EXPLORING THE INFORMATION NEEDS OF YOUTH LIVING WITH CEREBRAL PALSY AND THEIR PARENTS DURING THE TRANSITION TO ADULTHOOD

EXPLORING THE INFORMATION NEEDS OF YOUTH LIVING WITH CEREBRAL PALSY AND THEIR PARENTS DURING THE TRANSITION TO ADULTHOOD

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Abstract

Background

The transition to adulthood is a time of information needs for youth living with cerebral palsy (CP) and their parents. Access to information and being provided information may assist youth and their parents in making informed decisions. Youth with CP and parents of youth living with CP have reported lack of information as a challenge during the transition to adulthood. Little is known about the information needs of youth with CP and parents during the transition to adulthood from their perspective.

Objectives and Methods

The objective of this thesis was to explore the information needs of youth with CP and parents during the transition to adulthood. A scoping review was conducted seeking to understand what was known in the transition literature about the information needs of youth with CP and parents (Chapter 2). To clarify the methodological framework of this dissertation the application of interpretive description (ID) to a case study example within childhood disability research was explored (Chapter 3). The information needs during transition in a sample of young adults living with CP were explored using ID (Chapter 4). The information needs of parents of youth with CP currently in the transition to adulthood were then explored, using ID because it was learned in the study of adults living with CP that their parents initiated information seeking or had information needs of their own during transition (Chapter 5).

Findings

Primary findings from this dissertation include the recognition, from both the scoping review and the two studies, that both youth living with CP and parents of youth living with CP in the transition to adulthood have information needs during the transition to adulthood. More specifically, both youth and parents are seeking to receive information related to goals in adult life, such as employment, postsecondary education, leaving the family home and relationships. Youth prefer to receive their information from peers living with CP. Parents prefer to receive information from peers, but some also desire a direct connection with service providers. Other parents recommend adults living with CP as an information source. Youth and parents agree that information should be delivered in individualized tailored ways. In addition to rehabilitation professionals, youth and parents highlighted the need for information from educators and other community providers.

Implications for Clinical Practice

Rehabilitation professionals have an important role in helping to provide tailored information. Rehabilitation professionals can initiate conversations about the transition to adulthood around the beginning of high school that focus on improving the self-management of youth of their own transitional journey. In addition to having conversations with clients, rehabilitation professionals should also connect clients with community supports.

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List of Abbreviations

ABI = Acquired Brain Injury

CP = Cerebral Palsy

SB = Spina Bifida

ID = Interpretive Description

GMFCS = Gross Motor Function Classification System

GMFCS E&R = Gross Motor Function Classification System Expanded and Revised Version

OT = Occupational Therapist

PT = Physical Therapist

SLP = Speech Language Pathologist

Acknowledgements

A recurring theme in this dissertation is the importance of support around an individual in their transitional journey. This dissertation is a tribute to the support that I’ve had throughout my own journey. I will be forever grateful to my supervisory committee for providing me the opportunity to challenge myself and perpetually pushing me forward. Dr. Gorter, as a supervisor, continually pushed me forward, while providing the time needed to incorporate knowledge. I am grateful that he was always able to understand and accommodate my needs. Professor Stewart provided me with a listening ear as I attempted to figure out my identity as a rehabilitation scientist mixed with tough encouragement completing this dissertation. This dissertation marks the end of our working relationship, and I will forever be grateful for the opportunities and experiences you provided me over the years. Dr. Cunningham provided a critical voice in shaping my plan of research, and this dissertation in my professional development. I am grateful for the realistic and pragmatic feedback and guidance for the rest of my career.

Throughout this journey I’ve also had the opportunity to work with individuals external to my committee that have provided tremendous emotional support. These people include: Michelle Phoenix, Briano Di Rezze, Lisa Rivard, Marlice Simon, Alice Soper and Donna Johnston. I am also grateful for the lifelong support of Peter Rosenbaum, a doctor, colleague and friend who has seen me through all stages of development.

Above all, I am grateful for the love and support provided by my family. To my wife, who is always up for the journey provided there is preparation and a landing spot with a nice view, I appreciate your patience.

I am grateful for the support from the Ontario Federation for Cerebral Palsy and the McMaster Child Health Research Institute.

Declaration of Academic Achievement

I am the sole author of Chapters 1 and 6 in this dissertation. I received guidance and feedback from my supervisor Dr. Jan Willem Gorter, and committee members, Dr. Charles Cunningham and Professor Debra Stewart.

I was the primary author of Chapters 2, 3, 4 and 5, and the role of my co-authors for these chapters is as follows:

In Chapter 2, I was assisted by the guidance of my supervisory committee when establishing the scope of the scoping review. Dr. Gorter, Prof. Stewart and Dr. Cunningham are listed is co-authors. I was responsible for conducting the initial literature review and I was assisted by Prof. Stewart when conducting title and abstract reviews. In areas of disagreement, Drs. Gorter and Cunningham offered judgement to determine articles to be included or excluded. I was then responsible for data extraction, which was reviewed by Prof. Stewart. After I wrote the initial draft of the manuscript, my committee provided feedback and revisions, led by Dr. Gorter.

In Chapter 3, I am grateful to my supervisory committee for providing guidance and direction as I initially drafted the manuscript. Dr. Gorter and Prof. Stewart are listed as co-authors and help me to present my ideas in a clear way. Dr. Cunningham refrained from being listed as a co-author because he was not directly involved in the case study project on which the manuscript is based. However, Dr. Cunningham regularly participating in meetings where the manuscript was discussed and provided feedback.

In Chapters 4 and 5, I was responsible, with the guidance of my supervisory committee for study design, data collection, data analysis and writing the primary draft of the manuscripts. Drs. Gorter and Cunningham and Prof. Stewart are co-authors. Drs. Gorter and Cunningham and Prof.

Stewart all participated in each element of study design and data collection. Prof. Stewart provided guidance and oversaw the data analysis. I appreciate her willingness to read and review transcripts often.

Chapter 1: Introduction

Objective of the dissertation and research questions

The objective of this dissertation was to explore the information needs of youth with cerebral palsy (CP) and their parents during the transition to adulthood. Broken down into a series of research questions, this dissertation first aimed to explore what is currently known in the published literature about the information needs of youth with CP and their families in the transition to adulthood. The second aim was to understand the information needs of youth with CP during the transition to adulthood as identified by individuals who have already transitioned from adolescence to adulthood. The third aim emerged from the work with youth and focused on the information needs of parents of youth with CP currently in the transition process to adulthood.

Urgency of the issue: Transition to Adulthood in the Media Spotlight

In June 2018 families and researchers gathered for a town hall discussion in Toronto, Ontario initiated by CBC radio's Dr. Brian Goldman, host of the radio series and podcast "*White Coat, Black Art*" (Goldman, 2018). The purpose of the town hall was to discuss what Dr. Goldman termed a "crisis in care" as families struggled to find support for their disabled children as they aged out of pediatric services into adult services. Families began listening to introductions from the expert panel, which included doctors, researchers, a young person in the transition to adulthood, a lawyer, and parents. One by one, each of the experts highlighted the lack of coordinated services in the void left by transitioning into the unknown. Following the expert panel discussion, parents lined up at microphones to ask questions and to share their experiences. Importantly, when sharing their stories exasperation and sometimes desperation could be heard in their voices. Participant shared their experiences showing varying levels of support for young people living with developmental disabilities in Ontario. Some parents shared that they were waiting to receive government funding for adult services, but had been waitlisted, while other parents shared that they had met with the ministry responsible for administering funds for youth with disabilities, to secure funding for their children into adulthood. There were also individuals who shared stories of trying to find solutions outside of those currently available to their children. For example, one father shared his experiences trying to develop a new housing model that incorporates individuals with disabilities like his son.

Also, in the spring of 2018, CTV's "*W5*" (W5, 2018) aired a segment discussing the difficulties that one family was having accessing services for their child living with developmental disabilities. *W5* had been following this family for many years. The program had previously highlighted the rehabilitation opportunities available to assist families and youth in childhood. In contrast to their previous stories, which focused on the inclusion and support available to the young person, this story highlighted the barriers faced and concerns weighing on the mind of parents of youth with disabilities as they transition to adulthood. Not only were the young person's parents concerned about accessing healthcare in adulthood, they also wanted information about where their son could live, and what activities were available to their son.

Background

Recognition of the difficulties faced by young people with disabilities and their families during the transition to adulthood is not new within academic literature. Starting in the 1990s research began to emerge highlighting the struggles faced by young people and their families during the transition to adulthood (Hallum, 1995; Logan, 1997). Initially, this research was conducted by pediatric clinicians faced with the following clinical question: "why are graduates from my treatment centre or medical practice continuing to contact me into their 20s looking for support and services?" (Logan, 1997; Stevenson, Pharoah, & Stevenson, 1997; Stewart, 2006). Reviews of early literature on transition to adulthood for youth with disabilities found that studies focused primarily on the individual and outcomes in adulthood in the domains of education, employment and social relationships (Stewart, 2006; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). A critical review of literature about the transition to adulthood for youth with disabilities was conducted in the mid-2000s (Stewart, Stavness, King, Antle, & Law, 2006). This review marked an important shift by encouraging researchers to begin exploring participation-based outcomes, creating opportunities for youth with disabilities and their family to connect with other youth and families going through a similar experience and provide education and information about opportunities available in adulthood (Stewart et al., 2006). In addition to the direct education for young people in transition and their families, an additional recommendation included that provision of service be tailored to the individual and recognize developmental factors, such as readiness, and consider environmental factors and community supports available (Stewart et al., 2006; Young et al., 2009).

Since the end of the second decade of the millennium, researchers have found little improvement in the preparation of youth with disabilities for the transition to adulthood. Most concerning is that a recent review synthesizing transition literature reported international use of a common analogy of either falling off a cliff or being pushed from the cliff as a metaphor for the transitional process (Joly, 2015). Joly (2015) found that a key impediment for youth and families during the transition to adulthood is a lack of information provided to youth and their families. Definitions of information are provided below; however, it is important here to recognize that information is a multidimensional and multifaceted concept within transition to adulthood literature. As shown in Chapter 2 of this thesis, information provided to youth and families may include: 1) conversations with healthcare professionals, 2) the opportunity to connect with adult providers prior to leaving pediatric services so that youth and their families can prepare for the expectations of adult services, and, 3) the sharing of information between pediatric and adult service providers.

My journey as a transition researcher

To this point I have discussed the transition to adulthood for youth with disabilities generally. But the truth is the topic is a personal one for me. I am an individual living with cerebral palsy (CP) and began studying the transition to adulthood and working with Professor Debra Stewart in 2006. My role was to assist in the development of a transitional tool for youth with disabilities known as the Youth KIT (Stewart et al., 2009). The aim of the Youth KIT was to assist youth in giving information about themselves and to provide an organized physical binder to store information received from others (Freeman et al., 2015). I also had the opportunity to participate as an advisor in the research project exploring the utility of the Youth KIT when used in a variety of populations and settings (Freeman et al., 2015). Through this work, the need for information became more and more apparent. As I read through transcripts, I began to see that youth felt the transition to adulthood was daunting and encompassed more than one domain of life. I also reflected on my own experience when, at the time of transition from my Children's Treatment Centre, I simply received a sheet of paper with phone numbers with little explanation of what the purpose of these numbers was. I also began to see individuals with disabilities within my circle of friends struggle to successfully transition in their own lives. For example, they were fully employed or attending school, but did not know how to access supports if they wanted to leave their family home and did not know how to start the process.

As I began to read more and more academic literature, I was struck by how relatable the findings and supporting quotations were (Young et al., 2009) to my own experiences. When discussing my graduate application, I read the work by Young and colleagues (2009), which demonstrated the need for information on the part of youth and their parents. The uncertainty of youth and parents resonated with me on a personal and professional level. As I decided to pursue my PhD, I wanted to research information needs and provision for youth with CP and their families during the transition to adulthood to alleviate some of the anxiety caused from not knowing where to find answers to questions. I recognize that the field of transition research has now moved to a more non-categorical approach, which explores the common experiences across diagnostic categories and health conditions, but I selected CP because it was something that I intimately understood and has remained a commonly diagnosed childhood disability (Rosenbaum et al., 2007).

Methods Used to Explore Information Needs

The three research aims outlined above were explored using the following methodological approaches. First, in order to understand what is currently known about information needs, a scoping review was conducted. A scoping review seeks to map what is known about a research topic (Daudt, van Mossel, & Scott, 2013).

Second, to address the information needs of youth with CP and their parents, qualitative studies, using interpretive description (ID) as an approach were conducted. Explored in greater detail in Chapter 3, ID is a qualitative methodological approach that seeks to answer research questions arising from clinical settings (Thorne, 2008, 2016; Thorne, Kirkham, & MacDonald-Emes, 1997).

ID views knowledge as socially created. Social constructivism argues there is no single understanding of “truth”, but we should strive to understand the conditions in which multiple versions of truth exist (Mills, Chapman, Bonner, & Francis, 2007). Within the constructivist perspective, researchers are not viewed as separate from participants (Mills et al., 2007). While there is debate in some qualitative traditions about the possibility of the researcher setting aside, or bracketing their assumptions and perspectives about the phenomenon under study, such as descriptive phenomenology in contrast to interpretive phenomenology (Lopez & Willis, 2004), qualitative research generally sees researchers as connected to the same social world as their participants (Mills, Bonner, & Francis, 2006). Qualitative methods are becoming more widely used within rehabilitation science (VanderKaay et al., 2018), as are the benefits of exploring the social context that influences clinical practice. (Mills et al., 2006). For example, a study exploring the preferences of clinicians receiving information when using knowledge brokers found that it was necessary to analyse the context in which clinicians would be using the knowledge (Hurtubise, Rivard, Heguy, Berbari, & Camden, 2016). Hurtubise et al. (2016) identified that therapists faced barriers when introducing interventions or concepts into practice and looked for guidance from peers about how to introduce new interventions or theoretical concepts when working with schools, which may not have the same understanding of the students’ needs.

Thorne encourages clinicians to consider the ways in which the social world may impact their clinical practice and the individuals experiencing the phenomenon being explored (Thorne, 2008, 2016). Building on this point, it is important to consider some of the contextual assumptions made in my understanding of CP, the transition to adulthood and information needs and provision.

Contextual Assumptions

There are three topic areas that must be understood in order to achieve the aims of this dissertation. First, we need to understand how CP as a health condition impacts individual on a personal and societal level. On a personal level, CP may impair an individual's bodily functions (Schiariti, Selb, Cieza, & O'donnell, 2015). On a societal level, the disablement may result from environmental factors, including barriers (Oliver, 1990) and societal stigma impacting young people and their families (Read, Morton, & Ryan, 2015). Second, it is important to understand how the transition to adulthood is conceptualized in terms of theory and the Western understanding of successful outcomes in adulthood. Finally, it is important to develop an understanding of how information needs are conceptualized, which includes exploring what people want to know, who they want to receive information from, how they want to receive information, where they want to receive their information, when they want to receive their information, and, equally as important, why individuals feel this information is important to know.

Cerebral palsy.

CP occurs in 2.11 of every thousand live births based on a global systematic review (Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013). For the purposes of this dissertation, I define CP using the following widely accepted definition from Rosenbaum and colleagues:

> "[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 cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and

> behaviour, by epilepsy, and by secondary musculoskeletal problems (Rosenbaum et al., 2007, p. 9)”.

Advances in medical treatment and technology have made it possible for individuals born prematurely to survive into adult life. Indeed, many of those living with childhood disabilities are now likely to survive into adulthood (M. C. Allen, Cristofalo, & Kim, 2010; Alriksson-Schmidt, Hägglund, Rodby-Bousquet, & Westbom, 2014).

The definition above is reflective of how CP impacts the individual, but it is also important to consider the sociopolitical aspects of living with a disability and its impact on the lived experience. Historically, disability was viewed through the lens of individual deficit, which required correction through medical intervention and rehabilitation. Rehabilitation and health-related treatment for individuals with CP has changed dramatically in the last half-century. There has been a shift away from the focus on individual deficits and correction to healthcare professionals considering the interaction between individuals with disabilities and their environment (Rosenbaum & Gorter, 2012). This shift is best demonstrated by the World Health Organization's (WHO) understanding of disability through its models of functioning (World Health Organization, 1980, 2001). The manual for the International Classification of Impairments, Disabilities, and Handicaps, or ICIDH, (World Health Organization, 1980) tells readers that it is a model intended to classify the “consequences of disease” in its subtitle. The ICIDH suggested a causal link between disease, impairment, disability and handicap (Hurst, 2003). In reaction to this model, people with disabilities drew attention to the lack of consideration of the environment in creating and perpetuating disabling barriers (Hurst, 2003). Criticisms also arose from rehabilitation clinicians arguing that impairments did not always lead to disabilities (e.g. (Badley & Lee, 1986).

In 2001, the WHO revised the classification system, which is now titled the “International Classification of Functioning, Disability and Health” also known as the “ICF” (World Health Organization, 2001). Instead of viewing disability as a consequence of disease, the current model views disability as an interaction between the person and the environment (World Health Organization, 2001). The recognition of the barriers created in the lives of individuals with disabilities within the classification system is reflective of the perspective of individuals with disabilities arguing for the decoupling of the causal link between impairment and disablement (Hurst, 2003).

Advocates of the social model of disability (Oliver, 1990) asserted the argument that disability does not stem from individual infirmity or impairment, but rather is a result of attitudinal and environmental barriers existing within society. If disablement was a result of attitudinal and social barriers, disability advocates also argued that society had a responsibility to eliminate barriers and create inclusive environments for individuals with disabilities. Within the context of youth with disabilities, this means instead of focusing on a young person’s ability to manage the stairs to get into a local school, the built environment should be modified to include accessibility features such as elevators and ramps.

Advances in environmental accessibility and shift of attitudes towards people with disabilities and their inclusion within society, stemming from disability rights legislation has led to a push to find more nuance and insertion of context into the discussion of barriers faced by disabled individuals today. The Affirmational Model of Disability (Swain & French, 2000) enhances our understanding of the social model by asserting that disablement is fluid rather than binary. The affirmational model, instead of focusing on the person and the environment, examines the person within their environmental context and recognizes that it is possible to experience varying degrees of disablement. This nuance can be best explained using an example from Chapter 4 of this thesis. One young adult participant described her experiences attempting to find accessible housing. Although the city where she resided did provide accessible housing, the process of applying for the housing and completion of the forms was a barrier. Although she was able to enter the building and physically complete the housing form, she required additional information regarding how to complete the form. When she asked for assistance, she faced the attitudinal barrier of stigma regarding the ability to understand the instructions. This experience demonstrates that, although society has made efforts to rectify physical barriers within the environment, attitudinal barriers do exist regarding the ability of an individual to understand information and use the information provided.

The trend toward focusing on disability as a societal construct versus an individual deficit approach is also reflected in the research priorities (Gross et al., 2018) as identified by individuals living with CP and their families. Research priority number 8 states, "How do we best maximize functional independence and life participation of children and adults with CP?" (p. 1282). Also reflected in the research priorities, is the recognition that adults living with disabilities want to know more about how their CP will affect them through adulthood (Gross et al., 2018). Research priority number 1 reads: "Research the issues around ageing with CP, to understand not only how to treat adults now, but also to update our treatments & therapies with children who have CP to prevent some of the secondary impairments such as pain, fatigue, and functional loss." (p. 1282)

The transition to adulthood.

The transition to adulthood is a developmental process occurring as a result of the movement from adolescence into adulthood (Reifman & Grahe, 2016). Normative theories of the transition to adulthood suggest the transition begins between the ages of 13 and 19, and can extend through the 20s (Arnett, 2000). Theories of emerging adulthood suggest that young people will begin relying less on their family to develop their own worldview and may experience relationships and employment for the first time (Arnett, 2000). Critics of the construct of emerging adulthood suggest that it is not generalizable to the entire population, but rather a population of individuals living with privilege and opportunity to explore different pathways in adulthood (Côté, 2014; Côté & Bynner, 2008). Some youth, for example may have life events, such as the loss of a parent, which force them to take on greater responsibility at a younger chronological age (Hendry & Kloep, 2007). The main criticism of emerging adulthood as a distinct developmental phase is its optimism bias toward the future rather than a realistic evaluation of the sociopolitical structural facets of many Western societies today (Côté, 2014).

The trend of young adults finishing high school, entering postsecondary education, completing their identity formation, finding a job and starting a family possesses a strong narrative appeal. However, this perspective only recognizes individuals capable of following the path. This is not to say that individuals with CP are unable to follow this path, indeed many do. Research validated that individuals with CP value employment (Benner, Hilberink, Veenis, van der Slot, & Roebroeck, 2017) and intimate relationships (Wiegerink et al., 2010) and leave the family home (Alriksson-Schmidt et al., 2014). But an important consideration is what is happening to the individuals with CP that are both on this path and off this path. For example, Arnett’s conception of emerging adulthood may view evidence that youth with disabilities including CP often achieve advanced degrees in University as a sign that they are still forming their own identity and worldview (Arnett, 2000). This analysis, however, would ignore important structural factors including the difficulty of those with physical disabilities finding employment, and that many with disabilities find postsecondary education to be an accessible environment where disability-related needs are better understood and accommodated (Zarifa, Walters, & Seward, 2015). In contrast to those youth with CP who are able to attend postsecondary education, those unable to attend postsecondary education often find themselves on a patchwork path that is dependent on their communities and the opportunities available to them (Cooper, Balandin, & Trembath, 2009).

A consideration not normally seen in the emerging adulthood literature is the forced timing of the transition resulting from the distinction between pediatric and adult services. The age-related demarcation point between pediatric and adult services is often determined by the biological age of 18. Unlike their nondisabled peers, youth with CP and their families may experience disruption during the transition to adulthood as a result of the need for support services stemming from possessing a childhood disability that will require support in adulthood.

The largest difference between pediatric and adult services in the lives of youth with CP and their families is the design of the services. Within the domain of healthcare, pediatric services are designed to be *family centred* (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2012), which places the needs of the child, along with their goals and the goals of their families, at the centre of any treatment plans or specific interventions. Also important is that a pediatrician or a pediatric specialist often acts as a resource person to coordinate necessary medical care for patients. Nguyen and Baptiste (2015) have reported that youth with CP and their families confront a shift in culture. Rather than the holistic construction of family centred services, youth with CP are now confronted with the expectation that they are able to guide their own medical care and possess enough understanding and information to navigate the various and fragmented adult services available. Youth with CP and their families have reported difficulty adjusting to the expectations of adult health care due to the lack of knowledge about CP and other childhood disabilities possessed by adult providers (D. Allen, Scarinci, & Hickson, 2018). Allen and colleagues (2018), in a systematic review exploring the nature of family and patient-centred care for young adults with chronic medical conditions found across qualitative studies that patients expected their adult providers to respect their values and allow them to act as collaborators in their own medical care rather than be viewed as recipients of medical knowledge. This partnership may be difficult as adult health care providers may not have the required understanding of CP or collaborative practice (Cassidy, Campbell, Madady, & Payne, 2016).

Current research now explores the transition to adulthood as a developmental process in an individual's life course rather than a discrete event (Rydzewska & Pirrie, 2016). The focus on transition during the life course recognizes that living with a disability will continue over the life course, which will require ongoing support in all areas of health, including physical, mental and social health (Palisano et al., 2019). A life course perspective also recognizes the transactional nature of interactions between the person and the environment (Palisano et al., 2019), which is a cornerstone of rehabilitation models, such as the ICF and the models of disability discussed above.

Information needs and provision.

Defining the terms information and information needs is not straightforward. Case (2006) defines information as "any difference you perceive in your environment or within yourself. It is any aspect you notice in the pattern of reality(p. 5)". Case (2006) describes an information need as, "a recognition that knowledge is inadequate to satisfy a goal that you have (p. 5)."

Originating in the discipline of library science, the discipline of information science is comprised of two, often intertwined strains of research, information behaviour and information literacy (Shenton & Hay-Gibson, 2011). Information behaviour research seeks to explore the ways in which individuals search for and use information. Information literacy, in contrast, explores the skills required at a societal level for individuals to use information. Efforts have been made to develop a grand theory of how individuals seek to find information (Wilson, 1981). This grand theory of individual information seeking generally falls under the behaviorist approach of information needs research. A behaviorist approach finds that information needs originate from the individual. However, more recent efforts have focused on developing an understanding of information needs that are congruent with an individual's purpose when seeking information (Omiunu, 2014). In contrast to behaviorists, constructivists seek to explore the sociopolitical context in which information needs occur (Hicks & Lloyd, 2016). In their work Hicks and Lloyd (2016) used the example of the experience of refugees attempting to access healthcare services during resettlement and they found that having access to information does not alleviate information needs directly. Although information resources had been gathered together for refugees, they still required assistance and knowledge to evaluate the information and give it utility in the context of their lives (Hicks & Lloyd, 2016). This finding also fits with Case’s (2006) reminder to readers that often service providers, although well-intentioned, will attempt to provide information they feel individuals need to know rather than exploring the actual information needs of the populations that they serve.

Within the field of health sciences, Johnson and Case (2013) view the trigger for seeking information as a health change in status or diagnosis (e.g. a cancer diagnosis). One problem with this approach is that it fails to consider the information needs of those with chronic conditions over time, but instead focuses on individuals primarily seeking immediate intervention.

For the purposes of this dissertation, keeping in mind the clinical and constructivist underpinnings of ID as well as the aims of the research questions, the application of one specific model of information needs is not as valuable as understanding some of the applicable principles of information seeking, which are seen across information seeking literature and models across academic disciplines.

An important principle of information seeking research is the Principle of Least Effort, asserted by George Kingsley Zipf in 1949 that human beings will choose the option that requires the least effort when seeking to achieve a goal (Chang, 2016). When applied to information seeking behaviour, Case (2006) identified the example of one scientist asking another scientist for information rather than conducting their own individual inquiry.

Another principle of information seeking is that individuals will avoid seeking information (Sweeny, Melnyk, Miller, & Shepperd, 2010). For example, an individual may resist going to the doctor for medical care because they are fearful of the diagnosis.

There is also a body of research within information needs that seeks to explore unconscious or latent information desires when provided with an array of choices. This is known as a discrete choice experiment (Cleland, Porteous, & Skåtun, 2018). In discrete choice experiments, participants select between two or more choices in an array of options and their responses are grouped and categorized to look for latent patterns (Cleland, Porteous, & Skåtun, 2018). Within the field of information needs this method has been used to model information preferences of young adults within the field of mental health (Cunningham et al., 2014).

Although not the primary objective of this dissertation, it is my hope that the findings presented will contribute to the preparatory work needed to enhance the ability to explore latent information preferences by informing possible choice task options (Vass, Rigby, & Payne, 2017). As demonstrated by the following chapters, although there is agreement from all youth that information during the transition to adulthood with CP and their parents is necessary, there is no agreement about the information that should be provided, whom should be providing the information, when the information should be provided or where the information should be provided.

Layout and Description of Chapters in This Dissertation

Chapter 2 (Freeman, Stewart, Cunningham, & Gorter, 2018b) presents the findings of a scoping review exploring what is known about the information needs of youth with CP and their families during the transition to adulthood. The scoping review also explored preferences related to the content, source, delivery method, location and timing of information provision. The scoping review is connected to the thesis objective of understanding information needs.

Chapter 3 provides a rationale for the use of ID in childhood disability research, using the example of a qualitative study, in which I was a part of the research team, that explored how the understanding of healthy living of an individual living with CP changes from childhood to adulthood. This chapter describes how the research team used ID as a methodological approach to answer the research question and then addressed some of the strengths and challenges of using ID as a methodological approach within the multidisciplinary field of childhood disability research. This paper provides the reader with a more complete understanding of my methodological approach when designing and conducting my own original research projects.

Chapter 4 (Freeman, Stewart, Cunningham, & Gorter, 2018a) presents findings from a qualitative study of young adults living with CP between the ages of 18-40 looking back at their own transition to adulthood. The three themes that emerged highlight the need for information support, how young adults living with CP navigate barriers to information and some of the identified gaps when seeking information. This chapter is related to the thesis objective of understanding the information needs of youth with CP during the transition to adulthood.

Chapter 5 presents findings from a qualitative study exploring the information needs and information provision preferences of parents of youth with CP aged 16-30 currently in the transition to adulthood. The three themes that emerged highlight the content needs and reasons parents are looking for information, which are related to the adult goals, in many cases, that their children possess. Parent participants often found it difficult to navigate information seeking including where to look for information, who to ask for information and finding information specific to their child. The third theme highlights dilemmas parents faced when deciding how and when to share information about their adult children to support providers or community agencies. This chapter meets the objective of seeking to understand the information needs of parents of youth with CP in the transition to adulthood.

Chapter 6 presents a synthesis of research findings from the previous four chapters. The aim of this chapter is to discuss the results within the context of other youth with disabilities and chronic medical conditions transitioning to adulthood and directly connect research findings to clinical practice. This chapter also presents a critical appraisal of the research and provides suggestions for future research.

Conducting research as an "insider": recognition of the need for reflexivity

As a qualitative researcher, I acknowledge that I am the research instrument (Creswell, 2013). This means, I must be sensitive to acknowledging my potential influence on the research process (Thorne, 2016). The purpose here is not to declare potential biases in analysis but to identify my relationship with the research and potential areas in which I may have influenced data collection and analysis. Although I have kept notes on my own reflexivity (influence on the research process) during the two original studies (Chapters 4 and 5), it is also necessary for me to consider my own personal journey and evolution as a researcher seeking to combine my identity as a person with a disability and a rehabilitation scientist. Previously in this chapter I discussed my own experience as a transition to adulthood researcher and my lived experience with CP. This means I identify as an *insider researcher* (Unluer, 2012) when conducting qualitative research.

