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Exploring the experience of sexuality and gender during the healthcare transition of the youth with Cerebral Palsy

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

Background: Transition from the pediatric to adult health care system is an important phase of healthcare for youth with cerebral palsy (CP). Sexuality and gender are two very important components of health that are mostly ignored in the healthcare transition process. It is possible that health care providers only see a client's disability, and therefore, key aspects of sexuality and gender diversity may be ignored, or deemed irrelevant as a result of their disability status. Therefore, the purpose of our study is to explore how gender and sexuality may influence the experience of health care transition for youth with cerebral palsy. **Method:** This is a qualitative study guided by van Manen's phenomenology of practice (van Manen, 2014). van Manen's phenomenological approach is a form of qualitative study approach which is grounded in life experiences and gives attention to the day-to-day life and it is very well suited for studying health care realities. The study population was youth with CP and Health care providers who are directly connected with the health care transitioning experience of the youth with CP. **Results:** Six main themes emerged from the participants narratives; 1) current state of gender identity and sexuality in CP, 2) knowledge and curiosity about gender identity & sexuality among youth with CP, 3) challenges with sexuality and gender identity, 4) societal influence and pressure, 5) sexual health support during healthcare transition, and 6) opportunities for change. **Implication for practice:** The findings suggest that incorporating conversations about sexuality and gender identity during health care transition is important because there is curiosity and lack of knowledge about sexuality and gender identity among youth with CP. It also suggests that increased training and education for health care providers will encourage these discussions and increase support to youth with CP.

Keywords

Cerebral Palsy, Healthcare transition, Healthcare provider, Sexuality, Gender identity, Intersectionality, Sexual health, Sexuality education

Summary For Lay Audience

Sexuality (who someone is attracted to and their activities to express sexuality) and Gender identity (who they are) are two core elements of human personality. Transition from childhood to adulthood is the prime time when an individual develops these core elements of life. It is evident that adolescents or young adults with cerebral palsy do not receive enough education or support from the healthcare providers during their transition period regarding sexuality and gender. People with cerebral palsy may require additional education and support due to physical impairment; however, their needs are generally overlooked and they are often considered as asexual by their healthcare providers. In this situation, we understand that people with cerebral palsy who have different sexuality and gender identities may experience hardships in communicating their needs to health care providers. Our goal was to understand the experience of sexuality and gender identity formation during the healthcare transition experience among youth with cerebral palsy. Online qualitative interviews were used to gather information about the experiences of healthcare providers and youth with cerebral palsy. HCPs e.g., physiotherapists, psychiatrists, occupational therapists, social workers, who had experience in the HCT process of the youth with CP were recruited for the study. Adolescents or young adults aged 14 to 25 with cerebral palsy of any gender was recruited for the study.

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Introduction

This study was conducted to explore how gender identity and sexuality are experienced by youth with cerebral palsy (CP) during their healthcare transition (HCT). Sexuality and gender identity are typically developed during the life stage of transition from adolescence to adulthood, which coincides with when youth with CP are transitioned from pediatric to adult healthcare settings (Wiegerink et al., 201; Saxe & Flanagan, 2016; Bungener et al., 2022). The HCT is often poorly managed for youth with CP (Ryan et al., 2020), and many face challenges during this time that they are not prepared for (Normann et al., 2020). Healthcare providers (HCPs) play a vital role in the HCT process of youth with CP but research has shown that there is a lack of knowledge among professionals about the health concerns related to CP for example; effects of CP in adulthood, how CP interacts with women's sexual and reproductive health, effects of CP on other acute conditions and lack of knowledge about the diagnosis of CP itself (Young et al., 2009; Shah et al., 2022; Carroll, 2015). Youth with significant disabilities often do not receive adequate education regarding sexuality and sexual health (Sellwood et al., 2017; Travers et al., 2014). Furthermore, many youths with CP feel that HCPs see them as asexual beings that do not need sexuality or gender related information (Sellwood et al., 2017). Research has also established that people with disabilities who identify as transgender have more unmet healthcare needs than those who identify as cisgender (Mulcahy et al., 2022). This chapter introduces the readers to the definitions and relevant background literature about sexuality, gender identity, CP, HCPs, and HCT.

Sexuality

A core part of individual identity and human personality is shaped by sexuality (Ventriglio & Bhugra, 2019). It is usually expressed by sexual behaviour, attitudes, attractions, thoughts, beliefs, roles, and practices (Ventriglio & Bhugra, 2019). Sexuality and relationships are two vital factors that contribute to the quality of life of youth with CP (Davis et al., 2009; Sellwood et al., 2017). Youth develop significantly in this life domain (e.g., sexuality, intimate relationships, physical changes, sexual identity, sexual orientation) during the transitional period from adolescence to adulthood (Wiegerink et al., 2011). However, young adults with CP have been shown to be significantly less experienced with all the steps of sexual development (for instance, intimate and sexual relationship) compared to their peers without disability (Wiegerink et al., 2011). Several studies have documented that individuals with significant disabilities lack adequate sexual health support and sexuality education including topics such as relationships, pregnancy, contraceptives, sexually transmitted infections, and sexual activity (Sellwood et al., 2017; Travers et al., 2014; Galea et al., 2004). Lack of information about sexuality among youth with significant disability may put them at increased risk for sexually transmitted infections and unwanted pregnancy (Cheng & Udry, 2005; Travers et al., 2014).

Sexual identity is constructed socially and culturally (Ventriglio & Bhugra, 2019), as such it depends on the social and cultural beliefs and norms that a person is exposed to. Sexual identity is also closely related to, but separate from, sexual orientation, which is defined as the romantic or sexual attraction towards men, women or both sexes (Fausto-Sterling, 2019). Therefore, one's sexuality might be heterosexual, lesbian, gay, bisexual, pansexual, or asexual. Read and colleagues (2015) have highlighted significant and ongoing stigmatization and discrimination in

regard to the sexuality of people with disabilities (Read et al., 2015). For example, individuals with disability are often forced to identify with a heterosexual identity, which is the dominant sexual identity in most societies (Stanojević et al., 2023; Ramasamy et al., 2021; Noonan & Taylor Gomez, 2011; Hyatt, 2008). This is because, people in the society assume that individuals with intellectual and developmental disabilities are incapable of identifying as LGBTQAI+ due to their limited cognitive abilities (Stanojević et al., 2023; Ramasamy et al., 2021). Society tends to prioritize the disability identity and overlook the fact that individuals with disability are capable of identifying and accepting their sexuality (Stanojević et al., 2023). Another relevant social misconception that is pervasive is that people with disabilities are asexual, in which an individual does not feel sexual attraction (Sellwood et al., 2017; Manor-Binyamini & Schreiber-Divon, 2019). Based on this evidence, it is expected people with CP with significant impairments experience additional challenges associated with these misconceptions and difficulties related to developing their own sexual identity and sexuality.

Moreover, youth are generally accompanied by their parents during their medical visits which can make it difficult or uncomfortable for them to talk about sexuality or sexual health concerns with HCPs (Wiegerink et al., 2011). Parent's perception of their children's sexuality may also impact the sexuality or sexual health seeking behaviour of the individuals with disabilities. How parents perceive the sexuality of their children can be complex which is conveyed in the vagueness of the parent's concept of their children's sexuality (Manor-Binyamini & Schreiber-Divon, 2019). In a study focused on the perception of parents regarding the sexuality of adolescents with intellectual disabilities, researchers found that many parents denied the existence of sexuality and sexual needs of their children (Manor-Binyamini & Schreiber-Divon, 2019). Saxe and Flanagan (2016) stated that personal beliefs and attitudes about sexuality among

the caretakers of individuals with developmental disorders hinders the sexuality education for them. Wiegerink and colleague (2011) also found that 90% of young adults with CP did not discuss sexuality with their HCPs, despite the fact that adolescents and young adults with CP have a need for information about the impact of CP on sexuality and reproduction, about medical devices and medicines and about challenges with their partners. In pediatric rehabilitation, HCPs also do not discuss sexuality with the parents of individuals with CP. Furthermore, many young people with CP with mild disability leave the pediatric rehabilitation at an earlier age (before age 18), and therefore, sexuality does not come up as a topic of discussion with them or their parents and HCPs (Wiegerink et al., 2011). Overall, Wiegerink and colleagues (2011) found that only 14% of young adults with CP had received specific information regarding disability and sexuality, and they received it from a variety information sources, including school, parents, literature, radio/television, or peers (Wiegerink et al., 2011). It is evident that there is an immense lack of knowledge, educational or professional training, and organizational policies or guidance on how to support people with developmental disorders in sexuality-related issues (Saxe & Flanagan, 2016; Shah et al., 2022; Mulcahy et al., 2022; Bungener et al., 2022).

Gender Identity

Sexuality and gender identity can greatly influence each other (Ventriglio & Bhugra, 2019). Gender, until very recently, has predominantly been seen as binary, male or female, based on a pattern of features related to masculinity and femininity (Ventriglio & Bhugra, 2019). However, it is now recognized that gender is related to how we perceive ourselves; it is socially constructed and thus can be different from sex assigned at birth. Gender identity is a spectrum and can change over time. An individual can identify as a male, female, non-binary, gender fluid, gender queer and trans gender. Ventriglio and Bhugra (2019) have defined gender identity as “the

individual experience as well as acknowledgement of one's own gender" (p.31). Very little is known about gender identity formation experience among the youth with CP. However, recognition and acceptance of gender diversity is important and often coincides with the developmental stage of emerging adulthood as young people begin to explore and negotiate their identity as a whole, including their sexual and gender identity development (Wiegerink et al., 2011; Saxe & Flanagan, 2016; Bungener et al., 2022; Wilkinson et al., 2015). A recent study suggested that there is a greater number of young adults with CP identifying as LGBTQAI+ (Lesbian, Gay, Bisexual, Transgender, Queer, Asexual, and Intersex people collectively) compared to the general population (Soros et al., 2022), although this study used snowball sampling which could have resulted in recruiting a non-population-based sample therefore prevalence estimates from this study should be interpreted with caution. Despite the increased interest in exploring gender identity in this population, there is no research to inform how these youth with CP experience the development of their gender identity and what influences it.

Research evidence has shown that individuals with disabilities often mask themselves as cisgender (people whose gender identity matches the sex they were assigned at birth) when interacting with disability-related services (O'Shea et al., 2020). Young adults with CP face threats in how they see themselves while they are dealing with the stigma in society and seeking healthcare service because of their disability (Read et al., 2015). Stigma and discrimination are also challenge for people with diverse gender identities, as this can cause delays in receiving appropriate healthcare and/or result in unmet healthcare needs among people who are transgender (Mulcahy et al., 2022). Furthermore, it is evident that individuals who are at the convergence of various disabilities and identify as LGBTQAI+ are often overlooked (Stanojević et al., 2023). In fact, the compounding effects of disability and gender identity have been

hypothesized to be the major contributor to unmet healthcare needs among people who are transgender and have a disability compared to people with disabilities that identify as cisgender (Mulcahy et al., 2022). People with disabilities who identify as transgender or non-binary need the same access to healthcare as others and may require increased supports to address unique issues or concerns relating to the intersection of their disability and gender identity (Mulcahy et al., 2022). Thus, there is a significant need to explore the intersectionality of gender identity, sexuality, and disability (Cain & Velasco, 2021) and how youth and young adults with CP are experiencing their healthcare services. Research has also showed that primary care physicians need increased education and experience in providing accessible healthcare to people with disabilities and diverse gender identities (Mulcahy et al., 2022). Another study by Soros et al., (2022) emphasised the need for occupational therapists to have, at minimum, basic knowledge regarding the sexuality of young adults with CP to optimally support their clients with CP. Therefore, it is likely that not only these two professions alone, but also all the other HCPs working in the HCT area should have this knowledge as it relates to their scope of practice

Youth with Cerebral Palsy (CP) and Healthcare Providers (HCPs)

CP “describes 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” (Rosenbaum et al., 2007 p.9). CP is one of the most common childhood disabilities and its impacts persist throughout the lifespan. It is anticipated that the number of people living with CP in Canada will be more than 94,000 in 2031 (Amankwah et al., 2020). Worldwide, the prevalence of CP is approximately 2-3 individuals per1000 people (Paul et al., 2022). People with CP experience primary impairments of movement and posture, but they

also experience multiple and varied secondary impairments - spasticity, pain, fatigue, etc. - that often require assistance from family members, caregivers, or support workers for activities of daily living.

In most cases, CP is diagnosed within the first two years of life; however, some diagnoses can occur later in childhood (Amankwah et al., 2020). Children with CP can have a wide variety of presentations including neuromotor impairment, spasticity, dystonia, impairment of cognition and communication, intellectual impairment, disturbances of sensation, perception and behaviour, epilepsy, secondary musculoskeletal problems and other comorbidities (Gulati & Sondhi, 2018; Mudge et al., 2016). Behavioral problems may include anxiety, oppositional defiance, and specific phobias (Gulati & Sondhi, 2018). Individuals with CP may also have other comorbidities including intellectual disability, visual and hearing/speech problems, gastrointestinal problems, urinary problems and activity limiting pain (Gulati & Sondhi, 2018). As a result, individuals with CP often need a multidisciplinary management approach.

A survey of Ontario youth and young adults with CP, identified that they had lower health status and quality of life than their peer group of youth with other severe chronic health conditions (Young et al., 2010). A diagnosis of CP may also be accompanied by increased social and economic challenges. There is a higher prevalence of high-burden medical conditions (causing excess healthcare costs and a considerable patient and caregiver burden such as, pain, fracture, other non-communicable disease including ischemic heart disease, cerebrovascular disease, diabetes mellitus, malignant cancer, osteoarthritis, mood affective disorders, kidney and liver disease) among adults with CP compared to adults without CP (Whitney et al., 2019). Which in turn causes higher usage of healthcare resources, increased healthcare costs, and significant

patient and caregiver burden. Caregivers of people with CP experience considerable amount of psychosocial burden, due to stress, depression, stigmatization, feeling socially isolated and poverty (Vadivelan et al., 2020).

The multidisciplinary and specialized care for individuals with CP involves numerous HCPs, e.g., medical, rehabilitative, psychological, and social care providers including physiatrists, physiotherapists, occupational therapists, orthopedists, and psychologists (Gulati & Sondhi, 2018; Oskoui et al., 2012). Individuals with CP and their families develop a bond with their pediatric HCPs as they see them consistently across the first 18 years of their life (Oskoui et al., 2012). When youth with CP begin their transition to the adult care, this stability is lost, and they receive new HCPs, in a fragmented system, and often must navigate the adult healthcare world alone (Oskoui et al., 2012). HCPs have an active role in providing care to youth with CP, but they also function as an advocate for youth and young adults with CP in the adult healthcare system (Wood et al., 2008). Lack of knowledge about the diagnosis of CP and related health concerns among the HCPs, particularly in adulthood, is often postulated (Oskoui et al., 2012). Additionally, youth with CP have expressed their concerns about experiences with HCPs during the transition and in adult healthcare in multiple studies (Carroll, 2015; Read et al., 2015; Ryan et al., 2020). A scoping review conducted to explore the access and utilization of sexual and reproductive healthcare for women and girls with CP demonstrated that women with CP in adulthood face enormous problems associated with receiving good quality sexual and reproductive healthcare due to HCP's limited knowledge of the effects of CP in adulthood (Shah et al., 2022). In another study, youth with CP expressed with frustration that there is not enough awareness of the diagnosis of CP among the general practitioners and stated that medical professionals look confused when they encounter these individuals in their practice (Read et al.,

2015). Study by Ryan et al., (2020) demonstrated that adult HCPs are not sufficiently trained in pediatric-onset conditions. Furthermore, a study of young adults with CP provided accounts of alarming experiences where they allege HCPs had explicitly stated that they are not sure about the care they can provide and the effects of CP with aging because they (HCPs) do not know enough about CP (Carroll, 2015). This led to the individuals with CP feeling uncomfortable when receiving care from HCPs who lack knowledge about CP-related health problems (Carroll, 2015). Therefore, it is crucial to understand the HCT experience of the youth with CP from the perspective of HCPs and youth with CP themselves.

Healthcare Transition (HCT)

Healthcare transition (HCT) is defined as “the intentional, planned process of transferring care from a pediatric-based to adult-based healthcare setting” (Berens et al., 2020, p.159). The transitional process should address the medical, psychosocial, educational, and vocational needs of young adults with chronic medical and physical conditions (Ryan et al., 2020, Blum et al., 1993). For emerging adults with CP this transition is often difficult (Ryan et al., 2020) as they are not prepared for the changes and challenges, they encounter during their transition to adulthood, and specifically the adult healthcare environment (Normann et al., 2020). Youth with CP have special healthcare needs to be fulfilled including maintenance of optimal function, mobility, and continuous supportive care with the aging process. It is evident that CP-related impairments change and the severity of disabling impact among adults with CP increases with age, often requiring a greater need for healthcare services with age (Mudge et al., 2016).

As children, people with CP receive the medical and rehabilitative care they need in well-structured pediatric care programs by a team of skilled professionals with extensive knowledge

regarding CP (Carroll, 2015). In Ontario, pediatric care programs provide services until the person is between 18 to 21 years of age (depending on whether the child is still enrolled in school or not). Due to several medical advancements in recent decades, there has been an increase in the life expectancy of people with CP such that 50% to 90% of children survive into adulthood (Young et al., 2010). However, once youth age out of the pediatric care and fall into the fragmented (Carroll, 2015) and unfamiliar adult healthcare model they encounter various difficulties regarding access to the proper healthcare services (Oskoui et al., 2012). Young adults with CP report feeling that they have been abandoned by the healthcare system (Normann et al., 2020). It is evident from the literature that individuals with CP need significant support during transition to adult-oriented healthcare, and comprehensive care beyond the transition that considers the lifelong impacts of the disorder (Carroll, 2015); however, access to this type of care is limited.

Transition from pediatric to adult care is an important event in the life of youth with CP and there are many factors that impact the success of this transition. When transition goes poorly it is often because there is a lack of collaboration between pediatric and adult care providers, young adults with CP, and their families (Carroll, 2015). Furthermore, a lack of understanding of CP and how to assist a person with disability by the HCPs can lead to poor healthcare experiences (Mudge et al., 2016). This often translates to a lack of information provided to youth with CP and creates uncertainty about the transition process (Oskoui et al., 2012; Young et al., 2010) which contributes negatively towards transition and its outcomes. Additionally, people with CP encounter several barriers to accessing healthcare in new spaces in adult healthcare due to mobility limitations, inadequate or unavailable equipment for access or transfers, and limited time during doctors' visits for comprehensive consultation for youth with CP (Myers et al.,

2020). All these factors combine to produce a poorly managed transition for youth with CP (Ryan et al., 2020). Poor management of transition is known to be associated with deterioration in health conditions, development of new chronic diseases, frequent hospitalization or emergency service use, and reduced quality of life of youth with CP (Ryan et al., 2020). It is also important to note that adolescence (from age 12 to 24 years) is the life stage when most mental health disorders develop (Colver, 2018), and young adults with CP have been shown to be at a higher risk of developing various mental health conditions such as depression and anxiety compared to their peer group (Smith et al., 2019), potentially compounded by feelings of abandonment by the healthcare system (Normann et al., 2020). A well organised transitional healthcare service can provide a better healthcare experience to youth with CP (Mudge et al., 2016). As quality of life of youth with CP depends highly on appropriate transitional care, there is a need to explore the HCT experience of these youth to know more about the challenges they face and how their quality of life and healthcare can be improved. The current literature base demonstrates that people with CP in Canada will continue to experience reduced quality of life, increased disability, and inadequate supportive services if no changes are made to the current care system (Amankwah et al., 2020).

When all these concepts are considered together, it becomes clear that there is a gap in knowledge and the associated understanding of how sexuality and gender identity is experienced by emerging or young adults with CP. The available research findings on sexuality, identity development and disability have mostly focused on young adults with cognitive disabilities (East & Orchard, 2013; Greydanus et al., 2002; Travers et al., 2014). Furthermore, youth with physical disabilities, including CP, do not always receive necessary sex education or specialised

information from HCPs (East & Orchard, 2013). Transition to adulthood is an important life stage for people with and without disabilities and co-occurs during the main developmental phase of sexuality and gender identity (McLeod, 2019; Ventriglio & Bhugra, 2019; Saxe & Flanagan, 2016; Wiegerink et al., 2011), making it an ideal period to intervene. This is also the stage of their life when they experience one of the most important, but challenging, phases of the healthcare service, the HCT. What results is an intersection of sexuality and gender identity formation, HCT, and navigating adult life with a disability at a particularly vulnerable life stage. It is therefore important to explore that how sexuality and gender identity formation is experienced in the context of HCT for youth with CP. In 2014, East and Orchard described a “painful reality” such that, no one overtly asked youth with disabilities about their ideas of sex, dating, intimacy, or their bodies. Furthermore, the authors reported that HCPs consider education regarding sexuality as ‘somebody else’s job’ – someone who is more qualified to handle this kind of situation (East & Orchard, 2014); over the last decade this reality has not changed substantially. There is a gap in knowledge about how youth with CP and their HCPs experience the HCT process regarding sexual health support and sexuality education that is needed for the youth to form their sexuality, sexual identity, and sexual orientation. Moreover, sexuality related perceptions, lack of knowledge, organizational policy and the overall complexity of the intersections between identities creates the need to explore how these can impact on the HCT experience of the youth with CP from the perspective of HCPs and the youth themselves.

