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Examining the Relationship Between Disability, Impairment, and Chronic Pain in Childhood Cerebral Palsy: a Scoping Review and Critical Analysis

Muning Zhang, *Western University*

Supervisor: Teachman, Gail M., *The University of Western Ontario*
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Abstract

Young people with cerebral palsy (CP) experience chronic pain at rates higher than their non-disabled peers. Despite this recognition, there have been no studies that have addressed how young people with CP's experiences with chronic pain are represented and studied in the literature, and especially not through a critical disability studies lens. Foucault's notion of discourse was used to guide critical analysis of studies. This scoping review was guided by the research question: *"What is known about the relation between children's experiences of chronic pain and cerebral palsy in the health and rehabilitation literature?"*. Thirty-five studies were included in this review. On average, chronic pain was reported to be of moderate intensity, and interfered with activities of daily living. Young people with CP report chronic pain most commonly in the lower limbs (e.g. feet, legs). Reviewed papers tend to use agreed-upon definitions of "chronic pain" as pain that persists beyond 3 months, and cited interventions to address CP as common sources of pain. Critical analysis of the reviewed texts highlights how experiences of chronic pain were complex and impacted young people's lives across many areas of everyday life. The findings suggest that individuals have deeply personal experiences and perspectives of chronic pain. Current understandings of childhood disability and chronic pain are still predominantly rooted in biomedical perspectives of health and wellbeing, which can place blame and burden on the individual to deal with their own disability.

Keywords

Cerebral palsy, chronic pain, disability, children, critical disability studies, rehabilitation

Summary for Lay Audience

Cerebral palsy (CP) is the most common childhood disability, and many young people with CP experience chronic pain. Disabled children experience chronic pain at much higher rates than their non-disabled peers, but despite this knowledge, there is limited research that addresses the relationship between childhood disability and chronic pain. In this study, I conducted a scoping review that summarizes how the health and rehabilitation literature conceptualize disability, impairment, and chronic pain. I applied a critical lens to the analysis in order to bring forth and challenge taken-for-granted assumptions about disability and chronic pain. A total of 35 studies were included in this review, which painted a picture of how young people with CP experience chronic pain, and how the current health and rehabilitation field thinks about and addresses these concerns. On average, chronic pain was reported to be of moderate intensity, and interfered with activities of daily living. Reviewed papers tend to use common definitions of "chronic pain" as pain that persists beyond 3 months. Interventions that addressed CP were noted as common sources of pain. Young people with CP report chronic pain most commonly in the lower limbs (e.g. feet, legs). The findings suggest that chronic pain is a deeply personal experience, and that individuals have different understandings towards their pain. Current understandings of childhood disability and chronic pain still heavily stem from biomedical perspectives of health and wellbeing, which can place blame and burden on the individual to deal with their own disability. We must challenge how we think about this topic, and push ourselves and our social systems to consider how social and environmental forces outside of individuals impact their experiences in order to move towards more inclusive and accommodating ways to think about disability and chronic pain for young people with CP.

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1 Chapter 1

1.1 Introduction

Cerebral palsy (CP) occurs in an approximately 2 per 1000 live births worldwide, and is reported as one of the most common childhood disabilities (Stavsky et al., 2017). Amongst young people diagnosed with CP, the prevalence of pain is a concern, with an estimated 32 to 77% of this population experiencing chronic pain at some time in their lives (Kingsnorth et al., 2015). This range is disproportionately higher than rates reported for non-disabled youth, where estimated pain prevalence ranges between 11 to 38% (King et al., 2011). As a note, definitions and perspectives of disability are varied across different models of understanding (Goodley, 2013). In general, I use the critical disability studies interpretation of “disabled” to refer to individuals who experience incongruence within their body from so-called ‘normal’ social, cultural and spatial expectations (e.g., an impairment), and face social exclusion and oppression as a result[1](M. C. Hall, 2019). Further information about critical disability studies and other perspectives of disability will be discussed in Chapter 2.

Despite this discrepancy, there is scant research focused on CP and chronic pain, and almost no research that foregrounds young people’s perspectives on this topic (Schiariti & Oberlander, 2019). Furthermore, dominant social assumptions about disability, impairment, and chronic pain promote narratives about childhood disability, including potentially harmful ideas about what disabled children ought to do and how to behave (Gibson et al., 2016). These assumptions are reflected in deeply ingrained language and norms that frame disability as necessarily tragic or burdensome. These ways of thinking can contribute to assumptions that living with impairment means that pain is inevitable or unavoidable, and limits our understanding of what chronic pain truly looks like for disabled young people.

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[1] In contrast, “non-disabled” refers to young people whose bodies are deemed to be fit the “normal” or “typical” social, cultural, and spatial expectations.

In this study, I begin with an overview of research surrounding CP and chronic pain. Then, through a scoping review I synthesize what is known about and what might be problematic about that knowledge and/or how it was produced, and what further knowledge is needed concerning chronic pain among young people with CP. My work is oriented by a critical disability lens which has helped me to consider how different framing of disability and impairment shape narratives about chronic pain in this population.

1.2 Situating the Thesis

This thesis describes work that contributes to a larger project focused on exploring the perspectives of disabled young people with chronic pain, titled the "Childhood Disability and Chronic Pain" (CDCP) study. There is an urgent need for foundational knowledge about chronic pain and disability that has been co-produced with disabled children and is attentive to the complex relations among chronic pain, impairment, and disability that mediate their experiences. Alongside the scoping review conducted as part of this thesis, the broader CDCP study will also involve a qualitative, art-based project that directly explores the ways in which disabled children represent and narrate their experiences and understandings of chronic pain. Beyond the scope of this thesis, the CDCP team will be conducting further consultation with key knowledge users with expertise in the childhood disability and chronic pain, including clinicians and researchers, regarding the scoping review's findings. We expect this group to provide novel insight into the relevance and applicability of our preliminary findings, as well as any alternative perspectives not found in the literature review alone. All components of the CDCP study are broadly framed within a critical disabilities study perspective that questions the taken-for-granted assumptions underlying this field of study (Goodley, 2013). Overall, a critical disabilities perspective considers the role of power across the research process and acknowledges the relationship between young people and their social, political, and economic contexts. I will elaborate about the critical perspective further in Chapter 2, as well as within the next section as I situate myself as a researcher.

1.3 Situating Myself as a Researcher

Adopting a reflexive stance is considered a key component of rigor in critical research studies (Darwin Holmes, 2020). Reflexivity starts by identifying preconceptions brought into projects by researchers that are attributed to the individual’s unique social values and experiences. Through reflexivity, which requires sensitivity to the cultural, social, and political contexts the researcher is situated in, we can describe the “positionality” of the researcher and the research itself. “Positionality” describes both a researcher’s worldviews and the perspective they adopt about the social and political context of a research task (Darwin Holmes, 2020). One’s positionality influences all aspects and stages of the research process, acknowledging that researchers are part of the social world they are researching and not separate from the social processes being studied.

I approach this project as a novice researcher who is an outsider to the disability community. Coming from a background in health sciences that addressed the social and relational forces that contribute to health beyond an individual level, it was easy at first for me to think I was applying the same way of thinking to disability studies. I recognized non-biomedical perspectives of health and disability and acknowledged the harms of portraying disability as inherently something to be overcome by the individual. However, this recognition was not enough to prevent me from defaulting at times to taken-for-granted beliefs and assumptions about not only disability and impairment but childhood, pain, and health in general. The more I immersed myself in critical scholarship and challenged myself to think beyond dominant ideas– discourses in which I am immersed– the more I recognize the blind spots created by dominant biomedical perspectives of health, revealing deeply ingrained assumptions about childhood disability that seeped into the studies I reviewed, and inevitably within myself as well. This made me uncertain about whether I had the necessary knowledge or even the right to be speaking on these ideas in the first place. While I am not sure if this uncertainty has or ever will go away, it also reminds me to be continuously open and learning, especially from the perspectives of disabled people themselves and from knowledge produced in disability studies. Through my master’s training, I have reflected on my positionality as a non-disabled researcher, recognizing the complex relationships of power and knowledge that influence my research, and strive to continually be reflexive of the potential consequences and impact of this work.

1.4 Organization of the Thesis

In Chapter 1 of this thesis, I have introduced the main aims of the thesis and my positionality as a researcher. In **Chapter 2**, I introduce and describe various understandings of disability, including models of disability and surrounding discourses. In **Chapter 3**, I introduce background information about cerebral palsy and chronic pain, outlining the research rationale of this thesis and objectives of the scoping review. In **Chapter 4**, I describe the methods used to conduct the scoping review, as well as introduce how I have implemented a critical lens to my analysis. In **Chapter 5**, I will present the results of my descriptive analysis, which provides an overview of how CP and chronic pain are addressed in the literature. In **Chapter 6**, I present the results of my critical analysis, where I applied a critical lens to some of the ideas about CP and chronic pain emerging from the literature. Finally, I conclude in **Chapter 7** with discussion of the contributions of this work, consideration of what future research is indicated, and final thoughts, summarizing the implications of this work.

2 Chapter 2

2.1 What is “Disability”?

2.1.1 A Critical Disability Studies Approach

Critical inquiry in general is an approach to research that seeks to disrupt and challenge the status quo in order to address inequities and oppression through conceptualizing reality within a socially and historically situated context, and recognizing how power shapes social relations (Ponterotto, 2005). The field of critical disability studies is a merging of epistemologies and ontologies across disciplines, drawing on the embodied experiences of disabled people themselves to identify areas of discrimination (Goodley et al., 2021; Reaume, 2014). Instead of disability as being related to pathological differences within individuals, critical disability studies represent a paradigm shift that identifies disability as being produced through inequitable social conditions. Disability is then a construct created and imposed on individuals by external forces and systems, rather than as an inherent feature within themselves (Reaume, 2014).

In holding a disability studies approach, it is important to differentiate between the oft-conflated terms *disability* and *impairment* when considering the impact of chronic pain in disabled children. Emphasis is placed on understanding how a child’s health conditions interact with their personal and social environment, including discriminatory and ableist social relations and conditions, to produce functional limitations, thus producing “disability” (National Academies of Sciences et al., 2018) “Disability”, in this lens, is a socially constructed phenomena and separate from “impairment”, which arises from the functional limitations caused by physical, mental, or sensory differences (Anastasiou & Kauffman, 2013). Children with impairments are disabled when they are situated in an environmental context that discriminates, disadvantages, and excludes them because of their differences (Anastasiou & Kauffman, 2013).

Another important consideration regarding language is this study’s use of identity-first language (e.g. “disabled child”), as opposed to person-first language (e.g. “child with disabilities”). While there is no one right way to talk about disability, identity-first language is often preferred by the disabled community (Best et al., 2022). Identity-first language recognizes disability as produced by social structures, social relations and attitudes rather than as an innate characteristic within the individual. While person-first language is meant to promote respect for an individual, for example in referring to someone as “having an addiction” rather than as being an “addict”, within critical disability scholarship the use of person-first language is viewed as problematic since it implies that disability is located within a person and inherently negative. On the other hand, identity-first language such as ‘disabled youth’ signifies recognition that disability is socially produced and linked with structural and social disadvantages while also acknowledging it as an integral part of a person’s identity that might be embraced (Best et al., 2022). In aligning with a critical disability studies approach and keeping with the view that disability is produced through social relations rather than because of within the individual, I will use identity-first language throughout this study (e.g. “disabled young person”).

2.1.2 Medical Model of Disability

The medical model of disability draws on disease theory to conceive disability as an individual problem that arises due to biological or acquired dysfunction of a body part of system (Gibson et al., 2016). Within this model, disability is able to be quantified, classified, and measured as deviations from a standardized “normal” (Smart, 2009). Disability is considered to be the inevitable result of impairment of body functions and structures, conflating disability and impairment with being “sick” in some form (Haegele & Hodge, 2016). The medical model also places authority in the hands of medical professionals who diagnose and treat disabled individuals, due to their assumed understanding of health and “normal” presentations of such (Retief & Letšosa, 2018). Medical professionals are often seen as gatekeepers who provide access to resources, such as rehabilitation (Haegele & Hodge, 2016). The medical model views rehabilitation as a necessary way to “fix” the individual, bringing them closer to a standardized and socially recognized “normal” (Gibson et al., 2016; Smart, 2009). The medical model reinforces the notion that there is something inherently negative and disabling about impairments, and that challenges faced by disabled individuals are independent of the wider sociocultural, physical, and political in which they are situated (Haegele & Hodge, 2016).

Focusing on biological deficits and "fixing" disability is assumed to be the logical and 'best' path for individuals to optimize their function and independence (Haegele & Hodge, 2016).

Researchers who critique the medical model of disability highlight the ways it neglects to consider the politics of disablement, overlooking the importance of social and contextual factors that contribute to the barriers faced by disabled people (Bunbury, 2019). Despite this recognition and an overall shift in the fields of health and rehabilitation to move away from thinking about disability as something individual to be "fixed", the dominance of biomedical ideas remains evident in many of the taken-for-granted practices and understandings in these fields. For instance, Gibson (2016) argues that the encyclopedia definition of "rehabilitation" itself ("the physical process of restoring a person's ability to live and work as normally as possible after a disabling injury or illness*"* (p. 31)) reflects an attribution of disability to physical causalities, where the *injury or illness* is disabling, and the goal is to achieve a form of "normality". This, alongside the view of disability as a "personal tragedy", has historically contributed to harmful medical treatments and interventions for disabled people under the guise of "correction", such as sterilization or institutionalization (Retief & Letšosa, 2018). The dominance of the medical model may also be the driving force behind painful rehabilitative measures meant to shape an individual into some version of socially accepted norms, such as privileging walking as a more acceptable form of movement than using a wheelchair (Gibson et al., 2016). With the recognition of the potential harms of the medical model, disability rights movements in the 1970s produced alternative perspectives to thinking about disability that draw attention to dominant ableist discourses, practices, and policies that construct disability, namely the social model of disability (Retief & Letšosa, 2018).

2.1.3 Social Model of Disability

In contrast to the medical model, the social model of disability locates disability solely within the environment, where disability is the result of exclusionary social and material arrangements (Haegele & Hodge, 2016). Emerging from disability advocates and academics in the 1970-80s, the term was first coined by Mike Oliver in 1981, to describe the new paradigm of thinking about disability (Barnes, 2019). In the context of the social model, the terms "disability" and "impairment" are considered separate, where "impairment" is perceived as a difference in the body, and “disability” is the disadvantage caused by a social organization that excludes those with impairments (Haegele & Hodge, 2016). Disability is constructed entirely as an issue of social context, where certain human variations are faced with physical barriers, prejudice, discrimination, and stigmatization (Bunbury, 2019). Within this model, there is a shift from focusing on adapting individuals to fit into their environments, to challenging the dominant ideas within the environment that place individuals at disadvantage in the first place (Bunbury, 2019). To address these disadvantages, the moral responsibility does not fall on the individuals, but on society to address the burdens they imposed in the first place (Gibson et al., 2016). Improvement for individuals with impairments relies not on changes to their physical bodies, but on political action and social change in the environment around them (Haegele & Hodge, 2016). Since its emergence, the social model has remained the dominant framework in disability studies today and has been attributed to shifting the landscape of disability understanding and awareness, leading to legislative and policy reform place (Gibson et al., 2016).