Unfortunately, guidance for disability scholars researching other individuals living with disabilities, especially those to whom they can directly relate, is scarce. Disability scholars tend to focus on the personal and political rationale for their program of research (e.g. Whitburn, 2014)). There is, however, a warning to those rehabilitation professionals conducting research involving individuals with disabilities. Historically, rehabilitation scholars have profited professionally from the experiences of those with disabilities by mining their experiences in research projects without including them in the rewards (Hammell, 2006). In response, the field of rehabilitation has, through the use of participatory action techniques, attempted to be more inclusive of those with disabilities throughout the research process from design to dissemination, but these projects fail to enhance or uplift the lives of people with disabilities (Gelech, Desjardins, Matthews, & Graumans, 2017). While this does add pressure when conducting research as an academic early in my career, living with a disability and understanding the oppression that living with the disability brings and how that may influence the research process allowed me to ask critical questions of the literature. I was aided in this endeavour by the ID's analytic process (Thorne, 2016). Although a basic description is developed in ID, the description is then transformed into an interpretation that purposefully attempts to contextualize the findings within a clinical and larger socioeconomic context.

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Introduction to Chapter 2: Information Needs of Young People With Cerebral Palsy and their Families During The Transition To Adulthood: A Scoping Review

Chapter 2 presents findings from a scoping review that sought to identify what was currently known about the information needs of youth living with CP and their families during the transition to adulthood. In addition to identifying what the information needs are for young people living with CP and their families, the scoping review also identified what is known about who should provide young people with CP and their families information during the transition to adulthood, how that information should be provided, where that information should be provided and when that information should be provided.

The scoping review identified 11 fulltext articles for review. Seven of the 11 articles reviewed had a healthcare focus. Notably, young people living with CP and their families wanted to know more disability specific information and its impact on functioning into adulthood (e.g. CP and aging). Young people living with CP and their families were found to have a preference for receiving information from peers, sought information which was tailored to them. The review suggested that information regarding the transition to adulthood be provided to young people living with CP as early as age 12.

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Review

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Information needs of young people with cerebral palsy and their families during the transition to adulthood: a scoping review

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Abstract

The transition to adulthood is a developmental phase which occurs as young people move from adolescence into adulthood. Young people with disabilities, including cerebral palsy (CP), and their families have reported challenges during the transition to adulthood because they are required to move to adult supports and services, which are often fragmented and bring about new questions and expectations to find necessary supports. Young people and their parents have been found to lack information about where to find services in adulthood, how to access the services and what to ask during the transitional process. The aim of this scoping review was to explore the information needs of young people with CP and their families during the transition to adulthood. The goal is to map the current published evidence within the transition to adulthood literature base to explore what is known about information needs during the transition to adulthood of young people with CP and their parents. This review seeks to synthesize what is known about information content, timing, methods of provision and delivery. Databases searched were OVID Medline, CINAL, ERIC, EMBASE, PsycINFO, Web of Science, Social Science Abstracts and Sociological Abstracts. Initially 675 articles were retrieved. Four hundred and forty-two articles were selected for title review. Two hundred and five articles remained for abstract review. Seventeen articles were included for full-text review. Eleven articles were included in this review. Data were organized into five themes: (1) identified information needs during the transition to adulthood (content), (2) identified recommended providers of information during the transition to adulthood (who), (3) identified delivery methods of information during the transition to adulthood (how), (4) identified timing of information delivery of information during the transition to adulthood (when) and (5) location of information provided during the transition to adulthood (where). This review found that young people with CP, their families and adult providers all possess information needs during the transition to adulthood. Young people with CP and their families seek information about what adult services will look like and how to access supports. Adult providers require information about CP. Youth with CP prefer individualized information be delivered to them when needed rather than presented in group sessions or via paper handout. Other recommendations included the development of parent support networks to assist parents in the transition to adulthood. The opportunity to learn from real-life experiences was also viewed as an important source of information as well as method to provide information.

Keywords: cerebral palsy; information needs; scoping review; transition to adulthood.

Introduction

The transition to adulthood is a process in which young people move from one developmental stage to another – from adolescence to early adulthood. Entering adulthood requires a young adult to adopt new roles and expectations

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while gradually taking control of their own life. Arnett [1] describes this developmental phase as one in which young people begin exploring options for the future. This may include exploring postsecondary education, finding employment and pursuing long-term relationships [1]. Nguyen and Baptiste [2] note that the transition to adulthood for youth with disabilities and their families represents a shift in culture and service delivery. The pediatric system tends to be more integrated whereas adult services are less centralized and more fragmented [2–5]. Inherent within the exploration of new options, young people start asking questions and seek information, such as, *do I want to attend a postsecondary institution close to my family home*? or *how can I access transportation schedules so that I can get to work*? For youth with disabilities who have the same aspirations for adult life as their nondisabled peers [6], their questions may be similar but may come with disability specific information needs. For example, when it comes to selecting a postsecondary institution, a young person with cerebral palsy (CP) may ask, *does the school offer attendant care*?

The provision of information to young people and their families in the transition to adulthood is considered best practice [7, 8]. Qualitative literature discussing the experiences of moving from a pediatric system to the adult system from Canada [3], Sweden [9] and the United States [4] describe a lack of support regarding how to navigate adult care systems and find answers to questions. Literature also highlights gaps in the knowledge of young people with CP on topics such as their physical function [4, 10], and how their physical function or pain influences their participation in meaningful activities [11–13].

While providing information to families is a cornerstone of family-centred care [14], pediatric service providers often experience discomfort providing information to youth and families [15]. Reasons for this include clinicians feeling uncertain about whether they are providing the right information and having more comfort in giving direct 'hands-on' or practical service to families [15]. Current literature now recognizes that the provision of information to young people with CP and their families during the transition to adulthood is important [16], however specifics about information delivery, its timing and the methods of provision during the transition process have yet to be synthesized.

The aim of this scoping review is to map the current published evidence within the transition to adulthood literature to explore what is known about information needs during the transition to adulthood of young people with CP and their parents. This review seeks to synthesize what is known about information content, timing, methods of provision and delivery.

Methods

Scoping reviews seek to examine and map current knowledge and evidence regarding a phenomenon by "systematically searching, selecting and synthesizing evidence" [17] (p. 1292). Our scoping review is guided by the framework proposed by Colquhoun and colleagues [17], which synthesizes two previous framework iterations originating with Arksey and O'Malley [18] and Levac, Colquhoun and O'Brien [19]. Within this framework there are five recommended steps with an optional sixth focusing on dissemination of findings and consultation with colleagues, which was not used in this review.

Purpose of the review and the research team

In seeking to understand the information needs of young people with CP and their families, this review explores, in addition to content areas, other areas of information delivery, including suggestions from professionals and preferences from stakeholders with respect to timing of information delivery (when) and in respect to how information is delivered. The research team was comprised of two content experts in transition to adulthood for youth with disabilities (JWG and DS), a graduate student in rehabilitation science living with CP (MF), and a researcher familiar with information needs research and provision strategies (CC).

Identifying relevant studies

The inclusion criteria were peer-reviewed papers with full text available explicitly referencing the transition to adulthood, CP, and information needs or provision within the abstract. To assist in finding relevant literature the following databases were searched: OVID Medline, CINAL, ERIC, EMBASE, PsycINFO, Web of Science, Social Science Abstracts and Sociological Abstracts. No limitations were placed on year of publication or language of publication during the search, and all full text articles reviewed were published in English.

MF conducted the database searches in July 2017 in consultation with a health science librarian. The research team recognized that often a diagnosis of CP may be included in more general studies examining the transition to adulthood for youth with disabilities, which include CP as well as other conditions. Therefore, to be as inclusive as possible, major subject headings for CP, childhood disability and transition to adulthood or transitions were used on recommendation by the health sciences librarian. Data for the scoping review were managed using bibliographic management software and the creation of Microsoft Excel spreadsheets that allowed each reviewer to select their inclusion or exclusion option as well as provide a rationale, if needed.

Study selection

A summary of the study selection process is shown in Figure 1. Searching of databases retrieved 675 articles. After removing duplicates, 442 articles moved forward to title review. MF and DS performed the title review and met to discuss their decisions as well as reasoning to ensure agreement and reinforce the aims of the review. Following title review, 205 articles remained for abstract review. MF and DS reviewed all abstracts and CC acted as judge in areas of disagreement. Seventeen articles were included for full-text review by MF and DS. During full-text review, six articles were removed as they did not discuss information needs, CP and the transition to adulthood. The characteristics of the 11 included studies are summarized in Table 1.

Charting the data

Data were then extracted by MF from eleven articles and reviewed by DS and JWG. All articles were read and data pertaining to information needs and/or provision were charted (Table 2).

Collating, summarizing and reporting the results

An *a priori* coding scheme was developed using summative content analysis [20]. Patterns emerging from the raw data were then organized by identified information needs during transition (content), identified providers of information during transition (who), identified delivery methods of information during transaction (how), identified timing of information delivery of information during transition (when) and location of information provided during transition (where). It was recognized that it was necessary to make purposeful distinctions between

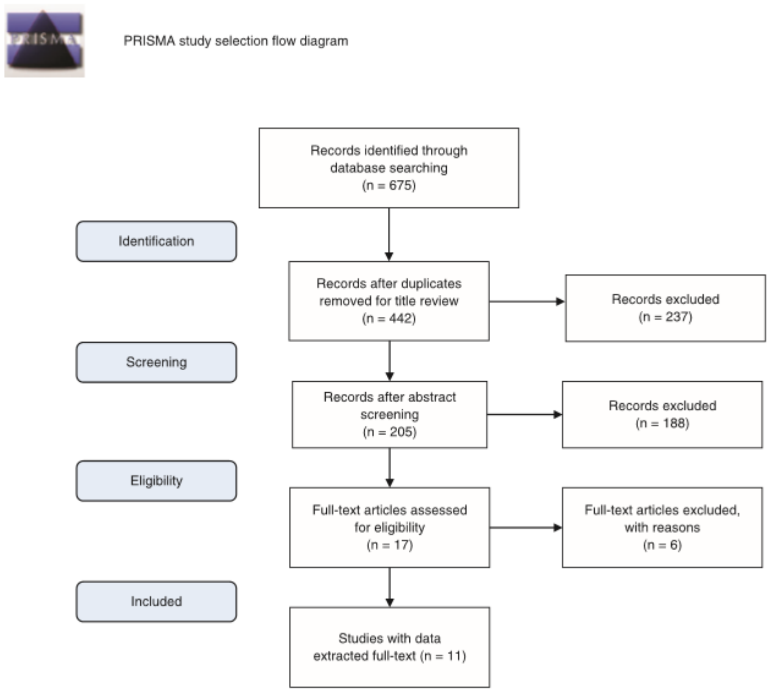

Figure 1: PRISMA study selection flow diagram.

Table 1: Characteristics of included studies.

Reference	Year	Location of study	Type of study and method	Purpose of study	Data sources
Bagatell et al. [4]	2017	United States	Descriptive qualitative	The aim of this study was to explore the transition experiences, perceptions, and needs of young adults with cerebral palsy living in one state in the southeastern United States	Data for the study were derived from nine individuals living with CP between the ages of 19–34 participated in focus groups
Bindels-de Heus et al. [25]	2013	Netherlands	Internet based survey with quantitative analyses of questionnaires; the responses to two open questions were subjected to qualitative content analysis	The aim of this study was to explore parents' experiences with and their appreciation of different health care services in a sample of young people with profound intellectual and multiple disabilities, and to collect parents' recommendations for transfer to adult medical care	Data for the study were derived from a convenience sample of 131 parents of young people with profound intellectual and multiple disabilities (this is presumed by authors to include CP)
Bjorquist et al. [9]	2015	Sweden	Qualitative – no specific approach named, used manifest and latent content analysis	The aim of this study was to gain a deeper understanding of how adolescents with CP experience their own health, well-being and need of support during their transition to adulthood	Data for the study were derived from 12 adolescents living with CP between the ages of 17–18 who participated in a combination of focus group and individual interviews
Camfield and Camfield [26]	2011	Canada	Review	The aim of this article was to discuss transition to adulthood for nine neurological conditions, including CP and to provide practical suggestions to improve the transition process	Data sources for this article were unclear. Article discussed the understanding of the authors of the problems that arise from current transitional models
Carroll [22]	2015	United States	Qualitative – phenomenology	The aim of this study was to uncover the meaning of transition to adult-centred care as experienced by young adults with CP	Data for this study were derived from nine interviews with individuals living with CP between the ages of 19–25 without intellectual impairment
Freeman et al. [23]	2015	Canada	Qualitative – phenomenology	The aim of this study was to evaluate the use utility and impact of the Youth KIT (an information management tool)	Data for this study were derived from 36 youth (ages not provided) with physical, developmental and intellectual disabilities (including CP). Number of individuals living with CP not declared

Table 1 (continued)

Reference	Year	Location of study	Type of study and method	Purpose of study	Data sources
King et al. [24]	2006	Canada	Qualitative – phenomenology	The aim of this study was to understand the nature and meaning of social support during turning points in life transitions for those living with chronic disabilities	Data for the study were derived from 15 individuals with nonprogressive, chronic disabilities (five living with CP) between the ages of 30–50
Lariviere-Bastien et al. [27]	2013	Canada	Mixed methods with only qualitative findings presented	The aim of this study was to explore the experiences of young adults with CP through an ethical lens	Data for the study were derived from 14 participants between the ages of 18–25 living with CP
Nieuwenhuijsen et al. [10]	2008	Netherlands	Quantitative	The aim of this study was to gain insight into the unmet needs and utilization of health care of young adults with cerebral palsy (CP) and to explore relations between unmet needs, health care utilization and subject characteristics	Data for the study were derived from 29 participants between the ages of 16–40 living with CP. Youth with learning disabilities (IQ <70) with inadequate language skills to complete questionnaires and additional diagnoses of motor issues were excluded
Stewart [5]	2009	Canada	Review	The aim of this review was to outline the evidence upon which best practice guidelines for transition to adulthood for young people with physical and developmental disabilities were developed in Ontario, Canada	Data for this review were gathered through literature review of best evidence, and through focus groups and individual interviews with 130 people, including youth with disabilities, parents of youth with disabilities across the Canadian province of Ontario. (demographic data not provided with respect to disabilities, but primary author was contacted to ensure individuals living with CP were part of the sample)
Young et al. [3]	2009	Canada	Qualitative – no specific approach named, used constant comparative approach for analysis	The aim of this study was to explore the common experiences of the transition to adult-oriented health care from the perspectives of youth and adults with CP, SB, ABI in childhood, and their parents	Data for the study were derived from individual interviews with 30 pairs: 30 youth and 30 of their parents (13 were living with CP)

CP, cerebral palsy; SB, spina bifida; ABI, acquired brain injury.

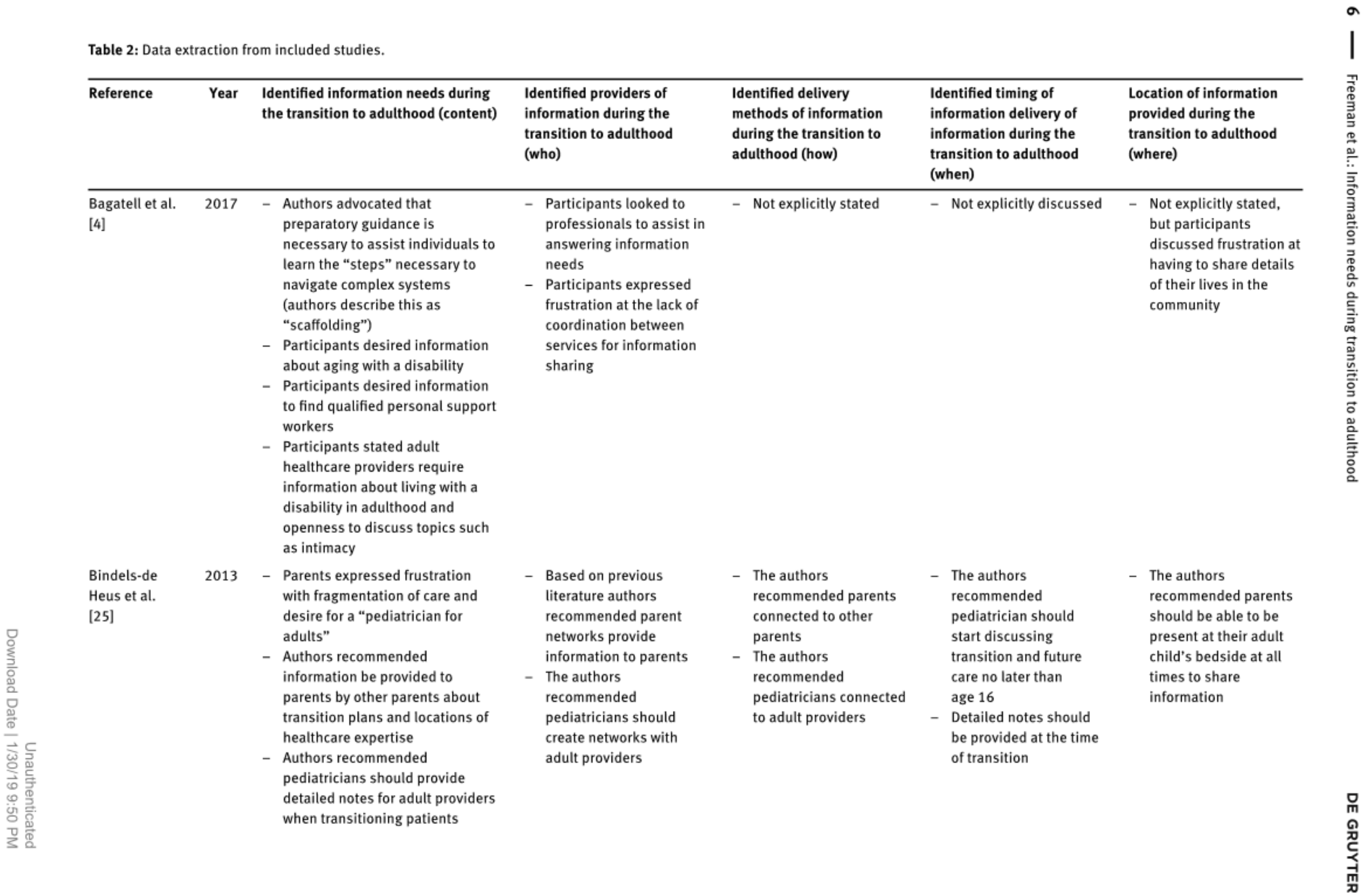

Table 2: Data extraction from included studies.

Reference	Year	Identified information needs during the transition to adulthood (content)	Identified providers of information during the transition to adulthood (who)	Identified delivery methods of information during the transition to adulthood (how)	Identified timing of information delivery of information during the transition to adulthood (when)	Location of information provided during the transition to adulthood (where)
Bagatell et al. [4]	2017	– Authors advocated that preparatory guidance is necessary to assist individuals to learn the "steps" necessary to navigate complex systems (authors describe this as "scaffolding") – Participants desired information about aging with a disability – Participants desired information to find qualified personal support workers – Participants stated adult healthcare providers require information about living with a disability in adulthood and openness to discuss topics such as intimacy	– Participants looked to professionals to assist in answering information needs – Participants expressed frustration at the lack of coordination between services for information sharing	– Not explicitly stated	– Not explicitly discussed	– Not explicitly stated, but participants discussed frustration at having to share details of their lives in the community
Bindels-de Heus et al. [25]	2013	– Parents expressed frustration with fragmentation of care and desire for a "pediatrician for adults" – Authors recommended information be provided to parents by other parents about transition plans and locations of healthcare expertise – Authors recommended pediatricians should provide detailed notes for adult providers when transitioning patients	– Based on previous literature authors recommended parent networks provide information to parents – The authors recommended pediatricians should create networks with adult providers	– The authors recommended parents connected to other parents – The authors recommended pediatricians connected to adult providers	– The authors recommended pediatrician should start discussing transition and future care no later than age 16 – Detailed notes should be provided at the time of transition	– The authors recommended parents should be able to be present at their adult child's bedside at all times to share information

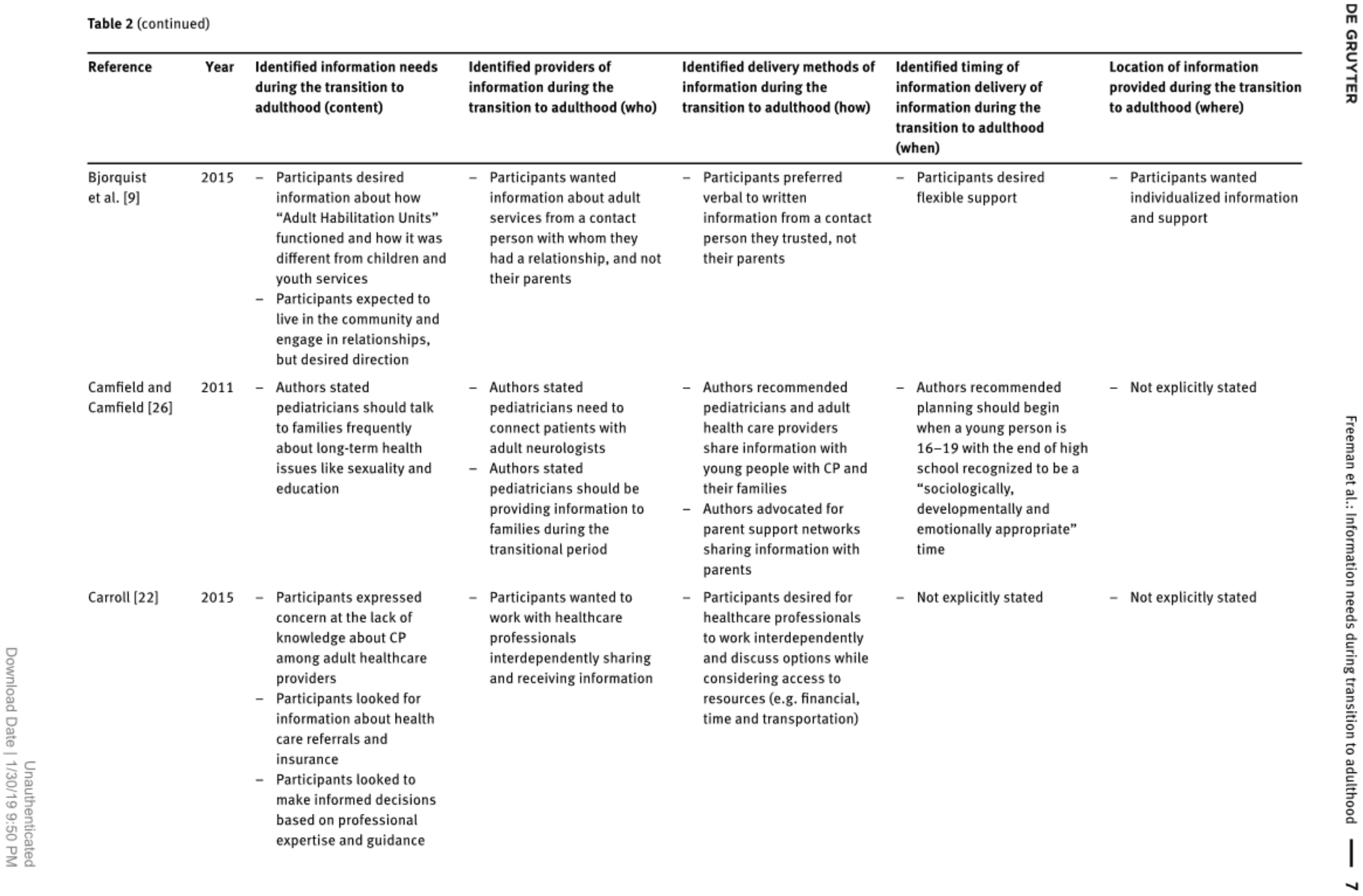

Table 2 (continued)

Reference	Year	Identified information needs during the transition to adulthood (content)	Identified providers of information during the transition to adulthood (who)	Identified delivery methods of information during the transition to adulthood (how)	Identified timing of information delivery of information during the transition to adulthood (when)	Location of information provided during the transition to adulthood (where)
Bjorquist et al. [9]	2015	– Participants desired information about how "Adult Habilitation Units" functioned and how it was different from children and youth services – Participants expected to live in the community and engage in relationships, but desired direction	– Participants wanted information about adult services from a contact person with whom they had a relationship, and not their parents	– Participants preferred verbal to written information from a contact person they trusted, not their parents	– Participants desired flexible support	– Participants wanted individualized information and support
Camfield and Camfield [26]	2011	– Authors stated pediatricians should talk to families frequently about long-term health issues like sexuality and education	– Authors stated pediatricians need to connect patients with adult neurologists – Authors stated pediatricians should be providing information to families during the transitional period	– Authors recommended pediatricians and adult health care providers share information with young people with CP and their families – Authors advocated for parent support networks sharing information with parents	– Authors recommended planning should begin when a young person is 16–19 with the end of high school recognized to be a "sociologically, developmentally and emotionally appropriate" time	– Not explicitly stated
Carroll [22]	2015	– Participants expressed concern at the lack of knowledge about CP among adult healthcare providers – Participants looked for information about health care referrals and insurance – Participants looked to make informed decisions based on professional expertise and guidance	– Participants wanted to work with healthcare professionals interdependently sharing and receiving information	– Participants desired for healthcare professionals to work interdependently and discuss options while considering access to resources (e.g. financial, time and transportation)	– Not explicitly stated	– Not explicitly stated

Table 2 (continued)

Reference	Year	Identified information needs during the transition to adulthood (content)	Identified providers of information during the transition to adulthood (who)	Identified delivery methods of information during the transition to adulthood (how)	Identified timing of information delivery of information during the transition to adulthood (when)	Location of information provided during the transition to adulthood (where)
Freeman et al. [23]	2015	– Participants desired opportunities to self reflect about previous experiences – Authors advocated for individuals assisting the young person who required information about how to support a young person during the transition to adulthood	– Participants liked working with individuals whom they had a relationship with (not necessarily parents) – Participants also recognized different individuals can serve as sources of information in different ways depending on their context	– Young people in the transition to adulthood may use transitional tools to help organize information in multiple areas of life	– Authors stated ongoing conversations should begin in early adolescence extending through young adulthood	– Location of information should be determined by the nature of the information need and context (for example home, school, clinical setting)
King et al. [24]	2006	– Participants noted the impact that social relationships with family and educators can have on their self-esteem – Authors advocated for information about the impact of social relationships, including family, doctors and educators on the development of young people in transition	– Authors advocated for service providers to share information with young people and their families, doctors and educators about supporting youth with disabilities	– Service provider should share information with young people in the transition to adulthood and those supporting the young person, including their families, doctors and educators	– Capturing of information should occur at points of life transitions	– Not explicitly stated
Lariviere-Bastien et al. [27]	2013	– Participants noted lack of communication between pediatric and adult providers – Participants desired more information about key contacts for adult health care	– Authors advocated sharing of information to young people	– Not explicitly stated	– Not explicitly stated	– Not explicitly stated

Table 2 (continued)

Reference	Year	Identified information needs during the transition to adulthood (content)	Identified providers of information during the transition to adulthood (who)	Identified delivery methods of information during the transition to adulthood (how)	Identified timing of information delivery of information during the transition to adulthood (when)	Location of information provided during the transition to adulthood (where)
Nieuwenhuijsen et al. [10]	2008	– 79% of participants reported an information need related to complications of CP (aging, causes) – 66% of participants reported of at least one unmet need related to mobility and formal health care services	– Authors advocated for more education of youth with CP about CP along with parents by a multidisciplinary Young Adult Team, which includes a doctor of rehabilitation medicine, psychologist, therapists and a social worker	– Authors advocated for conversations with health care team	– Authors advocated for ongoing conversations about CP with health care team	– Not explicitly stated
Stewart [5]	2009	– Participants suggested informational materials should recognize needs of audience – Participants suggested service providers (physicians, occupational therapists, physiotherapists) and educators should be educated about transition – Participants suggested materials for each stakeholder group should provide a "vision for the future"	– Participants felt youth and families need access to an unencumbered community based navigator	Participants advocated that service systems should commit to disclosing, in clear language, information about transition services and evidence of the benefits related to transition. – Participants advocated at the service level there should be a commitment to information exchange among professionals (i.e. service providers as well as those who could benefit from such information) on a regular basis to ensure all information is passed on at appropriate times and in efficient ways	– Participants suggested from childhood to post-secondary	– Participants desired a single point of access to information located at "visible location" in community

Table 2 (continued)

Reference	Year	Identified information needs during the transition to adulthood (content)	Identified providers of information during the transition to adulthood (who)	Identified delivery methods of information during the transition to adulthood (how)	Identified timing of information delivery of information during the transition to adulthood (when)	Location of information provided during the transition to adulthood (where)
Young et al. [3]	2009	– Parents and youth participants reported desiring more information about "what's next?" in the transition to adult healthcare – Parents and youth desired diagnostic and stage specific information – Parents and youth desired location specific information	– Parent suggested a "transition coordinator" Youth participant (a young adult two years post transition) wanted information from a one-on-one relationship with someone	– Participants and authors advocated for more professional training to address diagnosis specific needs – Participants desired a one-on-one relationship to discuss transition – Parents and youth participants desired a list of adult providers	– Young people suggested around "age 15/16, probably 16", because "around 14/15 you really don't care" – Authors suggested around 12 to allow pediatricians to engage adult counterparts in case based training	– Not explicitly stated

CP, cerebral palsy.

recommendations from participants in research versus recommendations from authors when summarizing the findings. These organizational categories consider the idiosyncratic and individual nature of information needs [21], which requires an examination of the preferences of knowledge users. Although this coding structure was developed *a priori*, ultimately these categorizations were validated by the review as many studies addressed these attributes in their findings or discussions.