In HCT programs for youth with CP there is rarely any specific educational components or consideration of sexuality and discussion of diversity in gender identity (Wiegerink et al., 2011; East & Orchard, 2013; Sellwood et al., 2017). O’Shea and colleagues (2020) have demonstrated that people with disabilities who also have different gender identities and sexual orientation

mask themselves as heterosexual and cisgender in disability services out of discomfort, frustration, and despair. It may therefore be hard for emerging and young adults with CP who have different gender identities to communicate their health needs concerning sexuality or gender because of the omission of these concerns in healthcare transition services. It is possible that HCPs only see a client's disability, and therefore, key aspects of sexuality and gender diversity may be ignored or deemed irrelevant because of their disability status (O'Shea et al. 2020; Wilson et al., 2018; O'Shea & Frawley, 2020). In their 2021 study, Cain and Velasco presented the life story of Gray, a person with a disability and a non-binary gender identity. They focused on the gender transition experience of this individual with disability and recommended that further research was required to explore how HCPs, using their therapeutic relationship, can help people with disability who are not sure about their gender identity, or are considering transitioning to another gender identity. It is also unknown how youth with CP negotiate their journey or gender identity in the context of the HCT process. Therefore, to extend support to these youth it is crucial to have more research investigating the HCT experience of the youth with CP with diverse gender identities from the perspective of HCPs and the youth themselves.

Hence, the purpose of our study was to explore how gender identity and sexuality are experienced in the context of HCT for youth with CP to support the youth to have a favourable HCT experience. This knowledge is important to: understand how youth with CP develop sexuality and gender identities, explore the level of support they need and/or receive from HCPs during the HCT, offer strategies for HCPs to address sexuality and gender identity during HCT, and enhance the understanding and importance of this experience to support the creation of appropriate organizational policies and programs.

Methodology & Methods

This chapter includes a description of the research methods used in this research project. I began with a brief overview of the study design and research objectives, followed by recruitment criteria, strategies, and sample size. I then provided detailed explanations of data collection methods, data management, and data analysis. Next, I described how I situated myself in the research and the paradigm this research is positioned within. This chapter concludes with the ethical considerations employed during the study and quality criteria to demonstrate the quality and the trustworthiness of the research project.

Study Design

This was a qualitative study guided by van Manen's (2014) phenomenology of practice which is grounded in life experiences and gives attention to the routine things of day-to-day life, thus making this approach well suited for studying healthcare realities (van Manen, 2014).

Phenomenology of practice emphasizes the lived experiences of a particular phenomenon, that is, how the phenomenon is experienced at the time it occurs not how it can be conceptualized or theorized. van Manen's phenomenology is a combination of interpretive and descriptive phenomenological elements (van Manen, 1990, Dowling, 2007). Therefore, it emphasizes rich description and interpretation of data; and according to van Manen it is the act of writing from which insights emerge. Phenomenological research is inseparable from phenomenological writing (van Manen, 2014), thus writing was emphasized in this study as a core component to the research method. The responsibility of the researcher is to write for their interpretation while the reader will also interpret the findings individually (van Manen, 2014). This study followed experiential and thematic draft writing; where experiential draft writing means being attentive to inserting lived experience material into the text, and thematic draft writing involves converting

themes (discerned from theme analysis) into narrative passages (van Manen, 2014). However, there is no established series of steps or consecutive stages of writing (van Manen, 2014), rather the author writes with the intention to be sensitive to the concerns of professional practices in professional fields as well as to the personal and social practices of everyday living (van Manen, 2014).

Research Objectives

The primary objective of this study was to explore how gender identity and sexuality are experienced by youth with cerebral palsy (CP) during healthcare transition (HCT). This was achieved by gathering the first-hand accounts of healthcare providers (HCP) and youth with CP through semi structured qualitative interviews. The literature base shows a lack of knowledge and education regarding gender and sexuality to support people with developmental disorders or disabilities (Saxe and Flanagan, 2016; Travers et al., 2014; Whittle & Butler, 2018; Stanojević et al., 2023; Sellwood et. al., 2017; Mulcahy et al., 2022). So, our secondary objective was to explore wants and needs of youth with CP or their HCPs related to education and/or support for gender and sexual health concerns that may help them have a favourable HCT experience.

Inclusion and Exclusion Criteria

We planned to recruit two populations for our study youth with CP and HCPs. Adolescents or young adults were eligible for the study if they had a diagnosis of CP, were between the ages of 14 to 25 years and were able to converse in English with an unfamiliar sender (someone unknown to them - Communication Function Classification System (CFCS) Level I or II). Generally, people with complex healthcare needs transition from pediatric care to adult care around the age of 18 years but the transition process begins around 12 years of age and is most often complete by the age of 25 years (Brandon et. al., 2019; American Academy of Pediatrics,

2011). The age range for the participants with CP in this study was 14 to 25 years, to capture individuals who had, at minimum, started the HCT process. Exclusion criteria involved being unable to converse in English with an unfamiliar sender (CFCS Level III-V) and having moderate to severe cognitive impairment (either self-reported or if unable to navigate the conversation with the researcher on the telephone). HCP participants e.g., physiotherapists, psychiatrists, occupational therapists, social workers, were eligible for the study if they had experience providing care in the HCT process of the youth with CP.

Sample Size

The sample size for a qualitative study should be large enough to explain and represent the phenomenon under study, and small enough to enable deep case-oriented analysis. Creswell suggested interviewing between 3 to 10 participants for a phenomenological study (Creswell, 2013; Govindaraj, 2020). Whereas Morse (1994, 2000) has suggested at least 6 participants for phenomenological studies. However, in phenomenological research, the main objective is to obtain a rich personal experience, saturation is usually not a main goal (van Manen et al., 2016). Hence, for phenomenological study saturation was not a determining factor for the sample size. Moreover, in the matter of qualitative research, generalisation from the sample to the population is also not a major concern, instead the role of the researcher is to interpret and explain the phenomenon under study (Maxwell, 2013; Govindaraj, 2020). We planned to recruit up to 18 youth with CP, with a maximum of 9 participants of any one gender, to compose a sample including diverse gender identities (youth with CP identifying as LGBTQAI+ and youth who do not identify as LGBTQAI+). We planned for a higher number of participants to include the experiences from all individuals with different gender identities and sexual orientations. Due to challenges associated with participant recruitment we eventually broadened the scope to include

the HCPs experience as well with a plan to recruit up to 10 HCPs with various professional backgrounds to have a profound experiential data and to create reflective phenomenological text (van Manen, 2014).

Recruitment

Recruitment began in October, 2022 and completed in March, 2023. Investigators communicated with community organizations that provide support to youth with CP including *CanChild* Centre for Childhood Disability Research, Empowered Kids Ontario, and other professional associations to recruit participants using posters/advertisements. The advertisement materials were shared by social media communications (various social media platforms of those organizations including organizational websites, Facebook, LinkedIn, and Instagram) and by email (in newsletters and other email communications to their clients). Additionally, advertisements were shared on various social media platforms of by the Child Health, Exercise and Rest Lab, including posting in Facebook groups for people with CP (with permission from moderators), as well as posted on LinkedIn and Instagram. Physical copies of the advertising material were also posted inside local recreational centers, gymnasiums, and health clinics. Study team investigators also reached out to their personal networks (professionals who had prior experience of working with youth with CP) with flyers.

The intention was to use a purposive sampling approach, but due to limited number of responses the study used convenience sampling approach. Convenience sampling includes selecting participants that are more readily accessible to the researcher (Suen et al., 2014). After receiving the interested participant's (HCPs and youth with CP) information, the primary researcher contacted the potential participants and confirmed their eligibility to participate in the study according to the inclusion and exclusion criteria through email communication.

Data Collection Methods

Qualitative data were collected by conducting individual interviews or, where appropriate, a group interview with participants, using a semi-structured interview guide and prompting questions when needed. The focus of the semi-structured interview guide (separate versions for youth with CP [Appendix A] and HCPs [Appendix B]) was to explore the experience of sexuality and gender identity formation for youth with CP during the HCT. Questions were also asked about consultation or education around sexual health during HCT.

Youth with CP participated in individual online qualitative interviews, HCPs participated in either an individual interview or in a group interview when multiple HCPs from the same transition clinic were interested in the study. The group interview was an option offered to facilitate recruitment and reduce the respondent burden on the clinics (multiple providers could participate in a 1-hour interview together rather than several individual interviews). Despite being run as a group interview, participants were asked to share their own individual experiences for each question asked. All participant interviews were conducted via a live meeting through Western's Corporate Zoom Platform lasting approximately 30 to 60 minutes. The interviews were audio recorded and transcribed verbatim using the live transcription feature of Zoom. Later the transcriptions were checked for accuracy by the primary researcher. Interview transcripts were stored and shared with the principal investigator by uploading it on a unique folder on Western's OneDrive.

Data collection followed phenomenological interview guidelines proposed by van Manen (van Manen, 2014). Specifically, focus was placed on gathering depth in experiential narrative accounts or stories and less on perspectives, cultural or socio-psychological opinions and beliefs,

unless they were a feature of a participant's experience. Participants were asked to provide accounts of instances, situations, people or events that describe their experience. For example, probing questions included: 'What exactly happened?', 'Who said that?', 'How did you feel?', 'What did you say then?', 'What do they say?', 'How did they respond to it?', 'What else do you remember about the event?', 'How was the experience?' etc. Probing and prompting was used throughout the interview to gain deeper understanding of their experience.

Data Management

Electronic copies of the consent form and survey were contained within the Qualtrics survey platform which uses servers which conform to Canadian data storage policies. If participants chose to turn on their video during the Zoom call, the video files were deleted immediately after it converted. The audio recordings of the interviews were destroyed after the transcription was completed and checked by the study team. The transcript data was kept in a password protected file on a secure institutional server, that is, on primary researcher's Western OneDrive.

Transcripts were de-identified during transcription, any identifying names of people or organizations were removed. Study IDs and pseudonyms were used to deidentify the data. The information regarding participant's pseudonyms or IDs and corresponding participant's names, email address was kept in a password protected file stored separately from the data on Western OneDrive and only accessible by the primary researcher. De-identified study data stored electronically will be erased after 7 years from the time of collection as per institutional policy at that time.

NVivo 12 (QSR International) software was used for data analysis process for this study. It is a software program specifically used in qualitative, and mixed method research to analyse unstructured text, audio, video, and image data including interviews, focus groups, surveys,

social media, and journal articles. In this study we used it to organise data, code the transcribed data, create memos and annotations, develop final themes from the child codes, and run queries.

Data Analyses

van Manen's (van Manen, 2014) methodological approach to phenomenology of practice emphasizes description and interpretation; therefore, importance was given to rich description and the primary researcher moved back and forth between raw data and interpretation during analysis. To have insightful experiential accounts and reflective phenomenological text, data collection and analysis were completed concurrently; for example, primary researcher started analysing the interview data of the first participant immediately after the interview and at the same time the researcher continued to recruit new participants and collect data from them. Data was collected until the research team had adequate rich and in-depth information to fully capture the experience.

According to van Manen (2014) there are two criteria that needed to be met for successful phenomenological analysis. First, an appropriate phenomenological question and second, sufficient quality experiential material to reflect on. Thus, the phenomenological question for our study was: "How do youth with CP experience sexuality and gender identity during their HCT?". The interview data also gathered in depth experiential material to reflect on, interpret and explain the HCT experience through the semi-structured interview guide, open-ended questions with follow-up prompts and revising the semi-structured guide with learnings or reflections from previous interviews as appropriate.

Data analysis followed a series of steps, repeated in cycles, consistent with the iterative analysis process described below. First, the primary researcher immersed herself in the lived experience data, the researcher read the transcribed data thoroughly and listened to the audio files carefully without taking any immediate action. The audio recordings were listened to multiple times during the transcription process. Secondly, while reading and re-reading the transcribed data, the researcher wrote down any thoughts, questions or comments in a memo attached to the transcript to note and revisit while analysing the data. Next, the lived experiences were coded to form anecdotes. Anecdotes are very short and simple stories describing a single incident or close to the central moment of the experience (van Manen, 2014). Anecdotes contains concrete details, and often contain several quotes describing what was said or done etc. The next step is thematization, van Manen suggests 3 approaches for thematization from the anecdotes; i) wholistic reading approach, ii) selective reading approach and iii) detailed or line by line reading approach.

The wholistic reading approach describes exploring the insights of the texts at the level of the whole story and investigates how the phenomenological meaning of the text as a whole can be captured. Wholistic reading approach was accomplished in this study by listening to and reading the transcripts followed by writing memos about the issues described by that participant at a high level. The selective reading approach entails reading or listening to a text several times to find out the important/evocative statement or phrase that reveals the phenomenon or the described experience. The selective reading approach was accomplished in this study by identifying a concept from the wholistic reading memo and searching for the concept within and across participant transcripts. Finally, the detailed reading approach explains an approach of thematic analysis that includes line by line reading to look at every single sentence and ask what that

sentence may reveal about the phenomenon. The detailed reading approach in this study was accomplished by using the data analysis software to perform line by line coding to facilitate the creation of themes related to the phenomenological experience. Each transcribed interview data was imported into the software and coded individually and when new participant data were added, they were again coded by reading line by line to existing codes or new code according to the meaning of the text. The primary researcher made new codes if needed until the coding of the last interview was completed.

Similar codes were grouped together to develop possible themes. All the codes were treated as child codes before developing any theme. Then, the primary researcher created annotations for each emergent theme to describe and record an introduction to the theme for later use in the analysis process. When all the transcripts were coded and grouped into emergent themes; codes and references were rechecked to confirm that the interpretation of those codes illustrated the emergent theme. Interpretation and depth of a text was given more importance over frequency of words or similar words. Finally, the themes were described and supported by participant quotes during the phenomenological reflective writing of the experience.

Situating myself in the research

I have always been fascinated by healthcare professions and finding ways to provide service to people to support them in their efforts to living a healthy life. My family also wanted me to pursue a career that involves healthcare. One of my relatives who had been working as a psychologist in United States of America encouraged me to study physiotherapy as he envisioned this to be a highly required profession. So, with little knowledge about physiotherapy, I started my undergraduate program, BSc in Physiotherapy. With time I explored, learned, and

dug deeper into the field and was thrilled to see the scope of work in my profession. After graduating, I started working as a physiotherapist in my home country, Bangladesh and had the opportunity to work in different sectors; pediatric, geriatric, orthopedic or musculoskeletal, neurological and sports. During my employment with a rehabilitation center, I worked with children and youth with neurodevelopmental disorders and disabilities. This brought me close to the experience and challenges the children and their families face when living with a variety of disorders. I also came to realise that there is a lack of comprehensive care for the people with neurodevelopmental disorders. I saw concerned and self-sacrificing parents, who did not know what they were doing, other than searching for the best healthcare for their children.

My experience during this employment created a connection and urge to do something for these children. I then switched to another clinic with better professional opportunities in my city where I was providing care to adolescents and adults with orthopedic and neurological conditions. One day I consulted with a young adult male with CP, classified as GMFCS level I, who had slightly abnormal gait due to muscle contracture but no other serious issues. He captured my attention as he mentioned that he was okay, but had concerns about his posture and gait pattern were because he was going to be married soon. He was worried that his disability might impact his conjugal life. He was also worried about how his new relatives or in laws will see him due to his disability. This interaction highlighted a number of challenges that individuals with CP may experience from due to their diagnosis/disability, including low self-esteem, body perception issues, concerns about sexual health, among others. However, during my clinical practice, I was frustrated with the lack of research about clinical problems such as the case I shared above, hence research became enticing. Therefore, I decided to recommence my academic career and looked for greater opportunities to learn and do research work in my field of

interest. Close to that time I had an online interview with Dr. Laura Brunton (my supervisor) as I was applying for the MSc in Health and Rehabilitation Sciences program at Western University. During our meeting I shared my experiences, my views and intention to do a research project in this area. I was fortunate enough to meet her at that time; our interests aligned, and she provided me the scope to work with her and build this research project.

I was unaware of the possible paradigmatic positions for how one knows what they know until I took a course about qualitative research methods during my MSc program. In the beginning I thought I understand and align more with the positivist or post positivist views of the world. But the more things unfolded, the more I saw myself aligning with constructivism. As a researcher, I believe in multiple, experientially, and socially constructed realities shaped by the dynamic interaction between researcher and participant. These realities are central to capturing and describing lived experience (Ponterotto, 2005). I acknowledge that the belief and understanding the researcher brings with them is inseparable from the data. According to van Manen (1990), our preconceptions will always be reflected in our work regardless of our attempts to bracket them and remove their influence. Therefore, understanding and embracing our preconceptions throughout the data collection and analysis process aligns with both the constructivist view and van Manen's approach. I carried out ongoing and iterative reflexive journaling activities, starting before the data collection phase, that continued throughout the data collection and analysis process, to acknowledge my own perceptions about the topic. I uncovered and acknowledged my own preunderstandings about this topic by writing down my thoughts, understandings, and beliefs about gender, sexuality, disability, and HCT. I also discussed my preconceptions with the principal investigator (my supervisor) during our bi-weekly meetings to reflect on my thoughts

and understanding. My preunderstandings were, for example, that people with disabilities are less familiar with gender fluidity, thus shows less interest in gender transition, HCT in western countries are more considerate and accommodating to the gender diversity to support people with disabilities. I come from a country that is very less welcoming to the LGBTQ+ community, even the mass population is not often aware of these concepts. So, during my clinical practice I never came across any patient who identified as LGBTQ+. My preconception therefore was, there are not many variations in gender identity and sexuality among people with disabilities. I also reflected on my previous clinical experience and why I was drawn to the topic of this current research. I continually reread these journals throughout data collection, transcription, and analysis to continue to acknowledge and reflect on how my preunderstandings were contributing to the data collection and interpretation and how they changed over time. For example, by the end of the study, I was much more aware of the different gender identities experienced by youth with CP.

Paradigm

This study is located within the constructivist paradigm; therefore, inductive research methods were emphasized in this study (Tashakkori et al., 2021; Adom & Ankrah, 2016). Ontologically, constructivism aligns with relativism which accepts local and specific constructed realities (Guba & Lincoln, 1994). Realities that are based on social and experiential elements, and perceptible in the form of multiple, intangible mental constructions (Guba & Lincoln, 1994). Reality is subjective (Adom & Ankrah, 2016) and under the influence of the context of the situation – participant’s narrations of their lived experiences and perceptions, social environment, and the interaction between the participant and the researcher (Ponterotto, 2005; Tashakkori et al., 2021). The researcher cannot be separated from the research process, instead their thoughts, experiences

and knowledge has a positive influence on the research (Tashakkori et al., 2021; Shannon-Baker, 2023). Epistemologically this is subjectivist and transactional in nature. So, the phenomenon under investigation and researcher are linked interactively and with the progress of the research, the findings are created. This implies that the knowledge is created or co-constructed through the researcher and participant interaction (Tashakkori et al., 2021). The varying social and individual constructions in this paradigm are compared and contrasted through dialectical interchange.

Ethical Consideration

Prior to recruitment, ethics approval was obtained from the Health Science Research Ethics Review Board at The University of Western Ontario. To complete the e-consent process, the qualified and interested participants were sent a study ID number and a Qualtrics link via an email. The participants read the consent form on the Qualtrics link and completed/selected a box saying they consent as their signature. The e-consent was provided for both participating in an online interview and audio recording of the interview. Once the consent was received, they were sent a zoom link through another email to conduct the interview at their preferred time. They were informed about their rights to share information or withdraw from the study any time they want to. Given the sensitive nature of the topics, the participants were also reminded during the interview that they could skip any question if they wanted to or if they did not feel comfortable, and that they could take breaks and come back to the interview if needed. The LOI was reviewed prior to the interviews. In addition to the prior e-consent, verbal consent was also confirmed during the interview just prior to starting the audio recording. Considering the sensitiveness of the topic for youth with CP they were informed prior to the interview that, if there were concerns about mental well-being, the participants will be contacted by the study PI (principal investigator) to discuss service options for them including referring them to see their general

practitioner. This was arranged to ensure the participant's safety and well-being. Participants were informed about the purpose of the study, the data collection methods (qualitative interview/group interview), provided with the interview guide, and any questions they had were answered through email communication before the interview. The researcher de-identified the interview data to protect the confidentiality of participants by removing any references to people or places that could identify the participant or the clinic they work in.

Quality Criteria

“Paradigms matter when considering how to assess quality because these basic assumptions guide what a researcher seeks to know, how they approach knowing, and what they believe are the best ways to know (Morrow, 2005)” (Ravenek and Rudman, 2013 p.440). This study was situated in the constructivist paradigm; the study design, methodology and framework were developed accordingly.

Morrow (2005) introduced both ‘paradigm specific’ and ‘transcendent’ criteria for examining quality and trustworthiness in qualitative research. The paradigm specific and transcendent criteria can be interrelated and each of the criteria can assist in achieving the other criteria. Both paradigm specific and transcendent criteria were used to increase the trustworthiness and quality of this study.

Paradigm specific criteria for constructivism consist of authenticities (specific to this study fairness, ontological and educative authenticity,), and meaning (verstehen, co-construction). Solicitation and recognition of different constructions is a must to fulfil the criteria of fairness. Different constructions were honored and solicited to fulfill the criteria of fairness by looking within each transcript to explain part of the phenomenon as it was lived by that person as well as across participants to examine similarities and differences in the description of the phenomenon.

Ontological authenticity requires participant's individual constructions to be improved, expanded, and elaborated. To promote educative authenticity, it is required to foster the understanding and appreciation of different constructions among the participants. Authenticity depends on improved and elaborated individual construction of participants, their understanding of and appreciation for the constructions, and the extent to which action is stimulated (Morrow, 2005). This study sought to provide multiple quotes from different participants to demonstrate authenticity of individual constructions.

To achieve the criteria of meaning, researchers must consider enhanced and deep understanding of participant's constructs and mutual construction of meaning (co-construction). 'Meaning' also includes (a) the extent of which participant's meanings are understood deeply- verstehen; (Patton, 2002; Ponterotto, 2005; Schwandt, 2000) and (b) the extent to which there is a mutual construction of meaning between and among researcher and participants (Morrow, 2005). In this study, we emphasized exploring the experiences of the participants from their perspective and context in the healthcare to have a deeper understanding of the participant's meaning. Also, researchers having a background of HCP and being familiar with CP or individuals with CP helped in better understanding of participant's context and meaning. Using a constructivist paradigm, the researcher and participants worked together to mutually construct the meaning of the phenomenon by discussion during the interviews.