Those who critique the social model suggest that by separating impairment and disability entirely, the model fails to address impairment as an attribute of individuals that is essential to their lived experience (Haegele & Hodge, 2016) In failing to adequately account for the multidimensional nature of disability, the “body” is rendered irrelevant in the conversation (Smart, 2009). This mirrors the objectification of the impaired body in the medical model, where the body is rendered inert and separate from the self and disablement process. The social model overlooks the impairment effects, downplaying the relational nature of impairment, disability, and social forces (Terzi, 2004). For instance, the effects of a visual impairment and a motor impairment can be very different, and barriers faced by these types of impairments vary in different contexts. Additionally, the physiological effects of impairment, such as the presence of pain or discomfort, often exist regardless of the social context (although these contexts may certainly play a role in their recognition and management) (Terzi, 2004). Similarly, another critique of the social model is that it does not account for differences between individuals with disabilities, failing to recognize the intersectionality of (dis)ableism with different forms of oppression, such as gender, race, or sexual orientation (Haegele & Hodge, 2016). The experiences of disability differ from person to person, and differences in impairment effects and intersectional experiences have emphasized the need to consider the relation between personal and social effects of impairment (Terzi, 2004). The development of the social model, and overall paradigmatic shift towards embracing a less biomedical model of disability has led to the emergence of models like the ICF classification.

2.1.4 The International Classification of Functioning, Disability, and Health (ICF) Model

Developed by the World Health Organization (WHO), the International Classification of Functioning, Disability, and Health (ICF) is a classification of health and health-related domains, integrating both the social and medical models of disability (Gibson et al., 2016; WHO, 2002). This model, which aims to classify notions of "health" and "disability" in a new light, provides a biopsychosocial perspective of disability that includes a consideration of levels of human functioning at the body or body part, the whole person, and the whole person in a social context (WHO, 2002). Disability is therefore a dysfunction at one or more of these same levels: impairment (body or body part), activity limitations (the whole person), and participation restrictions (the whole person in a social context). According to this model, disability is not solely a problem that resides in the individual but occurs within the context of interactions between individual health conditions and environmental and social factors (WHO, 2002).

A persistent critique of the ICF model is its reliance on statistical norms to define human dysfunction and disability, where "abnormality" is presented as an objective statistical variation (Mosleh, 2019). This reproduces notions of "normal" versus "abnormal", perpetrating views of disability as a form of deviance that ought to be addressed. In considering the issues of defaulting to thinking about disability in comparison to some type of "normal", it brings up the question of how certain ideas become entrenched in the social conversation. One way of thinking about this is to discuss the ways that "discourse" can be used to think about socially constructed norms. This form of critical framing allows us to begin to question how different models of disability contribute to how we think about it, and the consequences of continuing to reproduce certain ideas.

2.2 Considering Discourse

In situating the work further in a critical social paradigm, I introduce Michel Foucault's post-structural notions of discourse to think about socially constructed notions of disability.

Poststructuralism recognizes the constructed nature of knowledge and meaning that arises from the ways that language, power relations, discourses, and social institutions exist and intersect (Rolling, 2010). For instance, understandings of disability are influenced by (and influence) the use of language. Differences in person-first or identity-first language choice in discussing disability reflect this, and preferences for either option arise from constructed social and cultural contexts and conventions. At the same time as there are social regularities, norms, and discourses, there are also opportunities to reinterpret dominant patterns of thought and behavior, by identifying and challenging how and where knowledge arises from (Rolling, 2010). In highlighting discourse specifically, I draw on Foucault's framing of discourse as "the production of knowledge through language" (Hall, 1997, p. 44). By addressing ways that discourse contributes to the creation of "disability" as a concept, it is possible to consider how these discourses interact with language, power relations, and social institutions to perpetrate certain understandings, and the implication of these understandings in the context of CP and chronic pain.

"Discourse" in this sense refers to patterns of thinking, speaking, and acting that systematically produce or reproduce the objects of which they speak (Hall, 1997). In other words, without the existing discourse, the object itself does not inherently exist in a certain manner, and nothing has any meaning outside of discourse (Foucault & Gordon, 1980; Hall, 1997). While physical items and actions exist, these only become "objects of knowledge" within a socially constructed and circulated discourse, which includes the actions and practices of individuals and institutions (Foucault & Gordon, 1980; Hall, 1997). For example, discourse is also situated within historical and cultural context, and any knowledge produced and practiced would differ across these domains (Foucault & Gordon, 1980; Hall, 1997). We are all immersed in discourses that shape our understandings of the world, such as the discourses surrounding childhood disability and chronic pain, which I will expand on shortly.

Another element Foucault considered was the relationship between knowledge and power, and how discursive practices in specific institutional settings could be used to control the conduct of others (Hall, 1997). Especially when considering how to analyze discourse within a Foucauldian framework, it is important to consider discourses not for what they *say*, but rather what they *do* (Graham, 2011). In other words, discourses have effects. Through the circulation of specific types of knowledge, ideas are perpetuated in a manner that restricts the focus of something to only what the dominant discourse deems to be “real” or “true” (Foucault, 1982). When this occurs, individuals are limited in the ways they know, act, and speak about certain phenomena, which produces them as a certain type of “subject” (e.g., a disabled child). For examples, discursive notions of “normal childhoods” contributes to the creation of the “disabled child” by highlighting the ways disabled children can or cannot meet these created standards.

For Foucault, individuals are created to be particular types of subjects, both by society’s institutions, knowledges, and discursive practices, but also by the internalized discursive practices individuals act upon themselves (Foucault, 1982). This in turn continuously circulates a certain version of truth and power that reflects these ideals, which makes it difficult to think and act beyond discourses (Hall, 1997). Foucault’s thinking about discourse is not about blaming individuals who are situated in these ideas, but rather to encourage thinking about how discourse shifts over time and how discourses are perpetuated at structural and systemic levels, such as in the field of rehabilitation (Hall, 1997). How are the pervasive ways of thinking about childhood disability and chronic pain impacting the kinds of “truths” that are created and assumed about people labelled as having these identities? These questions begin to identify and highlight the ways that discourses have entrenched our understanding of this topic.

In thinking about my research topic, many discourses surrounding “childhood disability” and “chronic pain” are present in the literature. I will connect these two focuses together and highlight prevailing discursive ideas that have the most relevance when discussing this relationship.

2.2.1 Discourses in Childhood Disability and Chronic Pain

One major focus within childhood disability discourses is a preoccupation with normality (Priestly, 1998). In thinking about disability and “normality”, it is therefore important to recognize and acknowledge the forces in place that have painted the idea of a “normal” child, and the consequences this discourse has on children who fall outside of its boundaries. Within studies of children and childhood, an emphasis on “normative” development, often categorized into stages and bell curves has been the dominant approach to evaluating children (Graham, 2006). The dependence on these statistically derived norms can be problematic; they privilege particular ways of being based on culturally specific notions of ability, neglect to acknowledge natural diversity, and objectify children with the overemphasis on pathology and development into a “normal” adult (Graham, 2006; Priestly, 1998). The implications of the emphasis on “normal” inevitably means the identification of an “abnormal” narrative surrounding children deemed to have any form of difference or impairment. This notion leads to further disabling effects for children, as children deemed to be disabled are exposed to scrutiny, surveillance, control, and discrimination (Priestly, 1998).

Similarly in chronic pain discourses, “normalization” is an oft emphasized and promoted goal for patients, where individuals who fail to demonstrate an expected norm are viewed as “abnormal” (Wellard, 1998). Responses to this “abnormal” behavior include blaming individuals for failing to meet expected norms of health, or further categorizing into acceptable norms for those labelled as having chronic conditions, leading to increased judgement (Wellard, 1998). Underlying the drive for normality in both discourses surrounding childhood disability and chronic pain are Western society’s emphases on independence, productivity, and over-reliance on a biomedical framing of health (Priestly, 1998; Wellard, 1998).

Further related preoccupations within the childhood disability discourse are “vulnerability” and “denial of complex identities”. For all children, “vulnerability” is often seen as an inherent feature of the individual as a result of their biological age and development, rendering them innocent and morally incompetent (James & James, 2012). Depictions of disability as “tragic” and prominent narratives surrounding disabled people that highlight the mistreatment they experience also reinforces the notion of vulnerability (Hayes & Black, 2003; Priestly, 1998). By depicting disabled children as passive victims, this denies their role as social actors and refuses to recognize the complex social identities they develop (Priestly, 1998).

Issues of identity and exclusion impact disabled children just as much as any population. Social experiences related to race, gender, sexuality, class, and health (such as chronic pain) are often ignored through the imposition of “disabled” as the solitary label onto these children. In focusing on the relationship between disability and chronic pain, existing literature that does explore this relationship from the direct perspective of children themselves has been very limited. Research in this area acknowledges the need to address chronic pain in disability, but it is often through the use of quantitative assessment tools or speaking to parents and caregivers (Fitzpatrick et al., 2022; Petigas & Newman, 2021). Very rarely is the disabled child's voice acknowledged and considered in the conversation of their own chronic pain experiences, a result of the discourses that depict disabled children as unable to contribute to research, despite the existence of many works highlighting otherwise (Imms et al., 2016, Priestly, 1998)

In examining the existing discourses surrounding disabled children and chronic pain, I have highlighted how these contribute to the production of a subject (e.g., a "disabled child") that exists within certain boundaries of expectations. But as discussed earlier, acknowledging that these discourses are constructed also gives way for the opportunity to deconstruct them, to break down the creation of certain "truths" and recognize the interplay of power and knowledge that established them in the first place. That process begins with recognition of the powerful ideas that persist in the current health and rehabilitation sphere. In the next chapter, I discuss the current biomedical understandings of cerebral palsy and chronic pain present in more depth as these are represented in the literature, and I point to gaps in those ways of understanding that suggested there was a need to conduct a more formal scoping review.

3 Chapter 3

3.1 Background Literature Review

3.1.1 Biomedical Understandings of Cerebral Palsy

Cerebral palsy (CP) is a group of permanent disorders of movement, posture, and muscle tone, and is the most common cause of motor disability in children (Panda et al., 2024; Patel et al., 2020). CP is caused by damage to the developing brain in the prenatal, perinatal, or postnatal time period (Jones et al., 2007). Although the initial damage to the brain is non-progressive, children with CP may develop a range of secondary conditions over time. While symptoms vary from person to person, CP is associated with disturbances of sensation, cognition, communication, and perception, as well as behavior and/or seizure disorders (Agarwal & Verma, 2012). CP is usually diagnosed in infancy or early childhood through clinical observations of clusters of symptoms or evolving abnormal movement patterns indicative of CP (Jones et al., 2007).

There are many classification of CP due to its heterogeneity of presentation (Panda et al., 2024). The most frequently applied classifications are through Ingram's (1955) classification according to type and location of neurological syndrome and severity of symptoms, Hagberg's (1976) classification according to location of damage to the brain, and the Surveillance of Cerebral Palsy in Europe (SCPE)'s standardization three groups (spastic, dyskinetic, ataxic) according to characterizations of CP presentation, like muscle tension and movement or posture disorder. Individuals may also have mixed disorders, such as having both spasticity and dyskinesia (Sadowska et al., 2020).

CP may also be broadly classified by severity level (e.g. mild, moderate, severe) which while is a simple way to communicate scope of impairment, lacks specificity, especially when compared to the Gross Motor Function Classification System (GMFCS) and other functional classification systems (Ferluga et al., 2013). The GMFCS is a 5-level classification system that describes the gross motor function of an individual with CP, focusing on self-initiated movements and use of assistive devises (e.g. walkers, wheelchairs) for mobility (Paulson & Vargus-Adams, 2017). These five levels were designed to discriminate clinically meaningful distinctions in motor function, with GMFCS Level I presenting the least amount of functional limitations and GMFCS Level V the most. Other functional classification systems, such as the Manual Ability Classification System (MACS) or the Communication Function Classification System (CFCS) are standardized measures that describe functional performance and capacity as related to hand function and communicative function respectively, across different motor types and topographical distributions (Paulson & Vargus-Adams, 2017).

3.1.2 Chronic Pain

Chronic pain is defined by the International Association for the Study of Pain (IASP) as persistent or recurrent pain lasting 3 months or longer (Raffaeli et al., 2021). While this definition is broadly used, it has also been critiqued as being somewhat arbitrarily defined and in reality much more difficult to quantify (Kang et al., 2023). Other definitions of chronic pain are more functionally-based, such as “pain that extends beyond the expected period of healing” and “hence lacks the acute warning function of physiological nociception (Friedrichsdorf et al., 2016). In pediatric populations, an estimated 20% of young people experience chronic pain worldwide (Chambers et al., 2024). Chronic pain in children is recognized as being the dynamic integration of biological processes, psychological factors, and sociocultural variables, where these factors influence each other in a young person’s experience of chronic pain (Friedrichsdorf et al., 2016).

World Health Organization’s *International Classification of Diseases, 11th Revision (ICD-11)* included diagnostic codes that attempted to classify and categorize chronic pain (Treede et al., 2015a). The ICD-11 distinguishes chronic pain as either “chronic primary pain” or “chronic secondary pain”. “Chronic primary pain” is pain in 1 or more anatomic region that persists or recurs for longer than 3 months and is associated with significant emotional distress or functional disability that cannot be better explained by another chronic pain condition (e.g. chronic widespread pain, fibromyalgia) (WHO, 2024; Treede et al., 2015). “Chronic secondary pain”, which can be further differentiated for different forms of pain such as “chronic secondary musculoskeletal pain” or “chronic secondary visceral pain”, similarly describes pain in 1 or more anatomic region that persists or recurs for longer than 3 months and is associated with significant emotional distress or functional disability, but arises from an underlying disease beyond the pain itself (Perrot et al., 2019). Pain that arises from the underlying pathologies of CP would be classified as chronic secondary pain (e.g., pain arising from spasticity) (Vinkel et al., 2022)

3.1.3 Cerebral Palsy and Chronic Pain

Pain in individuals with CP is often attributed to musculoskeletal complications, increased muscle tone and spasticity, hip dislocations, and GI dysfunction related to the underlying pathophysiology of CP (Peck et al., 2020). Furthermore, pain has also been linked to the side effects of therapeutic interventions given to individuals with CP, such as physical therapy or injections. As mentioned previously, an estimated 32 to 77% of people with CP experience chronic pain, with these estimates often considered conservative, due to suspected under-reporting and under-managing of pain (Kingsnorth et al., 2015; Peck et al., 2020). It is important to acknowledge that acute pain is also a common concern for young people with CP, often resulting from interventions (Vinkel et al., 2022). Studies may not always discriminate between acute and chronic pain in young people with CP, leading to further challenges in classifying and recognizing chronic pain (Ostojic et al., 2020). This is worsened with the presence of cognitive and communicative impairments, and while expressions of pain in nonverbal or preverbal children may be challenging to recognize, it does not take away from the negative nociceptive experience of these children (Letzkus et al., 2021). One of the key issues in understanding pain and disabled young people is that it is not well assessed, with limited assessments of pain that considers outcomes like participation in valued activities, mental health, and sleep (Noyek et al., 2024). There exist a range of assessment tools for both chronic pain and cerebral palsy, and lack of training for health professionals leads to inconsistencies on how to assess and recognize chronic pain for this population (Kingsnorth et al., 2015). Unrecognized pain may significantly interfere with mobility and participation in daily activities, and may also impact sleep, mental health, social connections, and physical functioning (Kingsnorth et al., 2015).

3.2 Gaps in the Literature and the Present Study

Despite the recognition of chronic pain being a significant problem in young people with CP, there have been limited studies that address this relationship, perhaps due to the heterogeneity of both CP and chronic pain. While studies exist to classify the types of pain in children with CP (Vinkel et al., 2022), describe best forms of assessment and measurement (Harvey et al., 2022; Kingsnorth et al., 2015), and many cross-sectional examinations of chronic pain prevalence and characteristics (Østergaard et al., 2021; Ostojic et al., 2020), there have been no studies that have actively explored and summarized how young people with CP's experiences with chronic pain are represented and studied in the literature, and especially not through a critical lens.

While there has been a paradigm shift towards adapting "function based" understandings of disability, the predominance of biomedical understandings of health means that these ideas often linger within the narratives of studies that discuss the biomedical model's faults. In adopting a critical lens, this present study hopes to provide an overview of how ideas related to disability, impairment, and chronic pain are expressed and how they relate to each other. Without this overview, and with continued conflation of terms and ideas related to disability, impairment, and chronic pain, there is a risk that pain may be taken for granted and left untreated.