Results

Eleven articles were reviewed. All articles were retrieved from health-oriented databases. Six of the articles were qualitative studies [3, 4, 9, 22–24], two were quantitative studies [10, 25], two were reviews [5, 26] and one was a mixed methods study [27], though only qualitative findings from this latter study were reported. Six of the studies collected data in Canada [3, 5, 23, 24, 26, 27], two studies collected data in the United States [4, 22] and two collected data in the Netherlands [10, 25]. Seven articles focused on healthcare transitions [3, 9, 10, 22, 25–27], one article explored multiple dimensions of transition of youth with CP including managing their own care, managing government assistance and supports and healthcare transitions [4], one article explored the development of best practice guidelines [5], one article focused on the development and evaluation of an information management tool during the transition to adulthood [23], and one article focused on the role of social support during life transitions [24].

All articles reviewed recognized the importance of information to assist individuals in making decisions. Three main groups were recognized as having information needs in these articles: youth with CP, their families and clinicians in both pediatric and adult health care settings. Stewart [5] also identified educators as having information needs and a role in assisting youth with disabilities, including CP, in the transition to adulthood.

Identified information needs during the transition to adulthood (content)

The majority of the articles (7 out of 11) focused exclusively on healthcare transitions [3, 10, 22, 25–27]. The content of information targeted health-related domains such as aging with CP [10], sharing of information between pediatric and adult service providers [10, 22, 26] and how to share information with service providers, such as personal care attendants, that may not necessarily have an understanding or skill set in dealing with adults with CP [4].

Young and colleagues [3] found that both young people with CP and their parents sought information about where to find medical care entering adulthood. Nieuwenhuijsen et al. [10] found a need for young people to learn more about CP suggesting that disability specific information is often delivered to parents during a child with CPs early years, but limited information about the condition and changes in impairments is provided to children, adolescents or young adults as they age. Camfield and Camfield [26] expanded questions about individual function to include questions of sexual health. Parents of youth in transition often shared similar information needs with their children, but Bindels-de Heus and colleagues [25] highlighted information needs of parents of young people living with CP who also live with an intellectual disability. For this subgroup of parents, information about differences in adult care, such as the fragmentation of care versus a single pediatrician, and differences in the role of parents in the adult system advocating for their children [25] were key considerations when thinking about the future. Young and colleagues [3], Bindels-de Heus and colleagues [25] and Camfield and Camfield [26] discussed the importance of the continuing education of adult providers to further understand the needs of young people with CP and their families.

Four of the 11 articles were not specific to any transitional domain (e.g. healthcare or education). Instead, authors discussed the transition to adulthood broadly [4, 5, 9, 23]. Bagatell et al. [4] found in addition to health, young people also have to navigate new systems and find information or correct contacts to establish financial support and find employment or work while receiving benefits. Bjorquist et al. [9], found a desire for information about supported independence from their families, adult relationships, intimate relationships and finding housing. Stewart [5], in addition to the previous domains identified, also recognized that young people with CP are a part of the education system and educators therefore require information about transition to adulthood, which is important when planning their postsecondary education journey. Freeman et al. [23] discussed the development of a transitional tool for adolescents to organize information in various domains, such as health, employment, socialization and education. One of the benefits of the transitional tool was that it broke down information needs into manageable pieces for individuals and provided worksheets with developmentally sequenced questions that built on pre-existing knowledge (i.e. street address, intersections around the family home and the local accessible public transit bus route).

In summary, youth with CP and their families are looking for information during the transition to adulthood not only about their physical health, but also their social and emotional health. They are also looking for information about opportunities to further participate in their communities in adult life. The articles in this review also recognize that individuals interacting with young people with CP and their families also have information needs. This includes doctors, educators and those delivering governmental services.

Identified recommended providers of information during the transition to adulthood (who)

Preferences for provision of information during the transition to adulthood is different for young people with CP, their families and pediatric and adult providers. For young people and their families, several studies recognized that they can be both providers of information and receivers of information as they experience this transition [3, 4, 9, 22, 25]. For example, the healthcare transition literature reviewed highlighted the need for young people and their families to share information about themselves with their new practitioners in the adult world [26, 27]. At the same time, these studies also recognized the need for both pediatricians and adult clinicians to provide information to families to assist them in preparing for and navigating the new system and expectations.

Although it was found that young people with CP and their families should be viewed as having expertise about their own experience, some of the qualitative studies challenged this perspective with nuance. Carroll [22] introduced the concept of the "expert novice" as young people are trained by their pediatric care teams to understand their conditions and be experts. Entering at the adult world, they feel that they have an inadequate knowledge base and level of expertise. Other studies in this review also recognized young people may not possess the necessary skills to best share information about themselves [3, 27].

Studies about information needs also recognized the importance of social support during the transition to adulthood for youth and families. Although many studies advocated for an individual to assist youth and families navigating systems [4, 5, 9, 10, 22–26], who the individual was or should be varied among studies. The articles focusing primarily on healthcare transitions indicated that clinicians, such as a nurse [22] or social worker, or therapist [10] could act as a navigator Regardless of the discipline of the individual clinician, the studies reviewed made the important point that the navigator should be someone the individual connects with on a regular basis [10, 22, 23, 26]. In contrast, Carroll [22], Freeman et al. [23] and Stewart [5] considered the multidimensional and contextual nature of navigation and mentorship and argued for support coming from an individual that was a fit between the young person's interests and the mentor's interests and knowledge. An educational assistant may be helpful when assisting a young person with education-related information, but a friend may be more helpful in assisting with information about social activities. In summary, youth with CP and their families are looking to receive information from individuals close to them who can act as a navigator. Importantly the "fit" between young people with CP or their families and the navigator is a key factor to consider.

Identified delivery methods of information during the transition to adulthood (how)

Bjorquist et al. [9] identified two important findings: First, information was preferred to be delivered verbally, and second, young adults preferred information be delivered by individuals other than their parents. In addition to verbal face-to-face communication, other studies recognized that information can also be gathered through real-life experiences. Three articles advocated for young people to be connected with adult service providers early on in their transitional process [3, 4, 27] so that relationships can be developed and an understanding of expectations on both sides of the clinical relationship can be developed [3, 25, 27]. Freeman et al. [23] provided support for young persons to learn through experiences and to be given the opportunity to reflect on those experiences and use this new information to assess change throughout the course of their developmental journey.

For parents, delivery methods included verbal or face-to-face communication with clinicians as well as peer support. Bindels-de Heus and colleagues [25] advocated parent support networks which can play a key role in assisting parents during the transition to adulthood by helping to develop "transitional plans" with families. Camfield and Camfield [26] also identified the personal connections of parent networks as important delivery methods of information, pointing out that doctors and families may change their geographical location over time and require new information and networks for their communities.

None of the articles in this review discussed providing written information to families; however, Stewart advocates for service systems to provide information in "clear language" (p. 171). The sharing of written information was discussed within the context of sharing between service providers [5, 25–27].

In summary, youth with CP and their families require information delivered to them by individualized information methods. Examples of individualized information included young people with CP preferring information be delivered to them verbally rather than in written format. Parents of young people with CP also preferred face-to-face communication.

Identified timing of information delivery of information during the transition to adulthood (when)

There is no agreement about the timing of information delivery to young people and their parents during the transition to adulthood, but an analysis of recommendations suggests that sharing of information should begin at least at the beginning of the transitional phase [3, 5, 22, 26], which is typically between ages 14–16 [3, 25, 26]. Stewart [5] broke down the transition to adulthood into a series of phases described as preparation, journey and landing. In the preparation phase, youth may begin learning more about themselves and using transitional tools such as the Youth KIT [23] to gather and organize information. In cases where recommendations were made for young people and their families to experience connecting with adult services early, the suggested time was around 16 years [26, 27]. As the young person is experiencing the transition to adult services, suggestions included pediatric providers making every attempt to communicate and share medical information with adult providers and setting up networks to ensure that all providers have a good understanding of childhood disability and its management [3, 4, 25, 26]. Regardless of the lack of specificity of the timing of the information sharing, studies make clear that information sharing is a dynamic and ongoing iterative process in which the development of the young person, their expectations and abilities should be considered [23, 24]. Stewart [5] suggests that once a young person and their family have transitioned or "landed", new information needs may arise stemming from a change in context.

In summary, the transition to adulthood for youth with CP and their parents is a dynamic and interactive process that requires an ongoing conversation, which should typically begin in early adolescence and should always be approached in a developmentally appropriate fashion.

Location of information provided during the transition to adulthood (where)

The location of information was only explicitly discussed by three of the reviewed articles. The most specific recommendations came from Stewart [5] who advocated a central point of access within communities that is visible, though no guidelines are provided. Bjorquist et al. [9] shared that youth did not want their information provided in group settings, but rather individualized. Freeman et al. [23] built upon the theme of individualized information asserting that the location of information delivery is dependent upon the contextual nature of the information need. Interestingly, though not related specifically to location of information, participants in Bagatell et al. [4] expressed frustration at having to share information to providers repeatedly in different contexts.

In summary, the location of information delivery is dependent upon the individual for both youth with CP and their parents. The individualization is determined by the information need and the individual's context.

Discussion

The primary objective of this review was to identify what is known within published literature about the information needs of transitioning young people with CP and their families. We sought to explore what was known about the content of information needs (what) as well as preferences for timing (when), provision (who), delivery method (how), and location of that information (where). This review shows that young people with CP and their families, reported similar challenges addressing their information needs and desired similar strategies to improve transition experiences for themselves and others. Young people with CP and their parents desire individualized information about what to expect during the transition to adulthood, including information about health, education, social opportunities and intimate relationships. Both young people with CP and their parents desire support systems to assist them with addressing information needs, and delivery of information in the method and location that they desire.

Contextualizing the findings and service implications

Many of the findings emerging in this review come from qualitative studies that advance not only our understanding of information needs, but also insight into the burden felt when individuals and their families were unable to access the information when they needed it [3, 4, 9]. Repeated across studies was the theme of "falling off a cliff" or a sense of isolation [3–5, 10, 26].

Nguyen and Baptiste's [2] discussion of acculturation provides useful insight into why this sense of isolation may be occurring. Within pediatric systems there is an expectation of "family centred practice" often with the pediatrician at the centre of care [25]. Parents of children with CP have reported grieving the loss of a pediatrician figure to assist with care [25]. Without centralized service delivery, it is reported that parents are often having to fill the gap by seeking their own information [3, 25] and advocating for their children.

The notion that the individual with CP and their family are the experts of their own lived experience is an underpinning of family centred practice [11]; however, when thinking about information needs and the provision of information we must explore this concept with a critical eye. Expertise about one's impairments or conditions should be viewed within the context of the individual. For example, Caroll [22] found that young adults with CP often recognize the limitations of their own knowledge and look to professionals to provide suggestions based on clinical experience and expertise. Within the context of informational support, King et al. [24] suggest that social support networks play an important role as information providers, not only in providing direct answers, but also making suggestions which allow for the exploration of new options. However, King et al. [24] also recognized and exposed some of the potential conflicts and negative attitudes encountered by individuals when looking for social support, such as preconceived notions about ability to achieve goals within the context of an individual's perceived functional abilities, which was similar to those found in Freeman et al. [23]. Bagatell and colleagues [4] argue that, during the transition to adulthood, there is a difference between policy objectives and reality. Although policies advocate for young people with disabilities and their families to direct their own services and make independent choices about their future from an array of options, young people may not possess enough information to make informed choices about the options available.

Bjorquist et al. [9] explored the health and well-being of older adolescents aged 17 and 18 who preferred information be provided by individuals other than their parents. From a developmental perspective, this is congruent with theories of emerging adulthood [1], which suggests that individuals begin to rely less on their family to construct their worldview. This scoping review also highlighted the need for formal information support providers (e.g. doctors, educators or rehabilitation professionals) to move away from discussing the specific domains of an individual's life and rather looking at the whole person in context. For example, an individual client may be interested to know about the relationship between aging and physical functioning within the context of intimate relationships [28].

Clinicians working with young people with CP and their families in the transition to adulthood should be willing to provide clinical information and advice, and answer direct questions from their clients, as well as provide prompting to the young person and their families to ask questions. That said, it is recognized that clinicians have information needs of their own and may not have the opportunity to get a holistic history before seeing a client. Nevertheless, it is advisable for clinicians to adopt a "shared agency" approach recommended by Gorter and Gibson [29], which allows for mutual learning on both the part of provider and client. Nieuwenhuijsen and colleagues [10] provide a helpful list of questions young people are seeking answers to, which is a good guide for clinicians. For example, young people want to know about sexuality or driving a car, and this can provide opportunity for clinicians to inquire about whether young people or their families have considered expanding relationships or transportation opportunities. Asking these questions is an example of a "shared agency" approach.

Opportunities for future research

Many of the articles in our scoping review targeted information needs in the context of the healthcare transition. It is necessary to further study whether the barriers faced with giving and getting information during healthcare transition are also barriers faced in other transitional domains, including leaving the family home or finding employment. In the domain of employment, it is known that young people with CP and other lifelong conditions have difficulty communicating information about their accommodation needs with their employer [30]. One question is the degree that individuals with

CP are required to act as their own expert when advocating accommodations within the workplace or whether employers are working with professionals to universally accommodate individuals with disabilities within the workplace.

The findings in our review suggest that youth with CP prefer to receive information from people they have relationships with. Therefore, future research may explore the development and maintenance of parent supports or peer supports for youth with CP and whether they assist them in meeting their information needs and in making the cultural shift inherent in the pediatric and adult service and support systems. While a navigator was identified as being helpful and important in the literature, there is a lack of evidence on its effectiveness. Future research therefore should incorporate pragmatic effectiveness studies [31] to evaluate the effects of a navigator and the 'active ingredients' of such an intervention. There are also questions about whether navigation needs to occur in person or can be done over the Internet [32]. In this review the use of a mentor through internet-based connections was not mentioned; however, within the context of health information more generally as well as transition literature, internet-based strategies are emerging [32, 33], but the need for approaches tailored to the needs of the individual receiving support is highlighted.

Limitations and considerations

The use of scoping review methodology to synthesize knowledge is acknowledged within the context of this review. Scoping reviews examine all evidence to "map" concepts and, unlike systematic review methods, they do not include a stage where evidence is appraised for overall quality [19]. Our goal in this review was to understand identified information needs during the transition to adulthood published in journals after having been through the peer review process; however, we do recognize that some qualitative studies reviewed had smaller sample sizes than recommended for the chosen methodological approach. Examining the qualitative studies as a group, the repetition of themes across geographical locations lends to overall transferability of findings to other populations of young people with CP in the transition to adulthood. Nevertheless, we recognize that the studies reviewed are from "Western" nations and may have a bias toward individuals and families with long-term engagements with the pediatric healthcare system. Future research should explore the applicability of these findings to hard-to-reach families and individuals living with CP and their families immigrating from or living in non-Western nations. We also recognize that this review did not incorporate grey literature, which may not be formally published, aimed at providing information to young people with CP and their families in the transition to adulthood.

Another issue arising out of this review is terminology: only two of the 11 articles reviewed used keywords relating to information or knowledge. Prioritizing information as a keyword will help further define and develop the literature base about information needs for youth and families during the transition to adulthood.

Conclusion

Our scoping review identifies what is known about information needs of youth with CP during the transition to adulthood, their families, pediatric clinicians, and future adult healthcare providers. Information provided to individuals with CP and their families cannot be prescriptive, but rather responsive to the needs of the developing individual in multiple changing contexts over time. Even in a small body of published literature we found a consistent pattern of information needs regarding healthcare transition as well as transitions in other life domains throughout this developmental process. Scarce literature is available with less consistency to guide the optimal method of information delivery, in terms of when, by who, how and where.

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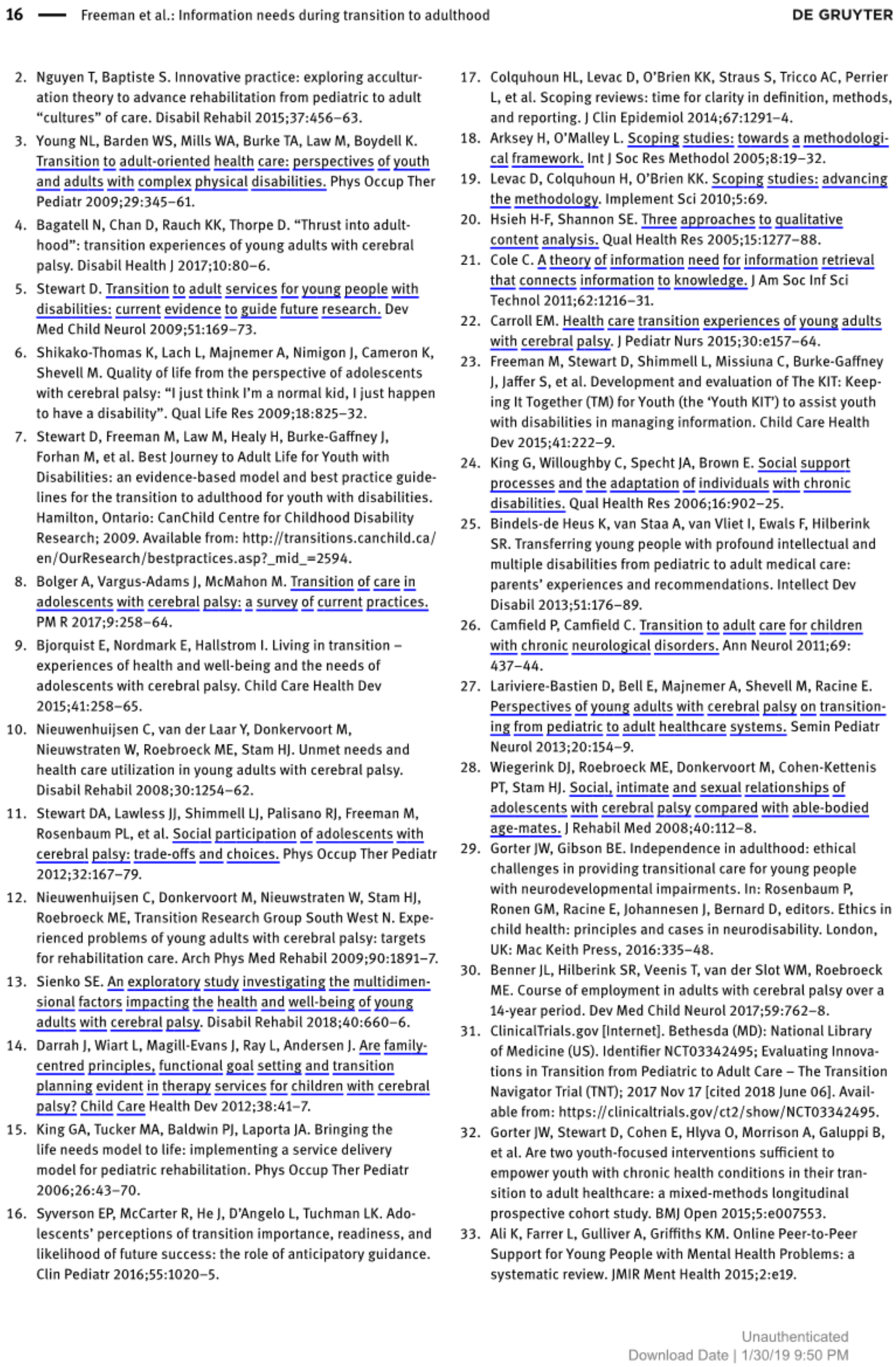

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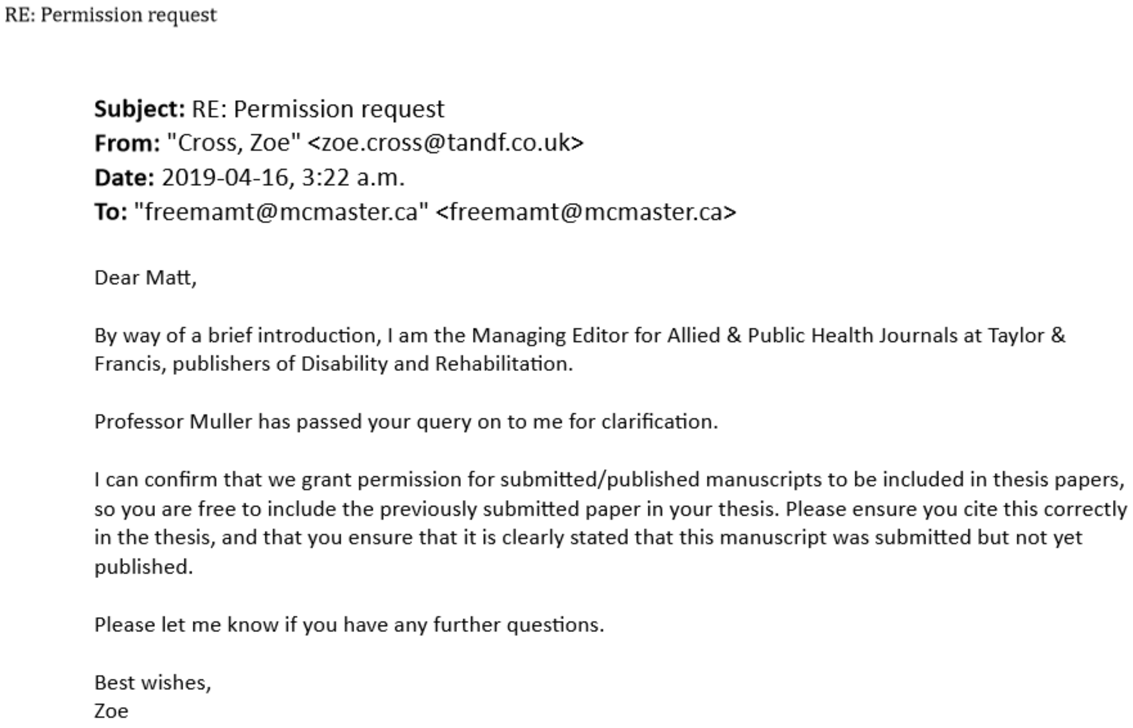
Introduction to Chapter 3: Finding our Lens: The Use of Interpretive Description in Childhood Disability Research

The aim of this chapter is to demonstrate the application of interpretive description in childhood disability research. This chapter describes my experiences applying interpretive description to a case study, which is included as an appendix to this chapter for the ease of the reader. This chapter outlines the benefits and challenges of using interpretive description when conducting childhood disability research. The multidisciplinary context of childhood disability research meshes well with interpretive description because it encourages researchers to declare and reflect on their own clinical lenses and perspectives. However, researchers may be challenged using interpretive description because its application to rehabilitation science is only emerging and the methodologically eclectic nature of the approach is something that may be challenging for researchers new to the approach. The purpose of including this chapter in my thesis is to assist the reader in further understanding interpretive description as a qualitative research methodology because it informs the research projects presented in chapters 4 and 5.

The manuscript has been submitted to Disability and Rehabilitation. I followed the Taylor Francis National Library of Medicine citation style as per the journal's instructions. The text below does not include abbreviations to avoid confusion, for example nonstandard abbreviations like ID for interpretive description typically were used to represent intellectual disability in this journal.

Permission for Inclusion in Dissertation



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Subject: RE: Permission request
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Date: 2019-04-16, 3:22 a.m.
To: "freemamt@mcmaster.ca" <freemamt@mcmaster.ca>

Dear Matt,

By way of a brief introduction, I am the Managing Editor for Allied & Public Health Journals at Taylor & Francis, publishers of Disability and Rehabilitation.

Professor Muller has passed your query on to me for clarification.

I can confirm that we grant permission for submitted/published manuscripts to be included in thesis papers, so you are free to include the previously submitted paper in your thesis. Please ensure you cite this correctly in the thesis, and that you ensure that it is clearly stated that this manuscript was submitted but not yet published.

Please let me know if you have any further questions.

Best wishes,
Zoe

Title: Finding our Lens: The Use of Interpretive Description in Childhood Disability Research

Running head: Use of interpretive description

Keywords: qualitative research methods, methodological application, qualitative research, rehabilitation research, research design

Type of article: case study

Abstract

Background: Interpretive description is a qualitative methodological approach originally developed within the discipline of nursing, which has expanded to the field of rehabilitation. The purpose of this paper is to describe the use of interpretive description to explore research questions within the field of childhood disability research.

Methods: Using a case example of a study that explored the lifecourse health development of individuals aged 23-33 living with cerebral palsy in Ontario Canada, we describe the challenges and opportunities created using interpretive description during the research process.

Results: The use of interpretive description was applicable to childhood disability research. We found that the clinical relevance of the findings was a strength of interpretive description, however preparation is required to ensure that team members have developed a common understanding of interpretive description. Team members should also identify their own clinical and analytic lenses when working with the data.

Conclusion: The use of interpretive description within childhood disability research as a methodological approach has value and is well-suited to the multi-disciplinary lenses often found on research teams within the field of childhood disability research.

Finding our Lens: the Use of Interpretive Description in Childhood Disability Research

Within the field of rehabilitation, the use of qualitative methods has grown [1]. Qualitative methods explore the various ways individuals experience phenomena within the context of their lived experience [1]. Interpretive description is a qualitative methodological approach that seeks to answer research questions emanating from the applied clinical practice environment of healthcare providers [19].

Originally developed within the discipline of nursing, interpretive description is now being used within rehabilitation [2], social sciences [3] and education [4]. Despite the growth of interpretive description research, its application to childhood disability research is only beginning to emerge.

The purpose of this paper is to demonstrate the appealing ability of interpretive description to a research question in the field of childhood disability research. We explore this through an example of a recent study in which we investigated the lifecourse health development of young people with cerebral palsy (CP) between the ages of 23-33 [5]. For the convenience of the reader, the published article detailing the case example is provided as an appendix to this chapter.

Prior to discussing the use of interpretive description in the research project, it is necessary to discuss the parallel paths of the development of interpretive description and trends in childhood disability research. We then articulate our understanding of interpretive description over the last 20 years and consider some of the criticisms surrounding its use as a methodological approach, as they directly relate to childhood disability research. Then we return to our project as a case example and discuss the application of interpretive description. This is discussed through the identification of similarities and differences emerging from our multidisciplinary and multi-experiential perspectives. The purpose of the next sections is to provide readers with an overview of childhood disability research trends as well as interpretive description literature to assist the reader in understanding the applicability of the approach. The purpose is not to provide a comprehensive systematic review of childhood disability research or interpretive description literature.

20 Years of Childhood Disability Research

Historically, childhood disability research has been impairment focused [6]. Focusing on impairment meant children living with disabilities and their families received interventions focused on remedying the impaired body function or structure associated with the health condition. Importantly, the interventions tended to be diagnosis specific. In the last two decades childhood disability research has experienced a move away from research exploring solely impairment-based (or component-based) outcomes to the exploration of goals and functional outcomes within the context of what is important to a child and their family in their life context [6]. Once a diagnosis is identified, recent studies have shown that families of children with disabilities have wanted to know more about how to accommodate individual needs within society to enable participation [7, 8, 9]. The shift in focus toward the exploration of participation, and environmental barriers and supports, and away from impairment related barriers has led to more noncategorical research [7]. Importantly, however, research has also shown that individuals with disabilities and their families are still pursuing diagnosis specific information, particularly in developmental periods of change, such as the transition to adulthood [10, 11, 12, 13].

Childhood disability services may involve professionals from various clinical backgrounds. Although it is possible for children who receive services from just one discipline, the youth with CP and their families discussed in the case example below may have interacted with occupational therapists, physiotherapists, speech language pathologists, physicians, nurses, social workers and other healthcare providers [14]. Delivery of pediatric services can be multidisciplinary, interdisciplinary or transdisciplinary [14]. Multidisciplinary services are those in which professionals work in parallel or conjunction but stay within their own discipline (e.g. Occupational Therapy) to set goals and provide interventions to a child [15]. Interdisciplinary refers to individuals from multiple disciplines working together to set goals and to create a shared intervention plan but working within their own disciplines on individual components of the plan [14]. Transdisciplinary refers to individuals working in roles beyond the boundaries of their individual disciplines in consultation with other rehabilitation professionals to execute intervention plans (e.g. an occupational therapist using a solutions-based coaching model to participate in therapeutic interventions) [16]. As a result, the clinical research questions emanating in the field of childhood disability are varied. Over the last decade, coinciding with an increase in interdisciplinary and transdisciplinary services and research, there has also been an expectation that stakeholders experiencing the phenomenon under exploration will be included in all aspects of the research process. Within the field of childhood disability research, this often includes family engagement or active participation of those with disabilities in the research process [17].

20 Years of Interpretive Description

Since originally proposed in 1997 [18], interpretive description has been the focus of two books by Sally Thorne [19]. Interpretive description is a qualitative methodological approach, which provides applied healthcare practitioners and researchers an approach aimed at providing answers to questions relevant to clinical practice [19]. In the second edition of her book [19], Thorne states that the original article published in 1997 [18] and an article in 2004 [20] discussing analytic issues in the use of interpretive description represent the “foundational articles” (p. 37). In the interest of fidelity, we will return to both the original articles published in 1997 and 2004 and highlight any changes occurring in the subsequent books.