Transcendent criteria comprise subjectivity and reflexivity, social validity, adequacy of data, and adequacy of interpretation. Managing subjectivity is important, this can be acknowledging and

even embracing it as a constructivist (Patton, 2002; Morrow, 2005). Reflexivity provides the researcher an opportunity to recognize how their world view and experience can affect the research process. To address these criteria, the researcher focused on various strategies of reflexivity and subjectivity. Congruent with the constructivist paradigm, the researcher embraced the subjectivity. According to van Manen, even if the researchers try to forget what they know, the preunderstanding persistently creeps back into their reflections (van Manen, 1990; Dowling, 2005). Therefore, the primary researcher acknowledged her preunderstanding and subjectivity, and incorporated reflexive practices throughout the research process. For the purpose of reflexivity, the primary researcher wrote down her pre-assumptions, consulted with the principal investigator of the research project weekly and revisited the preunderstanding notes during the data collection, analysis and interpretation. Acknowledging and embracing subjectivity also contributed to the 'fairness' of this qualitative study as participant's viewpoints were represented equitably and any lopsided interpretations were avoided, such that opposing views were considered and presented within the data and where an issue was raised by only one participant it was described this way in the results.

Social validity refers to the social importance of the topic of research. The eagerness of the HCPs to discuss this issue and volunteer for this study reinforced that this topic is of importance and contributed to the social validity of the question and research topic. Adequacy of data is achieved by having rich data not merely depending on the numbers of participants but on the in-depth, insightful, and meaningful data acquired from the participants. 'Adequacy of data' was demonstrated by having information rich data and using a sampling technique that allowed to include participants with knowledge and experience in the field of studied phenomenon, also by

asking fewer questions to allow the participants to elicit stories and deeper meanings of the phenomenon. Primary numbers of interviews or participants cannot speak to the fact of adequacy, the data must be in depth and profound in information. This study offers rich data from diverse participants. Data were gathered until we had sufficient in-depth information to capture the full experience and had common elements across participants and participant groups.

Finally, the 'adequacy of interpretation' during the process of data analysis, interpretation, and presentation is essential to round out the criteria for trustworthiness (Morrow, 2005). Adequacy of interpretation is demonstrated by immersion in the data, completing systematic analysis according to research design, and keeping a balance between investigator's interpretation and supporting participant's quotations during writing. Adequacy of interpretation in this study was confirmed by following an interactive process of data analysis, interpretation, and writing. The primary researcher immersed herself in the research by reading and re-reading the interview data, listening to the audio recordings repeatedly to deeply understand the data. Data analysis and interpretation was completed following a pre-determined analytic framework aligning with the study design. The writing or presentation of the findings were achieved in a way that demonstrates balance between investigator's interpretations and supporting quotations from participants in this study. Furthermore, the interconnected nature of the established themes demonstrated additional adequacy of interpretation. The actual words of participants were used to persuade the reader that the interpretations of the researcher were grounded in the lived experiences of the participants.

Results

This chapter explores the themes that emerged from the study data which were collected by conducting individual and group interviews. Before addressing the themes, I have described the demographics of the participants. Next, I have listed all the themes emerged from the data analysis and represented those in a diagram. As this study had two study populations, while presenting the themes and subthemes, I have explored the findings from the youth with cerebral palsy (CP) participant followed by the healthcare provider (HCP) participant's findings under each theme or subtheme.

Participants

Ten participants participated in online semi-structured interviews between January 24th to March 23rd, 2023. Participants were nine HCPs and one young adult with CP. Five HCPs and the adult with CP participated in an individual interview, whereas the other four HCPs participated in a group interview. The HCPs represented a wide variety of professional backgrounds and had many years of experience in their respective fields which made them capable of sharing valuable experiential data.

The participant with CP was Milly (pseudonym) - a 20-year-old person who identifies as a bisexual, cisgender female, she had completed her healthcare transition (HCT) phase and was now receiving care in the adult healthcare environment. Milly provided a self-reported distribution of involvement of CP of hemiplegia, and a self-reported gross motor function classification system (GMFCS) level of I. The investigator classified Milly as a communication function classification system (CFCS) level I. Additionally, an overview of the HCP participant characteristics is presented in Table 1.

Table:1 Individual participant Characteristics

HCP Participant (Pseudonym)	Profession	Length of practice
Daisy	Physiatrist	8.5 years
Sophie	Social worker	8 years
Julie	Physiotherapist	19 years
Emily	Nurse	5.5 years
Lucy	Physiatrist	4.5 years
Jane	Neuropsychologist	15 years
Freya	Social worker	8 years
Olivia	Nurse	40 years
Carolina	Occupational Therapist	1 year

Themes

Although the focus of the interviews was exploring the experience of sexuality and gender identity during HCT, participants talked a lot about the difficulties and challenges during the HCT for youth with CP generally – this was compiled under the major theme “Transition in General”. The subthemes under this theme included: advice about jobs and independent living, bridging care, challenges in adult care, death of caregiver, dependency on parents or caregivers, disability is expensive, frustrated youth, going into the abyss, HCP’s negative experiences, HCP’s positive experiences, increased medical issues, losing everyone, nobody is listening, ongoing care, overwhelmed family, role variability, struggling to be in charge of own care, transition challenges, troubles related to transition, and wheelchair funding. This theme is not presented in any more detail in this thesis as it does not include discussion of the main objectives

of this research. After separating out the general transition challenges, six main themes emerged using van Manen's three approaches of thematization (refer to Figure 1). The main themes identified were: Current state of gender identity and sexuality in CP, knowledge and curiosity about gender identity & sexuality among youth with CP, challenges with sexuality and gender identity, societal influence and pressure, sexual health support during HCT, and opportunities for change. Figure 1 represents these themes in a pictorial format that demonstrates several themes relate to the present transitional healthcare situation for youth with CP (represented by circles on the left side), and two themes that represent the possible solutions (represented by arrows) that may lead to a future, more ideal HCT experience.

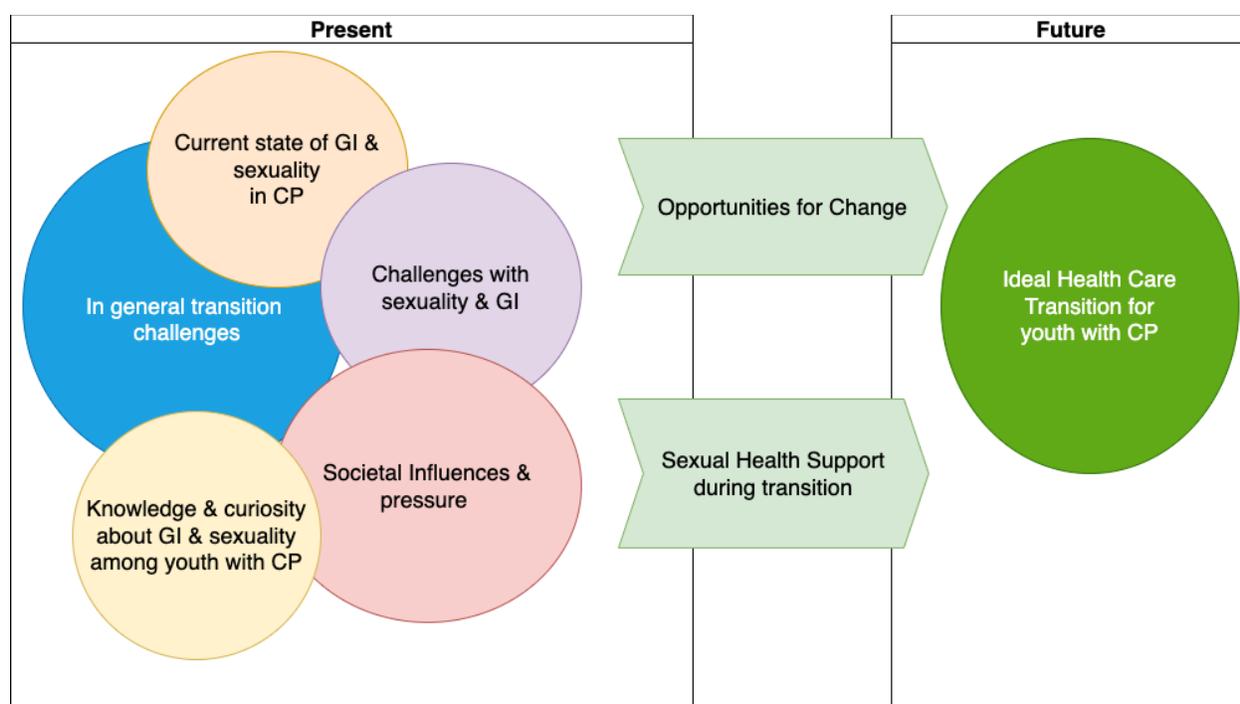


Figure 1: Diagram of themes. Size of the circles corresponds to the extent of impact of the themes.

The words that the participants used to describe the experience of sexuality and gender identity during the HCT among youth with CP is illustrated in a word cloud in Figure 2. The word cloud

constitutes of all coded text used to generate the six main themes. The size of each word indicates the frequency with which the word was mentioned across the total of ten participants during the semi structured interviews.



Figure 2: Word Cloud of the six main final themes.

Theme 1: Current state of gender identity and sexuality in CP

This theme explores the experiences regarding the current state of gender identity and sexuality in CP during the HCT. It shows the presence of various gender identities among youth with CP, at the same time reflects the reaction of youth with CP when asked or given opportunities to discuss sexuality and gender identity in the healthcare setting.

Gender Identity Transition

The young adult with CP participant shared that it was a long struggle to accept her identity and it required a lot of internalization. Milly mentioned there was a lack of support from HCPs and there was only one instance when she was asked about sexuality and gender, which she noted she appreciated. She further expressed the need for and importance of having a discussion about these topics.

Milly (adult with CP): ...There was nothing I don't think, certainly not from the HCP way of it. It was a long time of like struggling with the identity, and still in a bit accepting it, just cause, what does intimacy look like for women if there's one who has a disability? So yeah, I won't say there was any support through. It is a lot of internalizing it, and I think it was nice having that pediatrician finally asked me just, you know, to see if she could support me in anyway. And in terms of support, it wasn't like I needed her to do a whole bunch of things. It was just having that discussion, 'How do you feel?', 'Are you safe?', And that kind of thing. But other than that one instance there's been nothing.

HCP participants referred to the gender identity process as a journey that involved experiencing a lot of emotions; for instance, fear, conflict, suicidal ideation (as perceived or identified by the HCP participants in their clinical capacities). HCP participants also mentioned that youth with CP were very interested in exploring the gender aspect of their life and have sought healthcare support when considering transitioning to different gender. According to the HCP participants, youth are often unsure about their gender identity and need counselling to explore it, as reflected in this excerpt from a group interview:

Lucy (HCP): I also work in a clinic that used to be called the transition clinic. We renamed it because of a few reasons. But one of the big driving ones for me was, a few patients were also considering gender transition, and came to clinic really upset that we were not the gender transition clinic, and that was an important confusion that we needed to prevent. Also, our new name, better describes what we do...

HCP participants expressed that youth with CP shared during their medical visit that, they feel there is something wrong with them when they are not addressed with the gender they identify with. Participants described the mental health impact when youth with CP don't feel that they belong or that they can be themselves. Furthermore, HCPs raised concerns that going through this internal conflict for a long time may lead to other mental health impacts including suicidal ideations or attempts.

Freya (HCP): Yeah, no, it's annoying when people use the wrong pronouns, I think that there's something wrong with me, because it doesn't match with how they're feeling. So, I think that is a big piece where... And we do unfortunately have a lot of teens who come in and say, I feel suicidal, and I feel like I can't be myself. So, it's a huge mental health and yeah, cannot imagine that when the world is telling you something, but it doesn't match with what you really feel, what you really believe in, you know. Yeah, yeah, like the conflict, right? But when we're going through this conflict internally for very long time, a lot of teens are like, you know, I don't think I belong here. I don't feel I belong to this world. So, a big reason why I asked those mental health question is part of it. Like the sexuality piece is a huge part of self-identity.

HCP participants reported that often youth are scared or fearful of engaging with the gender transition process. They benefited from professional support to try or explore the elements and ways of talking about gender identity. This might look like not even knowing that they can have the conversations about gender identity, or how and who to talk about it with.

Sophie (HCP): There is one patient who really identified more as male, but was anatomically female, and so, they started trialing with me, being called a different name... So, in our program, we started referring to this person by their desired name. Now since then, they have returned back to, mostly identifying as female, and going back to their birth name. They were very scared at first, to try something, but they wanted to do it right. So, they expressed that they were fearful of trying something. For example, trying a preferred name. That person said, "well, I feel like 30% female. But there's a bigger part of me that's like really feeling more masculine", "And I really identify with that part more".

Work in progress

This subtheme also emerged from the HCP participant's experience. Most of the HCP participants talked about incorporating gender identity and sexuality questions in the HCT process. A few clinics are thinking of developing and incorporating step by step processes to support youth to have a more complete healthcare experience or are trying to develop strategies to include gender and sexuality pieces in their processes related to HCT. Participants voiced that the sexuality and gender identity conversation in healthcare, its impacts are very new to the healthcare system and the providers and so more work needs to be done to integrate and implement helpful strategies during the transition process.

Sophie (HCP): “We are trying to develop more processes. You know, in our program to do just what you're saying right to elevate and focus on that wholeness of a person's experience in life”.

Carolina (HCP): ...And all of this, cause I feel even sometimes, those gender conversations since are in the context of the hospital, are more medicalized, too, and just talking about those sexual relationships and that sort of thing. Yeah, it's just something that's been on my brain. I can't really elaborate on it. Because it's just a baby thought but, it's just something that I think our clinic is doing a good job is going beyond the medical and helping with that transition. Since it's so much more than the transition to adult healthcare. But yeah, it's this is good conversation. Just for me to start thinking about how I'm gonna implement this better.

One HCP participant, Olivia, also shared the fact that this issue has potentially been lurking under the surface for long time but maybe youth were not comfortable sharing this with HCPs. In recent years this topic has been evolving more in both general society and in clinical settings potentially resulting in youth being more forthcoming and comfortable talking about it therefore more attention to this issue is being provided.

Olivia (HCP): ...And I've noticed in the last 2 years this topic evolving more we're even thinking back 5 years ago, we didn't talk about sexuality on the clinic. And we certainly did not in the [other] clinic or [other clinic] either. Youth are more comfortable now talking about it and identifying who they are, which I think, of course, the topic has always been there, but they

didn't talk about it to adults, and certainly not the medical people, so they're more comfortable. And it's now coming out more in clinic.

Theme 2: Knowledge and curiosity about gender identity and sexuality among youth with CP

This theme represents the understanding that youth have about their diagnosis of CP in relation to gender identity and sexuality. In the interviews, participants discussed that youth with CP may have exposure to different gender identities through friends, peers, family members, schools and are thus aware of the concept but that there might not be any real engagement between the healthcare system and youth regarding how they identify themselves. Participants discussed that youth demonstrate curiosity and desire to learn more about gender identity and sexuality and how this might impact or be impacted by their disability or diagnosis. Furthermore, HCPs described that youth have a lot of questions and concerns related to their sexual health and acceptance in the society.

Misconception

Misconception about the diagnosis of CP and its influence on gender identity and sexuality experience among youth with CP was prominent in the conversations with all participants. The female participant with CP (Milly) expressed that she had a few misconceptions herself which she felt led to poor relationship, intimate partner violence and negative sexual health experiences. She reported not receiving clear information from HCPs and experiencing painful sex because of the misconceptions she and others held.

Milly (young adult with CP): So, for example, it sounds weird, but for women. I feel like, because of my disability, I wouldn't be as active partner, because, you know, mostly

digital...don't think physically I could be as good as that. A big thing that I face in terms of like I thought all sex was supposed to be painful, like I thought it was a CP thing. Learned that that's not the case. Yeah, it's like, a big thing is, finally realizing that it's not supposed to hurt. That was a big thing, because there were a lot of providers that told me like, "Oh, that's just normal". And it kept me in a bad relationship for a while as a result to that. So, I think that would have been good just to say like, it shouldn't hurt.

HCP participants expressed that, many of youth with CP do not have even a basic understanding or knowledge about their diagnosis related to sexuality and general sexual health. It became clear that there are numerous misconceptions and misunderstandings that youth with CP have and thus significant potential for education in this arena.

Lucy (HCP): A lot of people don't know whether or not CP is a genetic condition, or whether or not, if they had a kid, they'd be likely to have it. A few people have had false information about whether sexual activity is possible. Most people don't know, and are actually pretty curious. A few people already know, and that's great. One person thought ejaculating, would cause his brain to explode because it exploded before, when he had a stroke early in life, and so his brain was at risk of exploding. That was eye-opening.

Lucy (HCP): When I talk about, you know. Do you think, having your medical conditions or having CP would prevent you from getting a sexually transmitted infection? And so, most of them laugh and say no, but there have been a couple who weren't sure or and so, you know, I think it's important that any potential myths or biases [be discussed], you know, [just as] bathing in coke [coca-cola] doesn't prevent you from getting pregnant, having CP doesn't prevent you from getting pregnant. In almost all cases, there are a couple of exceptions.

Freya (HCP): How many teens come in and think that, "I have CP, so I can't have kids" and then we're like, Oh yeah, no, no, you can still have kids. What like "you guys do have to use protection because you can have sex" like you didn't know you could educate that piece and many things come out of the clinical "I never thought I could do that" right. But I think it's just a misconception of like what they really understand, CP and how that affects their body. And a lot of teenagers do truly believe that "because I have CP, my child will have CP", so then they set up a mind that "I will never have kids" or "I will never go into a relationship". Surprisingly how many teens think that like "because I'm dating the same sex. Then we can't have sex", or like, "it's okay to have sex, or we won't pass disease", things like that around, it's just a lack of understanding.

Response to sexuality or gender identity questions

HCP participants found youth with CP to be very open, enthusiastic, and ready to talk about sexuality and gender identity in the healthcare setting. Their response was overwhelmingly positive towards the discussion; once youth start sharing their concerns, and clinicians offer information the youth play an active part in discussion and are very forthcoming with information and questions. According to the HCPs, youth with CP appreciate the opportunity to have these difficult conversations with their HCPs and it provides confidence to continue conversations outside of these settings.

Sophie (HCP): So, I think that there's a lot of different emotions that are felt from what the feedback is been, when I inquire, like, 'How are you doing', 'how is it being today talking

about sexuality, gender identity?', you know. There's a mix.... Some have told me that they feel relieved. They feel very happy that they have a place that they can talk about this safely... and they often feel like, you know, a little bit soothed at that point... they're feeling that they're being valued as being a sexual person. And this is something that he's expressed. You know "I really love that, I can come in here, and I can talk and be seen as a whole person... I mean what I've heard from this person over the time that this was going on was a lot of positive feedbacks of feeling supported, of knowing that they were heard and accepted, no matter how they presented themselves in the world, and they actually told me that they found the courage to be able to, you know by themselves... talk to family members about this gender like this identity change right?

Daisy (HCP): So, I would say sometimes it's sort of like the floodgates open, and it ends up being sort of a significant part of our consultation that day, depending on the patient... But, also lots of people who are, very happy and maybe happy is not the right word, but are ready to talk about that... I've never had a patient say, I don't want to talk about that, or I don't want to tell you what my gender identity is when the door is open in general. They'll tell me. So, I can't think of a single instance where someone has declined to tell me their gender identity if they've been invited to do so, and often they might even offer that information, if we start having a conversation about sort of, you know, gender preferences, or you know that questions around intimate relationships and stuff like that.

HCP participants mentioned that they get a wide range of positive reactions or responses to the questions involving sexuality and gender identity. Youth are generally very curious about this topic and happy to discuss but some of them are scared and shy. In some of the cases the patients

said that they will talk about it later if they want to and they appreciated the chance to talk about sexuality and gender identity but they never reacted negatively towards these questions. Some youths are surprised to know that they can talk about gender identity or sexuality during transition.

Lucy (HCP): I don't think it's that different than youth without CP, except there's the spectrum of developmental abilities, cognitive abilities, behavior abilities. And so, we get more responses across the spectrum. Some are really shy and not, you know, not-interested. So, the reaction to the question, I think, is similar. Some are really curious. The information, when I ask the specific questions is very interesting. Most people don't know, and are actually pretty curious. A few people already know, and that's great. Yeah. Full range. Some have not thought it through at all and are completely petrified, some have not thought it through and have completely figured it out. Some have not thought it through and have a range of questions, or when I bring up topics, realize they don't know things, and then we have a conversation. Some have thought it through a little. Some have thought it through a lot, some are sexually active.

According to HCP participants, once the sexuality and gender conversations occur, some youth really open up with the HCPs and share their personal relationships and sexual preferences.

Freya (HCP): Yeah, even a lot of our teenagers, like, you know, some couple of girls would come and tell me like, I was dating a guy but now I am dating girl, and it's a lot of people like even parents like, I think you're lesbian. But the kid is like well, no, I don't define myself as anything. Like I'm not lesbian. I'm not gay. I'm not bisexual. I'm just is, I just in a relationship

with another human I feel really safe and comfortable with, right? So there, it's just so. No label, there's no label.

According to the HCP participants experience, youth with CP also provided positive feedback about being given the chance to talk to the HCPs without their parents/caregivers or anyone else being present in that room. On the other hand, one participant also mentioned that the youth have expressed their anger and frustration while talking about gender identity, mostly that people around them know very little about gender identity and they misgender them consistently.

Carolina (HCP): "I do get the chance to spend time with just the youth, and although, gender hasn't really come up, they are sort of, please don't tell my parents about this part. There's been conversations where it's like, oh, I would rather "just don't tell my parents about this part of the clinic that we've talked about".