3.3 Study Objectives

The scoping review was guided by the research question: "What is known about the relation between children's experiences of chronic pain and cerebral palsy in the health and rehabilitation literature?" The parameters included peer-reviewed journals focused on health and/or rehabilitation, as these are likely the places where clinicians and researchers would search for evidence-based resources. The objectives of this scoping review are to 1) learn about the state of current knowledge, and 2) learn about how the concepts of impairment, disability, and chronic pain are intertwined in the context of cerebral palsy.

4 Chapter 4

4.1 Methods

4.1.1 Scoping Review Methodology

A scoping review provides an overview of existing knowledge in a certain research area, allowing for “mapping” the landscape of evidence in a field and identifying possible gaps in the literature (Levac et al., 2010). Researchers may choose to undertake a scoping study to explore the overview of research in an area or clarify complex concepts. We chose the scoping review approach over other forms of review as we intended to locate and summarize what we expected might be scant evidence across the health and rehabilitation literature. Our research question was not the specific and focused type that would indicate undertaking a systematic review, and our intention to include analytical interpretations of the reviewed literature contraindicated use of narrative or literature reviews (Levac et al., 2010; Munn et al., 2018). We used the scoping review methodology outlined by Arksey and O’Malley, along with methodological advancements proposed by Levac et al. (2010)’s recommendations. Arksey and O’Malley (2005) developed a six-stage methodological framework: identifying the research question; searching for relevant studies; selecting studies; charting the data; collating, summarizing, and reporting the results; and consulting with stakeholders to inform or validate study findings.

4.1.2 Applying a Critical Lens

While scoping reviews are usually exploratory and descriptive in nature, the application of a critical lens onto scoping reviews has been done in some studies to bring in contextual evidence to challenge foundational assumptions of the literature (Forsey et al., 2021; Van der Kleij & Lipnevich, 2021; Webster et al., 2017). As discussed in the introduction, a critical approach encourages us to think about taken-for-granted assumptions and power structures that exist within a particular field. Through the acknowledgement and identification of these assumptions, it enables us to think about how and where these constructed realities arose from, a crucial step towards making social change beyond the existing status quo (Webster et al., 2017). In adopting a critical lens, I approached the analysis of results with this alignment in mind.

4.1.3 Identifying the Research Question

As mentioned in Chapter 1, this scoping review is part of a larger line of ongoing research in the area of childhood disability and chronic pain. Building on the core directions of exploring understandings of childhood disability and chronic pain, the research question for the scoping review specifically was developed through discussions with the research team and health sciences librarian. The research team consisted of the first author, L.Z., K.M., G.T, and F.W. Another graduate student (A.M.) participated in abstract and method screening, but was not part of discussions to identify the research question or analysis. Initially, the study population focused on all young people who identified as having a "physical disability" and chronic pain in general. However, upon a trial search and screen of this research topic, it was clear that the scope of "physical disability" was too broad to allow us to sufficiently capture the desired level of analysis, leading to an uncertain study population with insufficiently defined parameters for what counts as "physically disabled". To address this, we agreed it would be more valuable to limit the searches to one clearly defined study population. Cerebral palsy is the most common childhood physical disability and pain is often associated with the pathologies of CP (Stavsky et al., 2017). Therefore, the research team leading the broader study chose to focus on young people with cerebral palsy as the only study population, before developing the exploratory research question of: *What is known about the relation between children's experiences of chronic pain and cerebral palsy in the health and rehabilitation literature?*

4.1.4 Development of Search Strategy

Keywords were developed in relation to the concepts of "cerebral palsy", "chronic pain", and "child" (see Table 1 for an overview of the search strategies, adapted for each database). The following databases were searched for articles on November 28, 2023: Medline, Embase, PsycINFO, CINAHL, and Cochrane. Following database searches, references were uploaded and managed using Covidence, an online review management software (Available at: www.covidence.org). See Appendix A for full search strategy.

4.1.5 Eligibility Criteria

We included studies that were (a) focused on young people (defined as aged around 0-18 years old, although studies with a slightly higher age range were allowed (e.g., up to 24 years old) if that study classified that age range as youth), (b) diagnosed with CP and (c) experiencing chronic pain (i.e., pain lasting or recurring at least 3 months or longer). Other inclusion criteria included (d) being written in English language, (e) published within the last 20 years, and (f) conducted within a Western country or context. This was done to hopefully situate the study within more recent understandings of both disability and pain, as well within with similar social and medical contexts and understandings of health and rehabilitation.

Studies that included adult populations alongside young people were included only if the data related to young people as defined by the study were presented as separate and easily distinguishable as their own population. Similarly, studies that included other physical disabilities besides cerebral palsy were included if data about the population with cerebral palsy was presented separately and clearly identifiable. Studies focused on "chronic pain" were identified if the studies used the term throughout their paper, or provided a clear definition of chronic pain the study was centered around, distinct from acute or temporary pain. Studies that used other similar wording to refer to long-term pain (e.g. "recurrent pain" or "persistent pain") were included only if they also provided a clear definition of the parameters of such pain was distinct from acute or temporary pain. All peer-reviewed, full-text studies (e.g. empirical studies, reviews, metanalyses, etc.) were considered). Conference abstracts and dissertations were not included.

Studies were excluded if (a) young people were not a clear and separately presented population of focus in the study, (b) populations diagnosed with CP were not a clear and separately presented population of focus in the study, and (c) populations experiencing chronic pain were not a clear and separately presented population of focus in the study, or parameters for long-term pain were not clearly defined and distinct from acute and temporary pain. Other exclusion criteria included (d) study was not available in English language, (e) published before the last 20 years, and (f) conducted outside a Western country or context. Furthermore, studies that were (f) focused solely on the development or validation of an assessment/measurement instrument related to cerebral palsy and chronic pain were also excluded, due to these studies being focused on describing the processes of creating the instrument rather than its implementation and application. Studies that described the use of the assessment tool and not just its development were still included.

4.1.6 Literature Selection

Database searches yielded 462 references, of which 168 were duplicates removed by automatic detection by Covidence and manual identification during the screening process. This left 294 total references retained for title and abstract screening (see Fig. 1).

All 294 titles and abstracts were screened independently by two reviewers (the first author, L.Z, and A.M.). Conflicts were resolved through discussion by both reviewers. Prior to beginning the title and abstract screening, the reviewers met together to go over the inclusion/exclusion criteria and clarify questions related to screening. There was a total of 55 conflicts.

A total of 99 references moved on to full-text screening, which was also done independently by both original reviewers for all references. Conflicts were also resolved through discussion by both reviewers, and reasons for exclusion were recorded on Covidence. There was a total of 21 conflicts.

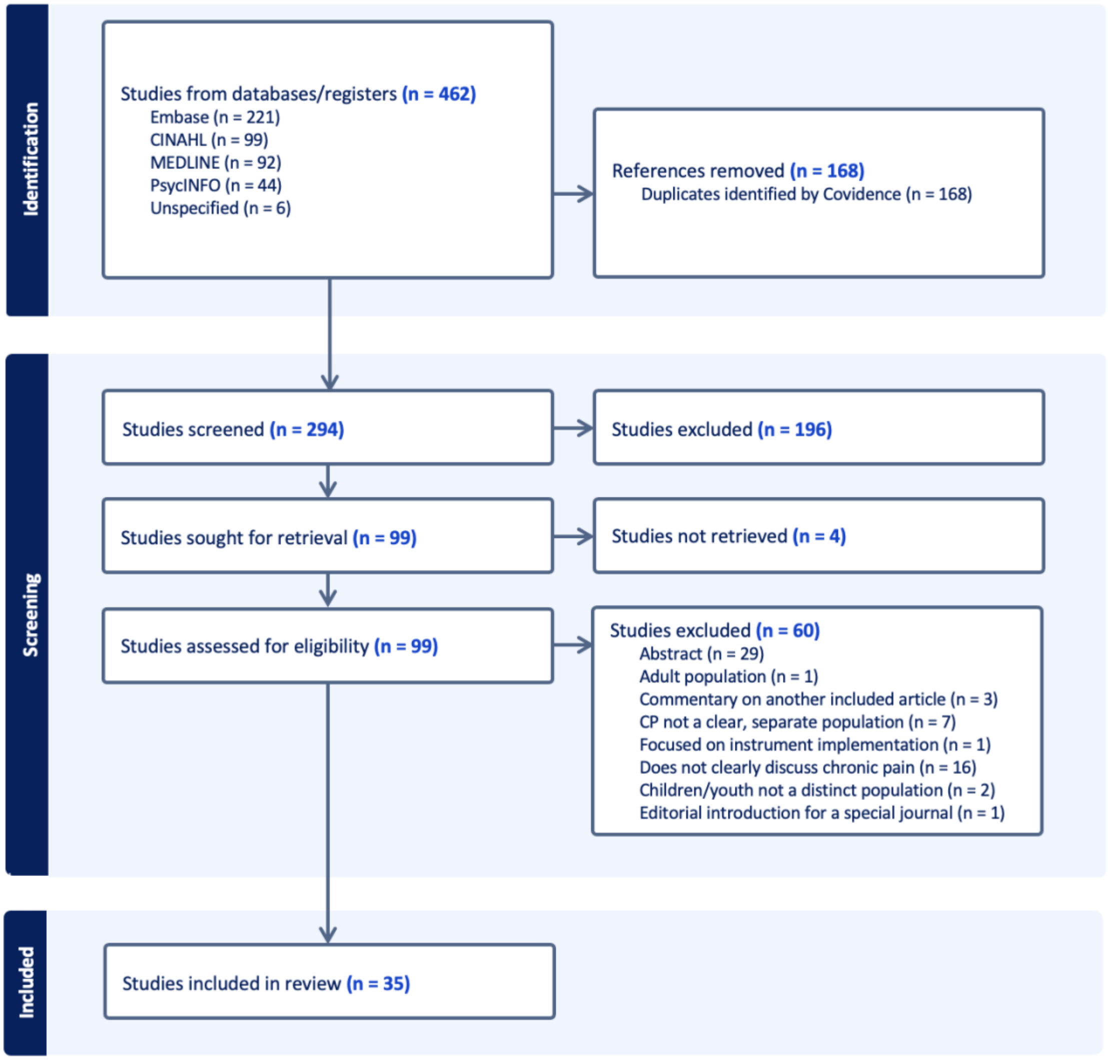

Figure 1: PRISMA diagram for scoping reviews of included studies.

4.1.7 Charting the Data

The data extraction form was developed by the study team via an iterative process during and throughout the full-text review. Following an initial data extraction of 10 articles, the form was reviewed, and variables evaluated and (re)considered by three study members: L.Z, K.M, and G.T. The final form included variables including study title, authors, publication date, journal, country of origin, study methodology and aims, nature and characteristics of chronic pain, age of the child at the time of the study, self or other (e.g. parent, clinician)-reports of pain , outcomes of interest, how pain is measured/addressed, and key findings (See Appendix B for questions included in the data extraction table). These variables formed the basis for a descriptive overview of research regarding chronic pain and CP.

Probing questions were also included in the data extraction form to address the scoping review's research question, including, for example: *"how is disability/chronic pain/impairment conceptualized in the study?"* and *"how are disability, chronic pain, and impairment conceptualized in relation to each other?"* These questions helped orient critical analysis of the texts to summarise information and describe recurrent themes and emerging ideas.

Data extraction was completed by the first author, with discussions and check-ins with the research team to iteratively develop directions of inquiry.

4.1.8 Analysis

As per scoping review methodology, analysis of findings resembled both a numerical summary of study characteristics as well as more a more qualitative and thematic summary, which involved iteratively sharing and discussing extracted data (Levac et al., 2010). Findings were considered against the broader social and cultural contexts alongside implications for practice and policy (Levac et al., 2010). Through discussions with the research team, emerging ideas were identified and considered in relation to the main research question. The team met every two weeks, with data and updates shared in between meetings. The data extraction sheet was reviewed, and potential ideas were discussed and elaborated on during these meetings and in back-and-forth exchanges. Multiple interpretations of results were discussed and considered against the background of the extracted data as a whole. As analysis continued, new ideas were introduced iteratively, and further data extraction occurred to capture these potential threads. The analysis, and consequently the results as well, were considered in terms of both descriptive and critical characteristics.

5 Chapter 5

5.1 Descriptive Overview of Included Studies

5.1.1 Study Information

A total of 35 studies met the criteria for inclusion. Studies originated from Australia (n= 11), the United States (n= 5), Spain (n= 3), Norway (n= 6), Denmark (n= 2), Canada (n= 1), and Sweden (n=1). Another 6 studies were reviews that did not specify country. In terms of study type, there were 28 empirical studies/studies reporting original research, broken down into 17 studies that use quantitative methods (e.g., questionnaires), 5 that used qualitative methods (e.g., interviews, focus groups), 6 that used both quantitative and qualitative methods (e.g., mixed methods, modified Delphi study). There were also 2 systematic reviews, 1 narrative review, 1 literature review, 1 scoping review, and 1 secondary data analysis. See Appendix C for a full list of included studies.

5.1.2 Focus of Included Studies

The focuses of studies varied across different domains, and can be broadly categorized into four categories: a) Describing the nature and characteristics of chronic pain in young people with CP, b) Exploring the impacts of chronic pain in young people with CP, c) Exploring chronic pain and CP related interventions and assessments, and d) Describing the experiences and perspectives of young people with chronic pain and CP. Studies often described multiple focuses and aims as part of their objectives.

The most common category of study objective was to describe the nature and characteristics of chronic pain in young people with CP (n= 14), which sought to characterize chronic pain in this study population [e.g. “The purpose of this study was an initial exploration to determine the nature of chronic pain among children and adolescents with cerebral palsy and to determine if such pain is problematic…” (Engel et al., 2005)].

Another common category was exploring the impacts of chronic pain in young people with CP (n= 14), which included studies focused on exploring the ways chronic pain influences everyday activity and function [e.g. “To document associations between parents reports of pain and multiple measures of daily functioning in ambulatory children with CP, impact on pain on child's physical functioning and behavior.” (Tervo et al., 2006)].

Studies also explored chronic pain and CP related interventions and assessments (n= 5), which included studies that described or evaluated the use and utility of chronic pain and/or cerebral palsy related interventions or measures [e.g. “To identify, describe, and critique pediatric chronic pain assessment tools currently available and make recommendations for clinical use for children with CP.” (Kingsnorth et al., 2015)],

Finally, a few studies also described the experiences and perspectives of young people with chronic pain and CP (n= 5). This objective focused on how children with CP and/or others (e.g. caregivers or clinicians) thought about and experienced chronic pain [e.g., “To explore the experience and impact of chronic pain on the lives of adolescents and young adults with cerebral palsy. (Castle et al., 2007)].

These categories of objectives show the range of focuses from studies addressing CP and chronic pain. Many studies focused on describing chronic pain, painting a picture of what young people with CP experience, as well as how this pain impacts their lives. This will be further summarized in the following sections.

5.1.3 How Data Related to Chronic Pain Were Collected in Studies

In the experimental studies, information related to chronic pain was collected via questionnaire, given either in-person or online/through mail (n= 24), in-person or telephone interview (n= 5), assessed by a clinician (n= 9), or recorded in a pain diary (n= 1). See Table 1 for further details.

Data was collected through self-report by the young person (n= 4), through other-reporting (n= 12), or a combination of self and other-report (n= 12). One study (n=1) was unclear about whether they used self or other-reporting. Other-report was provided by parents/caregivers (n= 21), and clinicians (n= 4) (most commonly physiotherapists, but also including pediatricians, occupational therapists, rehabilitation physicians, and speech language pathologists). See Table 1 for further details.