Thorne situates interpretive description as part of a paradigm shift within qualitative research [21]. Interpretive description shifts away from the previously dominant rule-based research methods, borrowed from the social sciences and the drive to theorize, to research that examines the experience of a phenomenon within its relevant clinical context [21]. Although research questions relevant to clinical practice are not unique to interpretive description, prioritizing clinical practice throughout the research process is [19, 20]. Thorne [21] argued applied healthcare researchers require a methodological approach that produces findings relevant to clinical practice and that are not primarily aimed at building or rebuilding detailed levels of description of the lived experience, which may lack relevance to a clinician’s experience in practice [20]. In this vein, interpretive description is not prescriptive or rule-based. Interpretive description in Thorne’s [19] words is “methodologically ecclesiastic” (p. 36) because it borrows data collection and analytic procedures from other qualitative methods, particularly grounded theory and phenomenology [22], and interpretive description integrates various methodologies in unique ways to achieve a flexible approach to research. Unlike where researchers are interested in developing a theory regarding why a particular phenomenon is occurring or uncovering the meaning of a particular experience as in phenomenology, the aim of interpretive description is to discover elements of a particular phenomenon that are relevant to healthcare providers in their clinical practice through describing a phenomenon and then interpreting the description through their clinical lens.

Prior to discussing the strengths and challenges when using interpretive description, we first wanted to acknowledge foundational questions about interpretive description. Critics of interpretative description, such as Berterö have questioned whether interpretive description should be viewed as a separate methodology or part of the grounded theory tradition [22]. While we found that Berterö's argument [22] is well constructed and argued, we are more convinced by Thorne's argument that the purpose of grounded theory is to build theory, whereas the purpose of interpretive description is to address research questions related to clinical practice.

Strengths and Challenges of Using Interpretive Description

Although interpretive description has become increasingly used in research, there are a limited number of publications discussing the application of interpretive description. To identify what was previously known about using interpretive description, the lead author (MF) conducted a broad review of the literature using electronic databases using the keywords "interpretive description", which yielded over 600 results including duplicates. MF then conducted a manual title and abstract search for articles relevant to the application of interpretive description, which yielded the following two papers. The first article was written by Hunt [25] and the second was by Brewer at el. [26]. Hunt describes his experiences using interpretive description when exploring the moral experiences of Canadian healthcare professionals participating in humanitarian relief work [25]. Brewer et al. discussed their experiences using interpretive description to explore how Māori (indigenous peoples of New Zealand) and their extended family experience living with aphasia within a transformative framework [26]. Importantly for this paper, Brewer et al. found that it was possible to conduct research reflecting the Māori cultural approach to conducting research while using interpretive description as the methodological approach [26].

Hunt identifies several strengths of using interpretive description including a direct connection to applied clinical practice, which, in his view, allows for the retention of the "clinical context" (p. 1289) as part of the analytic process. However, Hunt [27] does not explicitly describe his understanding of what the clinical context was with respect to his research. Hunt also identifies the discussion of "disciplinary biases" to be helpful. Brewer et al. on the subject of disciplines appreciated that interpretive description allows for the incorporation of current knowledge about a phenomenal and does not attempt to bracket knowledge [26] found that using interpretive description led to clinically relevant findings [26]. Other strengths identified by Brewer et al. are the nonprescriptive nature of data collection and analysis and that the knowledge resulting from interpretive description is a co-construction between researcher and participant, which creates "positive change" (p. 1294) [26].

Hunt identifies some challenges in his use of interpretive description. First, he considers the newness of the approach [25]. At the time of his writing in 2009, his research was conducted prior to the publication of Thorne's two books [19, 28], and thus Hunt was challenged by the lack of resources dedicated to using interpretive description. Hunt criticized the lack of robust scholarship available to assist in guiding students and novice qualitative researchers. Speaking of his time as a graduate student, Hunt writes that although his committee structure included two individuals with qualitative research experience, he found himself regularly explaining the method and justifying his findings [25]. Second, Hunt discusses challenges trying to find the appropriate balance between the descriptive and interpretive elements of interpretive description [25]. Hunt's concern is that researchers will fail to develop a robust interpretation which will limit its usefulness. Although Hunt does not provide specific strategies to address challenges, he does encourage researchers to "take risks" to ensure their research adds to the advancement of knowledge (p. 1290). Unfortunately, Brewer et al. do not discuss challenges when using interpretive description.

The challenges faced by Hunt when applying interpretive description are representative of our own experiences, although we acknowledge the eight-year time difference since his application of interpretive description in 2009. In the remainder of this article, we discuss the opportunities and freedoms that interpretive description as a non-rule-based qualitative approach offered us.

The Case Example: Life Course Health Development of Young Adults Living with Cerebral Palsy

Background

Our project sought to explore the lifecourse health development of young adults with cerebral palsy (CP) [5]. Specifically, we explored in individual interviews how young adults living with CP describe changes in their understanding of healthy living from childhood to adulthood. As will be described below, our understanding of "health development" became more dimensional as we began building our description. After fully understanding and describing the phenomenon of health development over a young adult's lifecourse from childhood through young adulthood, we interpreted our understanding of these experiences in the form of action messages for pediatric healthcare providers with the aim of applying our knowledge about the health development of young people with CP within the clinical context of pediatric health care [5].

The Research Team and Rationale for Using Interpretive Description

The research team was comprised of researchers with experience working together previously on interdisciplinary research involving young people with CP. The research team included two occupational therapists, a physiotherapist, one developmental pediatrician and one pediatric physiatrist, a doctoral student in rehabilitation science with lived experience and research experience with CP, and a research coordinator with experience as a researcher and lived experience as a parent familiar with childhood disability. A subgroup of the research team developed the interview guide and was responsible for data analysis. This subgroup was comprised of a doctoral student, one of the principal investigators (co-PIs), and the research coordinator. The interview and data analysis team possessed previous experience working together, but this was their first time using interpretive description and conducting data collection and analysis together.

Each of these individuals brought a unique lens to data analysis. The co-PI identified herself as an occupational therapist, with research experience in the transition to adulthood for youth with disabilities. The graduate student living with CP identified as a rehabilitation scientist and brought to the data familiarity with disability theory. The childhood disability researcher identified as someone familiar with childhood disability research as both a parent and researcher.

The diversity of perspectives caused us to question whether it was possible to find common ground. The answer is more pragmatic than declarative. This pragmatism will be unsatisfactory to some, but we believe is congruent with the principles of interpretive description recognizing the “methodologically eclectic” tradition discussed in Thorne’s second edition [19] when defending interpretive description’s epistemological underpinnings (p. 36). Instead of electing to develop a pure epistemological lens combining each of our perspectives, we sought to develop a lens that added new knowledge about health development over the lifecourse through incorporating the elements from each of these perspectives. This allowed us to follow Hunt's encouragement and "take risks" with our analysis. As with all qualitative research, this process was iterative and requires some explanation.

Interpretive description was selected as the methodological approach due to our desire to answer the research question in a way that was relevant to pediatric clinical practice. As described above, we also sought to select a methodological approach that allowed for the recognition of the multidisciplinary practice environment, which can be a hallmark of childhood disability services. We also recognize that that we were not seeking to create "new knowledge", but rather reframe the knowledge of lifecourse health development of young adults with CP and distill the clinically relevant findings.

Data Collection and Analysis

The primary source of data for the study were the 23 interviews conducted with young adults with CP. If the young person was not able to communicate on their own, parent proxies were offered the opportunity to facilitate interviews and participate in interviews. Data collection and data analysis occurred concurrently, and the team met biweekly to discuss progress. Each member of the analytic team reviewed the same transcripts and individually journaled and shared their thoughts with the whole team prior to the meeting. Thorne [19,20] strongly encourages researchers to avoid coding prematurely. To avoid this, we used Thorne's [19] two analytic questions: 1) What am I seeing, and 2) Why am I seeing that? These questions helped us identify pieces of data which then developed into patterns of data, which then served as the basis for our themes.

Data analysis resulted in the development of four themes. The themes were: 1) personal lifecourse, 2) contextual lifecourse, 3) everyday experiences, and 4) adaptive processes. Next, we describe how our analytical lens was refined and helped the four themes come into focus.

Finding our Lens

Getting on the Same Page Methodologically

The lack of experience using interpretive description as an approach within the team represented both a challenge and an opportunity. At first, the graduate student, similar to Hunt's experience, was responsible for explaining interpretive description and its differences in comparison to other qualitative approaches, especially the lack of a step-based structure. To enhance our understanding, copies of the second edition of Thorne's text were purchased for all three co-PIs and each member of the interview and data analysis team. Having access to the book improved the discussions within the subgroup because we began using the same common language. The larger group monthly meetings evolved from discussions of seeking to understand more about the approach to discussions about findings interpretive description lens. To enhance discussion, the analysis team provided larger research group summaries of their meetings, where interpretive description was discussed, so that an audit trail was developed for the analysis team's conceptual thinking as well as working with the data.

Articulating How We Saw and Worked with the Data

A second challenge using interpretive description was in the analysis stage, as the subgroup members had to come to terms with the multi-experiential and disciplinary lenses that team members brought to their analysis. While we had the advantage of working together previously and were able to avoid many of the teambuilding and power dynamic concerns identified by Hall et al. [29], all three had distinctive analytical lenses.

Qualitative research requires researchers to recognize their own influence over the research process. While some qualitative methodological approaches require researchers to document and account for their influence and assumptions during the research process, like descriptive phenomenology, interpretive description is more aligned with an interpretive phenomenological approach because researchers are encouraged to think about the ways they may influence the research process and discuss this as part of their analysis. In particular, within interpretive description the values and beliefs of disciplinary training as well as experience in clinical practice or life influences how researchers interpret what they read in transcripts [19]. Thorne [19] encourages researchers to think more deeply about the sociopolitical world that researchers and research participants are a part of, and how these factors may influence the research process as well as the descriptions provided by participants and how the description then becomes interpreted. To demonstrate this process, we present the following example.

Initially, the three members of the data analysis subgroup decided to review the same transcripts and come together to discuss what was beginning to emerge. Importantly, in keeping with interpretive description, and Thorne's recommendations, this was not a meeting to discuss initial coding [19]. Rather, the purpose of the meeting was to allow each of us to identify pieces of data in each transcript, and across transcripts that were similar, that we were not ready to identify yet as patterns.

Though the purpose and objective of the first meeting was to identify pieces of meaningful data across transcripts, the beginning of the meeting became a discussion of using interpretive description. At the time it was surprising, when we already had begun collecting data to be spending so much time discussing the already preestablished methodology. The methodological challenge was to move the conceptual boundaries of interpretive description as a methodological approach into reality when working with transcripts and within a research project, which may not be experienced when using other qualitative traditions with formal step-based processes for data collection and analysis.

We used a two-stage process to facilitate our discussions. First, we consistently reminded each other that interpretive description required two stages in data analysis, and the initial stage was to develop a description, which meant staying close to the data. Second, we allowed the co-PI on the analysis team to identify when she felt the conversation was deviating from description into a discussion involving interpretation. This was a useful check in assisting us to identify our own behaviour reflexively and to guard against prematurely completing data analysis with an incomplete or shallow description. During the first stage we described what we were seeing. After we had all stated our thinking, we allowed ourselves to discuss why we thought what we were seeing was important. While this did involve some initial interpretations, it helped us to distill some of the key factors that may be important when coming up with our subsequent patterns and themes. Actively stating and defending our rationale with pieces of data we identified as important helped each of us understand the influences of our previous work and training.

Nevertheless, the process of allowing each of us to speak about our initial responses to the data allowed us to more freely discuss description and to challenge each other. Through challenging each other about why we may have experienced the initial reactions that we did, we were able to build a richer description. Interpretive description encourages the use of the constant comparative approach [33, 19], which involves comparing across transcripts to find pieces and patterns. A comparative approach when documenting our thinking with each other during meetings [19]. As we followed Thorne's [19] guidance and moved from finding pieces and patterns and identifying our conceptual labels for the data, what began to emerge was our way to describe the health development of individuals with CP across the lifecourse.

Initially, the analysis team relied on their disciplinary understandings of health. Instead of referring to health as a singular descriptor, our participants described physical, mental and social health as distinct, although overlapping experiences. Therefore, looking at the data in a multifaceted way through different lenses, was really driven by, in our view, the need to represent more complexity of the phenomena. We began to realize that lifecourse health development was not a linear or discrete phenomenon.

The second layer of complexity that we began to see was participants describing not only their own personal journey with lifecourse health development, but a journey for the people, systems and services within their environment as well. Across transcripts we began to see that the environment changed over time with the individual, allowing them greater access to a range of experiences and activities.

In retrospect, this began to make sense and is congruent with current understandings of health and a recognition that individuals with CP live in a socially constructed world with health outcomes related to their adult goals. We are now viewing the environment and personal lifecourse as independent, interactional, transactional or interdependent [31, 32]. For example, a participant described the importance of participating in structured physical activity as a child, like figure skating for both physical and social health, because it was with their friends. When retelling the story, the participant described a coach willing to work within the individual's abilities, but always supportively encouraging the individual to participate as much as physically possible. The coach did not possess knowledge of CP, but supported and enabled participation. However, participation in figure skating became increasingly difficult given the physical limitations of their CP as they became an adolescent and participation in physical activity became less of a priority. In their young adult years, primarily looking for social activities to meet people, they returned to physical activity encouraged by their friends, this time bike riding, which reignited a passion for physical health.

Each month the data analysis team shared the preliminary results with the larger research team along with the exemplars from each theme to enhance the credibility of our emerging analysis. Thorne argues that since the aim of an interpretive description is the integration of findings within clinical practice, an essential “indicator” (P. 112) of credibility (the relevance of findings) is the direct connection to a clinician’s experience and their practice setting. These meeting also provided other team members the opportunity to work through some of the questions confronted by the analysis team regarding the use of interpretive description or other explanations of the description.

After the data analysis team presented their initial findings and interpretations to the larger team it was decided to follow Thorne’s encouragement found in the two books to shift away from traditional qualitative member checking (sharing findings with participants) and extend the interpretation [19].

Extending the interpretation involves engaging those familiar with the field of work, but not directly involved with the project [19]. We elected to extend the interpretation using the following approach. Over the course of a single day session, we invited clinicians familiar with pediatric rehabilitation, and young people with CP between the ages of 23-33 who had not been previously invited to participate in the project. Prior to the session, written information, including our initial descriptions and interpretations of the data and thematic analysis with exemplars was provided to participants. After receiving this information, individuals were invited to email the co-PI with any questions or comments.

At the beginning of the one-day session, participants were invited to share their reactions to the data and comment whether it confirmed or diverged from their clinical or life experiences. The afternoon session was then used to begin the process of developing clinical practice guidelines. We found the process of extending the interpretation useful because the individuals outside the project refocused our interpretive thinking and grounded the project firmly back into real life application and often discussed the relevance of findings to everyday experiences or clinical practice scenarios, which is very much in keeping with the applied nature of interpretive description.

Recommendations for Using Interpretive Description in Childhood Disability Research

Based on our experiences in using ID in this case example project, our team offers the following recommendation to any research team that is considering its use:

1) Prior to beginning the research process determine whether interpretive description is the best approach to address your research question by considering if the results will be relevant to clinical practice. In the second edition of her text, Thorne provides some example questions. Rather than exploring the meaning of the phenomena or attempting to build theory, interpretive description can describe potential forces influencing the experience of a phenomena. In the case example, we took what participants described about their lifecourse health development and applied a clinical lens to understand and interpret the forces including their development.

2) Embrace the novelty. As we have shown above, interpretive description is still a relatively new qualitative approach. Undoubtedly, this may cause apprehension, but our experience was that the novelty itself led to greater credibility and trustworthiness because the process led to explicit debates and challenging of assumptions, which as a team, we had not previously experienced while using more established qualitative approaches (e.g. grounded theory or phenomenology).
3) Embrace diversity and eclectic perspectives. As we have discussed, childhood disability research and clinical practice settings involving children with disabilities and their families are diverse and involve many different clinical disciplines who work in different approaches (multidisciplinary, transdisciplinary). In addition, there also can be diversity in the identification of research topics, and goals of both young people and their parents. Researchers should be encouraged to include as many differing perspectives as possible to ensure that the clinical lens being developed to address their topic is representative to ensure the evidence base to interpret findings allows for a blending of the subjective nature of the lived experience and rigorously developed high-quality research evidence.

Conclusion

The purpose of this article was to demonstrate the challenges and opportunities in using interpretive description in childhood disability research. Through our case-example we hope to have shared our experiences and processes, which provided a demonstration of how interpretive description as a qualitative methodological approach can provide clinicians the opportunity to understand clinical problems in their full context. In a research field as diverse as childhood disability research, the need to contextualize clinical findings, especially in a multidisciplinary and multi-experiential paradigm, is essential. The field of childhood disability research can apply interpretive description to define, refine and defend different clinical perspectives as researchers often work in teams to address complex clinical research questions.

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Declaration of Interest Statement

The authors have no conflicts to report.

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Appendix: Promoting Capacities for Future Adult Roles and Healthy Living Using a Lifecourse Health Development Approach

DISABILITY AND REHABILITATION
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Promoting capacities for future adult roles and healthy living using a lifecourse health development approach

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ABSTRACT

Purposes: First, to describe how young adults with cerebral palsy (CP) experience lifecourse health development, and second, to create key messages for pediatric health service providers to promote children's capacities for future adult roles and healthy adult living.
Methods: Interpretive description qualitative design. Participants were a purposive sample of 23 young adults with CP, 25–33 years of age, who varied in functional abilities, education, living, and work situations. Three experienced interviewers conducted 50–60 min interviews. Transcripts were analyzed to identify themes. Subsequently, a one-day meeting was held with an advisory group to inform our interpretive description of key messages.
Results: Four themes emerged from the interviews: personal lifecourse, contexts for healthy living, health development through everyday experiences, and healthy living as an adaptive process. Key messages for service providers are: (a) address healthy living across the lifecourse, (b) focus on contexts of healthy living, (c) focus on everyday experiences and experiential learning, and (d) pay attention to the timing of opportunities and experiences.
Conclusion: The findings provide first steps toward adoption of an approach to lifecourse health development for individuals with CP that emphasizes physical, mental, and emotional wellbeing and goals for desired social participation over the lifecourse.

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➤ IMPLICATIONS FOR REHABILITATION

- Young adults with cerebral palsy experience lifecourse health development as a personal ongoing and dynamic process occurring in many contexts.
- Individuals with cerebral palsy continually adjust to changing contexts (adaptive process).
- Everyday experiences and experiential learning enable individuals with cerebral palsy to develop capacities for current and future healthy living including social participation.
- "Timing" of opportunities and experiences is important for health development.

Introduction

Mr. and Mrs. Smith's 28-month-old daughter Sarah has cerebral palsy (CP). They have been attending their regional children's rehabilitation center where Sarah receives physical, occupational, and speech therapy aimed at improving many aspects of her function—mobility, hand activities, and communication. At their next clinic visit they ask Sarah's therapists: "What should be done at a young age to provide Sarah the foundational knowledge and skills she will need to develop into a happy and healthy adult?" Sarah's therapists are not aware of issues facing children like Sarah after they "graduate" from the pediatric health care system. A literature search reveals few systematic and longitudinal observations of individuals with CP into adulthood and the absence of an evidence-based framework to guide a lifecourse approach to pediatric health services for childhood onset chronic health conditions [1].

The information needs of the Smiths and Sarah's therapists reflect a growing awareness that, for children like Sarah, preparation for adulthood should begin in childhood. Although most children like Sarah can expect to live a long life, adults with childhood-onset conditions face challenges to health and wellness [2–4]. Developmentally, youth with CP have dreams for adult life like those of other young people; and aspire to become engaged and contributing members of adult communities [5,6]. To them, success and happiness involve being believed in, believing in oneself, and being accepted (belonging) [7]. Factors perceived by youth as important for the future include keeping close relationships, choosing a future life of one's own, and preparing for leisure in the years ahead [5]. For young people, transition to adulthood includes developing adult roles in relation to employment, leisure activities, maintaining relationships and independence [1,8].

Much of the research about youth with CP as they make the transition to adult roles has focused on the challenges they face in areas of health and wellness, socialization, housing, education, and employment [3,9,10]. In comparison to their peers without disabilities, the lives of young adults with CP may differ in several

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ways [2]. Young adults with CP are less likely to pursue post-secondary education, have lower employment rates [11], participate in fewer leisure and social activities [12], and are more dependent on their families for living arrangements [13–16]. As adults, they also experience poorer health than their peers without disabilities, and utilize more adult health services [17–19]. Several authors have advocated for services and systems that provide a holistic and functional approach that includes the necessary resources and supports to enable children and youth to develop the capacities needed for future adult life [1,2,7,20].

The lifecourse health development model by Halfon et al. [21] conceptualizes health development occurring through person–environment transactions that enable well-being and participation in desired social roles throughout life—areas that have not received adequate attention in healthcare. Lifecourse refers to a progression of socially defined events and roles in which a person engages over time [22]. Central to lifecourse health development is the concept of health development trajectories that describe changes in health capacities, especially during sensitive and transition periods. Halfon et al. [21] propose that health capacities develop through experiences that promote resilience and plasticity within changing environmental contexts. At any point in time, health development is determined by the interplay between protective (strengths) and risk (barriers) factors of the person and environment [23]. Lifecourse health development is aligned with a developmental assets framework in which children and youth are given a "voice" and provided opportunities, experiences, and supports for health and well-being [24,25].

Recently we proposed that a lifecourse health development approach, beginning in childhood, would promote coordination and continuity of health care between pediatric and adult systems, as well as education, social, and community services and supports for individuals with neurodevelopmental conditions, such as CP [26]. In accordance with the Social Model of Disability [27], we believe that modifiable environmental factors often restrict health development of individuals with CP, and that impairments in body structures and functions should not preclude healthy living and desired social participation. We shared the perspective that health development is dependent on a *person-environment "fit"* and that *readiness* for desired social participation occurs when there is sufficient person and environmental capacities. We proposed that timing and social structuring of experiences in "real-life" settings are critical to increase person, family, and community capacities.

The objectives of this study were to describe how young adults with CP experience lifecourse health development and create action-oriented messages for pediatric health service providers to promote children's capacities for future adult roles and healthy adult living. We were especially interested in the interaction of person and environmental factors perceived by young adults to have influenced their developmental capacities.

Methods

Design

Interpretive description [28–30] is a qualitative research method underpinned by pragmatism that presumes that theoretical, clinical, and scientific knowledge inform research. Three sources of knowledge provided the foundation for our interpretive description: (a) findings from our team's knowledge synthesis of developmental trajectories of youth (age 12–25) with developmental disabilities [2]; (b) evidence of the importance of real-life experiences throughout childhood and adolescence [30]; and (c) our perspective on lifecourse health development [26]. This knowledge provided us with a starting point upon which to build or "scaffold" [29] new understandings of lifecourse health development of individuals with CP. Thorne [29] contends that interpretive description is a more authentic approach than phenomenology for health service researchers to use, as it enables researchers to analyze clinical problems within the context of healthcare services.

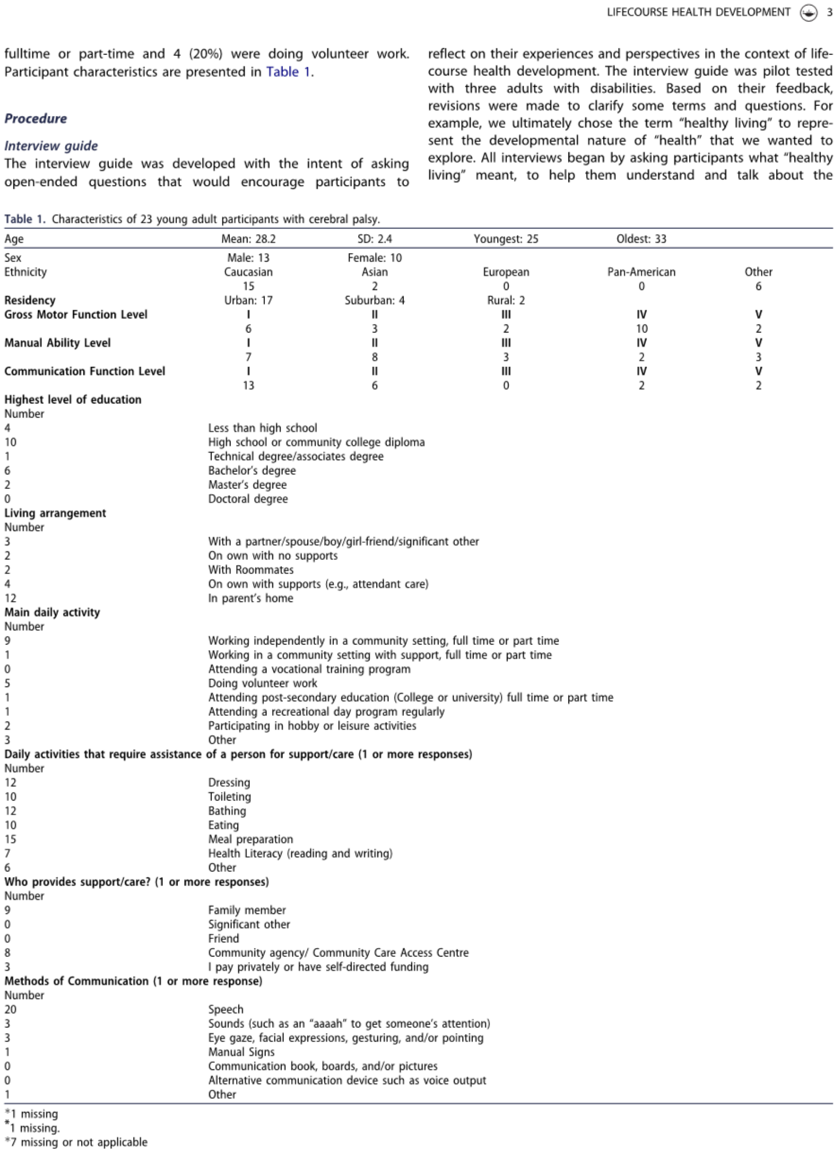
Participants

Participants were a purposive sample of 23 young adults with CP, 25–33 years of age (mean 28.2, SD =2.4). We sought maximum variation of key demographic variables: female/male, gross motor function (ambulatory/non-ambulatory), communication function (verbal/non-verbal communicator), education (post-secondary/no post-secondary education), residence (urban/rural), living situation (outside parents' home/live at home), and employment (job/no job). Research ethics approval was received from the Hamilton Integrated Research Ethics Board. All participants provided written informed consent.

Our accessible population was 212 young adults with CP, 22–33 years of age, who between 2002 and 2007 participated in *CanChild*'s Adolescent Study of Quality of Life, Mobility, and Exercise (ASQME) [31]. In January 2013, letters notified 210 participants in the ASQME study of our plans to submit a proposal and asked if they would be interested to continue working with us. About 63 (30%) individuals expressed interest, 133 (63.3%) did not reply, 4 (1.9%) indicated they were not interested, and 10 (4.8%) letters were returned based on an invalid address. Individuals who expressed interest where selectively recruited to achieve maximum variation of key demographic variables. All 23 young adults that we contacted agreed to participate. After 23 interviews, we determined saturation of data and no additional young adults were contacted.

Prior to the interview, participants completed a demographic questionnaire and reported their levels of function on three classification systems. The Gross Motor Function Classification System (GMFCS) [32], Manual Ability Classification System (MACS) [33], and Communication Function Classification System (CFCS) [34] are validated to classify function of individuals with CP. The five levels represent differences in function that are meaningful in daily life. For each classification system, level I indicates ability to perform the function in all situations; level II indicates ability to perform the function in most situations; level III indicates ability to perform the function in most situations with adaptations, assistive technology, or person assistance; level IV indicates ability to perform the function in some situations with adaptations, assistive technology and/or person assistance; and level V indicates performance is limited even with adaptations, assistive technology and/or person assistance. The gross motor function of 12 (52%) participants was classified as level IV or V (GMFCS), indicating limited self-mobility. The manual ability of 15 participants (65%) was classified as level I or II (MACS), indicating ability to handle most objects. The communication function of 19 (83%) participants was classified as level I or II (CFCS), indicating they were effective or mostly effective in sending and receiving information.

Participants included 13 males and 10 females. About 8 (35%) had a bachelor's or master's degree while 10 (43%) had a high school or community college diploma. About 11 participants (48%) lived by themselves or with a partner, spouse, or significant other and 12 (52%) lived in a parent(s)' home. About 9 participants (45%) worked independently in a community setting either



fulltime or part-time and 4 (20%) were doing volunteer work. Participant characteristics are presented in Table 1.

Procedure

Interview guide

The interview guide was developed with the intent of asking open-ended questions that would encourage participants to reflect on their experiences and perspectives in the context of life-course health development. The interview guide was pilot tested with three adults with disabilities. Based on their feedback, revisions were made to clarify some terms and questions. For example, we ultimately chose the term "healthy living" to represent the developmental nature of "health" that we wanted to explore. All interviews began by asking participants what "healthy living" meant, to help them understand and talk about the

Table 1. Characteristics of 23 young adult participants with cerebral palsy.

