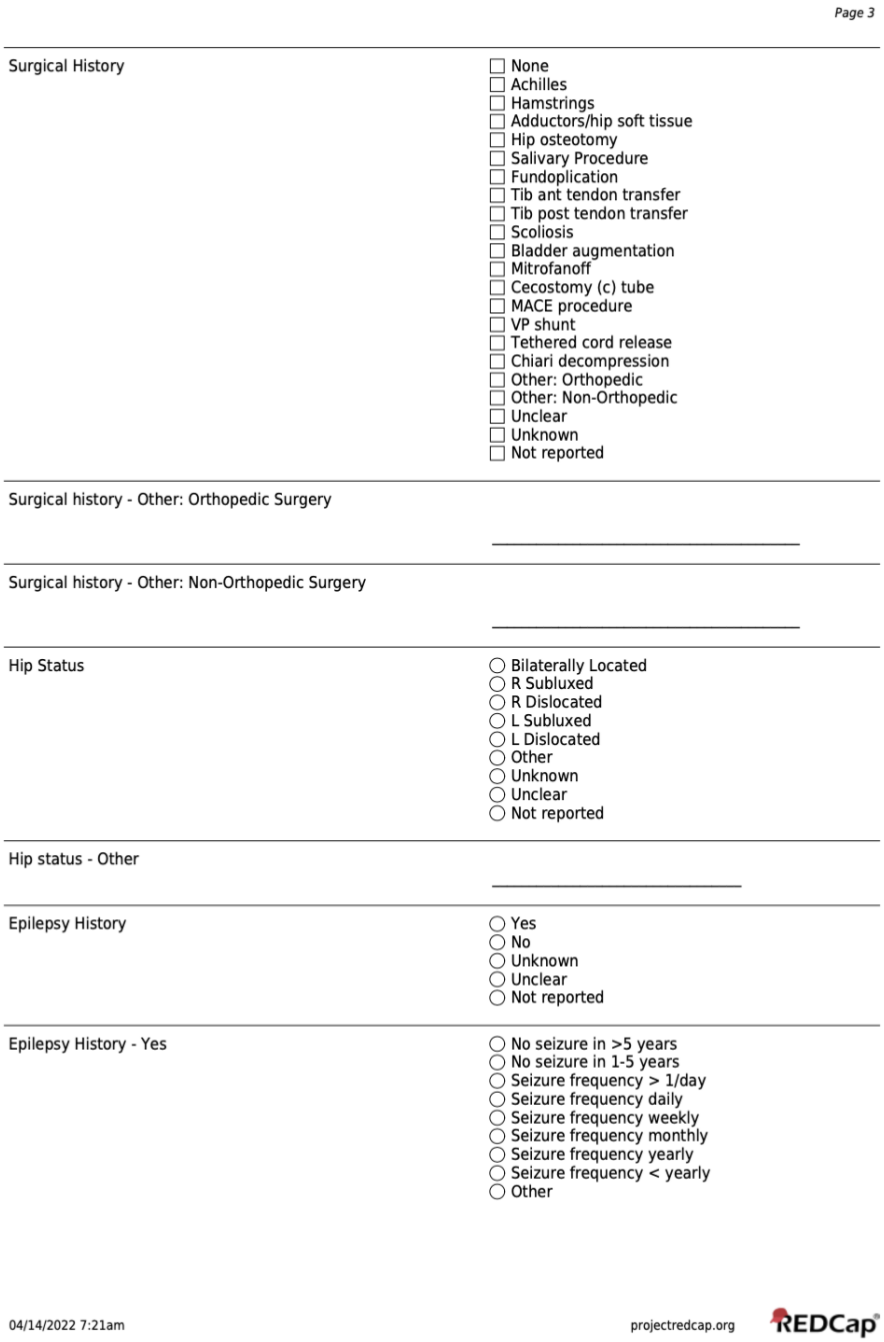
projectredcap.org REDCap



Surgical History	☐ None ☐ Achilles ☐ Hamstrings ☐ Adductors/hip soft tissue ☐ Hip osteotomy ☐ Salivary Procedure ☐ Fundoplication ☐ Tib ant tendon transfer ☐ Tib post tendon transfer ☐ Scoliosis ☐ Bladder augmentation ☐ Mitrofanoff ☐ Cecostomy (c) tube ☐ MACE procedure ☐ VP shunt ☐ Tethered cord release ☐ Chiari decompression ☐ Other: Orthopedic ☐ Other: Non-Orthopedic ☐ Unclear ☐ Unknown ☐ Not reported
Surgical history - Other: Orthopedic Surgery	______________________________
Surgical history - Other: Non-Orthopedic Surgery	______________________________