Table 1: How data related to chronic pain was collected in the included studies.

How data about pain was collected	**Number of studies**
Questionnaire (either in-person, online, or through mail)	n= 24 (Badia et al., 2014; Barney et al., 2020; Byiers et al., 2022; Carozza et al., 2022; Castle et al., 2007; Engel et al., 2005; Harvey et al., 2021; Larsen et al., 2022; Kingsnorth et al., 2015; McKinnon et al., 2020; McKinnon, Morgan, et al., 2020; Ostojic et al., 2020; Ostojic et al., 2021; Ramstad et al., 2011; Ramstad et al., 2012; Ramstad et al., 2016; Ramstad, Jahnsen et al., 2012; Ramstad et al., 2014; Rochani et al., 2021; Shearer et al., 2021; Sultan & Wong, 2023; Tervo et al., 2006; Yamaguchi et al., 2014)
Interview (in-person or over telephone)	n= 5 (Castle et al., 2007; Engel et al., 2005; McKinnon et al., 2020; McKinnon et al., 2021; Riquelme et al., 2021)
Assessed by clinician	n= 9 (Byiers et al., 2022; McKinnon et al., 2022; Ostergaard et al., 2021; Ramstad et al., 2011; Ramstad et al., 2012; Ramstad et al., 2016; Ramstad, Jahnsen et al., 2012; Ramstad et al., 2014; Westbom et al., 2017)
Recorded in a pain diary	n= 1 (Riquelme et al., 2018)
Data collected through:	**Number of studies**
Self-report only	n= 4 (Carozza et al., 2022; Castle et al., 2007; Riquelme et al., 2018; Shearer et al., 2021)
Other-report only	n= 12 (Badia et al., Barney et al., 2020; Byiers et al., 2022; 2014; Larsen et al., 2022; McKinnon et al., 2021; McKinnon et al., 2022; Riquelme et al., 2021; Rochani et al., 2021; Schiariti et al., 2023; Sultan & Wong, 2023; Tervo et al., 2006; Yamaguchi et al., 2014)
Both self and other-report	n= 12 (Engel et al., 2005; Harvey et al., 2021; Harvey et al., 2022; McKinnon et al., 2020; McKinnon, Morgan, et al., 2020; Ostojic et al., 2020; Ostojic et al., 2021; Ramstad et al., 2011; Ramstad et al., 2012; Ramstad, Jahnsen et al., 2012; Ramstad et al., 2014; Ramstad et al., 2016)
Unsure	n= 1 (Ostergaard et al., 2021)
Other report provided by:	**Number of studies**

Parent/caregiver	n= 21 (Barney et al., 2020; Byiers et al., 2022; Engel et al., 2005; Harvey et al., 2021; Harvey et al., 2022; Larsen et al., 2022; McKinnon et al., 2020; McKinnon, Morgan, et al., 2020; McKinnon et al., 2022; Ostojic et al., 2020; Ostojic et al., 2021; Ramstad et al., 2016; Ramstad, Jahnsen et al., 2012; Ramstad et al., 2014; Ramstad et al., 2011; Ramstad et al., 2012; Riquelme et al., 2021; Rochani et al., 2021; Sultan & Wong, 2023; Tervo et al., 2006; Yamaguchi et al., 2014)
Clinician	n= 4 (Badia et al., 2014; Harvey et al., 2022; McKinnon et al., 2021; Schiariti et al., 2023)

Pain-related questionnaires addressed a variety of pain-related characteristics including ‘general pain information’, ‘pain interference’, ‘pain intensity’, ‘pain severity’, ‘pain frequency’, ‘pain locations’, ‘pain impact on functioning’, and ‘pain anxiety’ (see Table 2 for names of measures and what they were used to measure. (Note: certain measures were often used to measure more than one domain). Often, chronicity of pain was determined by responses to questions about pain frequency. Twenty-nine separate questionnaires used to collect pain related data were identified. Of these, 17 questionnaires were developed specifically for children, 3 were chronic pain-specific measures, and 2 were both child and chronic pain-specific. There were no measures that were developed specifically for use in populations with CP, but the Pediatric Pain Profile (PPP) was developed specifically to assess pain in children with neurologic impairments, including CP (Kingsnorth et al., 2015).

Table 2: Names of pain-related variables and validated measures used in studies.

Note: *: Child-specific measure, ^: Chronic pain-specific measure.

What was being measured?	**Names of measures**

General pain (did not specify, or measured multiple facets of pain)	Brief Pain Inventory (BPI) Child Health Questionnaire (Pain Scales)* Bath Adolescent Pain Questionnaire (BAPQ)*^ Noncommunicating Children's Pain Checklist-Revised (NCCPC-R)* Varni/Thompson Pediatric Pain Questionnaire (PPQ)^* National Survey of Child's Health* Pain Management Index (PMI) Pediatric Orthopaedic Society of North America Musculoskeletal Health Questionnaire (PODCI) v.2.0 (comfort/pain-free scale)* Self-reporting scale in diaries Graded Chronic Pain Scale^ Caregivers Pain Survey* Dalhousie Pain Interview
Pain interference	Pediatric Pain Interference Scale (PPIS)* PROMIS Pediatric Short Form v2.0*
Pain coping	Pediatric Pain Coping Inventory (PPCI)*
Pain catastrophizing	Pain Catastrophizing Scale (PCS-C)
Pain intensity	Numerical Rating Scale Pediatric Pain Profile (PPP)* Faces Pain Scale Revised (FPS-R) Wong-Baker Faces Pain Rating Scale (W-B FPRS)
Pain severity	Pediatric Pain Profile (PPP)*
Pain frequency	Health Utilities Index-3 (HUI-3)
Pain behaviours	Patient Reporting Outcomes Measurement Information System (PROMIS) Pediatric Pain Interference Scale*
Pain locations	Body map diagram Childhood Arthritis and Rheumatology Research Alliance Body Diagram* QL07/00 Pediatric Pain Questionnaire*
Pain impact on functioning	Child Activity Limitations (CALI)*
Pain-related goal setting	Canadian Occupational Performance Measure (COPM)
Pain anxiety	Fear of Pain Questionnaire- Parent report (FOPQ-P)*

Alongside measurements related to pain, 25 studies also collected data not directly related to pain (see Table 3). These other domains include GMFCS level, health related quality of life, quality of life, psychological functioning, general health, behavioral functioning, walking abilities, physical and psychological wellbeing, heart rate, community participation, and degree of hypertonia. 21 different measures were identified, and of these, 15 were developed specifically for children, and 5 were developed specifically for use for populations with CP. There was also 1 measure that was developed specifically for use for children with CP.

Table 3: Names of other variables and validated measures used in studies.

Note: *: Child-specific measure, +: Cerebral palsy-specific measure.

What was being measured?	**Names of measures**
Health related QoL	KIDSCREEN* Pediatric Quality of Life Inventory (PedsQL)* Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD)*
QoL	Cerebral Palsy Quality of Life Questionnaire+
Gross motor function	Gross Motor Function Classification System (GMFCS)+ Manual Ability Classification System (MACS*+
Psychological functioning (mental health?)	Child Health Questionnaire (Mental Health Scale)* Strength and Difficulties Questionnaire (SDQ)* Revised Child Anxiety and Depression Scale- Parent Report (RCADS-P)*
General health	General Health Questionnaire (GHQ-30)
Behavioral functioning	Child Behavior Checklist (CBCL)* Behavior Rating Inventory of Executive Function (BRIEF)*
Walking abilities	The Gillette Functional Assessment Questionnaire (The Gillette FAQ)
Functional ability	Child Activity Limitations (CALI-21)* Functional Disability Inventory (FDI)* Care and Comfort Hypertonicity Questionnaire (CCHQ)*+
Physical and psychological wellbeing	KIDSCREEN-27* (Patient Reporting Outcomes Measurement Information System) (PROMIS) Pediatric Scales* State-Trait Anxiety Inventory
Heart rate	Heart rate monitors
Spasticity assessment	Modified Ashworth Scale+
Community participation	Pediatric Community Participation Questionnaire (PCPQ)*

5.2 Nature of Chronic Pain (including pain prevalence, locations, intensity, frequency, and other characteristics) of included studies

5.2.1 Prevalence

Across the included empirical studies that did not only focus on a population with chronic pain, the prevalence of chronic pain in young people with CP was reported to range between 31% (Ostojic et al., 2020) to 77% (McKinnon, Morgan, et al., 2020). Furthermore, Rochani et al. (2021) report that chronic pain was 4.5x more prevalent in children with CP than without.

5.2.2 Pain Locations

Chronic pain was reported to have been experienced in almost all areas of the body, with the highest frequency often reported across studies to be in the lower limbs (e.g. feet, knees, legs). The lower limbs, along with the back, were also reported to be locations of the worst pain (Carozza et al., 2022). Other common body locations to experience pain included the upper limbs (e.g. hands, wrist, arms, shoulder) and back (Carozza et al., 2022; Castle et al., 2007). For predominantly dyskinetic motor types, body locations of pain were similar to the broader CP cohort, but this population also experienced pain in the face, jaw, and temple (McKinnon, Morgan, et al., 2020).

5.2.3 Pain Frequency, Duration, and Intensity

Frequency of chronic pain ranged from having pain at all times, to once a month (Castle et al., 2007; Engel et al., 2006). Engel et al. (2006) further reported on the duration of pain, which ranged from 1 minute to 6 hours, average being around 1 hour 23 minutes.

In general, studies reported chronic pain to be between mild and moderate intensity (Badia et al., 2014; Larsen et al., 2022; McKinnon, Morgan, et al., 2020). For studies that used a 0-10 scale rating of pain, averages also fell around lower (2.4/10, standard deviation 1.4 (Shearer et al., 2021)) or mid (6.1/10, standard deviation 2.1 (Carozza et al., 2022)). Larsen et al. (2022) also reported a positive correlation between pain frequency and pain intensity.

5.2.4 Other Characteristics of Pain

5.2.4.1 Types of Reported Pain

Musculoskeletal conditions (e.g. muscle spasms, muscle tone, joint misalignment) were noted across studies as a major contributor to pain (Sultan & Wong, 2023; Vinkel et al., 2021).

5.2.4.2 Age

Overall, studies find that pain prevalence increases as young people age (Østergaard et al., 2021; Ramstad et al., 2011; Westbom et al., 2017).

5.2.4.3 Sex

There are mixed results for differences in chronic pain based on sex. Østergaard et al. (2021) report no difference between males and females, whereas Westbom et al. (2017) found that females reported more pain than males.

5.2.4.4 Motor Types and GMFCS Levels

Children with dyskinetic motor types were 3.5 times and children with mixed motor types were 1.9 times more at risk of developing chronic pain (C. McKinnon et al., 2021). Furthermore, pain prevalence was reported by Westbom et al. (2017) to be highest in dyskinetic types and lowest in unilateral spastic CP.

Regardless of GMFCS level, pain seemed to worsen overtime. While there was not reported difference in pain severity (Larsen et al., 2022; Ramstad et al., 2011), GMFCS level V was reported to be associated with the highest prevalence of pain (Westbom et al., 2017).

5.2.4.5 Communication

When children were reported to have speech limitations, they were perceived to have greater levels of pain by their caregivers (Tervo et al., 2006).

5.2.5 Origins and Causes of Chronic Pain

Chronic pain in young people with CP is commonly cited across studies as being caused by complications related to CP, such as abnormal muscle tone, spasticity, scoliosis, hip dislocation and/or subluxation, and gastrointestinal dysfunction. Dystonia and spasticity in particular are noted as both a common cause of and a reaction to musculoskeletal pain (Barney et al., 2020; Byiers et al., 2022). Chronic pain was also related to positional factors, as prolonged sitting or lying down without support, static positioning in a wheelchair, or lack of orthoses adjustments (Larsen et al., 2022; Ostojic et al., 2020). Overuse and exertion doing ambulatory activities like standing or walking were also noted to cause or worsen pain (Engel et al., 2006; Ostojic et al., 2020).

Furthermore, intervention used to address CP-related conditions were often noted as a source of pain. Common interventions like botulinum toxin injections, physical therapy, and orthoses/casting were described as a major source of pain for young people with CP. One of the most salient negative memories of childhood in adults with CP was related to the stretching and bracing done in physical therapy (Ehde et al., 2003), and up to 45% of young people with CP report pain during physiotherapy (Vinkel et al., 2022). Assisted stretching was also rated by parents as the most painful daily activity for their child, whereas surgery and physiotherapy were the most painful health care experiences identified (Letzkus et al., 2021). Standing frames, typically used in postural management, have also been reported to be painful in 14% of children with CP (Vinkel et al., 2022).

There were also new types of classifications of chronic pain for CP that have been proposed. Vinkel et al. (2022) proposed a classification of chronic pain in children with CP based on the causes of pain and the ICD-11 systematic classification of chronic pain (Treede et al., 2015b), differentiating between chronic primary pain and chronic secondary pain. *Chronic primary pain* referred to pain that does not arise as a result of CP or its associated conditions. Examples included complex regional pain syndrome, migraine or tension-type headaches, and pain of nociplastic origin, such as chronic widespread pain. These were not well discussed or explored in the existing CP literature, perhaps due to an assumption that all pain experienced by children with CP is related to CP only. *Chronic secondary pain* referred to pain whose etiology is related

CP, such as secondary musculoskeletal pain, secondary visceral pain, secondary headache or orofacial pain, neuropathic pain, or chronic postsurgical pain.

5.2.6 Treatments for Chronic Pain

Young people with CP were noted as willing to try many types of treatments to get rid of pain (Castle et al., 2007). Non-invasive procedures and non-pharmaceutical procedures, sometimes also referred to as "complementary therapies", were commonly cited as being used. In Sultan and Wong's (2023) study, more than half the participants utilized these complementary therapies. The most utilized nonpharmacologic strategies were massage, rest, thermotherapy, and hydrotherapy (Ostojic, 2020). Interventions like positioning, massage, stretching, exercise, and leg splints were cited as being used to treat pain, but were also noted as being a cause of pain in other circumstances (Larsen et al., 2022; C. McKinnon et al., 2021).

Complementary treatments were often used alongside pharmaceutical treatments. While commonly cited as an option for chronic pain, caregivers discussed their hesitance to rely on pharmaceuticals alone, due to drug side effects (C. McKinnon et al., 2022). However, studies noted up to 40% of participants had taken over the counter drugs, such as paracetamol or ibuprofen, to relieve pain (Ramstad et al., 2016).

For musculoskeletal pain related to dystonia, treatments of the dystonia itself may in turn reduce associated pain. Treatments like intrathecal baclofen and botulinum toxin have been noted as treatments to reduce spasms and subsequent pain (Ehde et al., 2003). However, these treatments may also be the source of pain, such as the pain from injections of botulinum toxin or surgery for an intrathecal baclofen implant (Barney et al., 2020; Ehde et al., 2003).

Psychological or mental strategies to managing pain were also identified and studied across included articles. Strategies like seeking distractions, relaxation and deep breathing techniques, and developing positive mental coping mechanisms were all presented as possible psychological supports to dealing with pain (Carozza et al., 2022; Castle et al., 2007; Sultan & Wong, 2023). One study described the pilot of an app-based biofeedback assisted relaxation training tool to manage chronic pain in children with CP, and found it may be a useful intervention as part of a multimodal approach with other therapies (Ostojic et al., 2022).

Letzkus et al. (2021) was the only study that discussed “experimental” treatments. This study identified treatments for children 0-2 years old in the literature. These include gabapentin, medical cannabis, and early developmental interventions like neurodevelopmental treatment, neuromuscular electrical stimulation, occupational therapy, head acupuncture, and Chinese traditional manipulation, with low quality of evidence for studies that describe these interventions.