Sexuality questions from youth

Youth with CP have shown a lot of curiosity regarding the sexuality and gender related topics. The HCP participants shared questions that the youth asked during their consultation or discussion with HCPs. For example, Sophie's (HCP) patient said that, *"I have these thoughts. You know what I mean. I want to be able to masturbate, I want to be able to have sex with a woman or sex with a man, how can I do that, Sophie?"* The youths with CP also want to know how their specific symptoms and disabilities can impact their sexual health, how do they meet people, will they be able to have kids, is it okay for them to be in intimate relationship, how can they initiate sexual relationship, can they date somebody who is older? Do they have to date somebody who also have the same medical condition? will their children also have CP? It demonstrates that youth have a number specific sexuality-related questions that directly relate to

their diagnosis of CP. The lack of knowledge of how to manage their diagnosis in this new realm of being makes them concerned about their sexual health and relationships.

Daisy (HCP): Can I have kids in the future? What would that be like”, or “I'd really like a boyfriend, or a girlfriend, or some kind of an intimate partner, And I just don't know how to even approach that”, or you know “I have questions about how my spasticity is gonna affect my ability to be sexually active”, or whatever the case may be. So, lots of different questions may come out of it in general. Definitely, we hear questions about, Ahmmm... I would kind of lump it all into healthy sexuality. You know questions about like, “how can I position myself for sexual activity?”, or “will I be able to have an erection?”, or “am I going to be able to get pregnant?”, or “will it be difficult for me to carry a pregnancy or have a baby?”, so questions like that I would say are common.

Carolina (HCP): [one patient shared] “Yeah, every time I'm around this person like all of these, like she has CP, too.” She's like “I feel so nervous and I'm sweating. I'm breathing so hard, and all of this stuff,” and she had no idea why

Theme 3: Challenges with sexuality and gender identity

This theme describes a few challenges associated with sexuality and gender identity that youth face during the transition to adulthood both in healthcare and in their personal lives. The main subthemes were: discomfoting sex talk, difficulty finding a partner, higher inappropriate sexual contact and lack of media representation.

Discomforting sex talk

The participant with CP (Milly), expressed her experience in that the conversation regarding sexuality and gender identity never happened, HCPs never initiated the “talk” and she was very scared to bring it up with the HCPs during her medical visits.

Milly (young adult with CP): “But it's never been brought up, and I've been too scared to bring up, like the physical disadvantages that could happen in terms of having sex”.

HCP participants also spoke about the discomfort attached to initiation of discussion regarding sexuality and gender identity. HCPs reported that youth often looked scared or shy to begin the conversation, and they don't know how to talk about it or if they are even supposed to talk about it, so it was often an uncomfortable experience. However, many participants reported that once youth get the opportunity to talk about it, they show signs of feeling relieved.

Daisy (HCP): ...what I observe is that often it seems like it's a little bit uncomfortable for them to start that conversation, but as soon as we start the conversation in general, it's almost like you can see them take a breath like “oh, thank goodness, someone knows that I want to talk about this”, cause often it seems like it's not something that they've had the opportunity to talk about before.

Sophie (HCP): ...sex is never, really, never been talked about, and also the conversation is largely discouraged, ... maybe that's a strong word, ... I think that like definitely, there's a ton of discomfort. And then the social worker starts bringing up the topic. You know it's often met with a little bit of shock... Like, cause it's like, “okay, wow, okay. All of a sudden, somebody's there who's ready to listen or able to talk, but I don't know if I'm comfortable with that”. It's like completely foreign. And “am I supposed to be talking about this?”

One important consideration related to this is that during and after the COVID-19 pandemic many consultations were and still are taking place virtually. One challenge to this model is that HCPs don't know if any other family members are present in the room or not. The presence of a parent or sibling can cause significant discomfort when discussing these challenging topics. Another noted issue was if there are multiple HCPs discussing these topics at the same time, then youth may show signs of discomfort.

Olivia (HCP): "I noticed that the youth are uncomfortable with....., our team is all women and with me, being older as well, I find if I step out of the room, or if I step away from the zoom call where there's like 4 women staring at this poor youth. Then they open up to Dr. X".

Difficulty finding a partner

This subtheme appeared from the experiences of the HCPs only. According to the HCPs experience, youth with CP find it difficult to meet somebody to date or be in an intimate relationship with. They experience frustration with not being able to connect with somebody. However, HCPs spoke about not having solutions from a medical sense, but that counselling is a large part of their role in HCT - being supportive and providing a safe space to talk about appears to have been helpful. HCPs also acknowledged that this is a role for advocacy in the medical system related to this issue and others.

Daisy (HCP): I think a lot of people have concerns about successfully finding an intimate partner. So, it's difficult to navigate those relationships for anybody. I think, an added layer of difficulty is found by people who have developmental or physical disabilities or differences. And so, I think a lot of people are worried about whether or not that's going to happen for them. And

questions about, “how can I do that?”, “How do I meet people”... and that kind of thing... they just say, like, “this has been a really hard thing for me”, and then it just sort of opens the door for us to be able to kind of talk about that and explore feelings related to that since I don't have necessarily a solution from a medical standpoint about where you're going to find your intimate partner. But having sort of safe spaces to talk about that, I think, has been a really helpful thing for people.

The struggle with finding a partner can sometimes contribute to mental health problems, and HCPs report that youth get upset and discouraged when they do not get opportunities to meet new people to build meaningful relationships. Some youth may also get involved in convenient and unhealthy sexual practices.

Sophie (HCP): this person wants to be sexually active, absolutely wants to meet women in his case, being heterosexual, and is just feeling quite discouraged and depressed about not having that in his life... if I can't get a girlfriend or boyfriend conventionally, like some of them, talk about being interested in their care providers like their PSWs and stuff like that. Some of them have dated their PSWs before and then some of them, some people with CP, that I've talked to have some interest in exploring sex workers, And this is, of course, a conversation that's difficult sometimes to have with families.

Higher inappropriate sexual contact

The young adult with CP and HCP participants both discussed a challenge that there are higher incidents of inappropriate sexual contact for youth with CP. Milly (adult with CP) spoke about sexual violence and expressed that, youth with CP are more vulnerable and prone to sexual violence than people without CP or disability, especially in scenarios where youth may not have

the strength to defend themselves because of their disabilities. Milly shared an experience of intimate partner violence, including a lack of support from HCPs and people around them when trying to process and heal from those experiences.

Milly (young adult with CP): I think as horrible as it sounds, it's just letting people know that there are higher rates of sexual violence against people with disabilities. And it's unfortunately something that I've had to experience, and not having that support at all, because a lot of shame and like expecting pain to be normal, because of the disability, even though that's not the case... I think there needs to be, not in a way of scaring people, but there does need to be some talk about, how sex can be slightly more dangerous for us. In the sense that like there are people that specifically go after people with disabilities, and, like I had the kind of core, not even a relationship that I was with. But not necessarily having the strength to fight back is harder.

Lucy (HCP): I know literature tells us that kids with disabilities are more likely to take part in risky behaviors, whether it be unprotected sex or drugs. I think a higher percentage like I haven't worked in a population that doesn't have disabilities. But I think the number of people who tell me about previous inappropriate sexual contact is probably higher than the typical population. I haven't tracked it systematically, but yeah, that has come up more than I expected it to unfortunately.

Theme 4: Social influence and pressures

Sexuality and gender identity is influenced by the greater societal understanding of these concepts as well as the pressures and understanding of patients in healthcare settings. The theme social influence and pressures included nine subthemes: CP is their identity, assumed asexual, misconception among HCPs, non-existent gender identity and sexuality conversation, parent's influence on the youth with CP and their healthcare, ableist view, sexuality and gender not being

the priority of care, gender identity just seen as pronouns on the charts, and unaware of gender identification process. The main subthemes will be discussed in further detail below. The subthemes that are not elaborated below, also demonstrates how the understanding of parents, HCPs and people in the society regarding sexuality and gender identity may impact the healthcare experience of youth with CP. The subthemes indicated the ableist view imposed by the society towards the individuals with CP and that they need support regarding this. One of the subthemes emphasised on the parental influence on the youth with CP and their healthcare. Some of these subthemes indicated that gender identity and sexuality are not the priority of care, they are merely question answers on the health charts.

Cerebral palsy is their identity

While talking about gender identity, young adult with CP and HCP both participants expressed that youth with CP are just seen as people with disabilities; they are not thought to have any other identities. The young adult with CP participant reported that, CP becomes their identity for HCPs and society at large, their sexuality or gender identity doesn't seem important.

Milly (young adult with CP): One thing I find like being someone with a disability, so that's the identity the same identity that you get associated with you're not really anything. You know, a sexuality or gender identity is not the most important, your disability is the main identity that you're thought of with healthcare practitioners and people in general. So yeah, in summary people with disabilities aren't just people with disabilities and just needing to have those conversations about what sex does look like for people with CP.

HCP participants shared that, while addressing a patient in healthcare setting, HCPs mostly see the disability they present with and focus only on that. They don't really give attention to the fact that they may have different gender identities or sexual preferences. Hence, it gets overlooked that they may have health impairments or concerns related to their sexuality or gender identity.

Emily (HCP): I think CP at a point becomes their identity. And there is not much relevance to their gender per se, or how they identify in that regards. their identity is CP. Not. If they're a he or she or them, that's not the focus at hand. Whenever I come across the patient it's more so. Okay, they have a CP patient. What are the things they're coming in with? And I think it's traditionally been like that. And it's just kind of carried forward that way... traditionally, the focus is more so on their CP diagnosis and the best ways to treat it or care for it rather, and inherently, that diagnosis becomes our identity and not their sexual preferences.

Society as a whole lacks awareness about the intersectionality of different identities held by people with disabilities. There is a presumption that people with physical disabilities don't experience the spectrum of gender identities and sexual orientations that are possible or available to the general population. Youth with CP may need support to manage these prejudices, heal from potential psychological harms they experience while navigating the development of their own identities and people who are willing to listen and support their choices and ability to choose.

Milly (young adult with CP): So, like I was on this one time when a group of people with disabilities were raising money for an LGBTQ plus organization and people were very surprised because why aren't you raising money for a disability charity. Like there isn't that understanding of intersectionality of people with disabilities. And it is just the disability.

HCP participants also highlighted this lack of understanding regarding the intersectionality of disability, sexuality, and gender identities among the people in the society. Figure 3 presents a representation of this intersectionality as discussed by participants.

Lucy (HCP): I do think there's intersectionality between groups that are ... essentially have prejudice against them for various reasons, and so there is prejudice against people with physical disabilities there's prejudice against people with alternative sexual orientations or gender identities etcetera and some of that intersectionality probably makes things worse, so they need more support.... but they need more support of society, not imposing, an ableist view that also extends to sexual health.

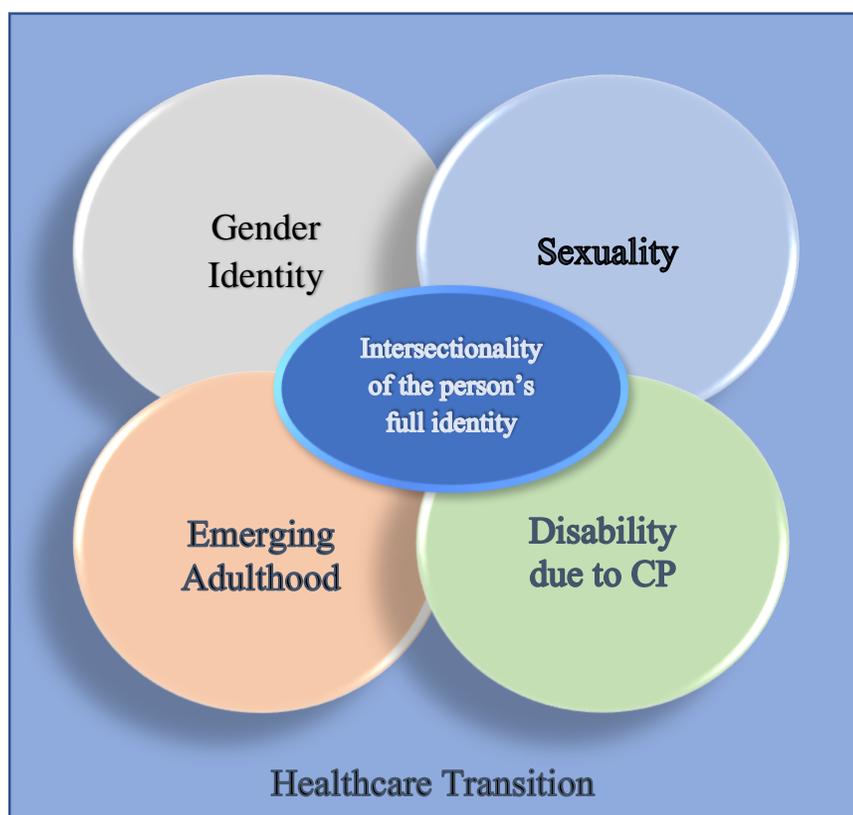


Figure 3: Intersectionality of Gender identity, sexuality, emerging adulthood, and disability due to CP during HCT.

Assumed asexual

HCP participants also mentioned that youth with CP are assumed to be asexual by the medical system; they are not expected to have questions about or be interested in discussing sexuality or gender identity. Which, unfortunately, has led to the current state where HCPs don't often discuss sexuality and gender identity with youth or their caregivers.

Sophie (HCP): and not to mention you know, a lot of the times these adolescents that are highly involved with CP, are often assumed to be asexual. I think, really big time about, because largely sexuality has been a taboo for some of these people who experience a lifelong health condition like CP, and like I say, especially if they're more involved medically with their caregivers... you know, they're angry, too, because people have assumed "well, you've got a disability. Well, you don't have sex. Why would you?" It's just like people saying, "Well, you're old, you don't have sex, do you?"

HCP participants reported that parents of youth with CP assume their children are asexual as well. Parents may infantilize their children; despite that they are adolescents or young adults and deny the fact that are sexual beings.

Freya (HCP): And like parents, ask the same thing. Parents like well, how like, you know, "Because my child use wheelchair full time. How do they have sex" right like and then so, because of that thought, many parents like, "Oh, yeah, we don't have to worry about that. My kids will never have kid of their own", and we're like, Oh, no! So yes,... educate the teens like, you know.

Misconception among healthcare providers (HCPs)

This subtheme emerged only from the experiences shared by the young adult with CP participant, Milly. Misconceptions about CP and related health issues is common among youth with CP themselves, their parents, caregivers, people in society and even among HCPs. Milly described her experiences with sexual health needs and the misconceptions she faced when she was trying to sort out a birth control option for herself. She was given an intrauterine device twice, both of which fell out, and no one believed her, and refused to prescribe other options.

*Milly (young adult with CP): That one falling out again, and again, no one believing me that it's falling out...like my own experiences, I know how I feel... My family doctor, she shares the practice **very hesitant** to prescribe me hormonal birth control. So, we're **worried** about the estrogen and the clotting and everything, even on the progesterone. Going to the physiatrist who specializes with CP and everything, and explaining my situation to her. You know me saying I'm not comfortable with another IUD. I've had two fall out. But in her words, like it seems that a lot of HCPs have been told hormonal IUD is the only option for women with disabilities... Being on the mini pill (for 6 months). Finally, seeing the OBGYN for 5 minutes to say, "Oh, yeah, you don't need to worry about hormones. You can get the arm implants, but it's gonna be 4 months before we can see you to put it in". So, I think it was just a lot of people being **very scared** to prescribe me birth control, which is, I guess, not the best thing because what would have happened if I had had an unwanted pregnancy. So, a lot of having to fight doctors to just please, you know. Please give it to me".*

Non-existent gender identity and sexuality conversation

The young adult with CP participant, Milly spoke about the non-existence of sexuality and gender conversation during the HCT process. She reported just one incidence when her pediatrician asked her about gender identity, apart from that there was nothing from the HCPs.

Milly (young adult with CP): So, gender identity specifically from my pediatrician. But not from, like physiatrists or orthopedic surgeons or neurologists. As an adult, it's something that I've never been asked [about gender identity] ...No [haven't faced any challenges with HCP because of gender status or sexual preferences], they mostly don't ask, so they don't know.

Milly also discussed a number of struggles she faced related to some sexual and reproductive issues she experienced. She further elaborated on conversations she had with friends who also have CP indicating that they had never been asked about their sexuality.

Milly (young adult with CP): Yes [asked about sexuality], again by the same pediatrician, and if I had to give a label, it would be bisexual. She's probably the first person that I told. She's the only one that ever, like doctor wise, has asked. So, she was great. Again, in the adult side of things. Never said, or something that's never been brought up. Yeah, about like a sexual identity in terms of sexual reproductive healthcare. There has been some aspects and I have faced issues in that side of things. But in terms of sexuality that never been asked...But, I mean, for my friends, who also have CP and have like, maybe are [GMFCS] 4 or 3, again, they've never had that just, it's never brought up.

It was evident from the interviews with the HCP participants that the conversation around gender identity rarely occurs during the HCT process. HCP participants described that the youth who have the cognitive ability, may be exposed to the idea or concept of the variances of gender identities due to exposure to the social media, school, or family members but they are not really engaged in any real conversation about that in the healthcare system. Most of the participants mentioned that they don't ask gender questions and they are not sure who asks. Olivia (HCP) said, "*No, we don't specifically ask, I don't know if [other practitioner] does. Oh, Dr. [other practitioner] and I do not*".

Emily (HCP participant) also mentioned that they can see or access it in the charts, systems, or documentation but nobody led any real conversation addressing gender identity. Other HCP participants, also stated that they do not ask about gender identity.

Emily (HCP): "I have not [asked about gender identity] personally, the triage nurse. I don't ask, because a chart is already made by that time.... if I'm in their direct care, I don't normally ask, because it's already on paper by that point."

Gender identity conversation is not a specific focus in the clinics, but participants said that this conversation may still be happening organically. Some of the HCPs said that if it comes up in conversation, they take the opportunity to expand on it. Other HCP participants expressed that they don't ask for gender identity specifically, but they note when it is flagged and then mindfully approach conversation throughout the appointment. The HCPs acknowledged there is room and a need to do better.

Lucy (HCP): Often. It is possible, like as much as we say we do things every time. I don't think that's one we do every time, but also, you know, if it's already documented on the chart, we have it... There's lots of people who can change it on the charts, so that everyone becomes aware but almost by having that system, it means that people forget to ask every time.

Just like the gender identity conversation, there is an absence of conversations focused on sexuality during the transition care of youth with CP. HCP participants expressed that, the youth are generally not asked about their sexuality or sexual health. During the interviews, the HCPs were referring to this as someone else's responsibility (other HCP's).

Emily (HCP): "At that point I personally don't ask if they're sexually active or not, because I have to be conscious of the fact that I don't want to. Usually there is a caretaker in the room, or a guardian that may speak on their behalf, so I personally leave that sexual health question towards the doctor".

Carolina (HCP): "Yeah, I haven't really asked the question upfront, cause I know the medical team usually covers like sexuality piece, but we do talk like about relationships sometimes".

HCP participants expressed that sexuality and gender identity are generally ignored as a healthcare concern for this population. The participants mentioned that unless there is an inappropriate sexual behaviour, sexuality or gender components are not a major component of the transition planning and education. HCPs rarely have discussions on this topic with youth with CP and referred to it as "the elephant in the room" that nobody talks about. Participants in this study suggested that the healthcare system needs to adapt to address this component of health.

Freya (HCP): And I feel like you're not, us as a medical system, even just... just look at our building, we're still very behind, right? Like we still just have a man and woman bathroom, right? Nobody ever talks about a [gender services] clinic. When you look at the elevator, we have the list of like clinics where everything is, [gender services] clinic is not part of. It's like nobody talk about it. It's like when we talk about it. Nobody knows it exists, nobody knows where it is in the building. It's something I feel like we're so behind because we don't talk about it. We're so afraid to talk about it. But then, when you can imagine, like when the children see adults are shying away from it, they don't feel safe, so they don't talk about it. It's like this elephant in the room, that's just, nobody talks about it. But I do hope that, like maybe, us as a healthcare system, we need to move forward a little bit with our teens.

Theme 5: Sexual health support during healthcare transition (HCT)

This theme describes the available sexual health support in the current environment, the challenges youth with CP face to access sexual health support during HCT, sexuality education and its importance, and making appropriate referrals to access proper care. Participants also discussed how they help their patients explore their sexual health and how they may modify the questions or approach to address sexual health in a better way. There was also discussion about which providers should have the responsibility to discuss sexuality and gender identity, hence the subtheme 'who would discuss sexuality'.

Difficulty accessing sexual health support and resources

The young adult with CP participant expressed that, as a result of their diagnosis, they struggle to access proper sexual health support and described occasions where HCPs dismissed their feelings,

concerns and experiences. These situations required significant and persistent self-advocacy to take charge of their own sexual health and receive the care they needed and deserved. Accessing sexual healthcare is difficult not only due to lack of resources and accessibility, but also because of long wait times and lack of understanding of the diagnosis of CP.

Milly (young adult with CP): Okay. So, I have really struggled, getting HCPs to prescribe me the birth control that I need and it has to do with CP. So back in 2021, I got a copper IUD through my family physician. Towards December I thought it was falling out and going to doctor like going to my doctor then, telling me, 'Oh, nothing's wrong' like, 'it's you feeling like it's wrong'. And then getting... I was right. It was falling out. So now there's that fear of like. Well, how long have I not been protected? You know I got an IUD because it is one of the most effective ones, I'm trying to be safe. Having to really self-advocate to get an emergency one put in at the specialized Sexual Health clinic that we have. That one falling out again and again, no one believing me that it's falling out... So, you have to get a hormonal IUD. Well go see a specialist, 6 months to see a specialist. And that was multiple times having to asked to be put on the cancellation list. So, 6 months of you know not being on the birth control that I wanna be, trying to get the arm implant from every doctor I could see. But they weren't comfortable giving it to me because of CP.