Age	Mean: 28.2	SD: 2.4	Youngest: 25	Oldest: 33	
Sex	Male: 13	Female: 10			
Ethnicity	Caucasian	Asian	European	Pan-American	Other
	15	2	0	0	6
Residency	Urban: 17	Suburban: 4	Rural: 2		
Gross Motor Function Level	**I**	**II**	**III**	**IV**	**V**
	6	3	2	10	2
Manual Ability Level	**I**	**II**	**III**	**IV**	**V**
	7	8	3	2	3
Communication Function Level	**I**	**II**	**III**	**IV**	**V**
	13	6	0	2	2
Highest level of education					
Number					
4	Less than high school				
10	High school or community college diploma				
1	Technical degree/associates degree				
6	Bachelor's degree				
2	Master's degree				
0	Doctoral degree				
Living arrangement					
Number					
3	With a partner/spouse/boy/girl-friend/significant other				
2	On own with no supports				
2	With Roommates				
4	On own with supports (e.g., attendant care)				
12	In parent's home				
Main daily activity					
Number					
9	Working independently in a community setting, full time or part time				
1	Working in a community setting with support, full time or part time				
0	Attending a vocational training program				
5	Doing volunteer work				
1	Attending post-secondary education (College or university) full time or part time				
1	Attending a recreational day program regularly				
2	Participating in hobby or leisure activities				
3	Other				
Daily activities that require assistance of a person for support/care (1 or more responses)					
Number					
12	Dressing				
10	Toileting				
12	Bathing				
10	Eating				
15	Meal preparation				
7	Health Literacy (reading and writing)				
6	Other				
Who provides support/care? (1 or more responses)					
Number					
9	Family member				
0	Significant other				
0	Friend				
8	Community agency/ Community Care Access Centre				
3	I pay privately or have self-directed funding				
Methods of Communication (1 or more response)					
Number					
20	Speech				
3	Sounds (such as an "aaaah" to get someone's attention)				
3	Eye gaze, facial expressions, gesturing, and/or pointing				
1	Manual Signs				
0	Communication book, boards, and/or pictures				
0	Alternative communication device such as voice output				
1	Other				

*1 missing

*1 missing.

*7 missing or not applicable

phenomenon of interest. Their perspectives about healthy living provided the context for further questions about their experiences through childhood, adolescence and the transition to adulthood. The interview guide is presented in Table 2.

Interviews

A total of 23 interviews were completed between November 2015 and July 2016. Seventeen interviews were with a young adult only, three with a young adult and parent, and three with a parent proxy of a young adult. In cases where young adults and parent were interviewed together, interviewers encouraged the young adult to participate in the interview and answer questions to the best of their ability. Interviews were conducted by three individuals (including two authors, MF, OH) who are experienced in interviewing young adults with CP. Two interviewers had personal connections with disability: one has lived experiences as a person with CP, and the other has a child with Down syndrome. The third interviewer was an occupational therapist with experience in qualitative interviewing. The interviewers prepared for interviews with one of the principal investigators (DS) who has qualitative research experience. Bi-weekly meetings ensured that interviewers were consistent and ethical in their approach. The group discussed how to shape subsequent interviews based on what they were learning from previous interviews.

Prior to the interviews, participants were mailed a letter that stated the purpose of the study and sample questions to help them decide if they wanted to participate. Those interested in participating were given the opportunity to ask questions by phone or email and were then sent a copy of the consent form to review. If they agreed to an interview, the date was scheduled. Before the interview started, the consent form was reviewed in person by the interviewer, questions were answered, and written informed consent was obtained.

Most interviews were completed by phone and averaged 50–60 min. Before beginning the interview, participants completed a demographic questionnaire and stated their level of function on the three classification systems. Audio-recordings of all interviews were later transcribed verbatim to written text for analysis. Identifying information was removed, and each transcript was assigned a unique and anonymous identification number.

Advisory group meeting

Following analysis of the interview transcripts, a one-day meeting was held in June 2017 with our advisory group. The purpose was for the advisory group to share their perspectives of the themes of the interviews and make recommendations for pediatric service providers based on our findings. A letter of invitation was sent to 13 people known to the investigators; 9 agreed to participate and 8 attended the meeting. The advisory group included three young adults with CP, two parents of young adults with CP, two service providers (a physical therapist and speech–language therapist), and one researcher who is an occupational therapist. None of the advisory group members participated in the interviews.

Prior to the meeting, advisory group members were provided a written summary report that described: (a) the purpose of the study, (b) lifecourse health development, (c) the interview process, and (d) themes from the interviews. During the morning, discussion focused on recommendations for how to “think differently” about services based on the interview themes and lifecourse health development. During the afternoon, discussion focused on recommendations for service providers on how to “act” on the themes. Following the meeting, notes from the advisory group were compiled and discussed by the research team to further support the themes from the interviews and inform the messages and recommendations developed by the team.

Data analysis

Analysis of interview transcripts

Analysis of the transcripts began with three team members (DS, MF, OH) inductively generating common patterns from within the data. These patterns were then reviewed, discussed and organized into emergent themes. The wording/phrasing of themes was purposeful, as we wanted to describe new, meaningful knowledge about the phenomenon of lifecourse health development of individuals with CP. For example, the phrase “adaptive processes” describes the transactional nature of health development. Similarly, social contexts for healthy living are also transactional in nature. The next phase of our analysis was to explore the relationships and associations among the themes, which enabled us to “describe” lifecourse health development. This step involved multiple team meetings to clarify our evolving understanding, and then writing a clear overall description of lifecourse health development that incorporated the themes from the interviews. The description was compiled into a report for the advisory group.

Table 2. Interview guide.

“The purpose of this study is to draw upon the knowledge and experiences of young adults with cerebral palsy to create guidelines for promoting healthy living from childhood to adulthood.

During the interview, I will ask questions about experiences that influenced your development as a child, an adolescent and a young adult, with a focus on healthy living. We are especially interested in learning how one’s ability for healthy living has developed over time”

During our interview, I will ask you questions like the ones below:

- What does “healthy living” or “being healthy” means to you?” (Our research team views “health” as physical, mental and social health, all together. We believe that experiences and opportunities through one’s childhood and adolescence help to develop one’s health in all these areas and to enable him/her to participate in different activities.)
- What do you (what activities) currently do to promote healthy living? What related experiences (positive or negative) do you/does your son/daughter have?
- Throughout your childhood and adolescence, what experiences influenced your development of abilities and interests in specific health promoting activities? What helped or hindered the development in this area?
- How do you manage health (physical, mental, social) now?
- Looking back, is there anything, any opportunity or experience that *would* have helped your development of abilities even more in managing health?
- We will also discuss development in some of the following areas that we believe are important for healthy living:
  - Eating, meal preparation, diet, nutrition
  - Physical activity, exercise, mobility
  - Social relationships—formal, informal, intimate relationships
- We want to develop guidelines for healthcare professionals, including doctors, nurses, and therapists, that focus on supporting the development of one’s abilities to participate in healthy living activities that we have been talking about. Do you have any specific suggestions for guidelines for health care professionals?

Key messages and action-oriented recommendations for pediatric service providers

Interpretative description guides the researcher to focus on application of ideas using a clinical lens, rather than just theorizing about the findings [30]. Our research team further analyzed the description of the themes after the input from the advisory group with pediatric health services as our lens. This critical step enabled us to generate key messages that are meaningful and applicable to end-users. Thorne [30] emphasizes the importance of organizing the findings within an overarching framework, which for this study was lifecourse health development. The research team then wrote action-oriented recommendations for pediatric health service providers to implement the key messages within the context of their clinical practice.

Results

Four themes emerged from analysis of the interview transcripts to describe lifecourse health development of young people with CP: *Personal Lifecourse, Contexts of Health Living, Health Development through Everyday Experiences,* and *Healthy Living as an Adaptive Process.* For each theme, we include representative quotes that participants used to describe their lived experience.

Personal lifecourse

Personal Lifecourse represents (or perhaps better yet "identifies") the dynamic and unique nature of a person's developmental journey. Individuals with CP are constantly changing throughout their life, with their potential for healthy living continuing to evolve. Examples of personal capacities described by participants include being able to self-manage their health and adapt to change. This theme pulls together everything participants said about how a person changes over time in response to different life experiences and situations.

> *"I don't know, I just try and be as outgoing as possible and take an interest in people and just try and be, I don't know, friendly, as friendly as possible and try and find common ground with people … and when I got older, I tried to take a more active role in deciding what specifically I wanted to do."*—Young adult D (GMFCS IV, MACS III, CFCS II)

> *"When I was younger, I lived with my parents. So quite often they would handle the management of a lot of that. I would give my opinions on various things but they would often make the final decisions because I lived with them, under their roof. Once I got to university I really had to learn to deal with these kinds of things myself because I was on my own. So when I was faced with various situations I really had to learn. Like, to problem solve a lot by myself. Especially in terms of my … keeping myself healthy."*—Young adult F (GMFCS IV, MACS II, CFCS II)

> *"Other things are just his achievement of being able to walk for himself; because we were told he would never walk. Letting, like just being able to learn that he could eat on his own was a positive experience also … and he graduated from his high school getting his diploma and stuff."*—Young adult A (GMFCS IV, MACS II, CFCS II) who was interviewed together with parent A

Contexts of healthy living

Contexts of healthy living characterize the transactional (ongoing, mutual, interdependent) relationships among a person and the many circumstances and situations in their life. Contexts can be multidimensional (e.g., family members, friends, healthcare services and professionals, community organizations), and often the participants talked about all of them together. Although we were learning from participants that it was very difficult to separate a person from their contexts, we believe it is essential to keep this theme separate from *Personal Lifecourse* to highlight that contexts are changing and developing throughout a person's lifecourse, and that a person influences their contexts as much as contexts influence the person (referred to as a "transactional" relationship). These relationships and influences are temporal in nature, change over time, and can be perceived by the person as positive and/or negative. Participants provided multiple examples to illustrate these multifaceted relationships.

> *"Ah, again, it's everyone's situation is different. Um, you can't go anywhere in this town that I live in … without some obstacle. It's, for example, the city bus, I will not do that, just because the idea of sitting where other people are sitting and a pile a snow can be just horrendous and very difficult to get around. And all the sidewalks can be there can be cracks everywhere. So, you definitely have to be aware of your surroundings. Emotionally, it can be very exhausting and you can't go anywhere without an obstacle. Just like traveling can be a tiring thing for me. So, it can be very much an obstacle in my town. I'm not saying that you can't work around it, you can, but it again, depends on the situation."*—Young adult A (GMFCS III, MACS I, CFCS I) who was interviewed together with parent A

> *"He has … brothers and he has always been treated like one of them, and so we've always—he has been a part of their social life as well with friends, hockey, baseball. Whatever they were playing, [name] played hockey and baseball as well. So there's always been, you know, it's all been a family. Every one of them played some sort of organized sports. He's made lots of friends that way. Being in the community, they've all known each other."*—Parent B (proxy for Young adult GMFCS II, MACS I, CFCS V)

> *"Um, his friend base is limited because he was taken out of our local school when he was young, in the public-school system, he was taken out of our school and put into a school across town, which we fought against at the time but they wouldn't listen to us, that he would end up with no friends and that is how he has ended up with one friend that made in high school."*—Young adult A (GMFCS III, MACS I, CFCS I) who was interviewed together with parent A

> *"Well in my case, both my good friends and my significant other were found online rather than … I guess it's more common now but traditionally you'd fall into a group of friends from activities, sports or school or so-on. And I think with online being more, it's much easier than I think if I had cerebral palsy say 50 or 100 years ago I think it'd be a lot harder to find a connection that—or a social grouping that would be more accepting."*—Young adult C (GMFCS II, MACS II, CFCS I)

Health development through everyday experiences

When participants described their personal lifecourse, they were usually talking about everyday experiences. Everyday experiences are viewed as the way by which a person develops their capacities for current and future healthy living. This theme reflects how transactional relationships take place over time, and capacities for current and future healthy living develop. Involvement in everyday experiences can be positive and/or negative. The participants provided many examples of how different experiences influenced their development of healthy living; they described how they reflected on what they learned from different experiences, and how an experience could either build capacity (of person and/or context) for healthy living or negatively impact healthy living. Related concepts that emerged within this theme include "opportunities" and "exposure" to experiences throughout the lifecourse. Representative quotes include the following:

> "How did I develop constructive ideas? … I think it's, you know, through your different experiences. Every experience can change your perception of self, right. So I think you know, and I had lots of different experiences in my life."—Young adult H (GMFCS IV, MACS II, CFCS I)

> *"Yeah, the exposure to this stuff really teaches you how to deal with it … The first time is always the hardest because you don't really know how to deal with it but consistent repetition of it helps to build more confidence. Even now with [name]-related issues. At the beginning when I first started*

> *it … Like when stuff would come up that was really irritating I would let it fester in my head for a while but now I'm a lot better at having to deal, with letting it all go."*—Young adult M (GMFCS IV, MACS II, CFCS II)

> *"He goes to a camp … which he thoroughly enjoys. Lots of people know him there and he seems to get along quite well there and is well accepted there. So, he looks forward to going there every year. He also does a lot of camping with our immediate family and we've been known to go camping with a group of people, like four or five families. So everybody looks out for everyone's children type of thing. So, he gets out in that type of aspect too. And then he goes for bike rides on his bike … In the wintertime we play sledge hockey. So that gets him out into the community too and playing in a sport, so he's working with his body also."*—Young adult A (GMFCS IV, MACS II, CFCS II) who interviewed together with parent A.

Healthy living as an adaptive process

Adaptive process involves reflecting upon and learning from different experiences, to enable the development of capacities for healthy living. The term "adaptive process" was selected as participants talked about having to adjust continually to changing circumstances and situations during development. There is a strong "temporal" (time) element to this process, such as the timing and sequencing of events and experiences (e.g., childhood experiences, adolescent experiences), changes in knowledge and understanding about health and disability over time, and timing issues related to system and societal contexts. For example, a student with CP adapts to meeting new people at high school and builds capacity for socializing with adolescent peers, and at the same time the high school students adapt to their new classmate to develop their capacities for awareness and acceptance of differences. The focus with this theme is development as a complex adaptive process that involves learning from different life experiences to develop the capacities of person and contexts together for healthy living. To illustrate, participants offered the following observations:

> *"I think everybody goes through that phase where it's you know you realize that it's not, that this is a process right and do I feel that there is a specific point in time? Um not really; I think it's more of a process, it's more of a growing process right and we know that neurologically and the brain doesn't stop developing at age 25. So, you know I think everybody should be aware of that so the human mind has a lot of potential and it's up to us what we do with it."*—Young adult K (GMFCS IV, MACS II, CFCS I)

> *"When [name] had 8 surgeries in 2 years, he was never home. So, when he did come home, he wanted to go out with his siblings but to build a life because he felt he missed something. So we have … his siblings as workers and they take him out and they make him a part of their social circle and that way he's, he gets out frequently and they also know enough about his situation that they can care for him adequately … ."*—Parent E as proxy for young adult E (GMFCS V, MACS V, CFCS IV)

> *"I mean I wish I had paid more attention when my mom would have made a grocery list when I was a kid. Like what to buy and what goes into the logistics of preparing a meal and stuff, I definitely, like I'm not a gourmet person but I definitely had to learn that all. So, I wasn't as able to cook but like myself, I think that there was definitely a big adjustment moving out on my own and just expecting to know what to do in terms of healthy, like taking care of myself. But that said, healthy as well, my parents were always supportive of me trying to be independent and trying new things and stuff like that."*—Young adult J (GMFCS IV, MACS II, CFCS I)

> *"Just generally it was kind of difficult for me to approach people. In elementary school there's kind of an air of equality, regardless of gender and stuff and yeah, the different echelons of social development. But then about four people moved away and as you move to middle school, there's kind of this heightened awareness of, I guess, gender politics and social development in that respect. So differences, I guess, in terms of being socially more adjusted and also the differences between being able-bodied and disabled became quite a bit more pronounced around that time. So I guess you become more aware of this and it kind of makes you feel more uncomfortable and less inclined to put yourself out there so to speak … ."*—Young adult N (GMFCS IV, MACS II, CFCS II)

Interpretive description

Four "key messages" were generated to interpret the themes in the context of pediatric health services. The messages are written for service providers, to guide them to think about their practice and lifecourse health development.

Address healthy living throughout the lifecourse

By asking children and families questions about living well in the present, learning from the past, and planning for the future, service providers encourage conversations about what is important now, how to build on past experiences, and what can be done to plan for the immediate and long-term future. Conversation about health, wellness, and aspirations expands the scope of pediatric rehabilitation services to include healthy living, participation in desired social roles, and achievement of personal goals. It also puts "therapies" into a context beyond addressing "body structure and function." Focusing on strengths and what a child or adolescent can do, and communicating hope, encourage new ways of thinking and new possibilities.

Focus on contexts of healthy living

Children, families, and life circumstances and situations are continually changing. Awareness of context enables service providers to consider person-environment transactions and what needs to happen to achieve goals for participation. Service providers are encouraged to check-in regularly with families and ask how everything is going. Partnering with children and families to plan for transitions, including the transition to adulthood, promotes readiness and innovative solutions to challenges. Flexibility and openness to different ways to think about services and supports are important for healthy living, as is awareness of parent-child dynamics and differences between perspectives of youth and parents.

Focus on everyday experiences and experiential learning

Desired social participation and achievement of personal goals are integral to lifecourse health development. Service providers are encouraged to ask children and youth about activities that they would like to do or are expected to do but have not had the opportunity to try or are difficult for them. Everyday experiences enable children and youth to learn and adapt to varied and changing contexts. Learning from past experiences is an adaptive process that is essential for health development.

Pay attention to the timing of opportunities and experiences

There is no "one size fits all" formula—everyone develops at a different rate and has a unique life journey. Service providers are encouraged to think about the timing of information, opportunities, and experiences to support children and youth to learn and develop when they are ready. Timing relates to readiness of the child, family, and context (i.e., physical, social, attitudinal environment) for opportunities and experiences.

To promote the adoption of the key messages of our interpretive description of lifecourse health development in clinical practice, we finished the project by providing clear action-oriented recommendations for pediatric service providers. Recommendations are presented in Table 3 and on the *CanChild* web-site (www.canchild.ca).

Table 3. Action-oriented recommendations for pediatric rehabilitation service providers to implement the four key messages.

Address healthy living across the lifecourse.

- Communicate effectively. Use strengths-based and ability-focused language. Think about how to communicate hope and possibilities to children, youth, and families.
- Ask children and families questions about living well in the present, learning from the past, and planning for the future. What are the child/family's aspirations and vision for the future? What's going well? What's challenging? What are priorities for the immediate future? Listening and asking open-ended questions facilitates conversations.
- Ask children/youth and parents about their information needs. Information needs change over time. Ask about current and future information needs. Be sensitive to family readiness for conversations about the future and intervention options (i.e., powered mobility, augmentative and alternative communication, home modifications).
- Engage children/youth in goal setting and planning as early as possible, and to the greatest extent possible.
- Support children and families during the transition process. Transitions, especially the transition to adulthood, are periods when youth/family needs for resources and supports often increase. Support children and families to begin early, plan ahead, and explore options.
- Address health and wellness in the plan of care. Health and wellness expand the scope of pediatric health services beyond remediation of impairments in body functions and structures and activity limitations to include healthy living, participation in desired social roles, and achievement of personal goals. Impairments in body functions and structures do not and must not preclude health and wellness.
- Address physical activity and prevention of secondary impairments and health conditions in the plan of care. Prevention of secondary impairments and health conditions are important, perhaps essential, for health development and healthy living.
- Address fun, family, and friends in the plan of care.

Focus on Contexts of Healthy Living

- Actively listen to children and families. Service providers are part of child and family context. Services are intended to support health development but when professionals are not listening to the needs and goals of children and families they may increase family stress. Priorities and needs of children and families change over time.
- Be flexible and open to different ways to think about services and supports. Children, families, and life contexts are continually changing. Be sensitive to parent–child dynamics, differences in perspectives of youth and parents, and preparing youth for adult roles and responsibilities.
- Think about child and family context during goal setting and intervention planning. Context changes over time and is intertwined with a child's abilities. Family and community contexts including availability of supports and services are critical to socialization, education, recreation, vocation, and community living.
- Consider how context influences whether opportunities and experiences build or restrict health development.

Focus on Everyday Experiences and Experiential Learning

- Ask children and youth about activities that they would like to do or are expected to do but have not had the opportunity to try or are difficult for them.
- Don't assume what a child/youth can or (especially) cannot do.
- Collaborate with children and families to identify opportunities for desired home and community participation. Encourage children and youth to express preferences and make decisions.
- Encourage social participation and experiences in multiple contexts throughout the day. Desired social participation and real-life experiences are integral to health and wellness. Through everyday experiences children and youth learn and adapt to varied and changing contexts. Learning from past experiences is an adaptive process that is essential for health development.
- Support children/youth and families to problem-solve solutions to participation challenges. Provide recommendations that are acceptable and practical in daily life.
- Provide information and support to teachers, leaders, instructors, and coaches to enable engagement of children and youth in school and community activities.
- Collaborate with children and youth, families, teachers, and instructors to provide person-supported experiences including with peers and mentors.

Pay attention to the timing of opportunities and experiences

- Consider child/youth, family, and community information needs and timing of information for future planning.
- Consider child/youth, and family readiness to achieve goals for activity and participation. Every child/youth and family are unique. There is no "one size fits all"—everyone develops at a different rate and has a unique life journey.
- Consider timing of interventions, assistive technologies, and environmental modifications to correspond with readiness to achieve desired outcomes.
- Consider timing of information, education, and advocacy related building community capacity for social engagement and participation of children and youth.

Discussion

Our study has generated new knowledge about lifecourse health development of individuals with CP from childhood through early adulthood. Our intent was to learn about life experiences that young adults with CP perceive as having influenced healthy development into adulthood. Interpretive description enabled us to identify four key messages for pediatric service providers to promote children's developmental capacities for future adult roles and healthy adult living. We believe that our findings provide conceptual and practical support for the lifecourse health development model by Halfon et al. [21] applied to individuals with CP and presumably other child-onset disabling conditions.

In our study, participants ascribed unique meaning to their personal lifecourse when describing development of their capacities for current and future healthy living. They viewed participation as an essential component of healthy living as well as self-management of their own health and self-advocacy. Participants placed much less emphasis on the development of component skills, such as fine and gross motor skills, unless these directly impacted on their ability to participate and live a healthy life. This finding suggest that pediatric service providers pay attention to their clients' capacities for healthy living to situate therapy recommendations within everyday activities and not just promote "functional skills" for their own sake.

Participants talked about how they experience health development as an ongoing, dynamic process occurring in many life contexts. Through everyday experiences, participants develop capacities and continually adapt to changing contexts. We learned as well that contexts also adapt during experiences, and more attention in practice needs to be paid to social context, that is, the people around young people with CP, to support them to develop their capacities for positive support and understanding. These findings are consistent with the lifecourse health development model by Halfon et al. [21] and our perspective [26]. The themes personal lifecourse and contexts for healthy living or contextual lifecourse are analogous to the concept of person–environment transaction [21,26] that emphasizes that person and environment are interdependent and always changing together and in relation to one another. We now prefer the terms *contexts of healthy living* rather than "environment" because contexts are multidimensional, transactional, and unique to individuals. This shift in thinking is beginning to emerge in the literature [1] and is reflected in our key messages to service providers.

The findings high-light the importance of everyday experiences and experiential learning for lifecourse health development. Participants told us that it was everyday experiences that enabled them to develop their capacities for current and future healthy living. Experiences involved transactions between person and context, changing and adapting together, which is consistent with the lifecourse health development model. This concept has not received a great deal of attention in pediatric health services. In our key messages, we suggest that service providers ask more questions about everyday experiences and promote opportunities and exposure to a variety of experiences for health development.

The theme *healthy living as an adaptive process* reflects new understanding about the process of health development. It represents the constant adaptations that characterize everyday life of individuals with CP. We found that an important aspect of this adaptive process is "experiential learning"—what everyone learns from different experiences. While there is value in participating in everyday experiences, there is a need to provide the opportunity to reflect on, and learn from, these experiences, as this learning builds capacity. Participants in our study suggested that much of their experiential learning came from their peers or family members. We believe that peer support groups for young people and family members are important sources of mentorship. Service providers can promote learning from experience with their young clients and families by asking relevant questions and suggesting "next steps" for building capacities for future healthy living. This is reflected in our key messages.

Consistent with the tenets of lifecourse health development, [21] our interpretive description found that the timing of opportunities and experiences is important for health development of individuals with CP. The notion of "sensitive periods" of development has been described in the literature [35] but our study findings indicate that these periods need to be related to the timing of opportunities and experiences, and learning from experiences, to promote the development of capacities of person and context for current and future healthy living. To optimize development of health capacity, we encourage a shift in thinking from developmental stages of skill acquisition ("normal" or "typical" development) to adaptive processes and "timing" of opportunities for experiential learning that coincide with an individual's personal and contextual lifecourse. In lifecourse health development, *health development trajectories* are conceptualized as non-linear; health capacities fluctuate over time based on person and environment "fit" [21,26]. Our findings support this perspective. For children and adolescents with CP, we recommend providing interventions at times of *readiness* when the *person-environment "fit"* is sufficient to achieve goals for social participation.

Several methodological strengths support the credibility and transferability of our findings. We achieved a purposive sample of participants who varied in sex, functional abilities, education, living situation, and work. The trained experienced interviewers met bi-weekly to discuss what they were learning from previous interviews and make changes for subsequent interviews. Initial interviews were characterized by participants telling their story, which it seemed they had told many times. Subsequently, interview questions were adjusted to ask participants to focus on the impact of their experiences within the context of adaptation (e.g., What did you learn from that experience?). Involvement of an advisory group in the research process had been used successfully in other studies by this research team to validate and enrich the research team's description and interpretation [36,37]. Interpretive description allowed us to understand how participants describe their health development and construct interpretation relevant to pediatric service providers and other community professionals. Although not typically part of interpretive description, our action-oriented recommendations are a first attempt to facilitate uptake of key messages by pediatric service providers. The action-oriented recommendations are congruent with the use of interpretive description due to their applied nature and recognition of clinical and life contexts.

Limitations and recommendations for further research

A single interview was conducted with each informant. This allowed us to capture where participants currently are in their lifecourse and to learn from their reflections on experiences during childhood and adolescence that influenced their health development. Among the 23 participants, three were interviewed with a parent, and a parent proxy completed the interview for three young adults. Individuals with CP may have associated intellectual and communication impairments, which we addressed through parent proxies. Use of parent proxy, therefore, allowed us to recruit a purposive representative sample with maximum variation of key demographic variables. Recall of childhood experiences is a potential limitation, however, the interviewers did not perceive recall to be a problem. A prospective longitudinal study would provide rich data on health development of individuals with CP including experiences that contribute to increased health capacity and environmental barriers to health development. More in-depth interviews than those in our study are recommended to better understand personal–contextual transactions that prepare children and youth for post-secondary education, work, and community living. Research also is recommended on lifecourse health development of individuals with CP during adulthood and lifecourse health development of individuals with other neurodevelopmental conditions.

Implications for pediatric health services

The key messages and action-oriented recommendations are first steps toward adoption of a lifecourse health development approach to services for individuals with CP. The key messages "*address healthy living"* and *"focus on contexts of healthy living"* expand pediatric services to encompass health promotion and wellness. This includes achievement of goals for desired social participation and prevention of secondary physical and mental health conditions. Actively engaging individuals with CP and their families in the goal setting and intervention process is consistent with client- and family-centered services. The key message *"focus on everyday experiences and experiential learning"* underscores the importance of opportunities for learning in real-life contexts of home, school, work, and community. Recognition that health development involves ongoing transactions between the person and their life contexts encourages consideration of task accommodations, assistive technology, and environmental modifications to enable desired social participation. A lifecourse health development approach shifts the focus of pediatric health services from development of component "skills' (e.g., fine motor, gross motor, social) to development of health capacities through opportunities and everyday experiences. The key message *"pay attention to the timing of opportunities and experiences"* emphasizes the importance of timing of opportunities and experiences. We propose that health development is optimized when timing of opportunities and experiences coincides with *person-environment "fit"* and *readiness* for desired social participation [26].

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Introduction to Chapter 4: "If I Had Been Given That Information Back Then": an Interpretive Description

Chapter 4 presents findings from a retrospective study of young adults looking back on their transition to adulthood aged 20 to 40 living in Ontario Canada. The findings from this study help to further contextualize and identify the stated information needs of young adults living with CP as they transition to adulthood. This qualitative study used interpretive description as its methodological approach. The first theme: "Recognizing and supporting information needs" demonstrates the importance of a support system around the individual when receiving and seeking information during the transition to adulthood. The second theme: "Getting creative" discusses the strategies used by young people living with CP in the transition to adulthood used to find information and address problems when confronted with environmental barriers. The third theme: "Gaps and advice for the future" discusses the unmet information needs these, now adults, had as they transition to adulthood.