5.2.7 Impacts of Chronic Pain

The most common stated impact of chronic pain was the way it interfered with young people’s abilities to conduct their activities of daily living, as well as participate in “everyday activities of childhood” (Carozza et al., 2022; Larsen et al., 2022). Pain interfered with self-care activities like dressing, bathing, sleep, and schoolwork. The ability to participate in leisure activities and physical exercise was also impacted. This negatively influenced young people’s social relations, including their relationships with peers.

Chronic pain was also overall reported to cause a lowered quality of life and negatively impact psychological wellbeing. Some children and adolescents reported strong emotional responses (e.g. anger, sadness, depression) towards living with CP and chronic pain (C. T. McKinnon, Morgan, et al., 2020). Feelings of frustration and helplessness over the pain, as well as reduced performance at school and in developing social connections contributed to a sense of isolation and separation as well (Castle et al., 2007). Anxiety about developing pain was also often noted as being more of a barrier to participation than the actual pain itself, further complicating the emotional response to pain (Yamaguchi et al., 2014). On the other hand, when participants viewed their chronic pain with acceptance and decreased efforts to control or avoid pain, participants reported better adjustment and improved experiences of pain (Carozza et al., 2022; Castle et al., 2007).

Pain also impacted families, where many young people recognized the efforts and sacrifices were made by caregivers and other family members to help with their pain (Castle et al., 2007). Caregivers also highlighted the impacts of their child’s chronic pain on their own emotional well-being, causing stress, anxiety, and low mood, to the point where managing the pain often took precedence over other valued life roles and interests (C. McKinnon et al., 2022)

5.3 Reviewed Studies' Inclusion and Exclusion Criteria

Several studies excluded young people with more than a "mild" cognitive impairment, which was often determined by either clinical or parental judgement. Some studies also only included individuals who could communicate verbally, but other studies recognized and included young people who use augmentative and alternative communication (AAC) methods as well.

Of the empirical studies, the majority (n= 21) did not have a specific type or classification of CP as part of their inclusion criteria. Other studies specified criteria such as bilateral CP between GMFCS levels III to V (Larsen et al., 2022), or predominant dyskinetic or mixed dyskinetic/spastic motor types (C. McKinnon et al., 2021, 2022; McKinnon, Morgan, et al., 2020).

6 Chapter 6

6.1 Critical Analysis of Included Studies

6.1.1 Defining cerebral palsy through a biomedical lens

Across studies, definitions of cerebral palsy, if provided, were presented through a biomedical lens, in that cerebral palsy was conceptualized as a biological product and considered to be a disability as a result of impairments of body functions and structures (Haegele & Hodge, 2016). For instance, CP was described as “a common physical disability among pediatric populations”(Kingsnorth et al., 2015, p. 948). Similarly, Østergaard et al. (2021) stated: “Cerebral palsy (CP) is the most common motor functional disability in childhood” (p. 301). Some studies also describe how CP is classified according to its “predominant neuromotor *disability*, into spastic, dyskinetic, or ataxic motor types" (McKinnon et al., 2020, p. 1294, emphasis is ours). Other studies, like McKinnon et al. (2020) and Ramstad et al. (2012) initially defined CP as a heterogenous grouping of disorders related to posture and movement, but then referred to CP as a “disability” throughout the rest of the article. Many studies did not provide a definition or description of CP at all, as if to assume that the readers have an understanding of CP already, or that when CP is mentioned, it can perhaps inherently be referred to as a disability.

The biomedical framing of cerebral palsy was expected, as it aligned with current dominant understandings of disability in the health and rehabilitation sphere. Biomedicine and those with biomedical knowledge, such as clinicians, hold cognitive authority in the field and is seen as the most valid, objective, and appropriate way to think about disability and health (Haegele & Hodge, 2016). While this framing is not necessarily wrong, the dominance of this paradigm limits other ways of thinking, unless these ideas are brought to attention. The following analysis begins to identify and critique these emerging ideas.

6.1.2 The Conceptualization of Disability

With the description of CP as a “disability”, a few studies went further to explain their conceptualizations of disability. For some studies, “disability” was conceptualized in relation to, or even as physical and functional impairment (further discussed later). Barney et al. (2020) defined CP as: “the most common motor disability in childhood and is considered a group of disorders that affect movement and posture, *causing limitations in activities* attributed to nonprogressive disturbances to the immature brain" (p. 2). The relation between disability and “limitations in activities” was echoed by many other studies, especially those that reference the International Classification of Functioning, Disability and Health (ICF) model (World Health Organization, 2002). As described previously, this model aims to classify notions of “health” and “disability” in a new light. It provides a biopsychosocial perspective of disability that includes a consideration of levels of human functioning at the body or body part, the whole person, and the whole person in a social context (WHO, 2002). This is different from the “biomedical” perspective, as the presence of impairment does not necessarily also indicate the presence of disability, but there are also a host of socio-political factors that influence how disability is viewed and perpetuated (Mosleh, 2019) . Disability is not solely a problem that resides in the individual, but occurs within the context of interactions between individual health conditions and environmental and social factors (WHO, 2002). Seven (7) of the included studies explicitly mentioned the ICF model within their study, although other studies may have been influenced by ideas related to the ICF model, which has become a widely used framework to conceptualize disability across many fields and settings (Kostanjsek, 2011). One study (Schiariti & Oberlander, 2019) went further and was focused on classifying CP-related assessment tools using the ICF as a conceptual framework.

Despite this framing, many studies still seemed to approach disability through a predominantly biomedical orientation, inevitably still locating disability as within the child. For instance, in McKinnon et al.'s (2022) study, they measured a child’s “capacity and disability” through classifications of their gross motor function, communication, and manual ability. In this study, and many others, “disability” itself was something measurable, and related to the child’s ability to function on different scales. This inherently still locates disability within the body of the child, as their assessments of function focus solely on traits associated with the individual. Even in studies that mention using the ICF framework to understand chronic pain and CP from a biopsychosocial perspective, consideration of factors beyond the individual are limited. This reflects a critique of the ICF, that despite its goals to move away from an overly simplistic view of disability from a purely biomedical lens, the ICF draws on discourses and ways of thinking that construct an inherently negative view of disability, which perpetuates these ideas into rehabilitation (Mosleh, 2019). For instance, by employing a "value-neutral" perspective of impairment as objectively defective as a deviation from what is statistically classified as normal functioning, the ICF continues to perpetuate problematic dualisms of normal/abnormal and natural/unnatural (Gibson, 2016; Mosleh, 2019). These dualisms privilege one idea over another, inevitably deeming the other as lesser.

By continuing to deem impairment as "inferior", the ICF continues to construct impairments as the primary source of harm for people who experience them, and disability retains the biomedical perspective as being something negative that needs to be fixed (Mosleh, 2019). When the ICF is used as a framework for research and treatment, it limits truly critical and innovative ways of thinking about disability beyond the biomedical. For instance, in Ostojic et al.'s (2020) study, which explicitly described their study aims as aligning with the ICF model and biopsychosocial model of pain, the measures of environmental factors impacting pain experiences included looking at "interventions for pain management" and "support or services to communicate pain". While these are important variables to consider in relation to pain, these do not truly reach examine the broader social dimensions contributing to disability, such as accessibility of services or attitudes towards disability. This framing of disability continues to situate the "problem" within the child, as well as placing the burden of seeking support on the child and their families. By hiding behind the "veil" of the ICF's proclaimed biopsychosocial perspective, studies' may feel as if acknowledging the ways socioenvironmental factors influence disability is helpful, but the underlying message continues to paint disability negatively as something to be fixed, and it is the responsibility of the individual to do so. This negates the drive towards true social and environmental change and continues to perpetuate negative framings of disability.

6.1.3 The Conceptualization of Impairment

The term "impairment" was rarely described or defined on its own but was often referred to in the context of "cognitive", "physical", or "motor" impairment. For most studies, "impairment" arose as a result of the pathology of CP. Additionally, some studies discussed "impairment" as a quantifiable domain that can be measured through validated instruments (Kingsnorth et al., 2015).

Studies that brought up the ICF model noted that “impairment” is distinct from “disability”, in that impairment exists at the individual level, and it is impairment in combination with activity and participation limitations that disability arises (WHO, 2002). For instance, Østergaard et al., (2021) stated: "According to the biopsychosocial model from the WHO: the International Classification of Functioning, Disability and Health, the overall well-being and quality of life of *individuals with disabilities* are closely related to the *experienced physical impairment*, activity limitations and how these are accommodated and managed" (p. 302) (emphasis is mine). However, even in the person-first language use of “individuals with disabilities”, disability was inherently located within the individual, and further implies that disability is a result of impairment, and impairment alone. In contrast, Schiariti & Oberlander's (2019), who also use the ICF as a framework to evaluate chronic pain measures, made the distinction between *impairment-based information* and “more meaningful” *functional-based information,* which describes the impact of pain on everyday activities instead of solely in relation to its impacts on the body (p. 2766). This distinction is an example of how we can truly begin to untwine the ways that impairment and disability are conflated, and the importance of language in addressing this topic. At the same time, it is important to still be cautious about where notions of “function” and what is considered to be “functionally appropriate” arise from.

Schiariti & Oberlander (2019) described functioning as “what a child with a health condition *can or is able* to do every day” (p. 2623). While on the surface this assumption seemed to provide a broader perspective of health beyond the biomedical framing, it is important to consider where conceptions of “can” and “able to” arise from. Where do the assumptions about what children with CP ought to or should do come from? What are the implications of such assumptions? As discussed in Chapter 2, discourses can create an image of a “normal” child, and children who fall outside of these ideals are deemed “abnormal” and needing to be corrected (Priestly, 1998). What this “normal” looks like is shaped by external forces of the social environment. For disabled children in Western societies (the inclusion criteria of this review), the emphasis on independence and productivity drives assumptions of children ought to do and learn (Priestly, 1998; Wellard, 1998). This may push disabled children who are unable to meet these expectations to internalize negative feelings about themselves, or undergo painful interventions in an attempt to reach a form of “normal” (discussed further in the next section).

6.1.4 The Conceptualization of Chronic Pain

Chronic pain was usually defined across studies as pain that lasts over 3 months. In the context of children with CP, chronic pain was often referred to as a common “concern” or “secondary condition”. The description of pain as a “secondary condition” was defined by Vinkel et al. (2022) as being the symptom of an underlying condition (e.g., CP), as opposed to chronic primary pain, where pain cannot be explained by another condition and may be considered a disease in itself. Some studies refer to chronic pain as a “common comorbidity” of CP (Ostojic et al., 2022, p. 34), implying that the disability is within the person, and all other related concerns are due to this inherent disability. Other studies referred to chronic pain in terms of being a “secondary problem for people who already have a disability…[with the] potential for pain to increase the negative impact of what may already be a very disabling condition” (Ehde et al., 2003, p. 3), locating the disability within the condition of CP itself. This also located disability at the individual level, where chronic pain is a biological condition within the individual that worsens the effects of the disability. These studies indicated that chronic pain is often the result of impairments and interventions associated with CP, and thus are not necessarily a separate condition of its own right. For instance, Engel et al. (2006) stated: “In recent years, pain has started to be recognized as a common secondary problem among those with CP (Chalkiadis, 2001; Ehde et al., 2003; Roscigno, 2002), and may be related to invasive medical and rehabilitation procedures.” (p. 74).

On the other hand, some of the reviewed studies differentiated the origins of chronic pain into two categories: i) pain as resulting from the pathology of CP or related comorbidities, such as musculoskeletal pain caused by spasticity, or ii) pain induced from the procedures/treatments for CP, such as post-surgical pain. The use of the word “comorbidity” to describe chronic pain implies a separation between CP and chronic pain as distinct conditions. McKinnon et al. (2021) described pain as a “potentially modifiable comorbidity” (p. 245), but also mention pain as arising from other “frequent comorbidities such as scoliosis, hip displacement, muscle contracture, and gastro-intestinal dysfunction” (p. 245), as well as being caused by different types of interventions. However, if we consider the definition of CP as being a heterogenous grouping of disorders related to posture and movement, these other “frequent comorbidities” may be considered to be related to CP, and thus the origins of the chronic pain result from the impairments associated with CP.

Of note, young people across studies cited pain related to treating CP as a major source of chronic pain. For example, one of the most salient negative memories of childhood in adults with CP was related to the stretching and bracing done in physical therapy (Ehde et al., 2003). CP is a lifelong condition that is unique to each individual, and children with CP may experience a variety of treatments to manage this condition, including rehabilitative therapy, non-operative modalities (e.g. splinting, medication), and operative treatments (Agarwal & Verma, 2012). These treatments are often done with the intent to “correct” deformities caused by abnormal muscle forces (Agarwal & Verma, 2012). While it is important to diagnose and treat the symptoms of CP, the implications around “correcting” CP presentation may reproduce more harmful narratives about how young people with CP ought to live and experience. There may be an assumption that young people with CP ought to be receiving some sort of treatment at a frequency that occurs frequently enough that pain related to it is considered persistent and recurrent enough to be classified as “chronic”. Again, discourses about the normal/abnormal ways of being may perpetuate the idea that disabled children ought to strive to achieve as close to a socially accepted norm as possible in order to live a ‘good’ life (Mosleh & Gibson, 2022). As mentioned in Chapter 2, the idea of what a “normal” child ought to be can shape the discourse around disability into something to be “fixed”. For children with CP, this narrative may force them to be exposed to potentially painful treatments and procedures that may have less to do with helping their symptoms, but more so focused on “correcting” their presentation and adapting themselves to fit with what is socially expected. Within rehabilitation, this reinforces a narrative about disability as something to be fixed, and therapeutic approaches may perpetuate these constructed ideals to detrimental levels.

While “3 months” was the often-noted timeframe for chronic pain, some studies added to this definition by including pain that persisted beyond the normal or expected healing time (Carozza et al., 2022; Castle et al., 2007). This is interesting to consider within the context of CP, a lifelong condition. For pain caused by interventions, perhaps this means in relation to the healing time of a certain intervention (e.g., recovery time after surgery). However, many children with CP require continuous interventions throughout their lives, and thus it can be hard to quantify what the “normal” healing time of an intervention is. In terms of pain arising from CP-related conditions, such as spasticity or dystonia, these can also be hard to define in relation to an expected healing time, as these may be lifelong concerns without easy solutions or treatments. Even with the 3-month timeframe, pain for children with CP may fluctuate based on several variables related to their CP diagnoses. Similar to other critiques of definitions of “chronic pain” (Kang et al., 2023), is a somewhat arbitrary timeframe of 3 months even the right or best way to describe the recurrent or persistent pain experienced by children with CP. While this understanding of chronic pain provides a quantifiable distinction from acute or temporary pain, it may also limit how we think about pain in children with CP as being arbitrarily chronic or non-chronic. Indeed, even this review’s search strategy, which only included studies that had a clear definition of “chronic” (or “recurrent” or “persistent”) pain, may have overlooked studies that did not directly use these terms, or discussed long-term pain in different parameters. Overall, the conceptualization of chronic pain was still very much situated in a biomedical lens, and suggestions to understand and address pain stemmed from this perspective as well.

6.1.5 The Relationship of Disability, Impairment, and Chronic Pain to Each Other

Across studies, despite a growing recognition of the biopsychosocial models of disability and pain, the biomedical conceptions of disability are still dominant. The prevalence of biomedical conceptions of disability inevitably lead to multiple studies that conflated “disability” with “impairment”, insinuating both as existing within the young person’s body. This perspective limits our understanding of disability by neglecting many of its social and environmental dimensions, further cementing harmful individualistic narratives of disability. This was most clearly seen in the use of language, where several studies used “disability” and “impairment” interchangeably, such as referring to both “physical disability” and “physical impairment”. In studies where disability and impairment were seemingly addressed as separate, “impairment” is usually presented as being a function/cause of “disability”, and disability was conceptualized in relation to how these impairments interact with the environment, rather than thinking about how the environment may contribute to the creation of disability instead. In the context of chronic pain, this also provided a very limiting perspective of the “disabling” effects of chronic pain, where the “disability” that arises from it was mostly related to the negative effects caused by individual impairments. Even in studies that mention biopsychosocial models or frame disability as related to “functional limitations”, much of the focus on these limitations still centered disability as within the child. For instance, Sultan & Wong (2023) described the impact of pain on a child with CP’s “quality of life, missed school days, less participation in activities, and reduced ambulation” (p. 550). While this study captured much of the limitations caused by chronic pain and CP and discusses both pharmacological and non-pharmacological interventions, there was no discussion about the social dimensions that also construct and reinforce disability, such as stigmatizing attitudes and unsupportive environments.