Lack of sexual health resources and difficulty accessing them was discussed frequently during the interviews with the HCP participants as well. Youth with CP may need adaptive tools or equipment to manage their sexual health, but these are not easily accessible to them. Furthermore, funding for assistive devices or equipment related to sexual health represents a significant barrier.

Daisy (HCP): There's also a lack of sort of easy access to resources in terms of you know what if you need sort of adapted tools for self-pleasure, or if you need different equipment or different types of sheets, or something to manage hygiene related to sexual activity... all of these different things, that they might, you know, actual equipment or tools, those might be difficult for them to access and they shouldn't be.

Sexual health support

The adult participant with CP described her experience with clinicians providing sexual health support as a simple “yes or no” question. She described being asked at healthcare centers that if she was sexually active or not, but was not provided with any more support or care for her sexual health and well-being.

Milly (young adult with CP): So, I wish there had been some physician started answers about like, how is it? Instead of just, are you active? Yes, and that's the end of the conversation... And like, yeah, it doesn't happen like the conversation has always been very sexually active, yes, no, and that's it. So, or how do you identify, so like? Not necessarily like occupational therapy, but just that there are. There are options... Not really. It took me a while to. It's only when I was in my current relationship. It's very healthy that I spoke to a psychologist about it, and helpful on that side of things. But I did end up mentioning it [sexual abuse] to my family physician, and it was kind of like, “well, don't do that again”, and that was it, like there was no follow up on. Are you okay? Or anything like that? I think just being better prepared, just having those conversations in the transition would be important.

According to the HCP participant's experiences, in general, youth with CP have reduced access to sexual health support. Currently sexual health support is not properly addressed during their HCT and there is a growing need of information and support regarding sexuality and gender among youth with CP. Without access to these resources from qualified HCPs, youth may be looking for the information for themselves from whatever resources they have and receiving misinformation or information that may be harmful.

Daisy (HCP): "So, it's [sexual health] in general under addressed. I don't think that they're asking their parents, and I don't think that they're asking their primary HCPs or, so I suspect that they are trying their best to find the information that they can get for themselves".

There is a perception that because youth have frequent medical visits, they likely have sufficient care for their sexual health. However, it was raised that HCPs do not have enough time to address all the necessary aspects of health and the transition process. One challenge HCP participants discussed is that in the adult healthcare environment, many people with CP don't even have general access to knowledgeable practitioners to discuss their basic medical needs; therefore, resources and time to discuss sexuality in that environment are potentially even much more difficult. HCP participants spoke about specialized sexual health programs which address sexual healthcare for youth with CP and other disabilities. Overall, HCP participants felt it was extremely important to provide care to address sexuality and gender issues as it allows youth with CP to experience the "wholeness" of life. Finally, HCP participants spoke about their role in and the need to develop more programs and processes to address sexual health concerns for youth with CP.

Julie (HCP): Well, it's a general topic that could occur to anyone, so I think they should be as informed as any other youth, their friends maybe in that situation they themselves might be in that situation ...I would hope they would have the same as, or more actually, because they're often involved in like more direct medical care. So I would hope that answer would be yes, they would have the supports needed for that, because they have frequent visits with the medical community, but I don't know.

Prejudice and preconceived notions of sexuality and gender identity among people with physical disabilities can hinder youth with CP from accessing the right healthcare at the right time. HCP participants expressed that when youth with CP present with physical impairments, questions about gender and sexuality concerns, the level of support needed increases as a result of this intersectionality, and that that level of support doesn't really exist everywhere. HCP participants also spoke about needing to support youth to have a stronger understanding of their diagnosis and the implications it may have for issues related to sexual and reproductive health.

Additionally, the need to plan or discuss these implications to make informed choices and retain their optimal health during life events such as pregnancy was seen as important and a supportive and guiding role that HCP can fill for youth and adults with CP.

Lucy (HCP): ... I don't think it's sexual health specific. I think youth with CP need more support around understanding their diagnoses... I think it's important for people to know that, yes, their mobility may be impacted, depending on their physical abilities by pregnancy, especially the women. But there is support... For someone who might start having problems with balance and ... of fatigue with walking if they became pregnant. But I think it's important that people know that they can ask and get more support, cause it's often something I think all of us are thinking about.

Referrals

This subtheme emerged from the experiences of the HCP participants. They spoke about the need to refer patients with CP to appropriate healthcare professional according to their needs as a crucial part of providing appropriate healthcare services during transition. If, at any point during the transition journey, youth with CP share concerns or challenges with their physical health, mental health, sexuality, and/or gender issues it is pivotal that they are heard, respected, and referred to the relevant provider who can intervene with the necessary resources. HCPs also needed to be mindful when the youth are expressing signs of low mood, depression or life changes, because these changes can be connected to sexuality and gender and issues that they find hard to express. HCP participants described youth opening up and casually discussing their sexual health concerns while receiving care for other physical health issues with a provider they feel comfortable interacting with. Therefore, all HCPs need to feel comfortable to explore and participate in these conversations as they happen and then refer or connect the client with the appropriate healthcare professional who can provide the ideal healthcare for them and their concerns.

Daisy (HCP): we're looking at this transition process in particular, we might be looking at sort of making sure, appropriate referrals are made. Then also offering the opportunity if they might feel more comfortable speaking with another member of our team, so that could be our nurse practitioner, our social worker. Those would be sort of the two most common go-to's, probably. I give them, you know, phone numbers and email addresses for other people that they can reach out to in our program if they so choose. Also potentially involve either physio or occupational therapist, depending on what their questions are. Same kind of thing I might

involve a social worker if they have more questions or concerns around exploring gender identity, especially if it's something that they're still kind of moving towards in their life.

Sexuality Education

In response to the question during the interview that if they received any sexuality education throughout the time of their HCT phase, young adult with CP participant Milly said “No. Never”. However, in the interviews with HCP participants, this has come up repeatedly that, education regarding sexuality and gender is important. There may or may not be differences in the sexual health needs between youth with and without CP but youth with CP having varied physical abilities need to know how their sexual health can be impacted due to their diagnosis of CP.

Daisy (HCP): I think you know as my role as the medical doctor on the team, I would definitely provide education around things like what they can expect is sort of normal sexual function for their body in the context of their disability, we could talk about their fertility and any issues around sort of pregnancy or childbearing. If they have questions that are more sort of logistics about sort of sexual positioning or things like that, then I might answer those on a basic level.

Sophie (HCP): So, I think largely conversations about sexuality with him include acknowledging the validity of him, feeling like he wants to express himself sexually, that there's everything absolutely normal about that and we talked about the impacts of his health condition on the ability to make relationships, develop relationships and put himself out there. Because there's certainly barriers in that regard.

HCP participants also raised concerns about the content of sexuality education in the school system.

Freya (HCP) said that, “when I look at my kids [school’s] like I must say, reality. Of course, I’m like, this is awful. This is like, so 1950s”.

Exploring sexuality and gender identity

This subtheme came from the interview data of the HCP participants; it represents a part of the current practice of how sexuality and gender identity is explored by the HCPs. What are the questions that the HCPs ask, when do they ask these questions, what is the appropriate age to ask these questions, privacy around this conversation etc. HCP participants stated that it’s good to ask questions in a different way or rephrasing the questions about sexuality and gender identity, so that the youth don’t think that these questions are asked because of their diagnosis of CP or disabilities. Youth are not always forthcoming about the questions or concerns they have regarding sexuality or gender, but when they are talked to or asked questions, they get an opportunity to share.

Lucy (HCP): We are a sub-specialized clinic. And so, we want to make sure that where the information would be different, potentially or that there's a risk that there would be biases because of their health that we're addressing those. So, for example, where I used to ask, “Are you interested in men, women, or both?”, And “are you sexually active?” I now ask, “do you think there's anything in your health that would impact relationships?” And then the next question is, “what about sexual activity?” And then, if they say No, I say, you know, like, would having hemiparesis impact sexual like, I try to ask him a further question. You know? “Do you think you can get pregnant, or do you think you can get someone pregnant?” And really, while they might not have questions, do they know the right answers?

According to the HCP participant's experience, exploring sexuality and gender identity is more appropriate when the parents are not around as youth might shy away and hide information or they might not have shared the information with the parents yet. Privacy should be an essential consideration during these conversations. Sexuality and gender components of the HCT are still new to the HCPs and most expressed that they are negotiating the ways of addressing it every day during their practice. Many approaches to address gender and sexuality concerns and education seemed to be work in progress.

Jane (HCP): "...Sometimes already coming into the assessment, knowing that there are some gender questionings, gender identity issues. Sometimes these are kids that have already been referred to some clinics in advance and they're on the wait list. So definitely, there is some conversations. I haven't really figured out yet, when that conversation starts. I don't typically do that with younger children, although I could. But I'm not really certain yet, when usually it's those kids that are 14 and above that, I'm sort of having sharing my own pronouns. And you know, asking if they have a pronoun that they use or pronouns that they use. But yeah, I'm still sort of going through that process of deciding. Do I start adding that into my typical day-to-day interactions with the younger children as well?

Theme 6: Opportunities for change

Our participants were HCPs who had extensive experience working with youth with CP, some for a long period of time, in the healthcare system. While sharing their experiences of supporting youth with HCT, they shared the opportunities to address the concerns about sexuality and gender in a better way. They shared stories of when certain tactics and approaches worked well to help them

support their patient explore their sexual health and gender identity and how this may be used to fill the unmet needs during HCT and beyond experienced by youth with CP.

Opening the door

Young adult with CP participant expressed during the interview that, it can be helpful for the patients if the HCPs start the conversation regarding sexuality or sexual health when the youth are having their medical visits.

Milly (young adult with CP): Yeah, I think it's just having providers start the conversation of "it's going to look different for you". "There's gonna be certain things that you're gonna have to consider". And like, yeah, it doesn't happen like the conversation has always been very sexually active, yes, no, and that's it.

Daisy (HCP): I think one of the biggest issues is just sort of opening the door to having the conversation which is, I think, the most important first step that is typically missing. Ideally, primary care providers could open the door to these types of conversations. You know, it doesn't need to necessarily come from one place.

Opening the door to the conversation can be prompted by assuring safe and protective space and allowing the youth to be with the HCPs alone in the room during the consultation or visit. During and after the covid pandemic many consultations have stayed online where the youth with CP could be talking with the HCP through the screen with the presence of other family members in the same room. This situation can prevent the youth from sharing any information about their sexual health or gender identity. So, steps can be taken to help the youth setting up the online meeting in a private place which will allow them to open up sensitive conversations.

Olivia (HCP): Are the youth opening up to us enough because they know that someone else is listening? ...a large portion of our clinic appointments right now are virtual and often we don't know who else is in the room, with the youth that we're speaking to, is there, you know, a brother or sister around the corner that can hear things, or another parent and the youth haven't been prepared before the clinic to be aware that this is one of the topics we're going to talk about, so that they can set up their Zoom call you know in a more private settings. So maybe that's something that I need to look at too when I'm doing my phone calls prior to the clinic is I didn't need parents to know that, that is one of the topics.

Safe space to revisit

Opening the door to the conversation strongly relates to having a safe space for the youth at the healthcare settings. This safe space refers to the physical space in the clinic where they can share this private information, but this can also refer to the person/HCP who is committed to keep the conversations safe and private and offer support. The young adult with CP participant, Milly appreciated the safe space provided by her pediatrician, *“but that pediatrician was very good at, you know, “if you do need anything I’m here”, like her office is always a very safe and inclusive space”*.

According to the experiences of the HCP participants, when provided the safe space for conversations, youth may open up on the session that day or they may open up in the later sessions. So, it is important to make sure that the youth know that there is a safe space if they want to share. Letting the youth know that the conversation regarding sexuality and gender identity will be kept confidential is another essential step to assure safe space. Most of the time youth with CP are accompanied by their parents or caregivers, even if they are not present in the session, youth may

feel like they will know what the youth discussed. Therefore, it's important to inform the youth that they can have the conversation confidentially, if they don't want their parents to know. The youth can also be provided with contact information or other resources to ensure there are opportunities for them to revisit that conversation as needed.

Sophie (HCP): I mean the reason why they come to me with it is because I've probably said somewhere along the line, you know, "hey, just to let you know, you could talk here about anything". "I'm not gonna go running to your caregiver. It stays safe here.", of course we talk about confidentiality... I absolutely revisit it in ways that will let them know that. "Look, this is what you may be feeling right now, and maybe 6 months or a year down the road you might change your mind, you may have marinated over things right. Know that you can reapproach me. Know that you can be like, you know that thing. Hey? You asked me if I wanted to talk? I said Hell no, you could come back and talk about that.

HCP participants shared that they have experience of youth coming back and asking them questions about sexuality or gender after months or years. Therefore, it's more important to let the youth know that they can talk about it safely, when they want, on their timeline, and that there is more information or support available. So even if they don't have any question on that specific visit or time of their life, they can revisit when they have concerns or questions.

Carolina (HCP): And I think just even thinking about the space around us, and how inclusive it is, like there's nothing saying that this space isn't welcoming, or anything like that, but just making sure that, you know, if we can have the little flags up just to say, "the space is safe to

talk about this”, and just some of those visual keys too just so then if they don't feel safe talking with their parents there. Then they know that this is a place that they can share those feelings when they are alone.

Importance of therapeutic relationship

The therapeutic relationship between youth with CP and their HCP, played a role in the ease of initiating those sensitive conversations and providing appropriate healthcare. When there is a strong therapeutic relationship, the youth put more trust into the process and feel more at ease exploring the options that are provided by their professionals. Long therapeutic relationship with the HCP may provide youth with the comfort to share sensitive issues such as gender identity, sexual orientation and any other sexual health concerns.

Milly (young adult with CP): “Yeah, I mean, I probably would only tell it, like even I don't tell my family doctor and all, because I just with my pediatrician having a relationship since I was 3 years old. There's that comfort. I wouldn't necessarily want people that I don't have that relationship with, to know”.

As stated by the HCP participants, this relationship also enables the youth to gain more courage to communicate their needs and preferences with others in the family and society. They learn to find words and express themselves in that safe space that can then be transferred to other people and spaces as they feel ready.

Sophie (HCP): “In our social work, you know, treatment and our therapeutic relationship was essential because they were able to trial... being called a different name, but that was after, getting to know them, developing a therapeutic rapport... where they were able to leverage that in any other sphere of their life, and in so much as they were actually also able in that process with

me, to be able to talk to their family about the preference, and find words and ways of expressing themselves... they actually told me that they found the courage to be able to, you know by themselves... talk to family members about this gender like this identity change right?

HCP participants found that youth are generally not forthcoming on their first visits, but they get more comfortable when they are having their 2nd or 3rd visit with the doctor and then they open up more about their sexual health concerns.

Daisy (HCP): "I've definitely had instances where people have sort of found opened up more on second or third visits as opposed to an initial visit like that might be an uncomfortable conversation for people, if we're just meeting the first time".

Training on sexuality or gender identity

This subtheme was derived from the experiences shared by the HCP participants. Sexuality and gender identity conversations can be very sensitive and complex, specifically when addressed with youth with CP who may have varying physical and cognitive disabilities. Hence, HCP participants mentioned the need for training on how to address these questions without offending the youth and their family and how to ask the appropriate questions. It came up in the interviews that sexuality and gender identity topics are very new to the HCPs in the healthcare context which make them feel that they are amateurs with these conversations. As Freya (HCP) said, *"So, I'm still learning as I'm practicing"*.

Emily (HCP): There aren't a lot of questions that I have been instructed to allow for that conversation to be made right then and there, so I think there is a little bit of like lack of training on how to even address appropriate questions without making the other person feel offended. Cause, I think that's our biggest priority. We are the face of the healthcare system. If you think about it, we're the entry point to anything. So, I personally haven't gone through any training, or as such to ask a I mean, definitely, considering the climate that we're in right now. We haven't been necessarily trained on how to address this question very nonchalantly, but also being respectful of the person sitting in front of me.

HCP participants emphasised on the need of training and education for the HCPs to allow them to become comfortable asking the questions about sexuality and gender identity. This education could be completed during training for future healthcare practice (entry to practice) or continuing education for clinicians working in healthcare system.

Jane (HCP): I think one thing that would have to happen is education, because I have a feeling, one of the things that we're talking about. People are not going to be comfortable asking the questions, or know how to ask the questions, and so there probably has to be some education. You know there's adolescent medicine where they're going to address that for sure, sexuality, and gender and sexual health, but should that be integrated in the clinics? ... And then, yeah, just education, you know, actually does that even go clinic for different people? Or is that even like education at the level of education, you're a physician, or you're you know you're an occupational therapist or psychologist, how to integrate that in and educate people earlier on before they come into a system.

Ways to include sexual education

Sexual education should be included in the transition care planning for youth with CP and other childhood disabilities. During the interviews, youth with CP and HCP both participants shared thoughts about how sexuality and gender education can be included in the healthcare system. According to the young adult with CP participant, providing the resources for sexuality and gender in different formats to the youth with CP can be very helpful, this allows easy access to information and less work/effort for the youth with CP.

Milly (young adult with CP): I know there are resources online about, like, adaptive positions, adaptive technology, like, if they had those resources to give out in some sort of format, I think that would be... having to do less of the research yourself, and maybe not the most reputable places. I think that would have been good. It's just those follow up questions other than yes, no, and then not getting into it.

HCP participants mentioned that because parents have a substantial influence on the life and healthcare of youth with CP, it was important to educating parents and caregivers about sexuality and gender as well, particularly if the youth have cognitive impairments. Parents can reiterate the education and knowledge over time and consult with the HCPs as needed. As Freya (HCP) said, “The education needs to come from the parents and having them really understand about like, we much rather open that conversation”.

Emily (HCP): I think there has to be a lot of education or re-education to the people that are taking care of a person with CP, and if you can make it somewhat more accessible to that team of people that's taking care of that patient, I think that could definitely help in getting the ball

*rolling regarding that whole transition process for them... I think **if you can educate that big chunk of their life**, it will hopefully have a conversation between those the guardians, caretakers, and the person with CP and hopefully allow for that, I think in a way that's your gateway, not only the primary care physicians and neurologists, but most importantly, it's the caretaker guardian.*

HCP participants shared previous experience of camps and group events where youth with CP were more comfortable sharing experiences about sexuality and gender identity in the presence of their peers. HCP participants also suggested that arranging peer support group meetings at the clinics for the incoming patients who are interested in discussing sexuality and gender, may be really helpful. HCPs could also be a part of those group meetings to create a safe group space to share information and openly talk about sexual health.

Jane (HCP): Going back to Camp, I would say the youth, many of them opened up. I think, having other peers that were there that were very supportive, and being able to share about sexuality, being able to share about relationships, their experiences, gender. Of course, there were some kids that were very shy, and that was always the piece in those groups that they didn't have to share if they weren't comfortable, and there were some that were definitely not comfortable. But I think the ones that were ready to be able to ask questions, to be able to comment and share stories, were very open. So, I think it was a really great experience. It's different than sort of a clinic one on one with professionals, but with the peers having the peers, I think there were many that were ready to be able to share. And you know often those sessions were towards the end of camp when they became more comfortable with their peers too.

Overall, participants felt it was important that education and conversation around sexuality and gender identity be started in pediatric healthcare system and not just in adult care or during HCT to make the journey towards good sexual health easier. Some of the HCP participants also said that other healthcare providers including primary care physicians and neurologists and school health providers also need to be comfortable discussing sexual health as youth with CP with higher functional abilities may not visit specialized clinics as often (if at all) so alternative sources of information and education are key. The other suggestions from the HCP participants involved being mindful to the patients and their family when providing healthcare to the youth with CP, providing handouts, pamphlets or booklets, and making sexuality and gender conversation a part of regular medical check ins. Having more transitional clinics where all the dimensions of life are focused during healthcare can be another step to successful transition to adult care for the youth with CP as often there is not have enough time explore anything beyond basic healthcare needs.

Lucy (HCP): Having transition clinics that remember to hit all the heads or shades, or whatever acronym you want to say of thinking about a multi-dimensional health, I think that helps a lot. It's really hard to fit that into most classic clinic structures. If you're trying to achieve a whole bunch of other things.

Discussion

The current study explored the experience of sexuality and gender identity during the healthcare transition (HCT) process of youth with cerebral palsy (CP). Healthcare providers (HCPs) in this study shared their perspectives on the wants and needs related to gender and sexual health education and support that may help youth with CP to have a favorable HCT experience.

Conversations with participants provided information on how to youth with CP experience and develop their sexuality, sexual health and gender identities, as well as an exploration of the level of support they receive and need from HCPs for these issues during the HCT. Additionally, the results of this study provide a number of strategies that HCPs can use address sexuality, sexual health and gender identity during HCT and enhance the understanding and importance of this experience to support the creation of appropriate organizational policies and programs to better the HCT experience for youth with CP and their families.

Experiences and the development of sexuality and gender identity as a youth with CP

As shared by the HCPs, youth with CP find it difficult to imagine how sexual or intimate relationships may work for them or others who have disabilities. They must chart their own path when forming their gender identity and sexual preferences, discover themselves, and then accept it. Youth sometimes struggle to understand their own feelings, specifically at the age when they are transitioning to adulthood, they have shared this with HCPs and seek information about why this is happening. These conversations open up opportunities to discuss health, sexuality, and more.