Hip Status	○ Bilaterally Located ○ R Subluxed ○ R Dislocated ○ L Subluxed ○ L Dislocated ○ Other ○ Unknown ○ Unclear ○ Not reported
Hip status - Other	________________________
Epilepsy History	○ Yes ○ No ○ Unknown ○ Unclear ○ Not reported
Epilepsy History - Yes	○ No seizure in >5 years ○ No seizure in 1-5 years ○ Seizure frequency > 1/day ○ Seizure frequency daily ○ Seizure frequency weekly ○ Seizure frequency monthly ○ Seizure frequency yearly ○ Seizure frequency < yearly ○ Other

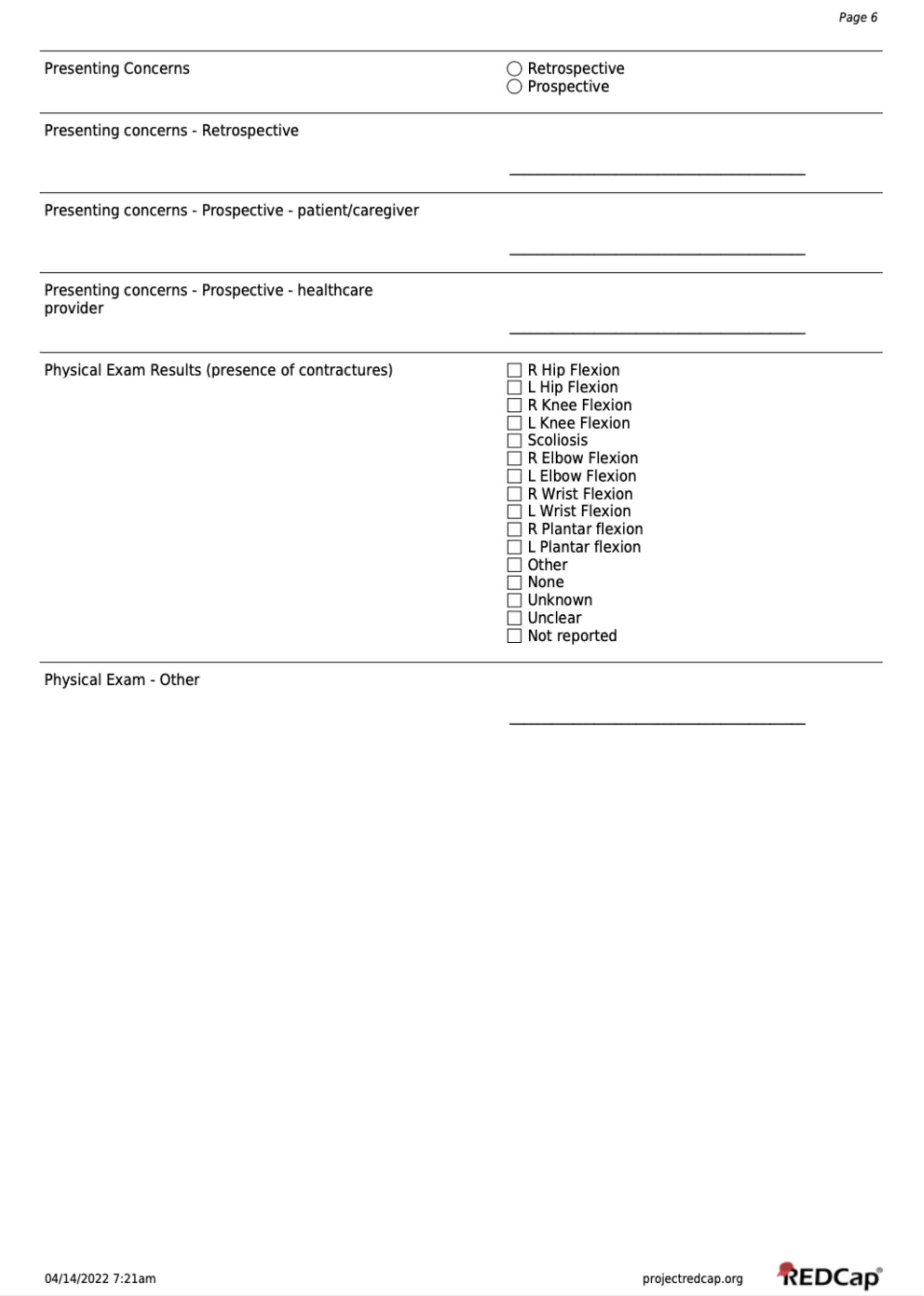
Epilepsy History - Yes: Other ______________________________

