Journal of Education and Human Development
March 2021, Vol. 10, No. 1, pp. 81-91
ISSN: 2334-296X (Print), 2334-2978 (Online)

Published by American Research Institute for Policy Development
DOI: 10.15640/jehd.v10n1a7
URL: https://doi.org/10.15640/jehd.v10n1a7

The Entwinement of Disability and Paediatric Chronic Pain and their Impact on the High School Education of Students with Disabilities

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Abstract

Globally, 20–35% of children experience chronic pain that negatively impacts their schooling and quality of life. Yet, few studies have focused on the entwinement of disability, paediatric chronic pain, and education. This qualitative study on disability and chronic pain used accounts of three female undergraduate students with physical and developmental disabilities to identify the impact of paediatric chronic pain on their high school education. Three significant concepts emerged from the data: the impact of chronic pain on academics, teacher-student discrepant views of ability, and collaborative pain-management approach. The study concludes that there is a need for school programs that target academic and personal needs to improve the education of high schoolers with disabilities experiencing chronic pain. It is particularly imperative to train educators in pain identification and management techniques to increase appropriate support for students so they can participate in learning and perform to their full potential.

Keywords: pain, disability, education, high school, quality of life

1.0 The Entwinement of Disability and Paediatric Chronic Pain and their Impact on the High School Education of Students with Disabilities

Paediatric chronic pain is a prevalent phenomenon affecting 20–35% of children globally (Friedrichsdorf et al., 2015; Gold et al., 2009; King et al., 2011; Pielech et al., 2017; Tutelman et al., 2021; Walters et al., 2018); an estimated 4–40% of children experience chronic pain in the United States (King et al., 2011; Miró et al., 2016; Tutelman et al., 2021). The rising number of school-aged children living with chronic pain is attributed to personal and environmental factors, including genetic disorders (e.g., kyphoscoliosis) and improved healthcare and pain identification instruments (Araujo et al., 2014; Walters et al., 2018; Yazdani & Zeltzer, 2013). Common complaints about chronic pain in children and adolescents include neurological pain (e.g., fever, headache), musculoskeletal pain (e.g., back pain, neck pain), and gastrointestinal pain (e.g., abdominal pain) (Gold et al., 2009; Kamper et al., 2016, 2017; Tutelman et al., 2021; Waddell, 2004).

Within the larger group of children and adolescents experiencing chronic pain are those with intellectual and developmental disabilities (Büğüșan et al., 2018; Kamper et al., 2016, 2017; McKinnon et al., 2020). Chronic pain affects the school functioning, relationships, and wellbeing of adolescent students with disabilities differently than peers without disabilities or adults (Gold et al., 2009; Miró et al., 2016; Nery-Hurwit et al., 2018; Oppenheimer et al., 2018; Shiu, 2001; Tutelman et al., 2021). It predisposes children and adolescents to anxiety and depression (Shelby et al., 2013; Simons et al., 2012), school absences, low academic performance, bullying, school dropout, discrimination, and exclusion (Maes et al., 2017; Özge & Yalın, 2016), and low quality of life (QoL—the emotional, social, and physical wellbeing of a student) (Tutelman et al., 2021). Unlike adults or nondisabled peers, because of different timescales for growth, for example, adolescents with disabilities have unique development patterns due to changes in their body systems (including musculoskeletal and neurological), hormonal changes, and substantial cognitive and emotional development occurring via environmental interactions such as physical space and social relationships (Clinch & Eccleston, 2009).