Transition from adolescence to adulthood is the period when youth develop their the sexual or gender identity (Wiegerink, 2011; Bungener et al., 2022). This is an important part of the transition to adulthood for youth with developmental disabilities; however, it is commonly overlooked (Saxe & Flanagan, 2016; Wilkinson et al., 2015). In the current study HCP participants referred to the gender identity formation process as a ‘journey’ that youth are on, where they continuously negotiate their identity. This is consistent with evidence from populations of youth with intellectual disabilities (Deaux and Perkins, 2001; Wilkinson et al., 2015); however, it is particularly troubling that there does not appear to be much support for youth on this journey for several reasons. First, it is known that the number of youths struggling with their gender identity is increasing (Bungener et al., 2022), and evidence shows that this journey is more difficult for youth with a disability (Bungener et al., 2022). Some of the HCP participants in this study identified that one of the reasons for the lack of support may be due to their disability identity ‘overshadowing’ the development of other important identities, which is consistent with the literature (Burns, 1993; 2000; Wilkinson, 2013). The adult with CP participant in this current study also indicated the lack of support from the HCPs regarding sexuality and gender. She expressed her struggle to accept her identity during the HCT phase but did not receive any support from HCPs. She communicated the need for and importance of discussing gender identities, sexual health and sexuality with knowledgeable HCPs who provide a safe space.

The HCP participants in our current study described situations where youth with CP were unsure of trying a new gender identity, often this transition can be accompanied by fear, conflict, hesitation, and suicidal ideation. Baril et al. (2020) indicated that going through the gender

transition process can put the youth with disability at increased discomfort because of their level of pain or fatigue (Baril et al., 2020). Additionally, evidence shows that mental health issues including stress and anxiety appeared to increase with the worry of being ‘misgendered’ (Baril et al., 2020); which is congruent with findings of this current study where HCP participants shared that, their patients with CP felt that there was something wrong with themselves if they misgendered because it did not match with how they felt or saw themselves. When this internal conflict exists inside the youth with CP for a long time and remains undisclosed, this may increase the risk of psychological problems including suicidality (Bungener et al., 2022). Youth also expressed anger and frustration to their HCPs that people in society have limited knowledge of gender identity and that they were frequently misgendered. A recent study of people with intellectual and developmental disability who identify as LGBTQ+ showed that they experience mental and emotional strain, for example, feelings of worry or anxiety, due to social misconception of their identity and resulting complications of their understanding and expression of their gender identity and sexuality (Stanojević et al., 2023). Even if the person resolves their internal conflict and becomes certain of their gender identity, it becomes challenging for them to disclose their gender identities and sexuality to others (Stanojević et al., 2023). Furthermore, youth with disabilities have reported feelings of depression, anxiety, or paranoia that have interfered with their ability to express their gender identity to others (Baril et al., 2020). HCP participants stated that after having a conversation with youth with CP regarding sexuality and gender, the youth provided positive feedback about the opportunity to talk about these issues. They felt supported, relieved, and reported being ‘seen as a whole person’. Particularly important was the reflection that positive feedback was received from the youth after giving them the chance to have a conversation with the provider without anyone else (e.g., parents, caregiver)

present in that room as that allowed the youth to express their concerns regarding sexuality and gender without anyone else being part of their conversation.

There is a dearth of literature that focuses on the gender identity among youth with disabilities (Mulcahy et al., 2022). Furthermore, the intersectionality of gender identity, sexuality, disability, and HCT, though extremely important, is rarely discussed (Cain & Velasco, 2021). The term ‘Intersectionality’ was first coined in 1989 by Kimberlé Crenshaw, an American civil rights advocate and leading scholar of critical race theory (Crenshaw, 2017). The concept of intersectionality as described in this thesis refers to “the ways in which race, class, gender, sexual orientation, age, religion, and other locations of social group membership impact lived experiences and social relations” (Harris & Bartlow, 2015). In this sense, intersectionality recognizes the fact that different social and political identities coexist and inform each other and the convergence of these different identities can sometimes compound themselves and create obstacles. The current study is unique in that it focuses on the intersectionality of these identities during the HCT process, which represents the same chronological period where youth negotiate these identities. We observed all these identities having significant influence on each other and on their HCT experience.

In our study the HCP participants described observing a variety of gender identities among youth with CP in their practice; but gender identity prevalence among people with disability has not been documented, often as a result of exclusion of gender identity from surveys and administrative health data (Mulcahy et al., 2022). Related to this, a recent study by Soros et al., (2022) found that, young adults with CP identify as LGBTQAI+ more often than the general population. A note of caution however, this finding may be due to their sampling approach

resulting in a non-population-based sample from which they then inferred prevalence of LGBTQAI+ identification. If there is an increased number of individuals with CP identifying as LGBTQAI+ then this indicates an increasing need of support during the HCT process (Bungener et al., 2022). In the current study, HCPs expressed that in their experience, youth with CP were very interested in exploring the gender identity aspect of their life. Some of the youth with CP had tried a new identity with their HCP and explored how much they fit in to that version of themselves. This demonstrated that youth with CP are curious and want to explore different gender identities, including transitioning to another gender; and that they are open to seeking support from HCPs regarding this. This is congruent with evidence that demonstrates increased number of youths seeking help related to gender identity issues from their healthcare professionals in recent years (Bungener et al., 2022) and should continue to be explored.

People with disabilities are often assumed to be asexual (Sellwood et. al., 2017), the findings from the current study confirm this stigma about sexuality of people with disabilities is still prevalent in society. People do not think them as sexual beings in general and even the medical system approaches them as asexual. This assumption is stronger with more severe levels of physical and cognitive disability. The HCPs assume that they do not have questions about sexuality, gender identity or overall sexual health. Confirming the findings of Sellwood and colleagues, that support workers, parents and doctors see the youth with disability as asexual, therefore, do not need any information or education regarding sexuality (Sellwood et. al., 2017; Collier et al., 2006). HCP and youth with CP participants in our current study established the fact that most people do not have awareness about the intersectionality of people with disabilities. Youth with CP can have multiple identities, they can be physically or cognitively impacted by

CP thus having a disability identity, at the same time they can be identifying as LGBTQ+. However, people in society, including HCPs and parents/ caregivers, only see the disability, they do not consider the youth's variability of gender identity and/or sexual orientation. So, as one HCP participant said, "their identity is cerebral palsy", not as a sexual being. According to our HCP participants, when a youth with CP seeks medical treatment, the main focus of their care is related to the diagnosis of CP and how that may impact the other domains of health or how medications can impact their body or how they can treat it best; the focus or consideration of gender and sexuality is often ignored unless the youth themselves seeks specific help for a specific sexual health problem. These findings are consistent with the existing literature; a recent study that was done on the people with intellectual or developmental disability (IDD) highlighted that, even if they are accepted as sexual beings, they are thought to be incapable of having LGBTQ+ identities and society prioritizes the IDD identity. In the aforementioned study some staff and caregivers openly opposed and ignored the non-heterosexual identities and experience of their clients with IDD and the authors reasoned it as lack of knowledge, training and personal beliefs. The study also mentioned that the barriers for the people with disability can exacerbate the stigma and discrimination if they identify as LGBTQ+ (Stanojević et al., 2023).

Our current study reveals that, parents/guardians play a role in representing their child (youth with CP) as an asexual being. HCP participants shared their concerns about parents not accepting the fact that their child can have sexual interaction or that their child can have their own offspring. HCP participants also stated that 'infantilization' is common among the parents of the youth with CP. The parents take on a lot of responsibility thinking that their children are still very young and they need protection from society and from everything else because of their disability, and that turns into overprotection towards the youth with CP. Other studies also found similar concepts of

infantilising people with disabilities, for example, viewing as childlike, hence non-sexual (Stanojević et al., 2023), and the child or young person having no interest in or understanding the concept of sexuality (Donnelly et al., 2023). According to Wiegerink et al (2006), overprotection is also common in raising children with CP (Wiegerink et al., 2006); and Whittle & Butler (2018) mentioned it as a self-fulfilling prophecy (Whittle & Butler, 2018). The authors also expressed that, the more these youth are protected from experiencing their sexuality and gender identity the more socially and sexually incompetent they may become (Whittle & Butler, 2018). Parents often deny that their children can have concerns or needs related to sexuality and they need support regarding these issues. These presuppositions may be one of the reasons why HCPs do not approach the youth with CP to talk about sexuality and gender identity. Some parents even asked the HCPs not to talk about sexuality or gender with their children. According to the HCP participants, most parents think that if they do not talk about these issues then the youth will not think about it. This has also been shown by Donnelly et al (2023), who found that parents think that discussing sexuality can encourage sexualised behaviour (Donnelly et al., 2023).

HCP participant's conversations during the appointments with their patients (youth with CP) often led to a wide range of questions, curiosity and sharing of experiences. Most youth showed great interest in further discussion about sexuality and gender, whereas some appreciated the scope to talk about it and wanted to discuss it in later appointments if needed. On the other hand, some of youth were surprised to know that they could talk about these issues at their healthcare services. According to the HCP participants in our study, most of youth were very enthusiastic, forthcoming, and ready to talk about these issues when they were approached to talk about it. It is kind of 'opening a floodgate' or the door to the conversation and it provided youth with CP a

chance to offer information regarding their sexuality, gender, sexual preferences, and sexual health issues and receive support in a natural, open, friendly environment. This may be because youth do not get the opportunity to share their unique problems regarding their sexuality with someone who is expert in this area of health. Such that, whenever given the chance to have their questions or concerns addressed by their HCPs, they are keen to participate in those discussions. In other cases, the reasons for not sharing sexuality information in the healthcare setting was due to feelings of discomfort, shyness and fear. Overall, the HCP participants shared that the youth with CP are as interested and curious as their peers who do not have CP or a disability.

Our findings suggest that youth with CP lack basic understandings of their diagnosis, their capabilities in sexual activity, effects of CP on pregnancy or child bearing, and sexually transmitted diseases. This is consistent with the findings of Travers et al. (2014), which indicated that people with significant disabilities shows low levels of knowledge about these issues. Another systematic review showed similar findings reporting that people with intellectual disability have incomplete or inaccurate knowledge about sex, relationships, bodily organs and functions (Whittle & Butler, 2018).

HCP participants in our study expressed that, few youths with CP demonstrated very clear concepts and opinions about their sexuality, sexual orientation, gender identity and preferences. While discussing sexuality with the HCPs, they shared their relationships and sexual preferences. They were very open to relationships with people with different gender identities and sexual orientation. But some of them did not want to define or label themselves as gay, lesbian, bisexual or anything else. They expressed that they were in a relationship with another human being with whom they were comfortable and safe with. This expression appeared very different than the

systematic review findings of Whittle & Butler (2018), which showed most people with intellectual disability could not identify or name various sexual orientations, there was no consideration of anything else other than heterosexual relationships in the studies. Moreover, in that systematic review, people with intellectual disabilities who at least had ideas of different sexual orientations described those as ‘wrong’ and ‘horrible’ (Whittle & Butler, 2018). This potentially shows more exposure and acceptance of variations in gender identity for youth with CP than previous studies or studies conducted with persons with intellectual disabilities alone.

Conversations about sexuality are often uncomfortable for youth with CP, their parents and for the HCPs. In our current study HCP participants repeatedly mentioned that the youth are often not comfortable starting the conversation, as they are rarely asked about these issues. The youth are shy, scared, uncomfortable and new to this kind of conversations, but the lack of opportunity to discuss the sexuality can also make the youth uncomfortable to ask for support regarding sexual health. Therefore, when someone suddenly initiates conversation about this topic, they either experience relief that they can finally talk about the burning issue in their mind or are shocked and uncomfortable and withdraw from the conversation. This is consistent with the literature that shows, topics of sexuality can cause uneasiness for individuals with disabilities (Saxe & Flanagan, 2016). The discomfort surrounding the discussion of sexuality is an obstacle that affects the sexual education of youth (Saxe & Flanagan, 2016). Another study indicated that, if the HCPs become comfortable in discussing sexuality and gender identity in healthcare settings then it gets easier for the youth to discuss these issues (Bungener et al., 2022). This highlights that healthcare providers in the pediatric and transition-related healthcare settings should endeavour to have these important conversations to sensitize youth to these issues early

on and reduce the levels of discomfort they may experience. Our current study findings also suggest that another reason youth may feel uncomfortable discussing sexuality could be a lack of privacy. Generally, youth with CP are accompanied by their parents, guardian, or caregivers while they are visiting the HCPs. The youth might not want their parents or caregivers to be a part of the conversation and so, they do not bring up the topic in their presence.

HCP participants in this study mentioned another challenge for the youth with CP, that is difficulty finding a partner. Youth with CP frequently expressed their interests, concerns and frustrations regarding finding an intimate partner, developing a sexual relationship, and less opportunity to date. This is consistent with the study findings by Wiegerink et al (2006; 2011) which showed that, young adults with CP are significantly less experienced with dating than their non-disabled peers (Wiegerink et al., 2011). Wiegerink et al (2006) also found that youth with CP struggle to find ways to meet people and they are less active in socialising (Wiegerink et al., 2006). Existing evidence confirms that socialising can be harder when youth have added layers of physical, developmental and/or cognitive disabilities because individuals with disabilities gets less social opportunity to express themselves sexuality than their peers (Guralnick, 1999; Travers et al., 2014). Current study findings reveal that dating and developing intimate relationship is an important part of the youth's life and when unable to find somebody, the youth share that with the HCPs and ask for support. Though according to the HCPs in our study, there is less scope for them from medical perspective to provide support in finding a partner; HCP participants acknowledged that discussion around this issue as part of the healthcare support and providing a safe space to share these can help the youth with processing the stress, frustration, and discouragement they face due to an inability to find a partner. This is

consistent with the evidence from population of individuals with intellectual disability (Whittle & Butler., 2018), it demonstrated a strong desire among the individuals with intellectual disability to be in a sexual or intimate relationship, but the study also indicates that, there is continuous monitoring, lack of privacy, excessive rules and restrictions that are imposed by support staff and caregivers regarding sexual behaviour and intimate relationships (Whittle & Butler., 2018). It gives us insight on why finding a partner and having a relationship could be harder for these individuals. HCPs can contribute in this regard by educating youth and their caregivers and allowing them more space, privacy and freedom to explore their sexuality when they have knowledge and tools to do it in a safe manner. Another study by Stanojević et al., (2023) demonstrated that people with intellectual disability identifying as LGBTQ+ often seek support from service providers to build connections with the LGBTQ+ community and to have a space to meet with peers to learn about the sexual norms and thus meeting potential romantic partners (Stanojević et al., 2023). So, building connections with other communities and arranging peer group sessions for sexual health education as a part of the HCT process could be helpful for the youth with CP in finding a partner.

However, not finding a partner for intimate relationships in conventional ways may lead to risky practices and inappropriate sexual contact. In our current study, HCP participants indicated that youth with CP shared intentions and experiences of dating people involved in their care such as PSWs or exploring a sexual relationship with sex workers. HCPs in our study also mentioned that there is a higher number of inappropriate sexual contact among the youth with CP than the general population. This is consistent with the literature that showed that people with disabilities demonstrates limited knowledge about safe sex practices and sexually transmitted diseases which

can also put them at greater risk of sexual abuse (Saxe & Flanagan., 2016) and sexual exploitation (Travers et al., 2014). The adult participant with CP in our study shared an experience of sexual violence and not having the strength to defend herself or remove herself from the situation. She felt that one of the contributing factors to being a victim of intimate partner violence was not being aware that sex should not hurt as a result of her diagnosis of CP. Additionally, she felt that this kept her in a bad relationship for longer than it may have had she not had a misunderstanding of how sex should feel. Furthermore, when she shared this experience with an HCP, she received no support or follow up care. That participant urged for the need to educate people with CP and other disabilities to be aware and conscious of risks related to sexual violence. This finding confirms what Saxe & Flanagan (2016) found when they called for increased education for youth with disabilities covering topics such as, sexual abuse and consent, contraception and ways to have safe sex (Saxe & Flanagan., 2016).

According to the adult with CP participant in our study, inappropriate sexual contact may also be due to a lack of media representation and thus acquiring knowledge or concepts of sex through pornographic content. Sexual activity is a common component of adolescent behaviour (Herbenick et al., 2010), so if they do not receive information from reputable sources, they may turn to other, often opportunistic, ways to learn; for example, watching television, reading magazines or by watching pornography (Whittle & Butler., 2018). This may provide youth with skewed views of sexual activity that could have negative consequences. The findings of this study and the other published literature, provide support for educating youth with disabilities using easy or clear language and concrete representation of information to increase the level of

knowledge and provide healthy sexual exploration for this population (Boehning, 2006; Travers et al., 2014).

Support received and unmet needs related to sexuality

In this section we will elaborate on the healthcare support and the unmet needs related to sexuality that the youth with CP received during their HCT. The current healthcare system does not provide youth with CP with enough sexual health support. They face difficulty accessing resources for sexual healthcare; for example, HCP participants mentioned that there may not be recognition of the need or funding for adaptive tools or equipment related to sexual health. One of the HCP participants stated, 'Disability itself is expensive', so it is undoubtedly difficult if the youth and their family need to spend more money to access sexual health resources. Similar findings were also noted from a study by Wilkinson (2013) that concluded funding is required to support youth to explore their sexuality safely (Wilkinson, 2013). Additionally, the adult with CP participant's experience demonstrated that the lack of understanding of CP among HCPs made the healthcare seeking process lengthier than it needed to be. Our findings suggest that youth may have to visit HCPs multiple times with the same problem or challenge. This may result in multiple visits or medical appointments for the same issue leading to misuse of healthcare resources, increased expense and challenges for the patient (transportation, missed work, etc.). The adult with CP participant shared her struggle when she had to self-advocate to access sexual healthcare. Advocating for one's health is another new skill that youth must learn to properly navigate and access sexual healthcare in adulthood. HCP participants expressed that, most of the time youth with CP are not prepared to assume this role during or after this transitional phase. All of these

issues make it difficult for youth with CP to access sexual health support and result in unmet health needs.

HCP and adult with CP participants expressed that youth need sexual health support and real engagement in sexuality conversations. It was evident that there is lack of sexual healthcare initiatives directed at this population. HCP participants in our study discussed taking steps in future, making new programs and the current limited discussions of sexuality and gender in their clinics. According to them, sexual health conversations are very infrequent, it comes up occasionally and only if there is any flagged issues or problem, or the youth actively brings forward a concern or seeks support. The current sexual health support and resources are very limited but the ability to provide support is growing, although the HCPs admit it is a slow recognition and adoption in their practices. HCP participants mentioned specifically that there are time constraints on their sessions that makes it hard for them to address all the complex issues the youth with CP have due to their impairments or disability, and at the same time address sexuality issues. Similar findings were also reported by another study that, healthcare practitioners did not include sexuality during healthcare visits due to lack of time, they also suggested that longer duration of the consultations were more likely to include sexuality conversations (Bungener et al., 2022). Our HCP participants also added that many youths do not even get medical appointments for their basic health needs, so it's hard to arrange appointments just to discuss healthy sexuality.

Our study findings suggest that, to provide better sexual health support during HCT, a crucial step is to support the youth understanding their diagnosis of CP and how that is impacting their

body and sexuality. For instance, youth with CP might need to know that their mobility can be impacted if/when they are pregnant, or that their balance and fatigue level can change with pregnancy. Youth need to know how sexual activity may look like for a person with disability across different gender identities and sexual orientations. Sadly, these conversations are beyond the scope of what is currently provided. According to the adult with CP participant in our study, sexuality and sexual health were often reduced to yes or no questions, such as ‘are you sexually active?’ without follow-up and supportive conversations to ensure sexual health goals can be met. An optimal HCT should include these sexual health support opportunities for youth with CP to better understand their diagnosis and prepare them for safe sexual health practice.

Our conversations with the HCP participants demonstrated possible ways to ask sexual health questions to youth with CP during the HCT that may create more comfortable and open discussion about their sexual health. Instead of asking a yes or no question like ‘Are you sexually active?’, one participant shared they ask “do you think there's anything in your health that would impact relationships?” If this is too broad, more probing questions, like “Do you think you can get pregnant?”, or “do you think you can get someone pregnant?” can be used to initiate a conversation about their sexual health concerns giving, by inviting conversation and providing an opportunity to correct any misconceptions or provide specific needed education.

It is evident that, misconceptions about disability, gender identity and sexuality of youth with CP are common among people in the society, but it can affect the youth more when these misconceptions exist among their HCPs. From our current study, we found that there is lack of knowledge about the diagnosis of CP and how it can impact sexuality, the reproductive system,

and how contraception work in a body with CP. The adult with CP participant in this current study, shared her experience seeking appropriate contraception care where multiple providers thought that hormonal IUD is the only option for women with disabilities. There was hesitation, fear, discomfort and worry among the HCPs in prescribing and suggesting the right contraceptive method for her, and only after waiting for months and seeing a OBGYN specialist was she able to receive the care that she herself was advocating for and knowledgeable about. This experience clearly demonstrated the lack of knowledge on how contraceptives may relate to the effects of CP. A study by Shah et al. (2022) found similar results confirming that family doctors did not reflect on how contraceptives relate to impairment effects for women with CP. The authors also demonstrated that one of the reasons women with CP face healthcare challenges is HCP's lack of knowledge on how CP interacts with women's sexual and reproductive health (Shah et al., 2022). Furthermore, our adult with CP participant was told by HCPs at different stages that sex can hurt and that is normal; which she then felt contributed to her staying in a bad relationship. Proper sexual education and information could have prevented further violence or abuse that she encountered in that relationship. This highlights the misbelief and lack of understanding of CP in relation to sexuality among the HCPs, which may contribute to ignorance of the topic of sexuality as healthcare component in their medical practice. This is consistent with the findings of Stanojević et al. (2023), who demonstrated that service providers including occupational therapists, special educators, and other HCPs may show unwillingness to support the sexuality of their patients with disability due to misconceptions around sexuality and disability (Stanojević et al., 2023). Both HCP and adult with CP participants in our study stated that sexuality is generally ignored as part of the youth's healthcare. One HCP participant in this current study referred it to as "the elephant in the room" that nobody talks about. They added that often in the transition

meetings for the youth with CP sexuality is only brought up when there is an inappropriate sexual behaviour or concern. The healthcare system is lacking in addressing sexuality in youth with disability and people do not know where they can find support or services regarding gender transition or sexuality. The healthcare system needs to incorporate these issues in existing services to provide an optimal HCT experience and set youth with CP up for successful and healthy lifelong sexual practices and relationships.