In contrast, Østergaard et al. (2021), who referenced the ICF model of disability within their study about participation in children with CP and chronic pain, discussed the ways that pain limits the child’s ability to participate in activities, but also mentions: “In addition to the impact of social factors on the reduced level of participation in physical leisure activities among children with CP, especially children with severe impairments, environmental restrictions may also play a role. As mentioned in a follow-up study by Willis et al., environmental factors constituted the main barrier for participation in physical activities for children with disabilities.” (p. 304). In acknowledging the ways that environmental barriers impacted participation, while also noting that children with more severe impairments may face more barriers, this study began to move the focus of disability beyond the individual child and recognize the broader social dimensions at play that impact how disability is constructed. It should be noted that despite this initial recognition, there is a lack of clarity about what “environmental barriers” truly mean and studies rarely went in depth about what these barriers actually are, whether they are physical barriers like inaccessible structures, or more theoretical barriers like legislative rules. In not explicitly identifying the broader social dimensions that contributed to these barriers, the conversations about these barriers remained surface level and lacked directive for future change. Additionally, across the included studies, much of the language use and discussion surrounding disability still centered disability within the individual young person and their impairments. While the ICF and biopsychosocial models of both disability and pain are referenced, it is almost as it they are being used as signposts to acknowledge a more nuanced view of disability than a biomedical model, but these framings themselves are often filled with implicit assumptions of ‘typical’ functioning that perpetuate harmful ideals of normalization. These ideas alone are not enough to move the field in a direction that truly recognizes the socially constructed nature of disability, and therefore not enough to offer effective suggestions to address it.

7 Chapter 7

7.1 Discussion

The results of this study as described in Chapters 5 and 6 reflect tacit and generally agreed upon directions and understandings of CP and chronic pain within the health and rehabilitation literature. This scoping review described the current state of knowledge about this population and chronic pain. Bringing a critical lens to my analysis enabled me to more explicitly identify and challenge taken-for-granted assumptions within the literature.

As introduced in Chapter 2, “discourse” as set out by Foucault refers to the production (and reproduction) of knowledge through patterns of thinking, speaking, and acting about an ‘object’ that only exists within the constructed discourse (Hall, 1997). Across the included studies, there was often a reference to the ways that chronic pain and/or CP impact a young person’s ability to engage in “typical activities of childhood” (Carozza et al., 2022). A predominant thread within childhood disability discourses is the emphasis on the value of being ‘normal’, defined and categorized into statistically derived bell curves and stages (Priestly, 1998). These assumptions about what a childhood ought to look like and what children ought to be doing inevitably creates a pervasive notion about how all children should be. For disabled children, the goals of care often become wrapped up in achieving as close to a version of ‘normal’ as possible, whether that is through “improving developmental performance” or “immersion” into social conventions (Mosleh & Gibson, 2022).

The assumption that approximating ‘normal’ bodies and abilities is the only way of achieving well-being promotes a pre-conceived idea of what constitutes a ‘good’ life (Mosleh & Gibson, 2022). By perpetuating certain type of biological or social norm, healthcare providers may focus solely on correcting these deviated norms, and disabled children may internalize ideas that they are ‘broken’ or in need of ‘fixing’ when they do not meet these standards. While the ICF addresses the limitations within the medical model of disease by encouraging thinking about health and function in relation to personal and environmental factors, it still perpetuates a binary of normal/abnormal through its reliance on statistically developed norms that create a biomedically ‘typical’ way of being that impairments deviate from (Mosleh & Gibson, 2022).

This inevitably still locates disability within the child, perpetrating harmful narratives of health and disability under the guise of achieving ‘function’ and ‘participation’ in typical childhood activities.

As mentioned in Chapter 2, discourses are deeply entrenched and continuously circulate a version of truth that is difficult to break away from. Even though I bring up the ways that healthcare providers may practice that perpetuate these discursive ideas, it is not the fault of individual practitioners that usually are following the guidelines of their respective fields with the best of intentions for their patients. However, part of the goal in highlighting how existing discourses impact their subjects is to also identify how we can begin shift these discourses (Graham, 2011). The uptake in changing the ways disability is understood– that is, not the same as impairment and not solely located within the individual– should begin at systemic levels. Discourses both reflect and reinforce power relations in society, and change over time and across different historical contexts (S. Hall, 1997). Current understandings of health and wellbeing are shaped by biomedical discourses that focused on pathology and impairment, and the bulk of research in this area is also dominated by this medical perspective (Priestly, 1998). This in turn informs how clinicians are trained and practice, further embedding these discursive ideas. There is a need for critical perspectives in research that challenge these ideas, and action at systemic levels, such as academic institutions or governments, is required to share and implement these alternative perspectives of disability.

Across the included studies, the most common form of assessing pain involved validated measures, including questionnaires and observational tools. These types of validated measures are common in pain assessment across multiple domains of pain (e.g., pain location, pain intensity, etc.), as well as to measure impacts of pain on daily life (Trottier et al., 2022). The use of a developmentally appropriate tool is recommended by the Canadian Paediatric Society as part of its best practice guidelines (Trottier et al., 2022). These tools are an undeniably useful way to assess pain and are relatively straightforward to understand and administer. However, it is important to consider *who* these scales are validated for. Many tools are initially developed and validated against a general and/or non-disabled population (e.g., the Varni/Thompson PPQ) or a broader disabled population (the Pediatric Pain Profile), and later adapted and/or validated for use with children with CP (Kingsnorth et al., 2015).

Additionally, a systematic review from Noyek et al. (2023) highlighted that pain assessment for youth with brain-based developmental disabilities (including CP) focused pain intensity or severity, with minimal holistic assessments of pain, especially as compared to neurotypical youth with chronic pain. This further highlights the inequity in how pain is addressed for disabled youth, and the need to address how chronic pain is currently being addressed for this population. A systematic review from Harvey et al. (2024) also identified a paucity of appropriate assessment tools in general for children with CP and chronic pain, and especially a lack of tools focused on chronic pain interference and coping. In this scoping review, and in Kingsnorth et al.'s (2015) systematic review of chronic pain assessment tools for children with CP, no tools that were developed specifically for young people with CP were identified. Even though many of the identified measures were validated for use in this population, there may be value in developing a more specific tool. The Canadian Paediatric Society recommends: "Pain scales should be employed as directed, using consistent, standardized scale anchors to facilitate comparison." (Trottier et al., 2022, p. 429-430). This suggestion, alongside the lack of measures specifically for young people with CP, also perpetuates a reference against a predetermined and statistically derived "normal". Young people with CP may experience pain in ways that are similar to children without CP, but also in very dissimilar, CP-specific ways as well, such as pain caused by spasticity or from treatments for CP. Without CP-specific measures, young people with CP may continue to be measured against an unattainable norm, limiting our understanding of what CP and pain truly may be like for this population.

As a further example of the need for more CP-specific considerations when it comes to chronic pain, there is the issue of care-related pain. One of the most frequently reported forms of pain in young people with CP, both in systematic reviews and across articles included in this scoping review, was pain related to interventions addressing CP-related conditions. Care-related pain is commonly reported amongst disabled children due to the frequent interventions they may experience (Bourseul et al., 2016). Care activities include both daily living tasks (e.g. washing and dressing) and rehabilitative therapies (e.g., mobilization, orthoses). These activities, especially rehabilitative interventions, have been noted to reduce pain, but at times also cause pain. Ostojic et al. (2019) was one of the only studies that directly called for healthcare professionals to reconsider the pervasiveness of this type of pain: "Similar to previously published studies, we found that interventions for the management of CP frequently cause pain.

Alarmingly, the most painful intervention, wearing splints, generally requires daily adherence to achieve the desired therapeutic goal. Repeated exposure to painful interventions may interfere with compliance to therapy, participation in physical activities, and well-being. It is critical to ensure that the benefits of a therapeutic intervention outweigh the consequences associated with a painful procedure." (p. 218). Additionally, the Canadian Paediatric Society's position statement of best practices suggests that the main goal of interventions for chronic pain emphasizes as rehabilitation approach of improving function as the treatment goal (e.g. physical therapy to increase tolerance of physical activity and improve participation), and not always about reducing pain itself (Trottier et al., 2022). Due to the heterogenous experiences of CP across all young people, it is important for clinicians to consider each child's case separately and evaluate the benefits of therapeutic interventions in consultation with young people and their families. Healthcare providers could open conversations that consider the reasons for conducting such interventions and determine whether there is agreement that they are truly for the benefit of the young person's wellbeing, or rather to help the young person conform to an expected "normal" way of being that is not necessarily essential.

The phenomenon of care-related pain also begins to raise the question of what truly defines "chronic pain", and whether the categorization of all types of long-term pain faced by young people with CP as "chronic pain" with a conventional definition and timeframe is limiting. Within this review, the appearance and nature of chronic pain varied, and pain was present in multiple body locations, at different intensities and durations, and across different GMFCS levels. These presentations of pain were all categorized under chronic or recurrent pain, with some studies further differentiating between chronic primary pain and chronic secondary pain. The origins of chronic pain also varied, and included pain caused by the underlying pathology of CP, as well as pain induced by treatments for CP. The interventions to treat these forms of pain differed as well. Categorizing these types of pain in distinct categories may benefit our understanding of addressing long-term better than a label of solely "chronic pain", which is usually distinguished by meeting quantifiable parameters of time and duration. Vinkel et al. (2022) presented a narrative review that classified pain in children with CP in the context of the ICD-11 classification and proposes a specific Cerebral Palsy Pain Classification (CPPC). This study described chronic secondary musculoskeletal, visceral, headache, neuropathic, and postsurgical pains as common chronic pain types, acknowledging that some pain types may fit into multiple categories depending on the underlying mechanism (Vinkel et al., 2022).

A possible benefit of having more clearly defined categories of pain is that practitioners can highlight different contributors to pain. For instance, Vinkel et al. (2022) mentioned that despite the presence of sensory disturbances in patients with CP post-surgery, post-operative peripheral neuropathic pain has been sparsely studied. Similarly, few studies have directly studied visceral and/or gastrointestinal pain, and this form of pain is often assumed to be of musculoskeletal origin (Vinkel et al., 2022). These examples demonstrate that classifying pain beyond just “chronic” might allow for greater attention being paid towards different presentations of pain. As mentioned above, having CP-specific tools to assess pain could also incorporate these classifications.

Of note, while Vinkel et al.’s classifications included post-surgical pain, they did not include pain for other forms of treatments and interventions. However, pain related to interventions for CP were one of the most noted sources of chronic pain across the studies included in this review. If care-related pain is also categorized, it may draw attention to the nature of care-related pain. It may also bring up the question of whether this type of pain is truly necessary for some children, calling into question how and why children experience certain interventions. Additionally, it may encourage further inquiry into the causes and solutions for this type of pain. The inclusion of complementary therapies was discussed in many of the included studies and were found to be useful in conjunction with pharmaceutical and rehabilitative therapies for experiences of both the effects of CP and pain. This is not to discount the effectiveness and usefulness of rehabilitative therapies, but rather to open the floor to question whether all painful treatments are necessary and helpful for all children, or whether some treatments are more for to align the young person with expectations of what a “normal” child or childhood ought to look like.

What individual young people themselves think about pain is another important element to consider when evaluating the current state of knowledge in this area The IASP notes that pain is always a personal experience that is influenced by biological, psychological, and social factors (Raja et al., 2020). For different individuals, the meanings and understandings behind certain types of pain also play a role in their overall chronic pain experience. It can be easy to assume that all pain is inherently negative, and from the biomedical perspective, it is necessary to focus on eliminating all pain. On the other hand, individuals experiencing pain may point to times when the benefits of enduring the pain outweigh the option with potentially less pain. As an example, chest binding is the practice of compressing chest tissue for transgender individuals to reduce feelings of gender dysphoria related to their chest (Peitzmeier et al., 2021). This practice often causes physical discomfort and pain, but many individuals also report the benefits of improved mood, reduced anxiety and depression, and improved overall emotional (Peitzmeier et al., 2021). In isolation, the harmful consequences of chest binding may seem to be an unnecessary risk for pain and even more serious consequences, but when the important social dimensions surrounding experiences and presentations of gender are considered, the benefits outweigh the harms for many. Similarly with chronic pain in young people with CP, many young people describe “pushing through” the pain in order to engage in activities meaningful to them (McKinnon et al., 2020, p. 9). For these children, knowing certain activities will cause them pain but continuing to do them demonstrates that for some, the experience of pain is worth the benefits gained in doing that activity, such as socializing with friends or playing sports. This is not to say that we should encourage young people to push through the pain, but just like how disability is not a one-dimensional experience, chronic pain is not either.

This is also not to suggest that young people should be advised that they should simply “accept” chronic pain or that clinicians can (continue to) overlook many of the concerns of young people have about their pain. Research and treatment for chronic pain, especially for disabled young people, should receive further attention and action. The difficulties of living with pain should be recognized and the desire for answers and solutions is also deeply personal and meaningful. However, like the impairments associated with CP, chronic pain for some may also be a lifelong condition. And like living with an impairment, perhaps it may be more productive to think about elements of chronic pain as not something to be “fixed”, but rather addressed through social level changes to accommodate and support those experiencing it. Instead of placing the entire responsibility (and at times, even blame) on individual young people and their families to deal with the pain, how broader social and environmental dimensions influence the chronic pain experience should also be considered. This begins to move the perspective of understanding pain away from a biomedical framework, something that was limited in the reviewed studies’ conceptualizations of chronic pain.

Several of the included studies mentioned the value of positive coping mechanisms to dealing with pain, and that having an acceptance attitudes often improved overall mood and wellbeing of young people with CP and chronic pain (Carozza et al., 2022; McKinnon, White, et al., 2020). However, the suggestion that young people ought to just "accept" their pain can seem patronizing and dismissive of their concerns. This is due to the prevailing narrative surrounding chronic pain as being an individual problem, one that often comes with a sense of being misunderstood and isolated. This can further add to the frustration experienced by young people and their families, who have often tried multiple avenues to address the pain (Castle et al., 2007). With mental health mentioned across studies as being an important area that is impacted by chronic pain, positive coping strategies and acceptance mindsets could be very useful. However, we cannot expect these strategies to work if the health and rehabilitation field continues to consistently view chronic pain as a solely individual, biomedical problem. If disabled children's experiences of pain are constantly questioned, overlooked, unaddressed, and unaccommodated for, then there will never be effective change towards changing the mindset around chronic pain. It is much harder for disabled young people to "accept" their own chronic pain if the environment they are in does not accept them either.

For children with CP and chronic pain, discussion of the social and environmental forces that impact their experiences are limited. While the increased adoption of the biopsychosocial perspective towards health has shifted the conversation to recognize the existence of barriers imposed upon disabled young people (Goodley et al., 2021), these conversations are usually vague and end at recognition. To address these issues, we must challenge ourselves further to identify how social forces and structures perpetuate disability, applying critical scholarship to consider areas of change (Goodley, 2013). How do our social systems make it difficult for young people with CP to manage their pain? What kinds of assumptions are embedded in medical culture that impacts how clinicians may recognize pain for disabled young people? How can cultural attitudes towards children and childhoods impact how we address chronic pain for young people with CP? Asking these questions begins to unravel deeply rooted ways of thinking that impact how young people with CP experience chronic pain. Additionally, the conflation of "disability" and "impairment" through language is problematic in that it continues to suggest that disability and impairment are equivalent locates the problem of pain at the individual level. This potentially draws attention away from social and systemic issues contributing to disability, since the primary focus continues to be on “impairment” (Anastasiou & Kauffman, 2013). Careful attention to the use of language when speaking about disability and impairment is required, and the language preferences of disabled people themselves should be prioritized.