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A poorly equipped classroom might have more of an impact on the physical and socio-emotional development than an accessible one, for example. Studies on children with cerebral palsy found that their chronic pain and fatigue caused them to experience significant disruptions to daily life that markedly lowered their QoL (Berrin et al., 2007; Buğüşan et al., 2018; McKinnon et al., 2020; Ostojic et al., 2020). While the intensity and frequency of chronic pain are known to lower children's and adolescents' QoL (Buğüşan et al., 2018; Gold et al., 2009), little is known about the impact of chronic pain on the education of teenage students with physical and developmental disabilities. The purpose of this study is to examine the effects of chronic pain on the education of high school female learners with physical and developmental disabilities, ultimately discovering and disseminating chronic pain management tools that promote school participation. While significant educational opportunities currently exist for learners with intellectual and developmental disabilities, a better understanding of their needs will improve education and health systems, mitigate painful conditions, and support their schooling. Specifically, the goal is to inform educators and other service providers about how to ameliorate chronic pain through appropriate interventions. Thus, the guiding research question was as follows: What is the impact of chronic pain on the schooling of high school students with disabilities?

2.0 Literature Review

The International Association for the Study of Pain defines pain as "[a]n unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (Treede, 2018, p. 2). The pathological causes of chronic pain include acute nociceptive pain, neuropathic pain, and psycho-social pain (Friedrichsdorf et al., 2016). In addition, pain can be categorized as acute or chronic (Linton et al., 2018) and as recurrent or persistent (Palermo & Chambers, 2005). Acute pain lasts for a short period (i.e., less than three months) and recovery either with or without any side effects (e.g., common cold, measles), whereas chronic pain lasts for more than three months and produces possible outcomes such as extended effects that lead to hospitalization lasting over a month (Linton et al., 2018; Nugraha et al.,2019; Tutelman et al., 2021).

Pain is influenced differently by a learner's behavioural and affective mechanisms (McKinnon et al., 2020); physical, psychological, emotional, and cognitive growth and development; and home and school environments (Araujo et al., 2014; Gold et al., 2009). Chronic pain lowers a learner's functionality, relationships, and QoL (Miro et al., 2016; Nery-Hurwit et al., 2018; Palermo et al., 2011) by causing school absenteeism, behavioural difficulties, social and academic problems (Gaultney et al., 2017; Palermo et al., 2011), and psychological health problems like depression and anxiety (Shelby et al., 2013; Solé et al., 2016). Chronic pain has devastating effects on children and adolescents, as it impacts their functional abilities, attention, concentration, sleep, and daily activities – and therefore, their social, physical, and psychological functioning and academic lives (Araujo et al., 2014; Kamper et al., 2016, 2017; Tutelman et al., 2021). Still, chronic pain causes many side effects such as fatigue (Gold et al., 2009), defined here as devastating weariness, tiredness, lack of vitality, and/or debilitation (Krupp & Pollina, 1996). Chronic pain and fatigue considerably interfere with students' daily lives, including eating, sleeping, and involvement in physical, social, cultural, and school activities (Gold et al., 2009). Chronic pain and sleep quality and quantity are also interlinked (de la Vega et al., 2016). Reduced sleep time increases pain sensitivity, and increased pain response interferes with sleep patterns (de la Vega et al., 2016; Edwards et al., 2008). Sleep is vital for the growth and development of physiological systems, including the brain (Sokoloff et al., 2014) – children and adolescents who experience sleep deprivation have increased problems with brain-regulated functions such as memory and alertness or consciousness.

Furthermore, chronic pain also has significant social and economic consequences for children and adolescents and their families. It leads to personal, family, and societal burdens and further predisposes children and adolescents to mistreatment and biases, opioid abuse, increased rates of outpatient appointments and hospitalizations, increased healthcare costs (Tutelman et al., 2021), loss of school time, and school failure (Buğüşan et al., 2018; Jastrowski Mano et al., 2020; McKinnon et al., 2020; Özge & Yalın, 2016). The treatment of paediatric chronic pain is costly; for example, it costs the United States almost $20 billion annually (Groenewald et al., 2014). Additionally, pain is invisible, and identification and measuring systems remain highly subjective because pain diagnosis mainly relies on individual reporting (Lee et al., 2017). However, subjectivity is detrimental to understanding pain, especially among educators of students with disabilities experiencing chronic pain. The difficulty in diagnosing pain means that practitioners may misunderstand the magnitude and impact of chronic pain on a student's education and QoL (Hirschfeld, 2014; Simons & Kaczynski, 2012).