When we specifically inquired if HCPs ask their patients with CP about sexuality, and gender identity, we got variety of responses that demonstrated inconsistent and scarce existence of sexuality and gender identity conversation in the HCT process. Furthermore, our participants reported addressed sexuality and gender together, as one concept, so we mostly discussed about sexuality and gender identity together in this paper. However, these are two different but interconnected variables; gender identity refers to one's internal sense of their self and gender, and sexuality refers to sexual identity, sexual orientation, sexual behaviour, relationships and sexual health. When we asked the HCP participants separately about gender identity, most HCPs said they do not ask the youth about their gender identity, and they are not sure who does ask that question but that it must get asked because their charts have a place for it to be documented, and then they just review that information.

When we asked HCPs if they ask the youth with CP about their sexuality, majority of the HCPs replied that they did not always ask questions related to sexuality, and many felt it was "somebody else's job" which is consistent with the literature (East & Orchard, 2013; Stanojević et al., 2023). HCP participants in our study were putting the responsibility of asking these

important questions on someone else (other HCPs) for various reasons. Some said that they do not ask because there is always a guardian or caretaker in the room which does not allow the privacy, some of the HCPs said that the assessment they do does not require talking about sexuality or sexual health, others said the medical team (nurse/physician) cover sexuality in their scope. The youth with CP participant also expressed that she was never asked about her gender identity, and there was only one pediatrician who asked about her sexuality, once.

Of note, all the HCPs were very positive about the conversation regarding sexuality, sexual health, and gender, and they all thought that this is important and should be incorporated in the healthcare practice. Some HCPs mentioned that the interview for this study was thought stimulating and they will start to practice better and incorporate these conversations in their future sessions with youth with CP. This has also been shown by Bungener et al. (2022); they studied mental healthcare professionals including medical doctors, psychiatrists, psychologists, group counselors, parent counselors, which stated that all the professionals think that sexuality and gender identity should be a part of their conversation and considered it to be their professional duty, but they seemed to be hesitant to discuss this topic with their patients. According to the author, gender identity and sexuality were very rarely discussed with the patients or their patient's parents. The Bungener et al. (2022) study also found that only the providers at a specific transgender clinic frequently talked about these issues. The authors mentioned hesitation, time, lack of awareness, presumed feelings of shame experienced by patient to be the reasons why the providers did not talk about sexuality. Another study by Saxe & Flanagan (2016), explained the cause of not being comfortable discussing sexuality, as lack of clarity in their organizational policies (Saxe & Flanagan, 2016). Furthermore, Travers et al. (2014) stated that healthcare professionals and caregivers of people

with significant disability might find it very difficult and elusive to have the conversation around relationships, sexual behavior, and sexual health (Travers et al., 2014). The participants in our current study did not mention concerns of discomfort as reasons why they did not ask these questions as a regular part of their healthcare practice but prior literature may indicate that not having the conversations could be related to the stigma around the topics, lack of specific organizational/ healthcare policies that enable discussion, influence of parent's beliefs, priority of care, lack of awareness and less time for consultation.

It is promising that some of our HCP participants mentioned that they have developed sexual health programs in their clinics and are still working on addressing sexuality in a better way because this is important “to focus on that wholeness of a person's experience in life”. Other HCP participants mentioned the intention to develop new strategies and programs to address sexuality of the youth with CP and other disabilities in their clinic.

Strategies for HCPs to address sexuality during HCT

HCT experiences with the youth with CP demonstrated that there was a lack of conversation about sexuality and gender identity, as well as lack of sexual health support. Undoubtedly this is important to incorporate these conversations in the HCT process to support the youth with CP in developing their sexuality, having better sexual health and improving the overall quality of life. HCP participants in our current study had many years of experiences of working with the youth with CP and disability, thus they shared ways or approaches to include sexuality in the HCT that worked well in their practice or that may work well if practiced. So, in this section we will be

offering some strategies that the HCPs can use to address sexuality and sexual health during healthcare.

Given the perception that conversation around sexuality may be discomforting to youth with CP (or their parents), HCP participants explained that simply opening the door to the conversation early on has the potential to allow youth with CP to explore and receive supportive healthcare related to sexuality and gender concerns. The initiation of conversation can be done by any member of the multidisciplinary healthcare team. It can come from a general practitioner, physiatrist, occupational therapist, physical therapist, social worker, psychologist, nurse or pediatrician; it should not necessarily be a “duty” for a specific one provider or professional, as what appears to be more important is that the HCP and youth have a strong therapeutic relationship where the youth feels safe and supported to have these challenging conversations. HCPs can open the door to the conversation and remind them that this is okay to talk about it, they do not have to feel scared or shy, there is no punishment for talking about these things and that they are safe. They can also open the door to the conversation and leave it open if a patient is not interested or prepared for that conversation, with a plan to revisit it at a further session. Overall, it’s important for HCPs to be proactive in initiating the discussion with youth with CP rather than waiting for an issue to arise (Wiegerink, 2011). Opening the door to the conversation also means to create the environment to initiate a sensitive topic discussion. HCP participants observed that whenever the youth get an opportunity to be alone with the providers in the room, parents or guardians are not involved in the session, the youth open up more and feel that their privacy is maintained. So, remembering and confirming the privacy during in person or virtual medical appointments or consultation is a vital component to open the door for the youth to be confined in the HCPs. Specifically related to gender identity, HCP participants mentioned that even when the parents are in the room, HCPs can start

by introducing themselves with their pronouns which may lead to further conversation in the moment or later when youth are alone with the HCPs. HCP participants also mentioned that small probes and changes can help the youth with CP to engage in a conversation regarding their gender identity or sexual health. For example, small creative changes or gestures like, pronouns listed on the name tags of HCPs, signal that the healthcare environment is an inclusive and safe place for these conversations.

Opening the door is very strongly connected with the next recommended approach to include sexuality and sexual health which is creating a safe space and allowing time to “revisit” difficult conversations. Bungener et al. (2022) established that healthcare professionals could create a safe environment to enable the youth to talk about gender identity and sexuality conversations, but that these conversations frequently occurred in follow up visits. HCP participants in our current study also mentioned the importance of creating a safe space in the healthcare setting for the youth with CP to talk about sexuality and gender issues. Safe space can be a space in the clinic that is private, inclusive, and gives the youth the comfort to share the sensitive issues. It can also be the assurance of privacy or confidentiality provided by the HCP enabling the youth to discuss sexual health. The youth may appreciate the safe space and have the conversation about their sexuality on that session, or they can consider coming back and discuss these issues at a future session. According to the HCP participants, it is also helpful to provide the youth with contact numbers or addresses to reach out if they decide to have a conversation about sexuality later. Youth can use the resources and make follow up appointments whenever needed, giving them time to reflect on their thoughts and knowledge, and composing questions they may have. Sometimes the youth might not have sexual health questions or concerns at that point of time, but if they are offered the support assuring the

safe space then the youth will be able to connect back with the HCP when they do have specific concerns. Once again HCP participants suggested using small visual cues or probes in the healthcare settings to let the youth know that it is a safe space where they can talk about sexuality and gender; for example, displaying pride flags or posters in the consultation rooms explicitly stating, “this space is safe to talk about sexuality or gender”.

The safe space can be enhanced by developing a therapeutic relationship between the youth with CP and HCP. Youth feel more comfortable sharing sensitive topics like sexuality and sexual health when they build a strong therapeutic relationship thus have more trust in the provider. When the youth are on a journey of understanding themselves and are exploring their sexual or gender identity, they may be confused, scared and shy. If the youth develop a strong therapeutic relationship with a specific HCP, it may be easier for the youth to navigate these complex feelings with the assistance of that HCP, regardless of their profession. It gives the youth more strength and confidence to try on new things and communicate their needs or preferences to their family and society. Strong therapeutic relationships allow open conversation about sexuality which enables the youth to find words to express their feelings to others. HCP participants in our current study shared that it becomes easy for them to monitor the youth’s health and address sexual health when they develop a strong relationship with the youth with CP. Long therapeutic relationships provides the comfort and opportunity to discuss sensitive issues like sexuality for the youth with CP. It is observed that youth are more comfortable with their providers after first few visits, this allows the youth to be forthcoming about any concerns they have.

Another important step to provide appropriate sexual health support during the HCT is making proper referrals. Youth with CP may need to visit the medical facilities for various health issues related to their diagnosis of CP, impairments/ disability, mental health, or sexual health. HCP's important role here can be listening mindfully to the youth's problems and providing needed support and referring to other healthcare professionals or providing resources to communicate other professionals if required. Sometimes conversations can come up during sessions with HCPs that reveals concerns regarding sexuality that the youth did not share with others, for example if the youth has developed a strong therapeutic relationship with a specific provider. HCPs can be mindful to these conversations and offer the youth with resources and refer them to the appropriate HCP or clinic if providing direct support is not within their professional scope. HCP participants in our current study shared that sometimes youth may not specify sexuality or gender issues because they are hard to recognise or express, but they do express signs of low mood, depression, or life changes which can be related to sexuality and gender issues. These signs must be recognized during their HCT so that youth can be referred to the appropriate healthcare support they need before they enter the fragmented and constrained adult healthcare system. HCP participants also mentioned that they refer youth with CP to gender clinics if the youth show interest in gender transition or wants to explore more of those identities, a referral that might be overlooked for this population.

HCP participants in our study also talked about age-appropriate conversation and maintaining privacy during sexual health conversation. One of the HCP participants mentioned that she asks sexuality related questions to the youth that are 14 years and above, but she is unsure about the age that is appropriate to start having the conversation about sexuality. These are relatively new

practices for HCPs and there are no specific guidelines for when and how to integrate these concerns, which means it is up to the individual providers or organizations to decide what to do in their own practice settings. Other studies have recommended professionals to use inclusive language and have age-appropriate conversations while talking about sexuality, gender or screening for sexual trauma (Bungener et al., 2022), though guidelines for how and when to integrate these concerns would be helpful to standardize the practice.

HCP participants in our current study shared that it can be helpful if the sexuality education start with pediatric healthcare providers in an age-appropriate way, not just during transitional care or adult healthcare. Likewise, youth with CP who have higher functional abilities may be discharged from specialized care before transitional age and so family doctors must play a supportive role in sexuality education. Several studies have shown that collaboration between pediatric and adult healthcare systems, youth and their families result in the best healthcare experiences (Carroll, 2015), therefore open communication, active discussions across the transitional divide and clear actions to support youth are required. Finally, some other suggestions made by the HCP participants for better engagement in sexuality education were to be open and thoughtful while having conversations with the youth and their family to understand their situation better, to provide handouts or booklets to the youth with CP and their families to facilitate ongoing education and conversation outside the appointment and to make the sexuality conversation a part of the regular medical check ins to sensitize youth and their families to the topic and demonstrate its importance in healthcare and emerging adulthood. Conversations about sexuality are important because it destigmatizes these concepts for youth and models a healthy conversation approach to sexuality which may help them be more comfortable talking about

sexual health and practices which in turn could assist them in making safe decisions related to sexual behaviours.

Organizational Policies and Programs to better the HCT experience

Our current study findings suggest that new and thoughtful organizational policies and programs can be helpful to deliver a high quality HCT experience with emphasis on sexuality concerns for youth with CP and their families. The HCP's role is crucial in the HCT experience of youth with CP; their knowledge, understanding and beliefs about CP and its relation to sexuality, as well as their practice standard impact the sexual health and overall quality of life of the youth with CP. Available literature and our current study found that HCPs do not have optimal awareness, confidence, education, knowledge, or experience to address issues regarding sexuality and gender among youth with CP (Mulcahy et al., 2022; Carroll, 2015; Shah et al., 2022, Saxe & Flanagan, 2016; Bungener et al., 2022). Mulcahy et al. (2022) demonstrated in their study, that lack of education and experience among the HCPs, contributed to negative experiences of transgendered people with disability and resulted in delays or those individuals avoiding healthcare services that they required (Mulcahy et al., 2022). Shah et al. (2022) found that limited knowledge and training on the effects of CP and how it relates to the sexual & reproductive health, act as a barrier for receiving quality healthcare for youth with CP (Shah et al., 2022). Therefore, it is imperative that HCPs have access to training, education and increase experiences addressing these topics with youth with CP. Studies have shown that providers with further training in sexuality have positive attitudes towards the people with disability while addressing sexuality issues (Saxe & Flanagan, 2016). Findings from Stanojević et al., (2023) also

advocate for the need for increased training, indicating that, untrained practitioners do not address the needs of people with disability identifying as LGBTQ+ (Stanojević et al., 2023). Lack of training also makes it difficult for the providers to discuss sexuality with the people with disability (Saxe & Flanagan, 2016). Training about sexuality in relation to disability will enable the providers to be comfortable talking about these issues with youth with CP during HCT. According to Stanojević et al. (2023), these trainings would also help the providers to acknowledge their own beliefs and enable them to better address the needs of people with disabilities who identify as LGBTQ+ (Stanojević et al., 2023). HCP participants in our current study expressed that addressing sexuality in the healthcare settings is a very new concept for them. Due to lack of training and knowledge of how to address these topics, HCPs shied away or avoided the conversations, eventually making them feel that they are not the right person to lead conversations about these issues. Some of the HCPs shared that they are learning as they are practicing and shared that there is a recognized need for HCP training related to sexuality in the context of disability. Sexuality training may help them address these topics better with the youth with CP and their families by increasing comfort level, providing knowledge about appropriate questions to address and how to ask these questions without offending the youth or their family. Training may also make it easier to integrate sexuality conversations at across the spectrum of healthcare settings and over time. It is our belief that HCP training should be included in the organizational policies and programs to support the HCPs and provide appropriate inclusion of sexuality issues in the healthcare for youth with CP and their families.

One effective way to include sexuality education for the youth with CP during their HCT is to arrange peer group meetings where youth will have a chance to interact with other youth with

disabilities. Focusing a peer group meeting on issues of sexuality and sexual health conversations and how these relate to disability would allow youth to share their experiences, questions and connect and learn together. HCPs could facilitate group sessions to ensure that these are safe group spaces to have these conversations. HCP participants in our current study shared their experiences of previous group events or camps where youth with disabilities were comfortable sharing their experiences and concerns about their sexuality, gender identity and overall sexual health. These peer group meetings can also help the youth to build a community and develop relationships and friendships to create ongoing peer support in an unstructured manner. Other studies have affirmed the significance of peers or peer groups; Sellwood et. al. (2017) indicated that socialising with the peers is important because the youth develop their sexual identities and learn about relationships through this interaction but youth with disabilities often lack opportunity to socialise with their peers in this way (Sellwood et. al., 2017; Gheng & Udry, 2005; Travers et al., 2014). Another study suggested that HCPs should motivate the youth to participate in online disability support groups to build a social identity with other people with CP (Read et al., 2015) in an accessible format. Read and colleagues (2015) further illustrated that these group activities can also be beneficial for the youth with CP as they get to know that the other people with CP are also facing similar problems (Read et al., 2015). Organizations can arrange peer group meetings as a mode of sexuality and sexual health education for the youth with CP and other disabilities.

HCPs and parents may shy away or decrease the importance of these topics of conversation leading to youth not feeling comfortable or safe to talk about it. Knowledge and education regarding sexuality, and its relation to CP are not only important for the HCPs, but also essential for the

youth with CP. According to Stanojević et al., (2023), comprehensive sexuality education is required for the people with intellectual and developmental disabilities, their families, caregivers and professionals (Stanojević et al., 2023). HCP participants in our current study shared a few ways to include sexuality education in the HCT for the youth with CP and their families. Family, specifically parents/ guardians of the youth with CP have a profound influence on their youth's life and their HCT experience. Parent's beliefs, misconception and knowledge about CP can impact the youth's sexual health, therefore, it is important to educate the parents about their children's diagnosis of CP, disability and the relation of sexuality with these. If many cases youth with CP with significant physical or cognitive disability require continuous care and support from the parents across the lifespan. HCP participants said that in those cases it is important to educate the parents as well, so that they can reiterate knowledge if needed, help youth to book appointments with the appropriate HCP or provide other resources when necessary. HCPs also suggested that often youth with CP are over protected and sheltered by their parents, which may not allow the youth to have the full experience of life when it comes to sexuality. Parents misconceptions may also restrict youth from receiving sexuality education from the HCPs. Donnelly et al. (2023) found that parents believe that their children do not require sexuality education because they are not interested in or do not have the ability to understand sexuality (Donnelly et al., 2023). Confirming the findings of Donnelly et al. (2023), HCP participants in the current study shared, from their experience, that some parents think that if the youth are not involved in conversations about sexuality, they will not know or think about these issues. However, youth with CP are thinking about sex and trying to learn about sexuality in other ways; therefore, having a conversation with them allows for expression of their concerns and to access the information they need in an informed and timely way. To shift these misconceptions and improve the knowledge and understanding of

the parents, it is pivotal to educate them properly about these issues. Educating the parents during the HCT process will support youth with CP to have healthy relationships, minimize risk taking behaviour related to sexual health, and understand how to handle these questions and concerns for their youth with CP. This is likely to be most successful if it is provided in sessions where they are separated from their child. Therefore, organizations should also consider providing support and education to the parents, families or caregivers, potentially individually or in group support meetings, to provide a better HCT experience and support lifelong sexual health management.

Youth with CP may be at risk for inappropriate sexual contact due to several different reasons. People with disabilities and their family members should be educated about this risk of sexual violence and how to recognize and/or prevent this unwanted sexual contact, and what to do if it does occur. Other studies identified 'consent' as an important component of sexuality education because youth with disabilities are vulnerable to sexual abuse (Saxe & Flanagan, 2016). Therefore, sexuality education should include the concept of consent to make them aware of their sexual health rights.

Finally, the evidence suggests that there needs to be a continued emphasis on individualised treatment plans. Youth with CP experience different levels of physical and cognitive disabilities and thus the impact of their CP on sexual health may vary widely. Specialists should recognise that the needs of people with CP are unique therefore services should be tailored according to the individual's needs (Read et al., 2015). Previous studies have provided a framework for teams to make decisions and individualised education plans which can be expanded to use for youth with

significant disabilities as it relates to sexuality concerns (Travers and Tincani, 2010; Saxe & Flanagan, 2016).

Clinical Implications

The findings of the current study indicate that HCPs need to be more aware of the lived experiences of the youth with CP. Awareness regarding sexuality and gender identity is required among the HCPs to provide better HCT experience for the youth with CP. Having a better understanding of the diagnosis of CP and its relation or impact on the sexuality, gender identity and overall sexual health for individuals with this condition is important for the HCPs to address the sexual health of youth with CP. HCPs are reminded to be mindful when there is a conversation that relates to sexuality and gender. Opening the door to the conversation of sexuality and gender identity can make it easy for the youth to relax and share their concerns regarding sexuality and gender. HCPs also need to be mindful of the privacy of the conversation, safe space can enable the youth to initiate a conversation about sexuality and gender allowing them to have a complete HCT experience. Parent's understanding and openness to sexuality and gender identity is another key factor that influences the HCT experience of the youth with CP. Therefore, HCPs should also be proactive in promoting awareness of sexual health issues among the parents of youth with CP and providing information during the medical visits where necessary to facilitate the sexual healthcare for the youth with CP. This is also important that the HCPs listen to the youth with CP mindfully during their visits and make appropriate referrals when needed to make sure that their sexual health needs are met.

Research Implications

Future research should include the youth with CP to explore their perspective of the HCT experience, how they shape their gender identity (whatever it may be), how the HCT contributes to forming their sexual identity, how sexuality education can be easily accessed by them, and what forms of sexuality education would best support their needs. A systematic review by Travers et al. (2014) on the sexuality education for people with significant disabilities, found only one study that included adolescents under 18-years-old (Robinson, 1984), suggesting that much more research that includes the voice of adolescents or youth with CP and other disabilities is needed to support efforts to increase knowledge and comfort with these issues. The current study described many challenges that youth with CP face during their HCT including struggles with to misconceptions about sexual activity among youth with CP, HCPs and parents, difficulty finding a partner, discomfort in talking about sex, higher rates of inappropriate sexual contact, lack of media representation, and difficulty accessing resources. Future research should explore the challenges from the youth's own perspective during their HCT. HCPs in our current study emphasized that peer group meetings may help address sexuality and gender identity issues during the HCT. The effectiveness of these peer group meetings to support sexual health and ways to include this in the healthcare setup should be explored in future research. Finally, research to find a framework or model to incorporate sexuality education in the HCT process may help to include sexuality and gender identity conversations and support in clinics for youth with CP and other disabilities.

Limitations of this study

The present study explored the experience of sexuality and gender identity formation during the HCT of the youth with CP mainly from the perspectives of HCPs, though we included the voice of one young adult with CP. Initially our plan was to include only the perspectives and first-hand experience of the youth with CP themselves. However, due to lack of response from youth with CP despite the use of several recruitment and advertisement methods, we broadened our sample to include the HCPs perspective. HCPs are an integral part of the HCT experience of the youth with CP and it is a shared experience. We investigated the healthcare experience which depends a great deal on the HCP's knowledge and understanding. Therefore, the HCPs were able to share their perspective of how sexuality and gender identity is experienced during HCT for the youth with CP. Additionally, we initially planned to collect both quantitative and qualitative data about the transition experience from youth with CP; however, we ended up conducting a solely qualitative study. We assume this limited response from youth with CP may have been due to the post-COVID timeframe where many individuals experienced burnout and disinterest in participating in additional voluntary activities such as research. Another consideration for the lack of interest and participation may be due to lack of understanding of the phenomenon of sexuality and gender identity among the youth with CP, as discussed in our findings by the HCPs. Finally, recruitment may have been limited by the relatively small number of youths with CP in Canada that identify with an alternative gender identity. Our recruitment materials stated that we were looking for youth with all gender identities (including cisgender) but this study may not have appealed to those individuals. Finally, another reason could be that youth are shy or

found it uncomfortable to participate and talk about the sexuality and gender identity with a researcher, especially given that this experience isn't common in the healthcare setting.