Medication(s)

☐ Amitriptyline (Elavil)
☐ Aripiprazole (Abilify)
☐ Baclofen (oral)
☐ Baclofen (intrathecal)
☐ Baclofen (unspecified)
☐ Botulinum Toxin
☐ Calcium
☐ Cannabis
☐ Carbamazepine (Tegretol)
☐ Citalopram (Celexa)
☐ Clonazepam
☐ Diazepam
☐ Dilantin
☐ Domperidone
☐ Duloxetine (Cymbalta)
☐ Escitalopram (Cipralex)
☐ Fluoxetine (Prozac)
☐ Gabapentin
☐ Iron
☐ Lacosamide (Vimpat)
☐ Lactulose
☐ Lamotrigine (Lamictal)
☐ Levetiracetam (Keppa)
☐ Levodopa
☐ Linaclotide (Constella)
☐ Melatonin
☐ Milk of magnesia
☐ Nabilone
☐ Nitrazepam
☐ Olanzapine (Zyprexa)
☐ Peg/peglyte/peg 3350/restoralax/lax-a-day
☐ Phenobarbital
☐ PPI
☐ Ranitidine
☐ Resotran
☐ Risperidone
☐ Scopolamine
☐ Serokot/Senna
☐ Seroquel (Quetlapine)
☐ Sertraline (Zoloft)
☐ Suppositories (Dulcolax, glycerin)
☐ Tizanidine
☐ Topiramate (Topamax)
☐ Trazodone
☐ Tylenol regularly scheduled
☐ Valproic acid
☐ Venlafaxine (Effexor)
☐ Vitamin D
☐ Zopiclone (Imovane)
☐ Other: PRN
☐ Other: Regular
☐ None
☐ Unknown
☐ Unclear
☐ Not reported

Medication - Other: PRN __________________________________

Medication - Other: Regular __________________________________



Presenting Concerns	○ Retrospective ○ Prospective
Presenting concerns - Retrospective	__________________________________
Presenting concerns - Prospective - patient/caregiver	__________________________________
Presenting concerns - Prospective - healthcare provider	__________________________________
Physical Exam Results (presence of contractures)	☐ R Hip Flexion ☐ L Hip Flexion ☐ R Knee Flexion ☐ L Knee Flexion ☐ Scoliosis ☐ R Elbow Flexion ☐ L Elbow Flexion ☐ R Wrist Flexion ☐ L Wrist Flexion ☐ R Plantar flexion ☐ L Plantar flexion ☐ Other ☐ None ☐ Unknown ☐ Unclear ☐ Not reported
Physical Exam - Other	__________________________________