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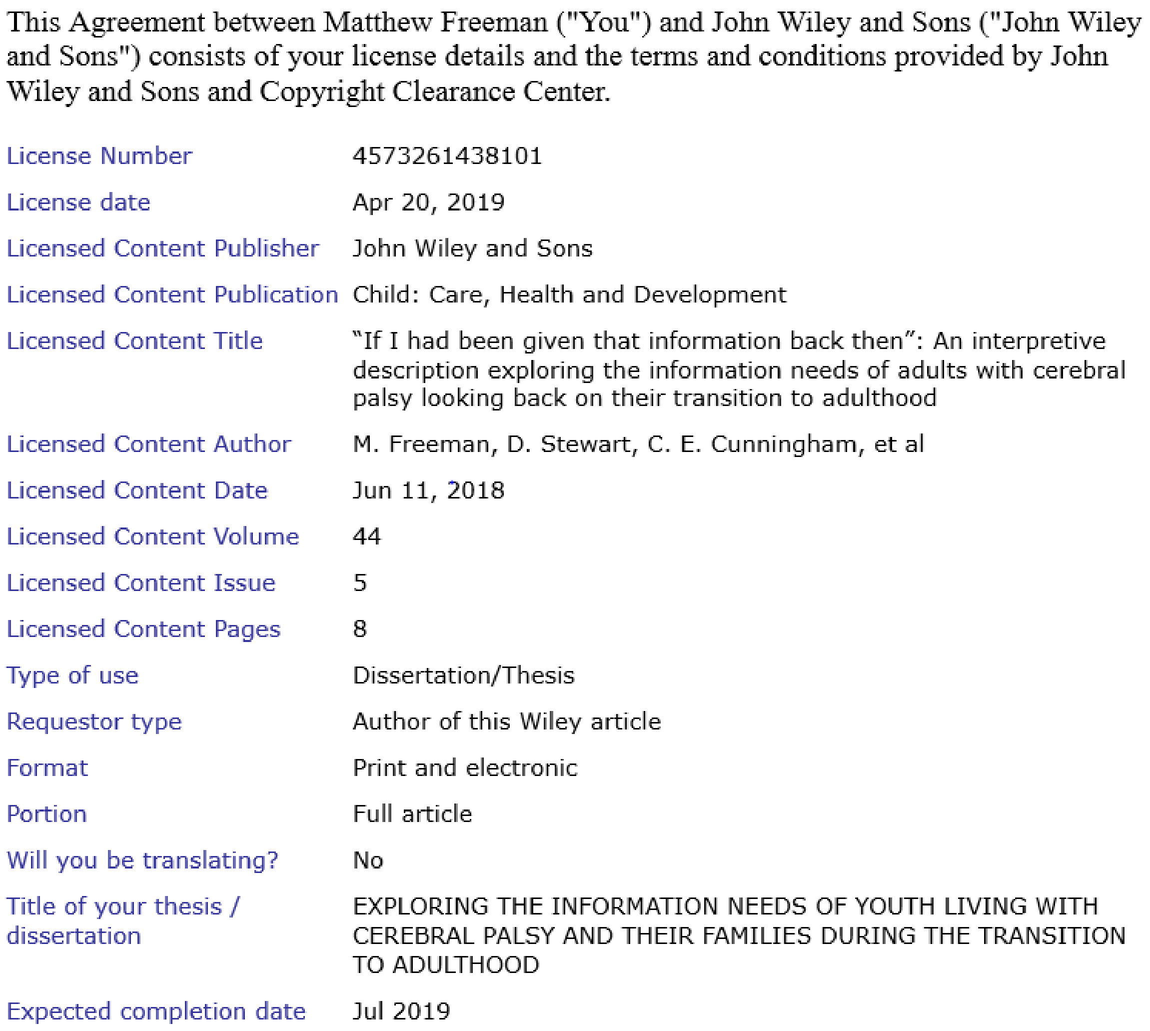

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“If I had been given that information back then”: An interpretive description exploring the information needs of adults with cerebral palsy looking back on their transition to adulthood

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Abstract

Background: Young people with cerebral palsy (CP) and their families have identified lack of information received during the transition to adulthood as a barrier to successful outcomes. To date, few studies have explored the information needs, preferences, timing, and method of provision from the perspective of individuals with CP.

Method: The methodological approach to this qualitative study was interpretive description. Nine adults living with CP, between the ages of 20 and 40, were purposively recruited in Ontario, Canada, to explore, retrospectively, their information needs during the transition to adulthood. Participants completed a 1-hour interview that explored their experiences seeking and receiving information. Interviews were transcribed verbatim, and data were analysed to create a thematic description of adults' experiences with information.

Results: Three themes emerged: (a) “Recognizing and supporting information needs,” which highlighted the importance of support systems to assist young people in receiving and seeking information throughout the transition; (b) “Getting creative,” which highlighted strategies young people use when confronted with environmental barriers when seeking information; and (c) “Gaps and advice for the future,” which highlighted the need for real-life opportunities, during the transition to adulthood, to experience some of the responsibilities of adult life.

Conclusion: Clinicians assisting young people with CP need purposefully to foster knowledge and skills during the transition to adulthood. They should be not only providers of information but also enablers of opportunities for immersion in real-life experiences to prepare for adult life. It is important for young people to have the opportunity to discuss challenges and exchange information with their peers.

KEYWORDS
cerebral palsy, information needs, qualitative, transition

1 | INTRODUCTION

Cerebral palsy (CP) is a child-onset condition that may impact development in the areas of movement, posture, and sensory processing over the lifespan (Rosenbaum et al., 2007). Individuals with CP, and their families, often receive therapeutic intervention and supports during childhood and adolescence, but it is likely that those services decrease drastically in the second decade, while their needs remain or may increase into adulthood (Usuba, Oddson, Gauthier, & Young, 2014). Therefore, the transition to adulthood can be a difficult time for adolescents with CP and their families. Findings from the literature show that adults with CP have difficulty achieving access to medical care, navigating employment (Benner, Hilberink, Veenis, van der Slot, & Roebroeck, 2017), and finding housing and may be delayed in establishing intimate relationships (Wiegerink, Stam, Gorter, Cohen-Kettenis, & Roebroeck, 2010b). Nevertheless, literature has found that youth with disabilities have the same wishes, dreams, and goals as their nondisabled peers and share a similar maturation process (Galambos, Magill-Evans, & Darrah, 2008).

One of the barriers identified in studies about this transition is the lack of information provided to young people and their families (Freeman et al., 2015; Stewart et al., 2009). Literature suggests that young people and families are looking for information about the future and adult life (Canadian Association of Pediatric Health Centres, 2016). The provision of information is a cornerstone of family-centred practice (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2012) and transitional best practice (Stewart et al., 2009). Case (2008) defines an information need as "a recognition that your knowledge is inadequate to satisfy a goal that you have" (p. 5). From a clinical perspective, the information needs of youth with CP and their parents obviously begin at the time of diagnosis. In early childhood, clinicians may be asked questions about function (Kruijsen-Terpstra et al., 2016), but entering adolescence, the questions shift to focus more on social and community participation (Kingsnorth, Gall, Beayni, & Rigby, 2011; Rosenbaum & Rosenbloom, 2012).

However, King at el. (2006) found that individual clinicians, while recognizing the value of information to families, may not always prioritize this in their scope of practice and often place greater emphasis on a more direct service model of delivery. Furthermore, literature has also shown that therapists may not be aware of available community resources. Although recent studies have begun to identify the information needs of young people (Nieuwenhuijsen et al., 2008), much of the literature still targets parents (Alsem et al., 2017) or the family unit as a whole (Palisano et al., 2010). The evidence base is therefore weighted towards the information needs of parents, and we are only starting to learn about the needs of emerging adults.

The aim of this study was to ask adults with CP between the ages of 20 and 40 to reflect on information they received during the transition to adulthood. We sought to learn about information gaps experienced and perceived by young people with CP transition into adulthood and understand the lessons learned in order to inform clinical practice.

2 | METHODS

2.1 | Methodological design

Interpretive description (ID; Thorne, Kirkham, & MacDonald-Emes, 1997) served as the methodological approach for the study. ID is a qualitative method with the primary objective of answering questions relevant to applied clinical practice settings (Thorne, 2016). In this study, the relevant settings are rehabilitation centres and services in which applied healthcare professionals interact with adolescents and young people with CP and their families during the transition to adulthood. The ID lens of inquiry is positioned within the constructivist paradigm, which recognizes that the world contains multiple constructed understandings of the phenomena from multiple perspectives. In this case, the phenomenon of transition to adulthood may include the perspectives of individuals with CP and their families as well as those of applied healthcare professionals working with them during their transition. Knowledge is understood as constructed through the lived experience of individuals with CP and their families, clinical training, and clinical experience. The objective is to frame findings through a clinical lens so that they may be applied to clinical practice.

Key messages

- The information needs of young people with CP and their families are ongoing throughout the transition to adulthood.
- Clinical conversations during the transition to adulthood should include information about all elements of adult life, including sexuality.
- Clinicians should recognize that young people have their own information needs, and this may differ from their parents' needs.
- Opportunities to receive information from peers, and to apply knowledge in real-life activities, are essential to help young people with CP gain information about themselves and to begin thinking about potential strategies to address environmental or attitudinal barriers.

2.2 | Recruitment and participants

Recruitment of participants followed a protocol approved by the Hamilton Integrated Research Ethics Board. All sampling was purposeful (Coyne, 1997): the initial sampling frame included individuals with CP between the ages of 19 and 29 living in Ontario (the upper age was later expanded to 40 to capture individuals who may have experienced delays achieving some of the markers of the transition to adulthood, such as moving out of their parents' home); and participants were recruited using a snowball sampling approach. Study information was sent to various family networks across the province of Ontario with the request to pass on information to those meeting the eligibility criteria. The same request was made to the Ontario Federation for Cerebral Palsy. Members of the research team represented various clinical backgrounds, including physiatry, occupational therapy, and psychology. Recruitment material was forwarded by D. S. and J. W. G. to individuals within their clinical circle familiar with the transition to adulthood adults with CP meeting the eligibility criteria. To ensure maximum variation of experience, those participating in the study were also asked to recommend names or pass on information to those they felt could contribute to the study. To address the diversity and functional abilities often seen in a diagnosis of CP, efforts were made to attract individuals across levels of the

Gross Motor Function Classification System—Expanded and Revised (GMFCS-E&R; Palisano, Rosenbaum, Bartlett, & Livingston, 2008).

2.3 | Data collection

Data were gathered through a semi-structured interview conducted over the phone by M. F., and all interviews were audio-recorded. The interview guide consisted of three parts. First, participants were asked to self-identify their GMFCS level using self-report GMFCS descriptions provided in the recruitment material. In this stage, participants were also asked to self-identify personal information about domains of education, financial support, participation in paid or unpaid labour, arranging of transportation, and participation in social and leisure activities, using a modified version of the Rotterdam Transition Profile (Donkervoort et al., 2009). The second part of the interview asked participants to reflect back on their transition and explored the what, where, how, when, and why they were looking for specific information during the transition to adulthood. In order to collect a range of experience, each participant was asked to identify a time when they were unsuccessful finding information they were looking for and what strategies they used and to identify a time when they were successful in finding information and what strategies they used. The third part of the interview asked participants to identify why they felt information was important during the transition to adulthood, how the information should be provided, the content of the information, and the timing of information provision. At the end of the interview, participants were asked, "If a young person with CP in the transition to adulthood came to you and asked for advice, what advice would you have?"

2.4 | Data analysis

Data analysis was initially conducted by two members of the team (M. F. and D. S.). The audio recordings of interviews were transcribed verbatim to text, and data were managed with NVivo 11 (QSR International, 2015). There are two components to data analysis when using an ID approach. First, transcripts are read using a constant comparative approach where the researcher identifies patterns (Thorne, 2016). In the second stage, the emerging themes are interpreted through a clinical lens, in this case, paediatric rehabilitation settings. In this study, M. F. and D. S. read transcripts and met to discuss common patterns and themes that began to emerge and to discuss the lens with which they were viewing potential themes. M. F. used a lens of someone who both experienced the transition to adulthood living with CP and is a rehabilitation scientist. D. S. used a lens of years of clinical experience working with youth in the transition to adulthood, as well as that of a transition researcher.

3 | RESULTS

The sample of participants was made up of seven females and two males with GMFCS-E&R ranging between Levels II and IV (see Table 1). All participants reported sources of income that were independent from their parents, whether from paid employment or income support from the government of Ontario. All participants were capable of arranging their own transportation needs and healthcare appointments. Interestingly, although participants reported financial independence from their families, many participants highlighted continuing family involvement throughout young adulthood and beyond.

TABLE 1 Description of participants

Pseudonym	Functional abilities and transitional domain descriptions
Cynthia	A 28-year-old female who is a power chair user who also walks with a walker at home (GMFCS-E&R Level III), living independently, receiving income from government benefits, currently in a relationship experience, and is capable of making her own transportation and medical appointments.
Derek	A 30-year-old male who uses crutches indoors and scooter for outdoor mobility (GMFCS-E&R III), living independently, receiving government benefits for income but is currently involved in volunteer and paid work, has previous relationship experience, and capable of making his own transportation and medical appointments.
Heather	A 26-year-old female who is a manual chair user (GMFCS-E&R Level IV), living independently, receiving government benefits and is self-employed, declined to discuss her relationship history, and is capable of making her own transportation and medical appointments.
Isabel	A 30-year-old female who is a manual chair user who also walks with crutches (GMFCS-E&R Level IV), living independently, receiving income from paid work, with previous relationship experience, and is capable of making her own transportation and medical appointments.
Jill	A 25-year-old female who is a manual chair user who also walks with walker at home (GMFCS-E&R Level IV), living independently, receiving income from government benefits, has no relationship experience, and is capable of making her own transportation and medical appointments.
Mary	A 37-year-old female who walks without mobility aids but uses a scooter for longer distances outdoors (GMFCS-E&R Level II), living independently, receiving income from paid work, has no relationship experience, and is capable of making her own transportation and medical appointments.
Nancy	A 38-year-old female who walks with crutches and uses a scooter for longer distances (GMFCS-E&R Level II), living independently, receiving income from government benefits and paid work, has no relationship experience, and is capable of making her own transportation and medical appointments.
Ryan	A 27-year-old male who is a full-time power chair user (GMFCS-E&R IV), living with his partner, receiving government benefits for income but is currently involved in volunteer and paid work, is currently involved in a relationship, and capable of making his own transportation and medical appointments.
Tonya	A 28-year-old female who is a full-time power chair user (GMFCS-E&R IV), living with family, receiving government benefits for income but has previous paid work experience, has experience with relationships, and is capable of arranging her own transportation and medical appointments.

Note. GMFCS-E&R = Gross Motor Function Classification System—Expanded and Revised.

In order to understand the information needs of the participants during the transition to adulthood, they were asked to identify information they had received, where they had received or looked for that information, who provided them with information, and the timing of the information they received. This descriptive information assisted during the interview process with the development of further probes to explore illustrative examples in which individuals described having information needs and their experiences addressing the needs. Participants described fragmentation in their sources of information, with the only common source being information from their high schools about postsecondary education options. The three themes below, illustrated with participant quotes, represent a descriptive interpretation of the information needs individuals possess during their transition to adulthood, the process by which individuals went about resolving information gaps and recurring unmet information needs.

3.1 | Theme 1: Recognizing and supporting information needs

When describing their journeys into adulthood, participants chose to focus on various life domains. Satisfaction with the experience of receiving information varied across participants, even within the same domain (e.g., postsecondary education and leaving the family home). A recurring factor was the level of support provided by others to assist in the seeking of information.

Ryan describes his experiences transitioning to postsecondary education, which was encouraged by others, this way:

> *[T]he area that I think I made the smoothest transition was university, because that was the area that everyone was focused on for me. [E]veryone had about told me about the various attendant care programs that were out there in the University—you know, the various universities. I phoned around to a few of them, I made appointments to see a few of them based out of [Name of City Removed] and I was living in [Name of City Removed]. [T]hen I made an appointment to go see [Name of University Removed], which had 24-hour attendant care provided, and I fell in love with the campus immediately and said, 'This is where I'm going', and I applied to [Name of University Removed] and got in so it was a very smooth transition. So the educational component of my life was I think one area where, not only did I find the information it was accessible, but the information was well thought out and well put together.*

In contrast, Mary describes her experience when individuals within her circle of support did not provide her with useful information as they attempted to redirect her postsecondary focus into what they perceived as more appropriate locations given her disability.

> *When I made the decision to go to college, my high school did not approve of the program I wanted to pursue and so they told my parents that they would not be helping with transition because they did not approve of my decision.*

Reflecting back on their transition, participants highlighted the importance of a peer support system entering adulthood, as peers have information from their own experiences. For some, like Tanya, the peer support was unstructured. She explains her experiences receiving and providing peer support this way:

> *Well, I guess in my dormitory I, kind of, unintentionally did … Or at least I had older girls that I, kind of made me feel safe and comfortable and that I definitely … You know, like, we, all of us, would exchange advice, and stuff.*

Isabel spoke of the power of interacting with others with disabilities, specifically CP, in their day-to-day lives, through her involvement in recreational activities, performing tasks of daily living that opened up the opportunity for bigger conversations.

> *[I]t was literally everything. Like, they had jobs, so I knew I could have a job and also through having that interaction with them, like, I got to ask, like, 'So how did you get your job? How did you learn to drive? How did you learn to put your socks on?' Like, I was able to have a really good dialogue and that was really helpful to me as well.*

Although peer support was discussed by all participants as an important source of information, other providers of information included multidisciplinary healthcare professionals and government agencies. However, unlike peers who share the lived experience of CP, several participants discussed important characteristics of those supporting individuals with CP to find information. Isabel emphasized the importance of clinical experience in establishing credibility, saying *"Like, knowing this person has worked with lots of people with disabilities in terms of this particular goal I'm trying to achieve."* Reflecting on her transitional experiences, Jill recalled the importance of her Children's Treatment Centre providing opportunities for experiences to develop skills into adulthood like a summer immersive skills programme: *"[E]ven though I hated the idea of it, it was crucial to do because it's one thing to talk about everything, it's another thing to try and do everything. It was, kind of, practice for me, you know."*

3.2 | Theme 2: Getting creative

Many of the participants talked about the need to "get creative" in order to meet their information needs. For many participants, information needs were not future-based or about collecting knowledge for the future; instead, the need was to address an immediate problem, such as the need for housing. Often this meant turning to informal supports like friends or family to find solutions.

An example of such an immediate problem is moving out of the family home. Derek spoke of needing to find accessible housing to attend graduate school, which was located in a different city. Heather expressed a desire not only to leave the family home but also to assist her friend looking for a place to live and seeking a roommate.

Derek described his experiences finding immediate housing accommodations when mistakes occur this way:

> *I originally applied for residence on campus, and I said that it had to be an accessible unit … All that kind of stuff and, attendant care the whole bit. So, I put that application in and that I didn't hear anything for about a month and a half … And I got a little bit worried, so I called the school and said what's the status of my application and how are things progressing because, you know, you apply in about April or May and then you sort of have to make plans to be there in September, and I wanted to make sure that all of my ducks were in a row and they said: 'oh yes, it's been taken care of, you have a residence spot for you'. And then I asked whether it was wheelchair accessible, to which they replied: 'oh, we didn't get that part of your application'. Uh huh … So, we've already assigned all of the accessible units for this year … Not in so many words because—good luck to you because we don't have anything left. About a month before school started it was a mad scramble to find housing.*

I: Who supported you through that, or were you on your own?

> *Again, it was my mom and myself. And I, honestly don't remember, I'm trying to think who told us about this building … And I honestly can't remember … I think, again, it was through one of the support … Like, one of the PSW [Personal Support Worker] companies. I'm fairly certain because we were looking for PSW support as well. And we had called some … A bunch of ones … And I think it was them who mentioned to us that this building … At the time when I moved in the building was only about a year old … So, they said, we know that it's geared to income and we know that you are in need, so here you go.*

Heather described her experience finding urgent housing this way:

> *… Yeah, because we were like desperate, right, so. My roommate only had a certain amount of time that she could stay at residence because she was no longer … technically I don't know … It was complicated. She was taking online courses to be able to stay at residence, but didn't want to leave the area and go back to where she's from. So, we had to find an apartment, and yeah … I called the local community housing whatever and they told me what forms I had to fill it, and then I used the Internet to find the number and I just went from there. And then I … Actually, we found this unit because my roommate's old attendant knew the superintendent so we were able to get in … Once we knew that … You know, when she knew that we were looking … I don't know why we didn't tell her this earlier … But we had the apartment within a week, so it was all about networking.*

The experiences of both Derek and Heather demonstrate the importance of connections with knowledgeable individuals to obtain information to assist them to achieve their goals. However, participants also described experiences in which individuals did not share information that would assist. Isabel recalls her challenges in attempting to find accessible housing when very little information was provided to her:

> *… I didn't realize how long the waiting list was for accessible affordable housing was, so had I known that, it was usually, like, a year—like a many-year waiting list … What I ended up doing is, since I couldn't fill out the [Name of Organization Removed] form I found the [Name of Organization Removed] has a database of accessible, like, houses or apartments that are for rent and I found a co-op so I just moved there, cause it is lower than market rent and its wheelchair accessible. And then, what I did was, when I finally figured out how to put myself on the housing list, I put myself in the housing list from there.*

Isabel also highlighted additional information barriers for individuals who may have difficulty completing forms and require assistance.

> *Well, and plus there's more accessible buildings, then like, I don't know, I didn't even know my building was accessible. I'm excited it is but, so yeah. But, what I found out after is once I sent the form in is that there is a call centre at [Name of Organization Removed] that you can call. And I called them and said, 'did I do this right', and they said yes, but what I found out after when I went to, like, drop off my birth certificate [,] you can actually call their office and be like, I don't read or write or I don't speak English and they'll have somebody sit with you to fill the form out.*

Young people with CP in the transition to adulthood were not the only people with information needs. Often other individuals within their circle of support, including parents, also had information needs. Nancy spoke of using staff in programs as advocates for her to provide her parents with information about independent living:

> *It took me a long time to move out of my parents' home and everything like that, just because the supports weren't there, and my parents were not ready to let me go, kind of thing, so I had to, you know, I reached a point where it was really important to me and I figured I'm going to do this or I'm not. It was just time and then I called the [Name of Organization Removed] and found out that they changed their mandate by then and they encouraged me to try it out. So, I said yes I will try it out but only if you promise I will be approved to get in because my parents are going to have a very hard time with me moving out. So, I had help from the [Name of Organization Removed] staff to, kind of, help my parents with the transition as well.*

3.3 | Theme 3: Information gaps and advice for the future

Participants all spoke of receiving information at the beginning of their transition to adulthood from their high schools about postsecondary education options. When discussing information gaps, most identified the lack of relevant and useful information from rehabilitation professionals about the whole transition process. Tonya shared her experience working with an occupational therapist:

> *[M]y OT tried to teach me things like, how to do a little bit of dressing and undressing myself, and stuff. But I don't think we had any big conversations. I think that we were all so hoping that I got into the [Name of University Removed], that like, I just don't remember having like conversations about what the transition would actually be like, and if we did I don't think much of that conversation stuck in my head. [Laughs]*

Participants spoke positively about receiving information regarding independent living and postsecondary education from peer supports or service organizations, but some participants did not feel all their information needs were addressed. The domain of social relationships into adulthood was recognized as an information gap. Ryan noted the lack of communication with professionals and information sources for adolescents with disabilities seeking information about the impact of their CP on their intimacy:

> *I think that a lot of 16 and 17-year-olds, regardless of whether they have CP or not, want to know about is sex. And, can I have sex, how do sex work[?] For me, because of physical limitations, and I didn't look into it too much because I was … It's not an easy thing for a 16 or 17-year-old to talk about, but I remember being frustrated by the lack of information that was out there and by everyone focusing on … You know, go to university without kind of realizing that what I wanted more than anything at that age was to get laid. And that, kind of, transitional element was very much missing for me.*

4 | DISCUSSION

This study explored the information needs of young people in transition to adulthood from the standpoint of adults between the ages of 20 and 40 living with CP in Ontario, Canada. Transition to adulthood is a developmental process, which raises many questions for young people regardless of whether they are living with a disability or not; however, as the themes above illustrate, living with disability adds factors and complexity and thus the need for more information.

The first theme, "Recognizing and supporting information needs," discusses how important it is for support systems to recognize that young people in transition to adulthood will have information needs. Importantly, the provision of information should not be dependent on a systemic view of what individual capabilities are, but rather provide opportunities for all young people to learn. Sources of information may include a combination of formal presentations by community agencies, peer support, and experiential learning. This finding is supported by current literature exploring the benefits of immersive life skills programs, which provide young people with CP the opportunity to engage in future adult responsibilities, such as directing their own care (McPherson et al., 2016). It is important to recognize as well that many of the individual journeys taken by participants during their transition to adulthood included a description of their postsecondary education experience. An increasing number of individuals with disabilities are engaged with postsecondary education, and many of them are receiving advanced degrees (Zarifa, Walters, & Seward, 2015). Some of the journeys discussed above highlight individuals staying in school in order to meet other transition goals, such as leaving the family home. More research is necessary to explore whether such strategies are common among individuals with CP during their transition in order to achieve satisfactory outcomes.

The second theme, "Getting creative," is reflective of environmental barriers youth with CP may face during their transition to adulthood. Some barriers may include waitlists for services (Magill-Evans, Wiart, Darrah, & Kratochvil, 2005; Michaels & Orentlicher, 2004), limited access to barrier-free housing, and difficulties seeking employment (Bagatell, Chan, Rauch, & Thorpe, 2017). The findings from this study do not contradict the existence of long wait list for services but show that individuals develop their own strategies and goals to create their own opportunities. Participants did this by forming relationships with service providers, asking assistance of service providers to find alternative approaches, or changing their circumstances in order to meet necessary criteria for services. These findings provide the opportunity for rehabilitation professionals, due to their expertise in accommodation for those with disabilities, to increase capacity within the community for adults living with CP. Pilot projects investigating the benefits of community capacity building have demonstrated positive outcomes, including increased understanding of the lived experience of disability and accommodation strategies (Wynn, Stewart, Law, Stewart, & Moning, 2006). However, community members participating in the research of Wynn et al. did not include members from housing or attendant care organizations. Research is also necessary to explore reciprocal information needs of both individuals with CP and these organizations. Research is needed to understand the attributes of individuals that are able to obtain tailored information from systems to access services they need, as well as identifying the attributes of individuals that challenge systems and seek their own information.

The third theme, "Gaps and advice for the future," is a reminder to paediatric and adult rehabilitation professionals alike that, from a developmental perspective, youth with CP need opportunities to explore and experience some aspects of adult life, such as directing their own care. This finding is also supported by multidimensional and dynamic models of development, such as the Life Course Health Development Model (Halfon & Hochstein, 2002; Halfon, Larson, Lu, Tullis, & Russ, 2014), which recognizes that individual adaptation occurs as a result of the fit between the individual and their environment that allows opportunities to explore new learning (Palisano et al., 2017). This finding is supported in the emerging transition literature, which seeks to evaluate the outcomes of providing immersive life skills opportunities for youth with disabilities (McPherson et al., 2016). These programs also must take into account the need for reflective opportunities to incorporate successes and self-discovery (Freeman et al., 2015). Further research should explore whether peer mentorship or immersive life skills programs, separately or together, have a greater impact on participant outcomes. There is also a need for rehabilitation professionals to engage in conversations about adult life, which includes sexuality and relationships. This finding is not true for all young people with CP but is supported by literature suggesting that intimate relationships may be a life domain that causes issues entering adulthood (Wiegerink, Cohen-Kettenis, Stam, & Roebroeck, 2010a).

The lack of involvement of rehabilitation professionals in providing information about the transition to adulthood is a concern. More research is necessary to explore if this is still the case for younger individuals currently transitioning to adulthood. However, possible explanations for the lack of information provided by rehabilitation professionals include systemic barriers such as the basic lack of ongoing rehabilitation therapy services beyond the age of 18 years in many jurisdictions (Bagatell et al., 2017), or paediatric providers feeling discomfort about their knowledge base and being reluctant to provide information about adult services. Nonetheless, these findings present an opportunity for increased collaboration of rehabilitation professionals, including occupational therapists and physiotherapists from both paediatric and adult services, to engage with community organizations and develop partnerships to address the information needs of their clients in relevant domains of housing, postsecondary education, employment, and personal/social relationships. Racine et al. (2014) assert the need for rehabilitation professionals to connect with community services in adolescence, but this need continues into adulthood. Ultimately, although planning and understanding what is to come in adult life for youth with CP is important, the information needs are driven by developmental factors and individual interests and desires, which may change over time. Rehabilitation professionals need to be open and flexible in providing information to each client and their family.

5 | LIMITATIONS AND CONSIDERATIONS

One limitation of the study is the lack of representation of participants across functional levels as indicated by the GMFCS-E&R levels, despite efforts to recruit participants from all five GMFCS-E&R levels. The findings from this study do assist us in understanding more about the challenges faced in the transition to adulthood by individuals with CP in Levels II to IV. We expect that many of the themes could apply to all functional levels as the issues are not specifically or exclusively determined by mobility level, but rather needs in various life domains and navigating new roles in adult life. The number of individuals interviewed may be seen as a limitation; however, the researchers believed that data saturation was achieved. It is noteworthy that all participants shared a story of confronting a challenge and what steps were taken to meet their need for information addressing the challenge. It is also recognized that the majority of the sample included individuals in the later stages of their transition to adulthood. Nevertheless, there is much to be learned about their recollection of previous experiences as a group of individuals during an important developmental process.

6 | CONCLUSION

Like their nondisabled peers, youth with CP have to navigate new contexts and roles as they emerge into adult life. These contexts may include postsecondary education, employment, and leaving the family home. This study's findings highlight the need for clinicians to provide useful and timely information that addresses the unique needs of each individual. Furthermore, providing opportunities for transition-related life experiences enables young persons with CP to learn from one another and from clinicians in supportive environments that allow information sharing and learning to occur naturally and in the context of everyday living. In the paediatric system, clinicians work with youth and their families to connect them with resources, and our findings demonstrate that this need extends into adulthood. Future research about living with CP into adulthood should explore strategies for clinicians to make more connections in their community to assist individuals with CP to make the transition successfully into inclusive adult life.