Lastly, I would like to acknowledge that my preunderstandings regarding CP, disability and sexuality, and my previous experience of working as physiotherapist with the people with CP may have shaped my interpretations of the findings of the study. These findings were co-constructed between myself and the participants, and I recognize that people who volunteered to participate in this study may have had different perceptions than those who did not volunteer to participate, thus the co-construction only represents the views of the participants in this study. Others may interpret the findings differently than I did, but as a physiotherapist having the experience of working with youth with CP offered a unique advantage to provide more insight into the findings and interpretations of the study.

Conclusion

The current study provided insight into experience of sexuality and gender during the HCT of the youth with CP. This study demonstrated the need and curiosity of knowledge and information among the youth with CP regarding sexuality and gender identity and how this is impacted by disability. The current study also illustrated the greater societal influence and pressures on the HCT experience due to misconceptions about disability and sexuality. We found a lack of conversations about sexuality and gender identity between the HCPs and youth with CP.

Furthermore, the lack of knowledge and training among the HCPs about sexuality and gender identity may contribute to the limited of sexuality and gender support available to youth with CP.

Future research including the youth's own experience is needed to shed more light on the struggles or challenges that youth face due to the lack of sexual health support and sexuality education. Recommendations for HCPs include opening the door to the sexuality and gender

conversation with the youth with CP, creating a safe space to revisit, building strong therapeutic relationship with the youth with CP, acquiring more in-depth knowledge about the diagnosis of CP and its impacts on sexuality or sexual health and incorporating sexuality education in the HCT process for the youth with CP.

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Appendix A – Semi structured interview Guide for youth with CP

Semi-Structured Interview Guide for youth with CP– Exploring the experience of sexuality and gender during the healthcare transitioning experience among the youth with cerebral palsy.

Thank you for agreeing to participate in this study. Today we'll be discussing your experience of health care transition and the influence of sexuality and gender on it. I will be recording this interview so I can focus on the conversation and type it out later. I just want to remind you that you can choose not to respond to any question without any problem. Are you ready to begin?

1. Tell me about your experience with the health care transition?
 - a. What exactly happened?
 - b. What were some of the positive experiences?
 - c. What were some of the negative experiences?
 - d. Can you tell me more about [experience]?
2. During your health care transition were you ever been asked about your gender identity or sexuality?
 - a. If yes – how was that experience?
 - What exactly happened?
 - Who said/asked that?
 - b. If no – do you wish you had been?
3. Have you ever faced any problems or challenges with health care providers because of your gender status or sexual preferences?
 - a. If yes – are you willing to share what happened and how felt?
 - b. What exactly happened?
 - c. Who said that?
 - d. How did this make you feel?
 - e. What did you say then?
 - f. What else do you remember about the event?
 - g. How was this resolved, if at all?
 - h. What would you have preferred to happen?
4. Have you ever received any sex education from the health care providers?
 - a. If yes – how was that experience?

- b. If no – do you wish you had?
5. Do you feel you have had enough support to take care of your sexual health?
- a. If yes – are you willing to share information that you found helpful?
 - b. If no – what supports would you like or do you feel you need?
6. Have you had any experiences where you had to hide or keep your gender identity or sexual preferences a secret?
- a. If yes – why did you make that decision? How did it make you feel? What else do you remember about the event? What did you say then? Would you do it again in a similar situation? Why or why not?
 - b. If no, what has empowered you to be yourself in potentially difficult situations? What exactly happened? What did you say then? How did it make you feel? Would you do it again in a similar situation? Why or why not?

Note: Further questions may be added or questions may be removed and adapted as necessary to the individual being interviewed. Probing will occur to gain a deeper understanding of the topics arising from these questions.

Appendix B- Semi structured interview Guide for Healthcare Providers
**Semi-Structured Interview Guide for Health Care providers– Exploring the
experience of sexuality and gender during the healthcare transitioning
experience among the youth with cerebral palsy**

Thank you for agreeing to participate in this study. Today we'll be discussing your experience as a health care provider regarding the health care transition process of adolescents and young adults with cerebral palsy and the influence of sexuality and gender on it. I will be recording this interview so I can focus on the conversation and type it out later. I just want to remind you that you can choose not to respond to any question without any problem. Are you ready to begin?

1. How long have you been practicing as a health care provider?
2. How long have you been providing care to adolescents or young adults with Cerebral palsy?
3. What is your role in the health care transitioning process for the people with cerebral palsy?
4. Tell me about your experience with youth with cerebral palsy during the health care transition?
 - a. What are some of the positive experiences?
 - b. What are some of the negative experiences?
 - c. Can you tell me more about [experience]?
5. During the health care transition process do you ever ask youth about their gender identity (Binary, non-binary, trans, cis)?
 - a. If yes – how has that experience been?
 - What exactly happened?
 - What do they say? How do they respond to it?
 - b. If no – can you explain why this question does not come up?
 - i. Do you ever intend to ask this question?
6. During the health care transition process do you ever ask youth about their sexuality?
 - a. If yes – how has that experience been?
 - What exactly happened?
 - What do they say? How do they respond to it?
 - b. If no – can you explain why this question does not come up?
 - i. Do you ever intend to ask this question?

7. Do you think this population has been exposed to different possible gender identities or are they aware of different gender identities? // Do you think they need help identifying themselves?
8. Do you observe different gender identities or variances in youth with CP in your clinical practice?
9. Have you encountered a situation where a client with CP had a concern that was related to their sexuality/ gender identity but they were not forthcoming about it? (If need to rephrase, Have you had any experiences where you think they hid or kept their gender identity or sexual preferences a secret?)
 - a. If yes – are you willing to share what happened?
 - b. How did you manage the situation?
 - c. How did this make you feel?
 - d. How do you think the client felt?
 - e. What did you say then?
 - f. What else do you remember about the event?
 - g. How was this resolved, if at all?
 - h. What would you have preferred to happen?

If No, do you think gender and sexuality is not a concern for this population? Why or why not?

10. Have you ever provided any consultation or had any discussion regarding sexual health or sexuality to adolescents or young adults with CP?
 - a. If yes – how was that experience?
 - b. If no – why not? do you wish you had?
11. Do you think the adolescents and young adults with CP have enough support to take care of their sexual health?
 - a. If yes – how or from where do you think they get that support?
 - b. If no – what supports do you think they need?
12. Do you think sexual education should be included in the health care transitioning experience for the people with CP?
 - i. If yes, why do you think so? How can this be included in their HCT process? Would you like to be a part of the sexual education process for them?
 - ii. If no, why do you think so?

Note: Further questions may be added or questions may be removed and adapted as necessary to the individual being interviewed. Probing will occur to gain a deeper understanding of the topics arising from these questions

Appendix C- Western Ethics Approval Letter



Date: 30 January 2023

To: Dr. Laura Brunton

Project ID: 121033

Review Reference: 2023-121033-75563

Study Title: Exploring the influence of sexuality and gender on the health care transitioning experience among youth with cerebral palsy.

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 21/Feb/2023

Date Approval Issued: 30/Jan/2023 16:35

REB Approval Expiry Date: 12/Oct/2023

Dear Dr. Laura Brunton ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Protocol Sexuality, Gender & HCT V4	Protocol	20/Jan/2023	4
LOI & Consent form for HCP V2	Consent Form	26/Jan/2023	2

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

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

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

Electronically signed by:

Karen Gopaul, Ethics Officer on behalf of Dr. Philip Jones, HSREB Chair, 30/Jan/2023 16:35

Reason: I am approving this document.

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

Appendix D- Letter of Information & Consent Form for Youth with CP participant



Letter of Information & Consent Form for Youth with CP participant

Title of Study: Exploring the influence of sexuality and gender on the health care transitioning experience among the youth with cerebral palsy.

Investigators: Principal Investigator:

Laura Brunton, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

Co-Investigators:

Umma Salma, BSc in Physiotherapy., Masters in Public Health., MSc Candidate Health and Rehabilitation Sciences Graduate Program, Western University

Janelle Unger, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

Treana Orchard, PhD, Associate Professor, School of Health Studies, Faculty of Health Sciences, Western University

You are being invited to participate in a research study exploring the influence of gender identity (who you are) and sexuality (who you are attracted to and your activities to express sexuality) on the health care transitioning experience among youth and young adults with cerebral palsy (CP). Currently there is very little information to show how gender and sexuality may influence the health transitioning experience among adolescents and young adults with cerebral palsy. This makes it difficult to what supports or education may help youth with cerebral palsy to have a good health care transition experience.

Since you are an adolescent or young adult with cerebral palsy and have experienced the process of health care transition (to adulthood), we are interested in your perspectives of your health care transition experience so far. This study will use an online questionnaire to help us learn about your transition readiness, skills and other general information about who you are. After this online questionnaire, you will be invited to participate in an online interview where we will ask questions about your experience of health care transition and the influence of sexuality and gender on it.

This research work is a master's student project. We expect a total of 18 youth and young adults with CP to be in this study. We are looking to get information from people with diverse gender experiences and so at most we will have 9 people of any one gender involved in the study.

If you agree to participate in this study, you will complete both, an online survey and an online interview. However, if you decide not to participate in the interview after completing the e-consent and survey, then your survey data will be removed and will be no longer included in the study. You were interested in this study during our initial telephone call, to participate in this study please read this letter and provide your consent to participate by selecting “Yes, I consent to participate in the study” at the end of this form, that will take you to the online survey. In the email you received you will also find your unique study ID number. You will use your study ID in the survey so your responses can be tracked and linked with what you tell us in the interview.

The survey questionnaire should take less than half an hour to complete. The survey questions will include demographic data (age, sex, gender, Gross Motor Function Classification System (GMFCS), topographical distribution of CP) and the Transition Readiness Assessment Questionnaire (TRAQ). The TRAQ is a validated patient-reported questionnaire consisting of 20 questions to assess the transition readiness and skills of adolescents and young adults with special health care needs. The TRAQ will ask you questions about managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities. The survey data will be used to support and emphasize the findings from interview data.

We scheduled a time for the online interview during the initial phone call. Once you provide your consent and complete the questionnaire, you will be sent another email containing a zoom link for the online interview. You will be interviewed individually by Umma Salma (MSc Student). You will be asked some open-ended questions about your experiences during the health care transition. Follow up questions maybe asked for clarification or to expand on your answers. The interview session may take up to one hour of your time. The interview will be audio-recorded and transcribed at a later date so the researcher can be focused on the interview and to ensure the transcript will be accurate. This session will occur online using the Western Corporate Zoom platform a video conferencing software. If you choose to turn on your video during the Zoom call, the video file will be deleted immediately.

You will not experience any direct benefits from this study; however, this knowledge may help the youth with cerebral palsy to have a favorable health care transitioning experience regardless of their gender identity and sexuality.

There are minimal risks associated with your participation in this study. The interview may discuss topics that are sensitive in nature. If at any point you feel uncomfortable you can choose to not answer a question, change topics, or end the interview. The researcher will also be able to provide you with resources and contact information for people you may talk to if you still feel distress or uncomfortable. In addition, we are collecting personal identifiers such as your name, demographic information, and contact information. As such, there is a small risk of privacy breach. However, we will implement best practices to decrease this risk, including using study ID numbers so your data is not linked to your name or other information that could identify you, passwords, firewalls, and use secure data servers at Western University to collect and store your data.

Participation in this study is voluntary. You may choose not to participate, refuse to answer any questions, ask to have some components of the interview excluded or withdraw from the study up until the point of data analysis with no effect on your care.

Electronic copies of the survey will be contained within the Qualtrics survey platform which uses servers in Ireland to store data. Exported copies of survey responses will only be stored on the personal Western University OneDrive that requires a username and password to login. Only Dr. Laura Brunton (PI) and Umma Salma (MSc student) will have access to it. Your research records will be stored in password protected files on password protected institutional network drives associated with Dr. Laura Brunton, the principal investigator. The research records will be destroyed after 7 years of study completion as per Western University policy. The transcript of the interview will be shared with you by email to a secure folder through Microsoft OneDrive, you will have the chance to review this transcript and remove or edit anything you wish. The audio-recording will be erased after you have reviewed and approved the transcripts. Survey data will be erased from the online platform at the end of the study. Only those individuals listed as investigators will be able to access your information.

Your confidentiality will be respected. When the results of this study are published, neither your name nor any identifying information will be used.

Representatives from the Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

If you have any questions about this study, please contact Dr. Laura Brunton.

If you have any questions about your rights as a research participant or the conduct of the study, you may contact The Office of Research Ethics at phone number or by email address. The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not a part of the study team. Everything that you discuss will be kept confidential.

You do not waive any legal rights by signing this consent form. This letter is for you to keep.

By providing the e-consent you will be consenting to participate in the online survey, the online interview and audio recording the interview. Do you consent to participate in the study?

- Yes, I consent to participate in the study
- No, I do not consent to participate in the study

Appendix E- Letter of Information & Consent Form for HCP Participant



Letter of Information & Consent Form for HCP Participant

Title of Study: Exploring the influence of sexuality and gender on the health care transitioning experience among the youth with cerebral palsy.

Investigators: Principal Investigator:

Laura Brunton, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

Co-Investigators:

Umma Salma, BSc in Physiotherapy., Masters in Public Health., MSc Candidate Health and Rehabilitation Sciences Graduate Program, Western University

Janelle Unger, PT, PhD, Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

Treena Orchard, PhD, Associate Professor, School of Health Studies, Faculty of Health Sciences, Western University

You are being invited to participate in a research study exploring the influence of gender identity (who someone is) and sexuality (who someone is attracted to and the activities they use to express sexuality) on the health care transitioning experience among youth and young adults with cerebral palsy (CP). Currently there is very little information to show how gender and sexuality may influence the health transitioning experience among adolescents and young adults with cerebral palsy. This makes it difficult to know what supports or education may help youth with cerebral palsy to have a good health care transition experience.

This research is a master's student project. We are looking to get information from health care providers involved in providing care to adolescents or young adults with cerebral palsy in different stages or services of the health care transition.

Since you are a health care provider for adolescents or young adults with cerebral palsy and have experience with the process of health care transition, we are interested in your perspectives of health care transition experience. To conduct the study, you will be invited to participate in an online interview (individual or focus group) where we will ask questions about your experience with adolescents or young adults with cerebral palsy while in the health care transition phase and

the influence of sexuality and gender on their health care transition process. To participate in this study please read this letter and provide your consent to participate by selecting “Yes, I consent to participate in the study” at the end of this form.

In the initial email you will find the link to the letter of information and consent form. Once you provide your consent, please respond to the initial email with any time preferences you have for the online interview. After receiving your consent and confirming your availability for the online interview, you will be sent another email containing a link for the online interview. You will be interviewed individually or in a focus group of up to 8 healthcare providers involved in the same transition clinic by Umma Salma (MSc Student).

You will be asked some open-ended questions about your experiences supporting the health care transition of adolescents or young adults with CP. Follow up questions maybe asked for clarification or to expand on your answers. The interview session may take between one to two hours (longer for group interviews) of your time. The interview will be audio-recorded and transcribed at a later date so the researcher can be focused on the interview and to ensure the transcript will be accurate. This session will occur online using the Western Corporate Zoom platform a video conferencing software. If you choose to turn on your video during the Zoom call, the video file will be deleted immediately.

You will not experience any direct benefits from this study; however, this knowledge may help youth with CP to have a favorable health care transitioning experience regardless of their gender identity and sexuality.

There are minimal risks associated with your participation in this study. The interview may discuss topics that are sensitive in nature. If at any point you feel uncomfortable you can choose to not answer a question, change topics, or end the interview. In addition, we are collecting personal identifiers such as your name and contact information. As such, there is a small risk of privacy breach. If you are being interviewed in a focus group, privacy cannot be guaranteed due to the nature of these groups. Therefore, please help us protect everyone’s privacy and confidentiality by keeping the conversation and information shared in the group interview confidential. However, we will implement best practices to decrease this risk, including using study ID numbers so your data is not linked to your name or other information that could identify you, passwords, firewalls, and use secure data servers at Western University to collect and store your data.

Participation in this study is voluntary. You may choose not to participate, refuse to answer any questions, ask to have some components of the interview excluded or withdraw from the study up until the point of data analysis with repercussions.

Your research records will be stored in password protected files on password protected institutional network drives associated with Dr. Laura Brunton, the principal investigator. The research records will be destroyed after 7 years of study completion as per Western University policy. The transcript of the interview will be shared with you by email to a secure folder through Microsoft OneDrive, you will have the chance to review this transcript and remove or edit anything you wish. The audio-recording will be erased after you have reviewed and

approved the transcripts. Only those individuals listed as investigators will be able to access your information.

Your confidentiality will be respected. When the results of this study are published, neither your name nor any identifying information will be used.

Representatives from the Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

If you have any questions about this study, please contact Dr. Laura Brunton.

If you have any questions about your rights as a research participant or the conduct of the study, you may contact The Office of Research Ethics at phone number or by email address. The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not a part of the study team. Everything that you discuss will be kept confidential.

You do not waive any legal rights by signing this consent form. This letter is for you to keep.

By providing the e-consent you will be consenting to participate in the online interview and audio recording the interview. Do you consent to participate in the study?

- Yes, I consent to participate in the study
- No, I do not consent to participate in the study

Appendix F- Email Script for Youth with CP participants

Email Script for Youth with CP participants

Subject Line: Invitation to Participate in a Research project titled “Exploring the influence of sexuality and gender on the health care transitioning experience among the youth with cerebral palsy”.

Hello **[Insert Participant Name]**,

We have received your name, email address and telephone number from **[insert local site recruiter’s name]**. **You have also been contacted by Umma Salma via telephone call who confirmed your ability and willingness to participate in the study. We are happy to let you know that you met all the criteria to participate in the study and** you are being invited to participate in the study that **Dr. Laura Brunton (Principal Investigator) and Umma Salma (MSc student)** are conducting.

As a reminder, the study involves answering an online questionnaire about health care transition readiness and your overall health, as well as participating in an online interview about your thoughts on sexuality, gender identity and health care transition. The survey should take less than half an hour to complete and the interview will last between 30-60 minutes.

You will receive a reminder email if you have not completed the survey at least 2 days before our scheduled online interview. Please reach out to the study team if you have any questions or difficulties.

If you would like to participate in this study, please click on the link below to access the letter of information (also attached to this email) and survey link, once you complete the e-consent and the survey by going into the provided link, you will receive another email with the online (zoom) interview link scheduled for the time you confirmed during the telephone conversation with Umma Salma.

You will be asked to enter a study ID number on the first page of your survey questionnaire, your study ID number is **[insert study ID number]**

“UWO Qualtrics link”

Thank you,

Laura Brunton, PT PhD
Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

**Umma Salma, BSc in PT, MPH,
MSc Candidate** Health and Rehabilitation Sciences, Western University.

Please note: Communication via email is not considered secure

Appendix G- Email Script for Recruitment of Health Care Provider Participants

Email Script for Recruitment of Health Care Provider Participants

Subject Line: Invitation to Participate in a Research project titled “Exploring the influence of sexuality and gender on the health care transitioning experience among the youth with cerebral palsy”.

Hello **[Insert Participant Name]**,

Thank you for expressing **willingness to participate in the study** titled “Exploring the influence of sexuality and gender on the health care transitioning experience among the youth with cerebral palsy” that **Dr. Laura Brunton (Principal Investigator) and Umma Salma (MSc student)** are conducting.

As a reminder, the study involves participating in an online interview about your thoughts on sexuality, gender identity and health care transition of youth with Cerebral palsy. The interview will take between 30-60 minutes.

If you would like to participate in this study, please click on the link below to access the letter of information (also attached to this email). Please complete the e-consent by going into the provided link and after that send us an email back to this email address with your availability for the online interview. Once you complete the e-consent and provide us with your available time schedule for the interview, you will receive another email with the online (zoom) interview link scheduled for the time you confirmed.

For your information, your study ID number is **[insert study ID number]**

“UWO Qualtrics link”

Thank you,

Laura Brunton, PT PhD
Assistant Professor, School of Physical Therapy, Faculty of Health Sciences, Western University

Umma Salma, BSc in PT, MPH,
MSc Candidate Health and Rehabilitation Sciences, Western University.

Please note: Communication via email is not considered secure

Appendix H- Recruitment material for Healthcare Providers

We're looking for healthcare providers to participate in a research study

"Exploring the Influence of Sexuality and Gender on the Health Care Transition"

If you provide support during the transition process for adolescents with cerebral palsy we'd like to hear from you



**Principal Investigator:
Dr. Laura Brunton**

Version Date: 11/29/2022



Western 

Appendix I- Recruitment material for Youth with CP

**We're looking for people with cerebral palsy
to participate in a research study**

**"Exploring the Influence of Sexuality and
Gender on the Health Care Transition"**

If you are between 14-25 years old and have CP
Contact us at:



**Principal Investigator:
Dr. Laura Brunton**

Version Date: 10/11/2022



Western 

Appendix J- Academic CV

Curriculum Vitae Umma Salma

Education

2023 – Present

Masters' of Science in Health and Rehabilitation Sciences Candidate
University of Western Ontario
Supervisor: Dr. Laura Brunton

2019 Master in Public Health

North South University, Dhaka, Bangladesh

2012 Bachelor of Science in Physiotherapy

Dhaka University, Dhaka, Bangladesh

Related work experience

Teaching Assistant (Fall 2021- Summer 2023)

Western University

School of Physical Therapy & Health Sciences

Publications

Salma, U., & Hasan, M. M. (2020). Relationship between job satisfaction and depression, anxiety, and stress among the female nurses of Dhaka Medical College and Hospital, Bangladesh. *Public Health Research*, 10(3), 94-102. doi:10.5923/j.phr.20201003.02.

Conferences

May 2023 Child Health Symposium presented by TVCC

Poster presentation: Exploring the influence of sexuality and gender on the health care transitioning experience among the youth with cerebral palsy.