Appendix C: 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	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	3.7	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	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	60	24.9	31.3
Dystonia/Dyskinesia	17	7.1	8.9

Concern Category & Individual Concerns	*n*	% of the Sample Size (*n* = 241)	% of the Concerns in Healthcare Category
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	1.6
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		
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 To/Planning for School	13	5.4	6.6
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		
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 Conduction Studies	10	4.1	6.8

Concern Category & Individual Concerns	*n*	% of the Sample Size (*n* = 241)	% of the Concerns in Healthcare Category
Investigations Needed (Continued)			
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 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		
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
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
Sialorrhea/Oral Secretions	12	5.0	7.3
Surgical Consideration/Inquiry	10	4.1	6.1
Swallowing/Choking/Gagging	8	3.3	4.8
Endocrinopathies	5	2.1	3.0
Dental/Oral Health	4	1.7	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

Concern Category & Individual Concerns	*n*	% of the Sample Size (*n* = 241)	% of the Concerns in Healthcare Category
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 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	4.6	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
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 Health	18	7.5	24.7
Mental Health	62		
Affective Disorder Concerns	28	11.6	45.2
Behavioural Concerns	16	6.6	25.8
Sleep	12	5.0	19.4
Mental Health Other	5	2.1	8.1
Diet	49		
Diet/Nutrition	22	9.1	44.9
Weight Loss/Gain/Management	15	6.2	30.6

Concern Category & Individual Concerns	*n*	% of the Sample Size (*n* = 241)	% of the Concerns in Healthcare Category
Diet (Continued)			
Dietary Management of Health Concern	12	5.0	24.5
Skin Health	32		
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

Curriculum Vitae

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Post-Secondary Education and Degrees:	Western University London, Ontario, Canada M.Sc., Health Promotion, Health and Rehabilitation Sciences 2020-Present
	Western University London, Ontario, Canada B.HSc., Honours Specialization in Health Sciences 2015-2020
Honours and Awards:	Western Research Forum Best Poster Presentation (Day 2) 2022
	Western Graduate Research Scholarship 2021-2022
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	Canada Graduate Scholarship – Master’s (Alternate Offer) 2021-2022
Related Work Experience:	Research Assistant St. Joseph’s Healthcare London 2022
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Conferences:

Winger, C., Cassidy, C., Brunton, L., & Starowicz, J. (2022). Describing Healthcare Concerns of Adolescents and Adults with Cerebral Palsy. AACPDM 76th Annual Meeting, American Academy for Cerebral Palsy and Developmental Medicine, Las Vegas, NV, USA, September 21-24, 2022 (Poster).

Winger, C., Cassidy, C., Brunton, L., & Starowicz, J. (2022). Describing Healthcare Concerns of Adolescents and Adults with Cerebral Palsy. Child Health Symposium, Western University & TVCC, Live Virtual Event, May 26, 2022 (Poster).

Winger, C., Cassidy, C., Brunton, L., & Starowicz, J. (2022). Describing Healthcare Concerns of Adolescents and Adults with Cerebral Palsy. Parkwood Institute Research Day, Schulich School of Medicine and Dentistry, Lawson Health Research Institute, St. Joseph's Health Care London & Western University, Live Virtual Event, April 21, 2022 (Poster).

Winger, C., Cassidy, C., Brunton, L., & Starowicz, J. (2022). Describing Healthcare Concerns of Young People and Adults with Cerebral Palsy. Western Research Forum, Society of Graduate Students, Western University, Live Virtual Event, March 15-16, 2022 (Poster Presentation).

Winger, C., Cassidy, C., Brunton, L., & Starowicz, J. (2022). Describing Healthcare Concerns of Young People and Adults with Cerebral Palsy. 15th Annual Health and Rehabilitation Sciences Graduate Research Conference, Western University, Live Virtual Conference, February 2-3, 2022 (Poster).