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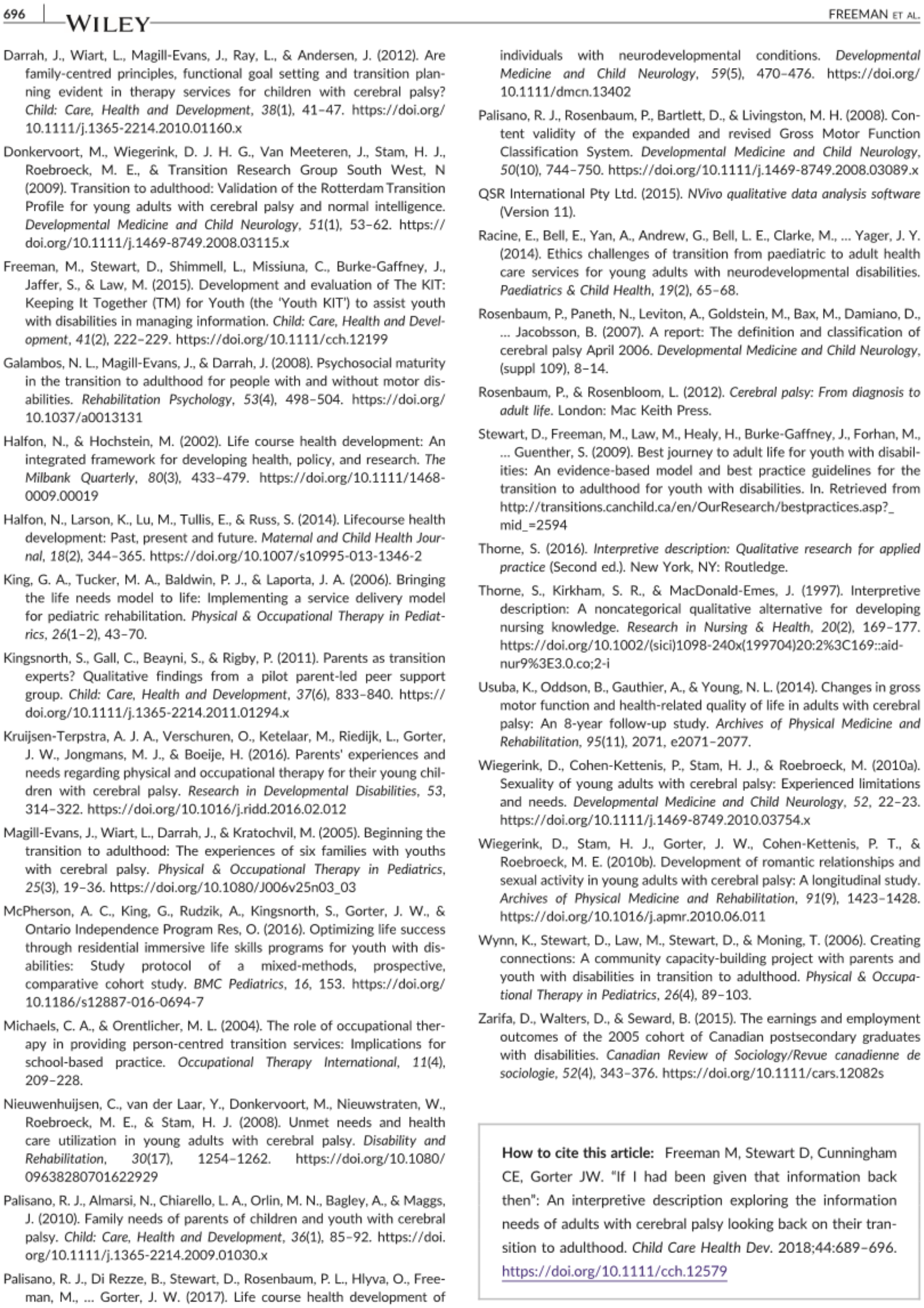

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Introduction to Chapter 5: "Exploring the information needs of parents of youth with cerebral palsy during their transition to adulthood through interpretive description"

Chapter 5 presents findings from a qualitative study exploring the information needs of parents of youth with CP between the ages of 16 to 29 living in Ontario. The purpose of this study was to explore their current information needs. Three themes emerged: 1) A place to belong, highlighting reasons why information needs emerge for parents during the transition; 2) Navigating the labyrinth, highlighting struggles parents have finding information from community organizations and government agencies; 3) Dilemmas on the continuum of support, highlighting dilemmas parents face during the transition to adulthood when deciding to share information about their children. Key conclusions included that parents have their own information needs during transition; parents are seeking information related to the desires of their children; and, parents preferred seeking information online and from other parents. Clinicians should consider their role as information providers to parents and the wider community.

Exploring the information needs of parents of youth with cerebral palsy during their transition to adulthood through interpretive description

Introduction

Parenting a child with cerebral palsy (CP) brings many questions and needs for information from the time of diagnosis and throughout childhood (Alsem et al., 2014; Reid et al., 2011). Parents of younger children may be curious about functional prognosis, but as the child ages and questions continue (Alsem et al., 2017), parents begin to wonder more about participation in social outcomes as their child transitions to adulthood (Kingsnorth, Gall, Beayni, & Rigby, 2011; Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013).

Research exploring information seeking behaviour has found that the information needs of individuals are often tied to major events and changes in life (Johnson & Case, 2013). One such major change in life is the transition to adulthood. Theories about emerging adulthood view the transition to adulthood as a developmental phase beginning in adolescence during which youth begin to develop their own worldviews and life goals (Arnett, 2000, 2007; Swanson, 2016). In contrast to childhood, when families are the primary influence on youth, Arnett (2000) argues adolescence and emerging adulthood are phases when youth begin to question perspectives and explore new opportunities to pursue in their adult life. Though youth may rely less on their parents for the construction of their own worldviews (Arnett, 2000), research has shown that parents may remain actively involved in their children’s lives through the provision of financial, housing and emotional support during a time when typical young adults are enrolled in postsecondary education or in the early stages of a career (Nelson, Padilla-Walker, & Nielson, 2015; Swartz, Kim, Uno, Mortimer, & O'Brien, 2011). These trends may well be true for parents of youth with CP and childhood disability as well; however, it is important to recognize the disablement stemming from physical, social and attitudinal barriers that may present additional challenges for youth with CP entering postsecondary education, moving out of the family home or finding employment (Benner, Hilberink, Veenis, van der Slot, & Roebroeck, 2017)

Parents of youth living with CP, like their children, experience their own transition as their child enters adulthood (Heath, Farre, & Shaw, 2017; van Staa, Jedeloo, van Meeteren, & Latour, 2011) and have information needs of their own (Freeman, Stewart, Cunningham, & Gorter, 2018b). Parents often find themselves working with their now adult children to access the appropriate supports, which will allow participation in meaningful activities (Björquist, Nordmark, & Hallström, 2016; Kingsnorth et al., 2011). However, they report feeling apprehensive about their ability to find supports and services available to their children with CP in adult life (Björquist et al., 2016). Literature suggests that parents rely on the combination of clinical expertise from both doctors and rehabilitation professionals, and peer support (Björquist et al., 2016; DiFazio, Harris, Vessey, Glader, & Shanske, 2014). In their recent systematic review and meta-analysis exploring the healthcare transition of youth living with chronic health conditions and disabilities, including CP, Heath, Farre and Shaw (2017) found that parents experience a shift in roles. Previously parents were in a managerial role, actively engaged in the management of their children's health. In adulthood, they find themselves as consultants in their children's health, or "passive initiators" (Heath et al., 2017, p. 87). While these descriptors capture the experience of parents in the specific domain of healthcare transition, other transitional domains, such as housing, suggest that at times parents may still be "managers" into young adulthood helping their children find support (Freeman et al., 2015).

This study is part of a series of research projects that seek to examine the information needs of youth with CP and their families in transition to adulthood from the perspective of both parents and youth. Previously, we explored the information needs of youth, which iteratively led to the need for this study because youth identified their parents as the primary sources of information during their transition to adulthood (Freeman, Stewart, Cunningham, & Gorter, 2018a). In the study presented here we sought to gain an understanding of the information needs that are emerging for parents of youth with CP aged 16-29 during their transition to adulthood. Specifically, we sought to understand the resources available to parents, as well as their preferences for how and when information should be provided.

Methods

Study Design and Ethics

Interpretive description (ID) (Thorne, 2016; Thorne, Kirkham, & MacDonald-Emes, 1997) served as the qualitative methodological approach for our study. ID seeks to assist clinicians in their day-to-day interaction with clients through the use of new evidence and knowledge generated through answering research questions (Thorne, 2016). The study protocol received approval from the Hamilton Integrated Research Ethics Board. All names used in transcripts and this article have been anonymized to protect the confidentiality of participants and their children.

Participants and Data Collection

The sampling frame for participants included being the parent of a youth with CP in the transition to adulthood between the ages of 16 and 29 living in Ontario Canada. The broad age range was intended to capture youth at various stages of transitioning into adulthood (e.g. those still in high school, those that have reached adulthood and individuals that have left the family home and are involved in community-based activities). The upper limit of age 29 was chosen to match the upper limit for many community-based employment programs for youth in Ontario (Government of Ontario, 2018). Participants were recruited purposefully, using a snowball sampling approach. Initially, members of the study team (JWG and DS) with links to clinical settings in which parents of youth with CP transitioning to adulthood may be engaged forwarded the study information to colleagues. Recruitment materials were also sent to community organizations and distributed on the social media platforms Facebook and Twitter by community organizations and the lead author's (MF) personal connections to community-based organizations. An interview guide developed by MF, JWG, DS and CC. A semi structured interview with participants was conducted by MF over the phone for approximately an hour. Interviews were audio recorded and transcribed verbatim for data analysis. After participants reaffirmed their consent to move forward the interviews consisted of three parts: 1) demographic information about the parent and their child, 2) an exploration of their current information needs and 3) an exploration of how and why receiving information is important as parents and their advice for other parents of adolescents with CP in transition to adulthood.

Data Analysis

All data were managed and coded with the assistance of N'vivo 11 ("NVivo qualitative data analysis Software," 2015). Transcripts were read by two members of the research team (MF & DS). They initially declared their lens and their rationale for viewing the data. MF described his lens as an individual living with CP, and a rehabilitation science graduate student and DS defined her lens as an occupational therapist and researcher with years of clinical experience working with youth and their families in the transition to adulthood. The two met to discuss patterns emerging from the data, and MF then independently worked to bring patterns and pieces of data together to construct a thematic analysis, which was discussed further with DS and refined. Once the thematic description of the data was agreed upon, MF and DS worked together to transform these themes into an interpretation aimed at clinicians working with adolescents with CP beginning the transition to adulthood and youth with CP during their transition, as well as their parents.

Results

Table #1 about here

Table #1 provides information about the eight parents participating in the interviews. All participants were mothers. The ages of youth in the transition to adulthood ranged from 16 to 28. The median age was 17.5 years. The Gross Motor Function Classification System, Expanded and Revised version (GMFCS-E&R) score of the youth ranged from level II (able to walk at home and in the community) to level V (minimal ability of self-mobility) (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). There was diversity within the sample regarding the daily experiences of the youth with CP. Some youth were actively participating in community-based activities, while others were limited in their opportunities to participate.

Table #2 provides information about the stated current information needs of parents and their sources of information. All parents discussed receiving information from provincial government support services; however, the information was not tailored to their individual needs.

Table 2 about here

Our analysis of the descriptions provided by parents yielded three themes. The first and second themes explore the preferences of parents when receiving information and their experiences seeking information, while the third theme explores dilemmas parents face as they share information with service providers in their community.

The first theme "a place to belong" explores the reasons for their information needs (the why) and describes what information parents are looking for, where they look for information and how they look for information. The second theme "navigating the labyrinth" explores the experiences of parents when looking for information to support their youth. The third theme "Dilemmas on the continuum of information provision" explores the dilemma parents face when sharing information with service providers in their community.

Theme #1: A place to belong

When asked about their aspirations for their children's future, parents spoke of being happy, healthy, "having a place to belong" and having meaningful relationships. When seeking information parents often described themselves as actively engaged in finding information related to these aspirations. In addition to healthcare parents sought information about options for postsecondary education, moving out of the family home, day programs with meaningful participatory opportunities and employment after high school. Often their youth would identify their interests and goals for the future, but required assistance finding more information. Emma shared one example, supporting her son's desire to enter a culinary program for individuals with developmental disabilities after high school: *"So, he's going to apply to be a cook - to take a cooking course. And, um, he found that article and he sent me the link[.]"*

Parents described various methods of information seeking. They described looking for information online, from other parents and formal community supports, which included high school staff (e.g. teachers and transition coordinators) and government support programs specifically for youth with developmental disabilities. Family members such as grandparents, aunts and family friends were mentioned as sources of information by some participants. In contrast to parents with additional family support, Grace described using professional services, such as a life coach to find information about services available for her triplets with CP, after the loss of her husband.

Parents presented contrasting opinions about receiving information through peer support. Some parents saw value in peer support. Linda, who identified herself as a leader of a parent network, asserted the need for a "*one-on-one relationship*" that met the needs of parents. In contrast Grace and Jessica felt that peer support was not helpful because other parents could not fully understand the complexity of their individual experiences. Olivia suggested that rather than parent-to-parent support, parents should have the opportunity along with their children to connect with adults with CP, noting:

> *"I'm going to listen to them [adults with CP]. I want to know because we're just parents, we don't know. We can say we understand we - we haven't been through this. Okay, it's you that's going through this we're, we're just trying to navigate, we don't know what were doing."*

Table 3 about here

Parents were also asked to explain the importance of information to them and make recommendations to other parents of youth with CP during the transition to adulthood. Table 3, focusing on possible information needs, who should provide parents information, where parents should be provided information, how parents should be provided information and when parents should be provided information. Several parents spoke of the importance of receiving information so that they can better support their children during the transition to adulthood. Sarah described it this way:

> *[I]t's better to have as much information as you can to try and make that transition a lot easier for all of us, you know, less anxiety, because I know [Name of Child Removed] she gets really stressed out with change and I know there's going to be a big change and (laughs) I don't know how it's going to go.*

Parents recommended that sharing of information about the transition to adulthood should start "*as early as possible*" recognizing that they may not act on it right away. Specifically, several parents recommended transition planning begin when youth with CP are beginning high school and that it begin at school, noting that guidance counsellors are available to youth without disabilities and should have a role with youth with disabilities as well, not just the special needs teacher. Parents also indicated preferences for information being available both in person and online.

Theme #2: Navigating the labyrinth to find information

Gathering information was often described as a frustrating experience. Grace described feeling "*alone*" when seeking information and stated that she had to be in "*the right frame of mind*" to contact individuals and sometimes found it difficult to always "*look into it*."

Lucy echoed this frustration, noting that, even with community support and planning meetings at the beginning of the transition to adulthood, it could be difficult to receive information. She explained:

> *"… I have a lot of community involvement, but you know, it just seems – [it's] sporadic, you know, we're just starting to transition through [Name of Community Organization Removed] the transitional years so we are very just into it. We're supposed to have a meeting, it gets cancelled, a lot of that happens. Meetings being made and cancelled, made and cancelled. Miscommunication is one of the biggest problems systemically, I'm losing my hair." Um, and time does not stop, though. That's the problem. Time does not stop, and so you have to be on it all the time and be the advocate because if you just take, if you just take it for granted the system's going to work, you're going to be quite frankly disappointed because it doesn't. You have to be on it and know what's going on and trying to figure out as much information, gather as much information as you can because it really is a society of don't ask, don't tell. And there's programs out there but you've got to find out - it's a labyrinth… It's the weirdest, darndest labyrinth, it shouldn't be this difficult."*

Lucy, whose daughter is currently transitioning to adulthood found it challenging to find information about supports and adulthood, saying:

> *"That's still our work in progress, the one part that has been I guess, the most challenging because I might not like the answers for what's available for day support or medical services, but I at least have the answers."*

For parents of children with complex medical or functional needs, parents discussed their desire to find information about how to best plan for the future. Lucy stated that "*Nobody wants to talk about when we're gone… what's in place*." For many parents, including Lucy, Olivia and Jessica, planning for their children financially was the primary concern. Grace also noted, in addition to financial support, she was concerned about who would help her son coordinate the day-to-day aspects of his life, such as getting to his orthotics appointments, stating: "*Who's going to get him to the dentist, who's going to get his orthotics fixed or replaced, who's going to, you know, when his scooter breaks down, who's going to do that[?...] Not the people at the [Name of Organization Removed], so I have to figure out what I'm going to do now."*

Theme #3: Dilemmas on the continuum of information provision

Many parents shared experiences of dilemmas they found when confronting gaps in service as their children aged out of pediatric systems in healthcare, education or out of the family home and they moved to the adult service world. One dilemma faced by parents was how to share information with providers of supports for their youth, especially those with complex care needs. For some parents, like Jessica and Grace, filing the legal paperwork required to become decision-makers and advocates for their children upon entering adulthood was important. This legal status ensured that they were still able to interact with and provide information to service providers after their child turned 18. Other parents described facing the dilemma of whether to advocate for change of environment or push for changes to resolve attitudinal barriers or support gaps within community organizations. Linda and Lucy discussed their advocacy for their children to change high schools to have better access to educational supports and programming that were aligned with opportunities for future and meaningful participation in society. Linda, speaking about moving her son from high school to a day program, stated:

> *But really, as a parent, I want to know that [Name of Child Removed] - what [Name of Child Removed] did, what activities did he engage in, did he enjoy them? What I like about the day program is that they tell me these things, and I tend to drop him off in the morning so I'll go in and I might chat with them for a few minutes and they'll "oh yeah, [Name of Child Removed] was really happy yesterday." "He loved the music program and he seems to really enjoy country, God forbid." Or "This particular activity… He didn't seem to enjoy it or he seems to really enjoy spending time with these people, he likes the male caregivers." Just, the things that those of us who are verbal take for granted. That people - we can talk about some of the nuances of our daily life. I don't have access to that sort of information about [Name of Child Removed] so a program that gives me that information is really nice.*

Similarly, within the domain of independent living, Grace described her experiences sharing information, on behalf of her son, and its impact on their relationship, to help improve his living situation this way:

> *"Well, at this particular location they do provide services for him, but it's an independent living facility and he has an apartment that's wheelchair accessible[…] They provide - people who are there, come up to see him, make sure he's eaten breakfast, his lunch, his dinner, his apartment is cleaned once a week, laundry is done for him, but he is required to do, um, a list for meals and shop for those meals. He does not know how to cook, so he hasn't figured any of this process out yet because I've had a meeting with the people at the services, because he's lost close to 20 pounds since he's moved in there six months ago, so he's down now to about 100 pounds. So, I'm quite concerned. They said they will cook for him, but he still has to create the weekly menu plan… But he doesn't know how to do this… He doesn't like me now… My son… Doesn't respond well to instruction from me. I guess it's been eight years of me riding on his coattails, and he's had enough of me (crying)."*

Throughout the interviews, several parents spoke of positive actions on the part of service providers and community supports, which allowed parents to have less responsibility sharing information to service providers and becoming an observer to support their children where gaps may exist. In contrast to parents acting as advocates, Charlotte discussed observing her son, who uses a communication device, navigate independent living in a supportive environment with life skills workers. Charlotte’s dilemma was to decide how much guidance to give. Charlotte discussed her son going to the grocery store and having to learn not only what food to buy, but also how to receive assistance when providing payment for groceries. Describing the process as a “learning curve” for herself and son, she hired, supported by government funding, a support worker to serve as his “hands” in the community and provide physical support. However, she stated her son decides the groceries he would like to purchase. Other examples of service providers helping to assert the autonomy of youth in the transition to adulthood included healthcare providers. Sarah and Emma both discussed their pediatric healthcare team encouraging and expecting young people with disabilities in the transition to adulthood to begin attending appointments without their parents, which shifted the information provision burden away from parents and onto youth themselves.

Discussion

The aim of this study was to explore the information needs of parents of youth with CP between the ages of 16 and 29 in Ontario, Canada. The findings from the study are in line with other research demonstrating that parents of youth with cerebral palsy in the transition to adulthood have information needs of their own (Bindels-de Heus, van Staa, van Vliet, Ewals, & Hilberink, 2013; Björquist et al., 2016; Freeman et al., 2018b). The use of interpretive description as a methodological approach was useful because it helps to focus the findings within the context of clinical practice. Some key considerations to assist clinicians working with youth with CP and their families in the transition to adulthood are also provided.

Placing the what, who, where, when and why of parental information needs during the transition to adulthood in the context

The finding that parents sought information online and from peer support is consistent with information seeking behaviour literature (Johnson & Case, 2013). Parents in this study did not demonstrate information avoidant behaviour, such as expressing a desire not to receive information because it was not the right time. (Sweeny, Melnyk, Miller, & Shepperd, 2010).

The first theme "A place to belong" showed that the information needs of parents of youth with CP in the transition to adulthood emerge due to developmentally appropriate transitions, such as attending postsecondary education, finding unpaid or paid work, moving from the family home (Bagatell, Chan, Rauch, & Thorpe, 2017), or the move to adult services (Nguyen & Baptiste, 2015). Parents in this study shared that they wanted their youth to participate in community-based activities, where the person makes a meaningful contribution and has the opportunity to foster social relationships. This vision of the future is congruent with the perspective of parents of youth with (Henninger & Taylor, 2014) and without disabilities (Jablonski & Martino, 2013; Sharon, 2016). As one of the six important "F-words" shaping the delivery of childhood disability, future is an important element of clinical practice (Rosenbaum & Gorter, 2012). The lack of discussion of information needs regarding future aspirations in adult life has led to parents turning to other parents in order to meet their information needs (DiFazio et al., 2014; Freeman et al., 2018b).

The second theme "Navigating the Labyrinth" is consistent with other transition literature with findings from studies across health conditions that the transition to adulthood brings challenges as parents and their children navigate the system changes from pediatric to adult services (Heath et al., 2017). Nevertheless, it is clinically relevant to note our findings suggest the labyrinth of information needs for parents in our study extended beyond the domain of healthcare and included other life domains such as transitioning to postsecondary education or out of the family home and estate planning. Transition to adulthood literature now advocates for the exploration of whether a navigator would be helpful to youth and their parents in helping to navigate the system changes (Joly, 2015). A Canadian example of navigation support for families during the transition to adulthood is found in the province of New Brunswick (The New Brunswick Navigation Centre for Children/Youth with Complex Care Needs, 2018). It is promising, however, to note that some parents in our study seemed comfortable taking on the advocate role themselves and asking for assistance when necessary. Importantly, this finding is consistent with information behaviour literature, which suggests that family members often act as information surrogates helping their loved ones find information when needs present (Johnson & Case, 2013). On a positive note, our findings suggest that community organizations and governmental supports are beginning to recognize the need to assist parents and youth in the transition to adulthood (e.g. The New Brunswick Navigation Centre for Children/Youth with Complex Care Needs, 2018), but more research is necessary to explore whether these transition resources are thoroughly satisfactory to parents or whether information provided to parents by community organizations is appropriately tailored to address specific needs. It is also important for clinicians to consider whether the information they are providing about supports or services will completely meet the needs of parents or their children and advocate for changes to address the gaps in services, including community care and health care.

The third theme “Dilemmas on the continuum of information provision” presents findings consistent with other literature suggesting that parents of youth with disabilities in transition are often engaged with their children throughout the transition to adulthood. Our study expands on the important work by Heath and colleagues (2017), which suggested that parents move from a managerial to a consultant role. Our findings help to provide additional context to explore what information and supports for youth with CP may help parents gradually shift from being the primary providers of information about their youth with CP. Our study found that parents are looking for information about activities for their children to participate in and finding supports that meet the needs of youth with CP. Finding appropriate supports may assist parents in navigating the dilemmas they face about how much advocacy to provide during the transition to adulthood. For clinicians, our findings suggest that, just as research has shown that gaining knowledge through connections with peers and mentors is an important source of information for youth in the transition to adulthood, the same is true for their parents (Freeman et al., 2015).

Considerations for clinicians as information providers

Despite being a cornerstone of family centred care, providing information to patients and their families is something that clinicians express trepidation about (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2012). Johnson and Case (2013) remind us that experts have “upper bounds” (p. 163) to their knowledge, which is important to remember when thinking about supporting youth with CP and their families during the transition to adulthood. Providing information to parents and youth with CP may not always mean the clinician is viewed as the expert. Instead, clinicians may choose to establish environments where information can be shared between parents and youth. Both parents and youth require opportunities to expand their own knowledge of services available in their communities. Just as healthcare transition literature recommends pediatric clinicians make connections with adult clinicians (Lariviere-Bastien, 2013), pediatric providers should also ensure that connections have been made with adult service providers in areas such as independent living or employment.

In addition to providing information to youth with CP and their families, our findings demonstrate that the communities in which these youth find themselves also require education regarding how best to support individuals with disabilities and this may be an important clinical role. The stories shared by participants in the study about the attitudinal and environmental barriers faced by their youth when attempting to participate suggests stigma about the abilities of individuals with disabilities in the workplace or volunteer environment (Zarifa, Walters, & Seward, 2015) or healthcare (Read, Morton, & Ryan, 2015). To assist in reducing stigma on an individual level, clinicians working with youth prior to the transition to adulthood can encourage parents and educators as well as youth with CP to explore employment and cooperative educational opportunities in the future. Lindsay and colleagues (2015) discuss the need for clinicians to work with youth on skill development, but also stated the need for community-based education to accommodate youth with disabilities.

In addition to healthcare clinicians, parents in our study suggested that guidance counsellors in the high schools, who have a role in supporting youth in their transition to adulthood with respect to vocational and educational planning (Nadon, Samson, Gazzola, & Thériault, 2016), provide information to youth with CP and their families, rather than delegating to a special education teacher or clinician. However, Nadon and colleagues (2016) note that guidance counsellors in schools in Ontario Canada do not have specific specializations as counsellors, but rather are teachers with additional undergraduate specializations and may not possess the requisite knowledge needed to support all students. Nevertheless, research from jurisdictions with greater formal training requirements suggest the delegation of the needs of disabled students to teachers or support staff is also evident (Pattison, 2010). Therefore, clinicians can play a key role in providing education and information to guidance counsellors in high schools about the transitional needs of youth with disabilities.

Limitations and considerations

During recruitment, efforts were made to ensure representation of all ability levels and ages for the study, but we acknowledge the results are reflective of individuals with CP with more severe motor impairment (GMFCS levels II-V) and may be reflective of parents motivated to actively participate in research. Nevertheless, these findings may be transferable to parents of all youth with CP because there are universal issues impacting families during the transition to adulthood regardless of functional abilities, such as the need to find information about healthcare providers, moving out of the home and engagement in meaningful activities. It is also noteworthy that our sample does not include the perspective of both parents, as we were only able to recruit mothers and was limited in scope to the Canadian province of Ontario.

Conclusion

The study found that parents of youth with CP in the transition to adulthood have information needs of their own. The information needs of parents identified in this study are reflective of the developmental stage of their children and the new expectations of adulthood as well as the impending transition to adult services. Parents are looking for information about how to be connected with adult services and to find opportunities for their children to participate. Parents are looking online for this information, but they are also turning to extended family members as well as other parents to find information. Clinicians should remember that information must be tailored to the individual needs of parents and their child in the transition to adulthood. This tailoring not only includes the content of the information provided, but also how the information is provided, when the information is provided and where the information is provided. Services and clinicians in both pediatric and adult services should be cognizant of the different and changing roles and responsibilities that parents possess during the transition to adulthood.

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Table 1: Demographic Descriptions of Participants

Pseudonym	Demographic Description
Olivia	Mother of two children including a 16-year-old daughter was living with CP GMFCS-E&R level III currently residing in the family home and attending high school.
Linda	Mother of three children, including a 17-year-old living with CP GMFCS-E&R level V who is currently enrolled in a young adult day program instead of attending school.
Sarah	Mother of three children, including 17-year-old daughter living with CP GMFCS-E&R level IV currently residing in the family home and attending high school.
Lucy	Mother of four children, including a 17-year-old daughter living with CP GMFCS-E&R level II currently residing in the family home and attending high school.
Emma	Mother of four children including an 18-year-old son living with CP GMFCS-E&R level IV who is currently living in the family home and attending high school.
Jessica	Mother of one child, a 20-year-old daughter living with CP GMFCS-E&R level IV is currently enrolled in high school and still living in the family home.
Grace	Mother of 25-year-old triplets all living with CP GMFCS-E&R levels ranging from II to IV all living outside of the family home.
Charlotte	Married mother of a 28-year-old son GMFCS-E&R level IV currently living outside of the family home and participating in volunteer activities.

Legend: CP = Cerebral Palsy, GMFCS-E&R = Gross Motor Function Classification System (Expanded and Revised) Version

Table 2: Identified information needs and sources during interviews

Identified areas of information needs (content)	Who is a source of information	Where they looked for information	How they looked for information	When they looked for information
• Financial planning and guardianship • Where to access services in smaller cities • Information about day programs, vocational, social and recreational opportunities • Information about therapeutic treatments (e.g. hyperbaric chamber, Botox) • Home modifications • How to advocate for children seeking opportunities • Access to adult health care, especially specialties (e.g. dental services and orthotists) available after age 18 • Information about support available to assist with activities of daily living	• Relationships with rehabilitation providers, including OT, PT, SLP, and recreation therapist • Government services • Lawyer • Social media including parent to parent network • Educators including teachers and guidance counsellors • School board transition support staff • Private support conducting assessments • Service providers and adult	• Online • Email with service providers and on distribution lists • In person meetings • Community-based advertising	• Conversations with family and friends • Online searches (e.g. Google) • Connecting with other parents informally at Children's Treatment Centre • Contacting service providers directly • Private service providers • Acting on recommendations from parents or professionals	• Transition meeting started at age 16 • As child's interests changed • When moving cities • Always looking for information since birth based on recommendations from other parents • When child indicated they wanted to know more about a specific opportunity

Legend: OT = Occupational Therapist, PT = Physical Therapist, SLP = Speech Language Pathologist

Table 3: Recommendation for provision of information to parents

Identified areas of information needs (content)	Who can be source of information	Where should parents receive information	How should parents look for information	When should information be provided to parents
• What services change in adulthood. • Information about programs promoting social opportunities in adulthood • Independent living • Estate planning • Community supports available in adulthood to assist with activities of daily living, beyond personal care • How to advocate for adult children when seeking opportunities in adulthood (e.g. paid and unpaid work)	• Community organization • Governmental supports • Parent to parent support networks • Adults with CP • Family and friends • Guidance counsellors at school	• In person meetings • Parent suggested that opportunities be available for parents to connect with each other at appointments • Community agencies create a guidebook	• Gentle conversations led by clinicians or "well educated parent" focused on the future • School guidance counsellors can provide information to parents about the transition to adulthood as they do for nondisabled young adults • During appointments • During Individual Education Planning meetings • Parents should have access to individuals to assist them in ensuring they fully understand information provided	• Dependent on the child • Beginning of high school

Legend: CP= cerebral palsy

Introduction to Chapter 6: Discussion

Chapter 6 is a discussion chapter, which intends to discuss ideas and bring together the new knowledge found through various studies as reported in the previous chapters. The aim of this chapter is to further contextualize research findings within transition literature more broadly with a noncategorical lens. I will also discuss the findings within the broader socioeconomic context in which youth with CP and other disabilities transitioning to adulthood are situated. Finally, I will discuss the next steps to assist in further understanding the information needs of youth and their families in the transition to adulthood and will end with recommendations for youth living with cerebral palsy in the transition to adulthood and their families, as well as recommendations for healthcare professionals.