Further inquiry requires careful listening to the experiences of disabled people, and opening the room for discussion of all impairment effects (Goering, 2015). Education around disability rights and disability pride may further encourage the health and rehabilitation field to think about addressing disability beyond individual impairments. This does not mean a complete disregard for the very real effects of impairment, such as chronic pain. Rather, discussion of these effects, good and bad, ought to be encouraged without fear of being of being viewed as inferior (Goering, 2015). These discussions also do not negate the social forces of disability and chronic pain either. Instead, they encourage us to recognize and challenge our embedded assumptions, as well as to listen to and engage openly with disabled young people. Across the included studies, pain data was collected through a mix of self-reports and other-reports. Interviews with caregivers, clinicians, and young people themselves were conducted to gather insight into their experiences with chronic pain. The incorporation of young people’s voices directly, including those with more severe cognitive impairments and those who use AAC, should be further encouraged. Disabled young people are capable of providing rich insights into their own experiences, and opening the floor for more diverse research methods may be a way to include more perspectives (Teachman & Gibson, 2018). Young people with CP and chronic pain’s experiences should be recognized and elevated, and clinicians and researchers should consider how our assumptions and existing social structures impact these experiences, and what we can do to push beyond them.

7.2 Limitations and Future Directions

This scoping review provides an overview of the ways that chronic pain has been described and characterized in studies focused on young people with CP. One limitation of this work was the use of search terms like “chronic/recurrent/persistent” pain to identify studies referring to what I have been referring to as “chronic pain”. This language likely captured the majority of studies focused on long-term pain. However, as this review proposes thinking about chronic pain in dimensions beyond duration, it is possible that other studies have done this already and were missed in my search. Future work to explore new ways of thinking about “chronic pain” could consider how different categorizations of pain have already been used and implemented across the literature.

For pragmatic reasons within the timeframe of a master’s degree, this study focused on young people with CP as the main population. This is not a limitation, as it allowed for deeper consideration into how CP-specific concerns impacted the presentation, understanding, and interventions for chronic pain. However, it might not reflect the literature in relation to the experiences of young people with different diagnoses or conditions. Future work in both the areas of disability studies and chronic pain studies could consider how similar critical work for different diagnostic or condition groupings could offer more specific insight, as well as contribute to the overall field. Additionally, research that explores the intersectional experiences of disabled youth across a range of identities (e.g., race, gender) was lacking across the reviewed studies, and may be an area of interest for future inquiry.

The scoping review focus was also restricted to studies published within the last 20 years and within Western countries, for reasons of both feasibility and to hopefully capture similar social and cultural contexts. It is possible that studies published prior to 20 years and outside of Western contexts reflect similar ideas that were missed by this study’ parameters. It would be interesting to consider future work that addresses how understandings of disability, impairment, and chronic pain have/have not changed over time, as well as in different countries and contexts. This could be considered alongside or in comparison to this scoping review, providing valuable insight into how social and cultural forces impact this topic.

For young people with CP and their families, the results of this study may reflect their experiences of chronic pain, recognizing their experiences and perhaps highlighting concerns about the ways that chronic pain is addressed and treated. For clinicians and researchers, these findings provide an overview of chronic pain for young people with CP and encourages them to challenge assumptions about pain and disability that are deeply embedded within the health and rehabilitation sphere. As a part of critical disability studies, it is not enough to just present theory, but to also identify areas of advocacy and resistance (Goodley, 2013). This work, and other critical disabilities studies work (especially those from disabled scholars themselves) has the potential to address funding and policy for health and rehabilitation. One way to ensure this information reaches more voices is through knowledge translation of these ideas, which is the next step for this study.

As part of the sixth stage of the Arksey & O’Malley framework of scoping reviews, the consultative stage involves sharing preliminary findings to gather alternative perspectives and interpretations of the work, as well as to also gain an insider awareness of the applicability of review findings in real-world settings (Arksey & O’Malley, 2005; Buus et al., 2022). This study could be strengthened by consulting directly with disabled young people to elicit their views about this work. Their insights into the findings and suggestions of this review would add greater depth and understanding to these ideas, as well as open space for sharing potential new ideas. However, as part of the larger CDCP study that this scoping review is situated within, the research team will begin by consulting with key knowledge users with specialized clinical knowledge working with young people living with disability, impairment, and chronic pain. (See Appendix D for the summary of preliminary results to be presented to knowledge-users in this phase of the study). Additionally, the second phase of the CDCP study will involve a critical qualitative inquiry into the experiences of disabled children with chronic pain. This study will use arts-based methods alongside semi-structured interviewing methods, piloting new ways of gaining insight from participants. We will involve youth advisors who live with disability and chronic pain to include their insights about the study. This scoping review serves to provide foundational knowledge and contributes meaningful insight towards our larger project’s goals of understanding the relation between disability, impairment, and chronic pain for disabled youth.

7.3 Final Remarks

The results of this study provided an overview of how the health and rehabilitation literature conceptualizes disability, impairment, and chronic pain for young people with CP. While discussions of disability and impairment have shifted over the years, the dominance of the biomedical perspective is still felt in the conceptualizations of all three ideas, and in their relation to each other. In order to begin challenging embedded understandings of disability, impairment, and chronic pain, I employed a critical analysis of these results, and encourage other researchers and clinicians to consider how implicit assumptions may impact the way chronic pain is addressed for young people with CP. There is a need to continue to advocate for shifts in how disability is understood by engaging with the work of disabled scholars and giving more weight to knowledge from disability studies. It is important to recognize that disability does not reside within persons, and acknowledge that many persons embrace disability culture, live well, and thrive with disability. The goal should not be to “fix” the disability, but to challenge our society’s current ways of addressing disability so that value is ascribed to all forms of difference. To support meaningful change, it is necessary to center disabled young people’s views and priorities in this area. A commitment to constantly challenge assumptions that risk conflating understandings of disability, impairment, and chronic pain will be needed to optimize health and social services for this group in ways that are more attuned and responsive to their needs.

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Appendices

Appendix A: Full database search strategies (Searches ran Nov. 28, 2023)

Medline Search Strategy:

Cerebral palsy

Exp Cerebral palsy/

OR

(cerebral-pals* or spastic-dipleg* or spastic-hemipleg* or spastic-quadrapelg* or ataxic cerebral pals* or athetoid cerebral pals* or hypotonic cerebral pals*).tw,kf.

Chronic Pain

Exp Chronic pain/

OR

(chronic pain or persistent pain or long term pain or recurrent pain or continuous pain or intermittent pain or frequent pain).tw,kf.

Child

Child/ or exp infant/ or adolescent/ or exp pediatrics/ or child, or (pediatric* or paediatric* or child* or newborn* or congenital* or infan* or baby or babies or neonat* or pre-term or preterm* or premature birth* or NICU or preschool* or pre-school* or kindergarten* or kindergarden* or elementary school* or nursery school* or (day care* not adult*) or schoolchild* or toddler* or boy or boys or girl* or middle school* or pubescen* or juvenile* or teen* or youth* or high school* or adolesc* or pre-pubesc* or prepubesc*).mp. or (child* or adolesc* or pediat* or paediat*).jn.

English language, 2003-Present

Results: 92

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Embase:

Cerebral palsy

Exp Cerebral palsy/

OR

(cerebral-pals* or spastic-dipleg* or spastic-hemipleg* or ataxic cerebral pals* or athetoid cerebral pals* or hypotonic cerebral pals*).tw,kf.

Chronic Pain

Exp Chronic pain/

OR

(chronic pain or persistent pain or long term pain or recurrent pain or continuous pain or intermittent pain or frequent pain).tw,kf.

Child

juvenile/ or exp adolescent/ or exp child/ or exp postnatal development/ or (pediatric* or paediatric* or child* or newborn* or congenital* or infan* or baby or babies or neonat* or pre term or preterm* or premature birth or NICU or preschool* or pre school* or kindergarten* or elementary school* or nursery school* or schoolchild* or toddler* or boy or boys or girl* or middle school* or pubescen* or juvenile* or teen* or youth* or high school* or adolesc* or prepubesc* or pre pubesc*).mp. or (child* or adolesc* or pediat* or paediat*).jn.

Limit to English language and 2003-current

Results: 221

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PsychINFO:

Cerebral palsy

Exp Cerebral palsy/

OR

(cerebral-pals* or spastic-dipleg* or spastic-hemipleg* or ataxic cerebral pals* or athetoid cerebral pals* or hypotonic cerebral pals*).tw

Chronic Pain

Exp Chronic pain/

OR

(chronic pain or persistent pain or long term pain or recurrent pain or continuous pain or intermittent pain or frequent pain).tw

Child
adolescent development/ or childhood development/ or pediatrics/ or exp Congenital Disorders/ or child psychiatry/ or (pediatric* or paediatric* or child* or newborn* or congenital* or infan* or baby or babies or neonat* or pre term or preterm* or premature birth or NICU or preschool* or pre school* or kindergarten* or elementary school* or nursery school* or schoolchild* or toddler* or boy or boys or girl* or middle school* or pubescen* or juvenile* or teen* or youth* or high school* or adolesc* or prepubesc* or pre pubesc*).mp. or (child* or adolesc* or pediat* or paediat*).jn.

Limit English language, 2003-present

Results: 44

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CINAHL:

Cerebral palsy

MH Cerebral palsy+

OR

TI (cerebral-pals* or spastic-dipleg* or spastic-hemipleg* or ataxic cerebral pals* or athetoid cerebral pals* or hypotonic cerebral pals*) or AB (cerebral-pals* or spastic-dipleg* or spastic-hemipleg*or ataxic cerebral pals* or athetoid cerebral pals* or hypotonic cerebral pals*)

Chronic Pain

MH Chronic pain+

OR

TI (chronic pain or persistent pain or long term pain or recurrent pain or continuous pain or intermittent pain or frequent pain) or AB (chronic pain or persistent pain or long term pain or recurrent pain or continuous pain or intermittent pain or frequent pain)

Child

pediatric* or paediatric* or child* or newborn* or congenital* or infan* or baby or babies or neonat* or “pre-term” or preterm or “premature birth*” or NICU or preschool* or “pre-school*” or kindergarten* or “elementary school*” or “nursery school*” or schoolchild* or toddler* or boy or boys or girl* or “middle school*” or pubescen* or juvenile* or teen* or youth* or “high school*” or adolesc*or prepubesc* or “pre-pubesc*” or (MH "Child+") OR (MH "Adolescence+") OR (MH "Minors (Legal)") OR SO (child* or pediatric* or paediatric* or adolescent*

Limit English results only, 2003-present

Results: 99

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Cochrane:

Cerebral palsy

Exp Cerebral palsy

OR

(cerebral-pals* or spastic-dipleg* or spastic-hemipleg* or ataxic cerebral pals* or athetoid cerebral pals* or hypotonic cerebral pals*):ti,ab,kf

Chronic Pain

Exp Chronic pain/

OR

(chronic pain or persistent pain or long term pain or recurrent pain or continuous pain or intermittent pain or frequent pain)

Child

Child or infant or adolescent or pediatrics or minor or pediatric* or paediatric* or child* or newborn* or congenital* or infan* or baby or babies or neonat* or pre-term or preterm* or premature birth or NICU or preschool* or pre school* or kindergarten* or kindergarden* or elementary school* or nursery school* or day care* or schoolchild* or toddler* or boy or boys or girl* or middle school* or pubescen* or juvenile* or teen* or youth* or high school* or adolesc* or pre pubesc* or prepubesc*

Results: 6

Duplicates removed: 168

Total number for title and abstract screening: 294

Appendix B: Questions used to guide data extraction

Article Title
Authors
Date
Journal/source
Country/location
Type of Document
Study Methodology, methods, and analysis
Aims of Study
Summary of the study
What does chronic pain and CP look like for this study? (What is the nature of pain? What is the reported prevalence of pain? What are the qualities of pain?)
What is the origin/cause of pain?
How is the pain being assessed?
How is the pain being treated?
What are the stated impacts of this pain?
How was diagnosis of CP confirmed?
What were the inclusion/exclusion criteria?
Age at time of study
Number of Participants
Condition/disease
Primary "voice" of study (young person, caregiver, HCP, etc.)
Outcomes/variables of interest
Key findings/important results
How is pain being measured/addressed in this study (e.g., self-report, interview, measurement tool, etc.)
What other measures (if any) are being used?
How is disability conceptualized in the study?
How is chronic pain conceptualized in the study?
How is impairment conceptualized in the study?
How are childhood disability, chronic pain, and impairment explored and conceptualized in relation to each other?
Is there one element that is more/less reflected than the others? Are certain ideas related to these concepts presented as interchangeable?
What are the main points expressed by young people labelled as disabled in regard to chronic pain? (if directly addressed)
How have the experiences of young people labelled as disabled who experience chronic pain been represented in the article?
Other/emerging ideas
Quotes

Appendix C: List of all studies selected for final data extraction.

Article Title	**Authors**	**Citation and Year**	**Journal/source**	**Country/location**	**Type of Document**	**Study Methodology, methods, and analysis**	**Number of Participants** (note: if not specified, value denotes children only)
Pain, motor function and health-related quality of life in children with cerebral palsy as reported by their physiotherapists.	Badia, M.; Riquelme, I.; Orgaz, B.; Acevedo, R.; Longo, E.; Montoya, P.	(Badia et al., 2014)	BMC Pediatrics	Spain	primary study	cross-sectional study, interview-based protocol, questionnaires	35 physiotherapists, 91 children and adolescents
A prospective study of pain pre-and postintrathecal baclofen pump implant in children with cerebral palsy	Barney C.; Merbler A.; Frenn K.; Stansbury J.; Krach L.; Partington M.; Graupman P.; Kim P.; Song D.; Symons F.	(Barney et al., 2020)	Archives of Rehabilitation Research and Clinical Translation	U.S.	primary study	cohort study design	32
Parental pain catastrophizing, communication ability, and post-surgical pain outcomes following intrathecal baclofen implant surgery for fatients with cerebral palsy.	Byiers, B.; Roberts, C.; Burkitt, C.; Merbler, A.; Craig, K.; Symons, F.	(Byiers et al., 2022)	Frontiers in Pain Research	U.S.	primary study	secondary data analysis	29
Chronic pain in young people with cerebral palsy: activity limitations and coping strategies.	Carozza, L.; Anderson-Mackay, E.; Blackmore, M.; Kirkman, H.M.; Ou, J.; Smith, N.; Love, S.	(Carozza et al., 2022)	Pediatric Physical Therapy	Australia	primary study	cross-sectional online survey	27