Chapter 6: Discussion

Objectives of the Dissertation and its Chapters

The overall objective of this dissertation was to understand the information needs of youth living with CP and their parents during the transition to adulthood. The desire to focus on the information needs of youth and their parents during the transition to adulthood arose from literature describing the experiences of individuals with disabilities during the transition to adulthood finding difficulty accomplishing their outcomes in adulthood (Bagatell, Chan, Rauch, & Thorpe, 2017; Bjorquist, Nordmark, & Hallstrom, 2015; Freeman et al., 2015; Young et al., 2009). In addition to the general trends of difficulties during the transition to adulthood for youth with disabilities, research began to emerge finding that youth and parents had information needs during the transition to adulthood (Freeman et al., 2015; Nieuwenhuijsen et al., 2008; Young et al., 2009).

The three aims of this dissertation were: First, to explore what is currently known in published literature about the information needs of youth with CP and their parents in the transition to adulthood. Second, to understand what the information needs of youth with CP during the transition to adulthood are, as identified by individuals who have already transitioned from adolescence to adulthood. The third aim, which emerged from the work with youth, is to understand the current information needs of parents of youth with CP currently in the transition to adulthood.

Chapter 2, using a scoping review methodology, explored what is known about the information needs of youth living with CP and their parents during the transition to adulthood. Chapter 3 explored the use of interpretive description (ID) methodology when conducting childhood disability research. Chapter 4 and Chapter 5 were both original qualitative studies:

Chapter 4 explored the information needs of young adults with CP retrospectively, and Chapter 5 explored the information needs of parents of youth with CP currently transitioning to adulthood.

The objective of this chapter is to synthesize findings generated in this thesis as presented in Chapters 2, 3, 4 and 5, to reflect on these findings, and to contextualize this knowledge to help inform rehabilitation professionals working with youth and their parents during their transition to adulthood.

Reflections on the Influence of Methodology

Prior to discussing findings, I will reflect on of the use of scoping review and ID as selected research methods in my dissertation. Both methodological approaches are significant in that they were developed as an alternative to already existing research methods. First, scoping reviews aim to provide researchers with a map about what is known about a topic (Colquhoun et al., 2014). Unlike systematic reviews, scoping reviews do not seek to assess the quality of evidence, but to understand how different types of evidence (qualitative and quantitative studies) can lead to a further understanding of the topic (Colquhoun et al., 2014). Without being too reductive or simplistic, using a scoping review methodological approach helped me to define the scope of information needs for youth with CP and their parents, which at the start of my thesis had not been done. Importantly, the scoping review helped me to identify common barriers faced in transition, regardless of geography. The scoping review also helped me to identify that in addition to youth and their parents, healthcare providers and other community-based service providers have information needs as well.

Second, interpretive description (ID) is a qualitative methodological approach, which seeks to explore phenomena within the context of the clinical practice of healthcare professionals (Thorne, 2008, 2016). This means that descriptions of the phenomena are interpreted using a clinical lens (Thorne, Kirkham, & O'Flynn-Magee, 2004), keeping in mind the sociopolitical context influencing practice. I selected ID because existing sources of knowledge, which includes high-level research evidence and experiential knowledge from clinical practice, could be embraced and not set aside by researchers (Brewer, Harwood, McCann, Crengle, & Worrall, 2014). This allowed me to begin to think about what participants were describing in the context of not only the sociopolitical context of rehabilitation science, but also the sociopolitical context of community service providers.

From the perspective of information needs, Case (2006) argues that service organizations create information to share with clients based on what service providers identify as needed information, not the clients they serve. As highlighted in Chapter 4 in this dissertation, young adults with CP shared their stories about transitioning from the family home, the information provided by community agencies reinforced existing expectations of what individuals needed to know rather than different options available. For example, in Chapter 4 Heather a 26-year-old female who uses a wheelchair for mobility, discussed about struggling to find information about accessible housing for those paying market rent rather than subsidized rent.

Literature has also shown that the shift from pediatric to adult services may involve a shift in service design (Nguyen & Baptiste, 2015). In a qualitative study of transition aged youth with CP, participants identified seeking guidance from service agencies, but confronted the barrier of shifting to consumer centred services and feeling ill-informed to make choices while bearing the responsibility of knowing what services are available and how to access them (Bagatell et al., 2017).

Situating the Findings Within the Literature on Transition to Adulthood for Youth with Disabilities and Other Chronic Medical Conditions

The aim of this section is to contextualize and situate the findings. I have chosen to discuss the findings within the context of youth with disabilities, regardless of underlying medical diagnosis or condition and their parents. These populations were selected because they are well represented in the literature and can be used to demonstrate the generalizability and transferability of the findings, which is an important demonstration of rigour when conducting qualitative research (Cypress, 2017). Also, within the transition to adulthood literature for youth with disabilities, researchers are now encouraged to adopt a noncategorical framework (Gorter et al., 2014). Therefore, it is important to explore whether the findings in a population of individuals living with CP are applicable to other diagnostic categories.

Healthcare Focus in the Literature

The scoping review in Chapter 2 found that healthcare transition was the primary focus of seven of the 11 articles reviewed about youth with CP. This finding is also found in reviews of literature of youth with other chronic medical conditions (Joly, 2015). The focus on healthcare transition is an important recognition of the importance of overall health as a person enters adult life (Heath, Farre, & Shaw, 2017; Shackleford, 2018), including those living with CP (Roquet et al., 2018). Research exploring youth with chronic medical conditions as they transition to adulthood has highlighted that young people may avoid medical appointments or may not adhere to medication regimens (Heath et al., 2017). Therefore, it is understandable that healthcare becomes a primary focus in the transition to adulthood literature. I also recognize that there are many adults with CP, as demonstrated by a participatory action study seeking to establish patient centred research priorities, that want to know more about how their disability will affect them as they age (Gross et al., 2018). Individuals with CP have expressed interest in knowing more about secondary health conditions or comorbidities that begin to emerge in adulthood (Gross et al., 2018), which may impact their participation in daily activities (Roebroeck, 2010). The same is true for other individuals living with childhood disabilities as well ((Kuo, Crapnell, Lau, Anderson, & Shattuck, 2018; Wagner et al., 2015).

Although it may make sense therefore that the transition to adult health care is dominant in transition literature, there is a growing body of literature exploring youth living with CP, and other childhood disabilities, within all of their everyday contexts (G. King, Imms, Stewart, Freeman, & Nguyen, 2018). The emphasis in current literature related to health and healthcare is on a person’s participation in everyday activities (Palisano et al., 2017). Therefore, if rehabilitation professionals are addressing an individual’s health and individual disabilities they should begin to explore the knowledge and types of information necessary to enhance participation in all activities of daily living and their contexts. For children with disabilities, this may include inclusion in the classroom and other social activities. But for adults, where work and vocational goals begin to play a larger role in one’s identity, participating in paid work or volunteer work needs to be explored (Lindsay, Chan, Cancelliere, & Mistry, 2018; Lindsay, Duncanson, et al., 2018). The work of Sally Lindsay and her colleagues is important because not only is there a focus on individual job readiness skills, but there is a more important recognition that employers possess misconceptions and can reinforce stigma about individuals with disabilities in the workplace (Lindsay, Duncanson, et al., 2018). The current focus on interactions between the person and their environment is important because it provides practical linkages for clinicians between theoretical understandings of disability and health and the lived experience of those they work with.

Individualized Information Needs during the Transition to Adulthood (Why are there information needs of both youth and parents?)

In Chapters 4 and 5 of this dissertation, youth and parents stated they were seeking information about various life domains including postsecondary education, employment, leaving the family home, healthcare and relationships. Many of the experiences shared by participants reflected the situational information need. For example, leaving high school meant needing to find information about postsecondary education or employment. For others, this may have meant having to seek information about housing because they were completing postsecondary education and could no longer live in residence. The pursuit of education, employment and leaving the family home are reflected in literature about youth living with CP, and others with disabilities more broadly (Bjorquist et al., 2015; Hendricks & Wehman, 2009; Liptak, Garver, & Dosa, 2013; Petner-Arrey, Howell-Moneta, & Lysaght, 2016). Qualitative studies exploring the transition to adulthood in the literature also discusses the situational aspect of information needs (Bagatell, 2017; Bjorquist et al., 2015). Participants in Chapter 4 also noted that the area of sexuality and relationships is an information need. The lack of discussion about sexuality and intimate relationships experienced by youth living with CP and by those living with other disabilities has been the topic of growing research (Grove, Morrison-Beedy, Kirby, & Hess, 2018; Mona, Cameron, & Clemency Cordes, 2017; Shakespeare, 2000).

When exploring this finding, it is important to examine the different contexts around the information needs. One of the contexts that is important to explore is the family. Findings from Chapter 4 of this dissertation show that there may be a confrontation between parent and child goals. Marshall and colleagues (2018) explored how youth living with intellectual disability and their parents jointly construct goals for adulthood. They found that when working together, youth and parents were able to discuss the future, but in some cases, youth were more guarded about their goals and, when asked specifically, parents and youth sometimes identified different goals for the future. This finding is consistent with noncategorical transition literature exploring the attitudes towards goals that individuals around the youth in the transition to adulthood possess (King, Willoughby, Specht, & Brown, 2006). This tension is particularly evident in the experiences of Nancy a 38-year-old female exploring leaving the family home, as discussed in Chapter 4. Nancy worked with the housing program to ensure that information was provided to her parents about the supports in place for her well-being. This is an important example showing that parents working with youth during the transition to adulthood may not necessarily have a complete picture of the possibilities for their child’s future. To remedy this, experiences focused on future possibilities may be beneficial for both youth and parents, as these experiences can provide information about the future, which may enable them to work together to identify transitional goals. (G. King, McPherson, et al., 2018). For example, during my work on the Youth KIT (Freeman et al., 2015) a parent participant shared that learning about the life experiences of the mentor, who shared a similar disability to her child, served as a trigger for her to have new, more positive thoughts about future opportunities (Freeman et al., 2015).

Another context related to information needs is the community, including community-based services such as education and employment. A recent meta-synthesis of barriers faced by parents of youth living with disabilities during the transition to adulthood identified lack of information sharing by adult service providers as a barrier (Hirano, Rowe, Lindstrom, & Chan, 2018). Importantly, parents identified lack of access to information in multiple sectors, including healthcare, education and employment (Hirano et al., 2018). In Chapters 2 and 5 in this dissertation, it was found that parents faced challenges attempting to share information about their children after reaching adulthood. The challenges faced by parents when their children become adults are well documented within the literature (Heath et al., 2017; Hirano et al., 2018; Joly, 2015; Nieuwenhuijsen et al., 2008; Young et al., 2009). For example, parents of youth with chronic medical conditions have reported finding the role change between manager to consultant to be challenging (Heath et al., 2017). The role changes for parents extend beyond the healthcare domain, as shown in Chapter 5 of this dissertation. Parents were also looking for information to assist their children and navigating barriers and participating in paid and unpaid vocational activities.

There is literature showing that parents can have a role in supporting in the

creation of new opportunities for youth with disabilities (Petner-Arrey et al., 2016). Petner-Arrey and colleagues (2016) explored how parents can assist in the creation of employment opportunities for adults living with intellectual disability. Importantly, there were opportunities for effective partnerships between parents and professional supports; however, professionals needed to be sensitive to the limitations of parental involvement (Petner-Arrey et al., 2016). Literature has shown that some parents can feel stress and responsible for managing transitional planning (Hirano et al., 2018; Kingsnorth, Gall, Beayni, & Rigby, 2011). The downloading of responsibility to parents is most evident in Chapter 5 where Grace, a mother of three children living with CP faced dilemmas working with service providers to share information about her son. In her case, when her son required greater support than usually provided, she felt the need to fill unmet needs so that her son maintained his health.

In summary, youth with CP and their parents have information needs of their own due to their different roles in the transition to adulthood and different contextual factors. However, both youth and parents desire information related to goals in adult life. Transition literature shows that the informational needs of parents are important because families can act as a barrier or support for their children when attempting to meet future goals.

Initiating Information Seeking

The finding that youth living with CP shared that information seeking was initiated by their parents during the transition to adulthood is consistent with other literature. For example, in the UK, youth with learning disabilities were found to not initiate their own information seeking, which was viewed as a hindrance to their transition (Medforth & Huntingdon, 2018). Healthcare transition literature recognizes that youth must be prepared to begin information seeking for themselves. The concept of readiness in the transition to adulthood is often connected to the idea that the transition to adulthood is a shared process between pediatric and adult providers (Canadian Association of Pediatric Health Centres National Transitions Community of Practice, 2016). The expectation is that youth are provided the opportunity to experience and understand the expectations of an adult system, which is now included in Canadian transition guidelines (Canadian Association of Pediatric Health Centres National Transitions Community of Practice, 2016). While there has been movement within healthcare to prepare youth and their families for transition, barriers are still found in other sectors. Within education, studies in this dissertation have shown that youth living with CP often have difficulty receiving information from their guidance counsellors in schools at the same time as their peers. This is not to say that guidance counsellors alone are the solution to better transitional outcome, but as school is a setting for youth starting the transition to adulthood, they have an important role.

If we view the transition to adulthood for youth with disabilities as a multidimensional and multifaceted series of preparations, journeys and landings, conversations about the future can be helpful in triggering planning and preparation. For American youth living with autism, stakeholders have suggested that preparation for the transition to adulthood begin as a series of conversations with parents to identify skills and goals of their children (Kuo, Crapnell, Lau, Anderson, & Shattuck, 2018). However, these conversations should account for the unique transitional trajectories (Gorter et al., 2014). Kuo et al. (2018) found that participants did not want information about a single option, but rather multiple options and experiences that may be available (Kuo et al., 2018). The finding that transitional trajectories follow their own path is also supported by other noncategorical studies for both youth living with disabilities (Gorter et al., 2014) and those that are not (Côté, 2014). In summary, the expectation that youth with CP become managers of their own information needs requires a readiness to receive information. The information should be tailored to each person's unique needs and interests. Tailoring information to the needs and values of patients is now a part of health care delivery more broadly. In health care, patient decisions aids have gained popularity as a method of assisting patients make choices about interventions that are congruent with their values (Stacey et al., 2017).

Mentorship (Who should provide information to youth and parents during the transition to adulthood, and how should it be provided?)

The finding that some youth living with CP and their parents preferred to receive their information from peers while others did not is particularly significant when discussing information seeking behaviour and the provision of information to individuals. Peer mentorship has been studied across conditions (Gavrila, Garrity, Hirschfeld, Edwards, & Lee, 2019) or disabilities, including those living with congenital (Ryan, Kramer, & Cohn, 2016) and acquired (Chemtob et al., 2018) disabilities. Mentorship literature has explored various attributes and dyads in relationships , including individuals with and without disabilities paired together

(Wilson et al., 2013) and individuals with disabilities paired together (Ryan et al., 2016). Systematic reviews of peer support and mentorship have shown some benefit including an individual's sense of support and increasing motivation to continue an intervention, but these reviews have generally been criticized for their low level of evidence and inability to identify factors supporting a successful intervention (Dale, Caramlau, Lindenmeyer, & Williams, 2008). Recently, there have been randomized controlled trials of peer support in the disease management of diabetes (Patil et al., 2016) and recovery approaches for persons living with schizophrenia (Duckworth & Halpern, 2014).The overarching consideration in a mentoring relationship is that individuals serving as mentors allow their mentees to make their own choices and decisions (Chemtob et al., 2018; Wilson et al., 2013). In Chapter 4, although attributes of mentors were not explicitly described, it is important to recognize that participants viewed peer support as a way to exchange information and find solutions without judgement.

The exploration of mentorship within the literature about the transition to adulthood for youth with disabilities remains limited, though it is emerging (Heppe, Kef, & Schuengel, 2015; Ryan et al., 2016). One study explored the potential benefits of using a transitional tool in combination with an online-based healthcare provider as a mentor (Gorter et al., 2015). Gorter and colleagues found that the online-based mentor was useful for certain members of the study, while not used by others. Participants who used the online mentor highlighted that they discussed more than healthcare transition (Gorter et al., 2015). For example, one participant looked for guidance regarding the transition to university and disclosure of medical conditions to their roommate (Gorter et al., 2015). These findings are also found in broader noncategorical mentorship literature recognizing that feeling supported in talking about different contexts during the transition to adulthood is an important consideration in mentorship relationships for individuals with various disabilities and medical conditions (Chemtob et al., 2018; Dale et al., 2008; Gavrila et al., 2019; Ryan et al., 2016).

I also recognize that the findings from the study of parent information needs (Chapter 5) and the scoping review (Chapter 2) showed a different perspective. In Chapter 5, instead of prioritizing a peer to peer-based relationship, some parents wanted a relationship with service providers or wanted to receive information from adults with disabilities who had already transitioned to adulthood. Although this seems like a different approach to information provision, when viewed in context, the dynamics of the relationships may be the same. The participants in Chapters 4 and 5 who were not looking for peer support were the ones who were looking for validation and support from service providers that they could feel free to discuss issues with on an episodic basis. Reviews have shown that both youth and parents highlight the loss of the collaborative pediatric system (Joly, 2015; Medforth & Huntingdon, 2018). In particular, parents shared stories of being able to call up a healthcare provider for guidance and commented on the relationship often being one that has existed over a period of time.

In summary, many parents and youth living with CP, and other disabilities, want to receive information from peers during the transition to adulthood. Others, however, seek information from service providers on an episodic basis. There is value in considering the characteristics that may be important in any mentorship relationship. The ability to discuss and ask questions of someone when information needs emerge is important. Another important characteristic may be the ability to engage in discussions with an individual viewed as credible by the young person with CP and their parents. As discussed in Chapter 4, credibility for those living with CP may be judged by either lived experience or professional experience. The final characteristic to consider is whether the individual is willing to provide information outside of their perceived scope of knowledge (Carroll, 2015; Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2012). Based on the findings in this dissertation, it is not possible to make any judgements about whether the type of mentor (peer versus professional) can influence and transitional outcome. However, what is clear is that when youth living with CP and parents are seeking information, the behaviours of the individuals they approach do make a difference. The ability of an individual to assess the reason for the information youth need within their life context and offer suggestions without judgement may have some positive influence on trajectories.

Future directions: Guide on the Side or Meddler in the Middle

When contextualizing these findings, especially the attributes of mentors, it is helpful to return to the field of information literacy to explore approaches toward information support. I will discuss the concepts of *Guide on the Side* (A. King, 1993; Morrison, 2014) versus *Meddler in the Middle* (Morrison, 2014). These two concepts are important because, although they are considered to be models of classroom instruction, the focus of each model is on interactions with individual students. The scoping review in Chapter 2 found that parents and youth both preferred information to be delivered in a tailored way and that information was preferred from people rather than another delivery format. The purpose of exploring these two models is to highlight approaches that individuals assisting youth and their parents in transition may use to assist in the acquisition of skills to address their own information needs and enhance self-management skills.

Guide on the Side

Guide on the Side (A. King, 1993; Morrison, 2014) is a concept emanating from the field of information literacy. Guide on the side is a critique of the sender receiver model of teaching and information provision. Instead of professors acting as wise sages, as viewed in the traditional lecture-based format, professors are encouraged to provide opportunities for students to lean on each other for support during their educational journey (Morrison, 2014). This is done through the use of questioning within lectures, the development of exercises where students work in pairs or groups to find answers to their own questions (A. King, 1993), and the professor provides guidance where needed.

One critique of this approach is related to learning outcomes. Morrison (2014) argued that the shift to students as active learners may increase their ability to find information, but does not necessarily evaluate whether the information collected becomes retained by the student to be used as knowledge at a later time. Stated more simply, students may become adept at answering questions, but can they extend the knowledge to other contexts?

Meddler in the Middle

Offered as an additional consideration to the Guide on the Side approach is the Meddler in the Middle. Taking the same approach as Guide on the Side by empowering students as learners, Meddler in the Middle shifts the instructor into a more active role within the learning environment as opposed to Guide on the Side. The instructor, encourages students to seek answers to their own questions, but when hearing their answers offers alternatives to stimulate further thinking on behalf of students (McWilliam, 2009). Ideally students learn the skills to not only think critically, but also creatively (McWilliam, 2009). In contrast to the previous view of creativity being inherent and idiosyncratic to an individual, creativity is a set of skills where an individual becomes increasingly comfortable exploring possible alternatives in any situation (McWilliam, 2009).

The question now becomes, how may these concepts from education and information literacy influence and relate directly to the information seeking and provision experiences of youth living with CP and other disabilities, as well as their parents in the transition to adulthood. Considering whether creativity is an innate talent or a set of skills is particularly important to consider in the context of this dissertation. The second theme in Chapter 4 discusses the creative strategies used by youth with CP to find information when it was not provided to them. On this point, returning to disability studies may be helpful. Often, disabled individuals are viewed as expert *problem solvers*; however, disability theorists argue that the need to problem solve arises from the fact that the needs of the individual are not appropriately accommodated within society as a whole (Oliver, 1990). Although not exhaustively explored in the themes in Chapters 4 and 5, the stories shared by individuals often included strategies to remedy immediate issues when supports were not available, so considering how individuals with disabilities view and use creativity may be worthwhile of future study.

Exploring a Guide on the Side versus Meddler in the Middle approach to information sharing may be an important consideration for both youth living with CP and their parents. Findings from the scoping review (Chapter 2) and both studies of information needs (Chapters 4 & 5), suggested clinical conversations start early about the transition to adulthood. Healthcare providers and educators are an appropriate parallel to a college instructor because they are viewed as having power and answers in a clinical situation. Research has shown that service providers, even when practising family-centred care often feel discomfort sharing information because they feel they do not have all the answers (Darrah et al., 2012). However, shifting the role of the healthcare professional or educator from that of *expert?* to *guide* to *meddler* may help to alleviate some of the anxiety and pressure felt to have specific answers rather than supporting parents and youth to find their own. The inherent danger in this approach is that youth living with CP, and other disabilities, and their parents in the transition to adulthood will now feel additional burden to be their own information gatherers (Carroll, 2015). To promote these new behaviours in healthcare practitioners as well as youth with disabilities and their families, the Canadian guidelines for healthcare transition from pediatric to adult services provide some useful guidance (Canadian Association of Pediatric Health Centres National Transitions Community of Practice, 2016). The guidelines rest on the principle of self-management, which means that a young person or parent will be responsible for certain aspects of their transition (Canadian Association of Pediatric Health Centres National Transitions Community of Practice, 2016). However, the guidelines also recommend that healthcare practitioners have regular meetings throughout the transitional journey to determine that the young person is ready to self manage the new expectations and responsibilities (Canadian Association of Pediatric Health Centres National Transitions Community of Practice, 2016). Ideally, this shift in responsibilities from healthcare professionals to their transitioning patients would be gradual, expected and prepared for. In this scenario, the healthcare professional would initially act as a *guide* introducing the idea of changing services in adulthood, but throughout the transition, become more of a *meddler* encouraging young people to find information that answers their own questions. Qualitative studies about transition have shown that youth struggle to understand the choices they may have because they are not fully aware of the options available to them (Bagatell et al., 2017; Carroll, 2015). One of the reasons for the indicated lack of awareness may be because tools to evaluate readiness such as the Transition Readiness Assessment Questionnaire (Wood et al., 2014) focus more on the ability of the young person to provide information about their health condition or disability. Instead of simply evaluating skills possessed or the ability to share information with other healthcare providers, evaluations of readiness should also consider whether a client has begun asking questions about what the possibilities are for their future, different intervention approaches etc. The ability to participate in a dialogue should be an important consideration of self-management or clinicians working through the transition to adulthood.

Considerations When Using Dissertation Findings in Future Research

Prior to proposing future research suggestions, some comments need to be made about using these findings as the basis for future research. It is acknowledged that both the young adult study and the parent study (Chapters 4 & 5) had relatively low sample sizes. As stated in the chapters efforts were made to increase recruitment, but this was not as successful as I had hoped. Nevertheless, findings from each of the studies are well situated within the context of other transition to adulthood literature for youth with disabilities. Future research would benefit from a greater distribution of youth living with CP across functional levels.

Future research should endeavour to take a longitudinal approach and explore how information needs change over time during the transition to adulthood. One may wonder about how the nature of information needs change over time throughout the transitional journey. Finally, the clinically driven nature of interpretive description means that the findings are directed at healthcare clinicians and those supporting youth living with CP and their families during the transition to adulthood, and not individuals in transition or their families directly. Research that focuses more on the needs and preferences of youth with disabilities and their families would broaden our knowledge about the process of transition to adulthood.

A Suggested Study

Although it is beyond the scope of this dissertation to propose an entire research study, moving forward, it is important to show how these research findings can be advanced and used to further research to better understand the information needs of youth living with CP, their families and clinicians working with them. The aim should be to enhance how information is provided so that there ultimately is improvement in transitional outcomes for those living with disabilities and/or special healthcare needs and their families. As stated in the introduction of this dissertation, one possible pathway for future research is the use of a Discrete Choice Experiment (Cleland, Porteous, & Skåtun, 2018) to uncover the latent preferences for information of youth and their families. Discrete Choice Experiments may now be needed because, although this dissertation found consensus regarding the importance of providing information to youth living with CP and their families during the transition to adulthood, there is no consensus about what information should be provided, who should provide that information, how that information should be provided, where that information should be provided or when that information should be provided. Stated more positively, there is consensus within the findings of this dissertation that preferences are idiosyncratic. For example, some youth and their parents may wish to receive information from peer support, but they would prefer that support to be provided online. In contrast, some youth and parents may prefer to receive their information from professionals and desire an ongoing relationship with an individual so that they can continue to ask questions during the transition to adulthood. Some youth living with CP may want to gain information through experiential learning opportunities, while others may already be using the skills offered by experiential learning, such as using public transportation, in their day-to-day lives. The benefits of a Discrete Choice Experiment are that we can uncover previously unconsidered arrangements for the provision of information (Cleland et al., 2018). This dissertation began to explore the stated information needs of youth living with CP and their parents during the transition to adulthood: it is now time to explore their preferences and determine whether it is possible to group individuals to provide more targeted information interventions based on their preference profiles.

Recommendations for Youth Living with CP in the Transition to Adulthood and Their Families

Despite the need for future research, given the urgency of these findings for both youth and parents living with CP during the transition to adulthood, and the guidance of Interpretive Description methodology, I want to offer some recommendations related to the clinical context of rehabilitation science. These recommendations are based on findings from the scoping review (Chapter 2) and the interviews with youth living with CP (Chapter 4) and parents of youth living with CP in the transition to adulthood (Chapter 5).

For the youth and parents who are clients of rehabilitation services:

1) Youth living with CP and their families should participate in their own transition planning by being active in regular conversations with healthcare professionals, starting as early as possible.
2) Youth living with CP should take part in all transition planning activities offered by their high schools, as they face many of the same issues as their nondisabled peers. These transition planning activities should be driven by the interests of the youth and not judgements of potential of the youth to meet their identified goals.

3) Parents of youth living with CP can play a supportive role helping their children develop through encouragement and gentle prompting to try previously unexplored opportunities, which will provide them with important information for the future.
4) Parents of youth living with CP and more complex needs, can continue to advocate for their children in order to create new opportunities. This advocacy, however, can be a burdensome task and should not be done alone. Peer support networks and connections with professionals may help to alleviate some of the burden on parents and provide an important source of information.

Recommendations for Healthcare Professionals

1) Professionals should recognize that they will be asked questions about transition to adulthood and that youth and their families need to be "ready" to begin discussing their future in adulthood and to potentially accept the responsibility of to self manage their own care, if they are able. Professionals can play a role in setting the expectation that clients will participate in discussions about the future. Professionals can help clients move toward the goal, by acting as a guide to meddler to prompt consideration of new ideas.
2) In order to evaluate readiness for self-management, healthcare professionals should use readiness evaluation tools or transition apps during their conversations with youth and their families. These evaluations will also help to identify current and future information needs for both youth and their families.
3) Healthcare professionals who are addressing strategies to improve transitional care for youth living with CP and their families, should seek to make connections with other professional disciplines to ensure that the information needs of the individual in all of their daily contexts are being met. For example, identified students with special education needs

may have meetings with healthcare professionals, teachers, guidance counsellors, parents and the young person in transition, and this would be an ideal time to discuss transition broadly, beyond each professional’s practice domain.

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