Being in pain: a phenomenological study of young people with cerebral palsy	Castle, K.; Imms, C.; Howie, L.	(Castle et al., 2007)	Developmental Medicine & Child Neurology	Australia	primary study	phenomenology, qualitative interviewing	6
Chronic pain secondary to disability: a review.	Ehde, D.; Jensen, M.; Engel, J.; Turner, J.; Hoffman, A.; Cardenas, D.	(Ehde et al., 2003)	The Clinical Journal of Pain	N/A	summary/literature review	N/A	N/A
Cerebral palsy and chronic pain: a descriptive study of children and adolescents	Engel J.; Petrina T.; Dudgeon B.; McKearnan K.	(Engel et al., 2006)	Physical and Occupational Therapy in Pediatrics	U.S.	primary study	structured interview, pain assessed through questionnaires	20
A pilot study of gabapentin for managing pain in children with dystonic cerebral palsy	Harvey A.; Stewart K.; Antolovich G.; Waugh M.; Copeland L.; Thorley M.; Rice J.; Baker F.	(A. R. Harvey et al., 2022)	BMC Pediatrics	Australia	primary study	feasibility pilot study	11
Establishing consensus for the assessment of chronic pain in children and young people with cerebral palsy: a Delphi study.	Harvey, A.; McKinnon, C.; Smith, N.; Ostojic, K.; Paget, S.; Smith, S.; Shepherd, D.; Lewis, J.; Morrow, A.	(A. Harvey et al., 2021)	Disability and rehabilitation	Australia	primary study	modfied Delphi method (designed to gather opinions and develop consensus from a panel of expert participants via surveys)	11 consumers, 83 total respondents (mostly clinicians and researchers)
Chronic pain assessment tools for cerebral palsy: a systematic review.	Kingsnorth, S.; Orava, T.; Provvidenza, C.; Adler, E.; Ami, N.; Gresley-Jones, T.; Mankad, D.; Slonim, N.; Fay,	(Kingsnorth et al., 2015)	Pediatrics	N/A	systematic review	N/A	N/A

	L.; Joachimides, N.; Hoffman, A.; Hung, R.; Fehlings, D.						
Recurrent pain in adolescents with cerebral palsy: a longitudinal population-based study.	Larsen, S.; Terjesen, T.; Jahnsen, R.; Ramstad, K.	(Larsen et al., 2022)	Developmental Medicine & Child Neurology	Norway	primary study	cross-section and longitudinal	67
A systematic review of assessments and interventions for chronic pain in young children with or at high risk for cerebral palsy.	Letzkus, L.; Fehlings, D.; Ayala, L.; Byrne, R.; Gehred, A.; Maitre, N.; Noritz, G.; Rosenberg, N.; Tanner, K.; Vargus-Adams, J.; Winter, S.; Lewandowski, D.; Novak, I.	(Letzkus et al., 2021)	Journal of Child Neurology	N/A	systematic review	systematic review	N/A
Pain in children with dyskinetic and mixed dyskinetic/spastic cerebral palsy.	McKinnon, C.; Morgan, P.; Antolovich, G.; Clancy, C. Fahey, M.; Harvey, A.	(C. T. McKinnon, Morgan, et al., 2020)	Developmental Medicine & Child Neurology	Australia	primary study	cross-sectional	75
The lived experience of chronic pain and dyskinesia in children and adolescents with cerebral palsy.	McKinnon, C.; White, J.; Morgan, P.; Antolovich, G.; Clancy, C.; Fahey, M.; Harvey, A.	(C. T. McKinnon, White, et al., 2020)	BMC Pediatrics	Australia	primary study	convergent parallel mixed methods design, cross-sectional and interviews, interpretive phenomenology approach to interviews	25

Caregiver perspectives of managing chronic pain in children and adolescents with dyskinetic and mixed dyskinetic/spastic CP with communication limitations.	McKinnon, C.; White, J.; Harvey, A.; Antolovich, G.; Morgan, P.	(C. McKinnon et al., 2021)	Journal of pediatric rehabilitation medicine	Australia	primary study	semi-structured interviews	10
Clinician perspectives of chronic pain management in children and adolescents with cerebral palsy and dyskinesia.	McKinnon, C.; White, J.; Morgan, P.; Harvey, A.; Clancy, C.; Fahey, M.; Antolovich, G.	(C. McKinnon et al., 2022)	Physical and Occupational Therapy in Pediatrics	Australia	primary study	focus groups	25
Pain is frequent in children with cerebral palsy and negatively affects physical activity and participation.	Ostergaard, C.; Pedersen, N.S.A; Thomasen, A.; Mechlenburg, I.; Nordbye-Nielsen, K.	(Østergaard et al., 2021)	Acta Paediatrica	Denmark	primary study	cross-sectional study based on longitudinal data and physical activity questionnaire	817
Acute and chronic pain in children and adolescents with cerebral palsy: prevalence, interference, and management.	Ostojic, K.; Paget, S.; Kyriagis, M.; Morrow, A.	(Ostojic et al., 2022)	Archives of physical medicine and rehabilitation	Australia	primary study	cross-sectional, use of questionnaires and some open word qualitaitve responses	280
BrightHearts: A pilot study of biofeedback assisted relaxation training for the management of chronic pain in children with cerebral palsy.	Ostojic, K.; Sharp, N.; Paget, S.; Khut, G.; Morrow, A.	(Ostojic et al., 2020)	Paediatric & Neonatal Pain	Australia	primary study	mixed-methods pilot feasibility and acceptability study	10

Characteristics of recurrent musculoskeletal pain in children with cerebral palsy aged 8 to 18 years.	Ramstad K.; Jahnsen R.; Skjeldal O.H.; Diseth T.H.	(Ramstad et al., 2016)	Developmental Medicine & Child Neurology	Norway	primary study	cross-sectional, questionnaires	153
Associations between recurrent musculoskeletal pain and visits to the family doctor (GP) and specialist multi-professional team in 74 Norwegian youth with cerebral palsy.	Ramstad, K.; Jahnsen, R.; Diseth, T.H.	(Ramstad et al., 2011)	Child: care, health, and development	Norway	primary study	cross-sectional	74
Parent-reported participation in children with cerebral palsy: the contribution of recurrent musculoskeletal pain and child mental health problems.	Ramstad, K.; Jahnsen, R.; Skjeldal, O.H.; Diseth, T.H.	(Ramstad et al., 2012)	Developmental Medicine & Child Neurology	Norway	primary study	cross-sectional	105
Mental health, health related quality of life and recurrent musculoskeletal pain in children with cerebral palsy 8-18 years old.	Ramstad, K.; Jahnsen, R.; Skjeldal, O.H.; Diseth, T.H.	(Ramstad, Jahnsen et al., 2012)	Disability and rehabilitation	Norway	primary study	cross-sectional, questionnaires	83
Self-reported mental health in youth with cerebral palsy and associations to recurrent musculoskeletal pain.	Ramstad, K.; Loge, J.H.; Jahnsen, R.; Diseth, T.H.	(Ramstad et al., 2015)	Disability and rehabilitation	Norway	primary study	cross-sectional	81
Influence of chronic pain in physical	Riquelme, I.; do Rosario, R.S.; Vehmaskoski,	(Riquelme et al., 2018)	NeuroRehabilitation	Spain	primary study	cross-sectional	26

activity of children with cerebral palsy.	K.; Natunen, P.; Montoya, P.						
Pain and communication in children with cerebral palsy: influence on parents' perception of family impact and healthcare satisfaction.	Riquelme, I.; Sabater-Garriz, A.; Montoya, P.	(Riquelme et al., 2021)	Children	Spain	primary study	cross-sectional descriptive correlational study	59
Association of chronic pain with participation in motor skill activities in children with cerebral palsy.	Rochani, H.; Modlesky, C.; Li, L.; Weissman, B.; Vova, J.; Colquitt, G.	(Rochani et al., 2021)	JAMA Network Open	U.S.	secondary data analysis	cross-sectional	151
Evaluating pain in cerebral palsy: comparing assessment tools using the International Classification of Functioning, Disability and Health.	Schiariti, V.; Oberlander, T.	(Schiariti & Oberlander, 2019)	Disability and rehabilitation	N/A	systematic review	three-step methodology to identify measures, categorize, and map conent related to pain to measure of ICF classification	N/A
Cerebral palsy pain instruments: Recommended tools for clinical research studies by the National Institute of Neurological Disorders and Stroke Cerebral Palsy Common Data Elements project.	Schiariti, V.; Shierk, A.; Stashinko, E.; Sukal-Moulton, T.; Feldman, R.; Aman, C.; Mendoza-Puccini, M.C; Brandenburg, J.	(Schiariti et al., 2024)	Developmental Medicine & Child Neurology	N/A	primary study	review? Including scoping review and public review, as well as team rating	N/A
Identifying pain trajectories in children and youth	Shearer, H.; Cote, P.; Hogg-Johnson, S.;	(Shearer et al., 2021)	BMC Pediatrics	Canada	primary study	pilot cohort study	10

with cerebral palsy: a pilot study.	McKeever, P.; Fehlings, D.						
Presence and grade of undertreatment of pain in children with cerebral palsy.	Sultan, T; Wong, C	(Sultan & Wong, 2023)	Scandinavian Journal of Pain	Denmark	primary study	cross-sectional	115
Parental report of pain and associated limitations in ambulatory children with cerebral palsy.	Tervo R.; Symons F.; Stout J.; Novacheck T.	(Tervo et al., 2006)	Archives of physical medicine and rehabilitation	U.S.	primary study	cross-sectional descriptive study	77
Classification of pain in children with cerebral palsy.	Vinkel, M.; Rackauskaite, G.; Finnerup, N.	(Vinkel et al., 2022)	Developmental Medicine & Child Neurology	N/A	review	narrative review	N/A
Assessments of pain in children and adolescents with cerebral palsy: a retrospective population-based registry study.	Westbom, L.; Rimstedt, A.; Nordmark, E.	(Westbom et al., 2017)	Developmental Medicine & Child Neurology	Sweden	primary study	cross-sectional	497
Pain, pain anxiety and emotional and behavioural problems in children with cerebral palsy	Yamaguchi R.; Nicholson-Perry K.; Hines M.	(Yamaguchi et al., 2014)	Disability and rehabilitation	Australia	primary study	cross-sectional	61

Appendix D: Summary of scoping review findings for knowledge-user consultation.

Invitation to Participate in a Knowledge-User Consultation

Cerebral Palsy & Chronic Pain in Young People

Our team has conducted a scoping review to synthesize available knowledge concerning cerebral palsy and chronic pain in young people. We have asked you to be a part of the consultative phase of this scoping review because of your specialized clinical knowledge of children and youth (aged 0-18 years) living with disability, chronic pain and impairment. As an expert knowledge-user, your insights may generate alternative interpretations of study results while helping us gauge the real-world relevance and implications of this research. You will notice that we use identity-first language in this document to align with Disability Studies scholarship where it is argued that disability is produced through inequitable social relations. We acknowledge and respect that there is no one 'right' way to talk about disability and some people prefer person-first language.

Background

Disabled young people experience pain at disproportionately higher rates than their non-disabled peers. In recent years, pain has been recognized as a prominent concern amongst young people with cerebral palsy (CP), with estimates predicting between 32 to 77% of this group will experience chronic pain at some point in their lives. Despite a growing interest in the pain-related experiences of young people with CP, no studies have synthesized knowledge concerning their experiences of chronic pain, nor how these are linked with impairment and disability.

Methods

We conducted a scoping review guided by the research question: What is known about experiences of chronic pain of children with CP as reported in the health and rehabilitation literature? Five electronic databases were searched using key words relating to "cerebral palsy", "chronic pain", and "child". Searches were completed on Nov. 28, 2023. After screening 294 abstracts, **a total of 35 peer-reviewed articles** met the inclusion criteria [published in past 20 years, English-language, study population children and youth (0-18 years old) with CP, focused on chronic pain (or recurrent or persistent pain)]. Exclusion criteria: conducted in Global South contexts, focused primarily on chronic pain physiology, pathology, measure development or validation.

Preliminary Results

Focus of reviewed studies: Impacts of chronic pain on activity and participation (n= 14); Nature and characteristics of chronic pain (n=14); Chronic pain-related treatments and interventions (n= 5); Youth experiences and perspectives (n= 10)

Reviewed studies noted that it is common for young people with CP to report pain in multiple body locations. The most common reported locations of chronic pain were the lower limbs (e.g. feet, legs), with other common locations including the hips, back, wrist, and shoulders.

Chronic pain in young people with CP was associated with:

- Abnormal muscle tone
- Spasticity
- Scoliosis
- Hip dislocation and/or subluxation
- Gastrointestinal dysfunction
- Prolonged static positioning (e.g., sitting in a wheelchair)
- CP-related treatments and interventions (e.g., physical therapy or surgery)

Youth with CP most often reported their chronic pain to be of **moderate intensity** when provided a scale between mild to severe. Pain intensity was reported across the reviewed studies using numerical rating scales (NRS), the Faces Pain Scale (FPS), or more comprehensive measurement tools such as the Brief Pain Inventory (BPI).

The most common reported impact of chronic pain was interference with young people's abilities to participate in **activities of daily living** such as self-care activities (e.g., dressing, bathing, sleeping) or school-related occupations. Reviewed papers also noted that chronic pain limited youth's ability to participate in leisure activities.

Reviewed papers used agreed-upon definitions of "chronic pain" as pain that persists beyond 3 months. Reviewed papers also often cited interventions to address CP, such as stretching or orthoses, as sources of pain. In the field of pain research, such pain is sometimes labelled '**care-related pain**'.
Many young people with CP experience the types and intensity of pain described across reviewed papers **throughout their lives**, and care-related pain is likely to persist in the context of ongoing treatments or interventions

Questions for Discussion

Regarding categorizing pain:

- Do the categories of acute vs. chronic pain adequately address the types of pain experienced by young people with CP?

Regarding care-related pain:

- How are clinicians thinking about care-related pain?
- Are proactive strategies to prevent such pain routinely considered in clinical practice?
- Do clinicians, young people, and families assume that enduring care-related pain is a necessary aspect of intervention?
- What knowledge is needed to better address care-related pain for youth with CP?

Regarding assumptions about the relation between pain, disability, and impairment:

- What are the risks of conflating disability, impairment and pain, even if unintentional?
- Could it be that the pain experienced by youth with CP is sometimes regarded as an inevitable consequence of living with impairment?

We look forward to discussing these preliminary results with you.

Curriculum Vitae

Name:	Muning (Linda) Zhang
Post-secondary Education and Degrees:	University of Calgary Calgary, Alberta, Canada 2018-2022 BHSc The University of Western Ontario London, Ontario, Canada 2022-2024 MSc
Honours and Awards:	Social Science and Humanities Research Council (SSHRC) Canada Graduate Scholarship 2023-2024 VOICE Student Stipend Views On Interdisciplinary Childhood Ethics (VOICE), McGill University 2022 Dean’s List Recipient Cumming School of Medicine 2019-2022
Related Work Experience	Teaching Assistant The University of Western Ontario 2022-2023 Graduate Research Fellow, Dr. Gail Teachman The University of Western Ontario 2022-2023

Presentations:

1. **Zhang, M.** Experiences of Newcomer Youth and Children in Canada Engaging with Education and Healthcare Systems and Shaping Occupational Possibilities. Western University Faculty of Health and Rehabilitation Conference 2022
2. **Zhang, M.** Use of Patient-reported Experience Measures in Pediatric Care: A Systematic Review. ACHRI-Libin-Owerko Summer Student Symposium

Publications:

1. Bele, S., Rabi, S., **Zhang, M.**, Oddone Paolucci, E., Johnson, D. W., Quan, H., & Santana, M. J. (2022). Patient-reported outcome measures in pediatric asthma care: using theoretical domains framework to explore healthcare providers' perceptions. *Journal of patient-reported outcomes*, *6*(1), 88. https://doi.org/10.1186/s41687-022-00494-3

2. Bele, S., Teela, L., **Zhang, M.**, Rabi, S., Ahmed, S., van Oers, H. A., Gibbons, E., Dunnewold, N., Haverman, L., & Santana, M. J. (2021). Use of Patient-Reported Experience Measures in Pediatric Care: A Systematic Review. *Frontiers in Pediatrics*, *9*. https://www.frontiersin.org/articles/10.3389/fped.2021.753536

3. [Under Review] Jessa, J., **Zhang, M.,** Bonhomme J., Richards, D., Lorenzetti, D., Chambers, C., & Birnie, K. Top priorities for child health research: A systematic review of Priority Setting Partnerships.