Children's and adolescents' chronic pain and QoL are entwined (Araujo et al., 2014). Chronic pain management strategies are essential in supporting students with disabilities with chronic pain to cope with their health conditions and manage pain triggers such as academic, social, and physical demands. These strategies can be pharmacologic and/or nonpharmacologic (Kamper et al., 2016, 2017; Özge & Yalın, 2016).

Pharmacologic approaches involve medications that prevent and treat acute attacks. Nonpharmacologic approaches involve timely and regular sleep, regular exercise, healthy eating (e.g., eating regularly and moderately, drinking a lot of water), and avoiding foods that trigger pain (e.g., the overconsumption of caffeinated drinks). Successful chronic pain management strategies depend on the collective involvement of the students and their families, peers, educators, and other professionals to help them and their families to cope with the demands of chronic pain (Coakley & Wihak, 2017; Friedrichsdorf et al., 2016; Miró et al., 2016; Tauben, 2015). Collective involvement extends to personalized school re-entry plans that consider challenges a student with disabilities with chronic pain may experience (e.g., bullying, unwarranted sympathy and attention, fear) (Sexson & Madan-Swain, 1995) whether they have an individualized education plan (IEP), a 504 plan, or no official plan (Valle & Connor, 2019).

3.0 Methods

Qualitative research techniques allow for the researcher–participant interactions and relationship-building, which are essential factors for an in-depth contextual investigation of phenomena related to specific individuals or groups like education, disability, and pain (Creswell, 2012). The subjectivity of chronic pain requires research *with*, rather than *of/on*, students to elevate their experiences, incorporate their voices, value their agencies, and address their needs and situations. As part of a larger study (Ressa, 2016) on the pre-kindergarten-college transition experiences of students with disabilities, chronic pain emerged as worthy of further investigation. The biopsychosocial model is best suited for conceptualizing chronic pain and the education of students with disabilities because the intensity and frequency of chronic pain are influenced by physical factors (e.g., anatomical pathology and physiological process), psychological factors (e.g., moods, cognitions, and beliefs), and social factors (e.g., relationships, social environment, and culture) (Kamper et al., 2016; Walters et al., 2018). Therefore, this study examines the impact of chronic pain on education as reported by undergraduate students with physical and developmental disabilities. The participants offer retrospective accounts of pain and its consequences on their early and middle years of high school.

3.1 Participants

The participants had physical and developmental disabilities and experienced chronic pain. However, only the data on chronic pain from three of the nine participants in the original study (Ressa, 2016) met the present research criteria (Creswell, 2012). Despite this low number, the data are rich with participants' schooling and chronic pain experiences, which qualifies the idea that in qualitative research, the quality of the data, rather than the sample size, matters most (Creswell, 2012). All the participants have been assigned pseudonyms to ensure anonymity.

Patricia is 20 years old and a third-year student studying chemistry. She was diagnosed with systemic lupus while she was in high school. She is deaf and uses hearing aids, and she often deals with swollen joints, rashes, allergies, hair loss, and organ problems (kidneys, heart, bladder, and ears). Karen is 21 years old and a second-year college student still exploring college courses; she was born three months premature and has cerebral palsy. Her secondary health issues include spastic ataxia, dystonia, pleurisy, arthritis, insomnia, and chronic pain as one of the sequelae of cerebral palsy. She can walk without aid for short distances but interchangeably uses braces and a wheelchair to enhance her mobility depending on her level of pain and environment (e.g., snow conditions). Debra is 20 years old and a third-year student majoring in mathematics and biochemistry; she was diagnosed with Tourette syndrome and chronic migraines in high school. In addition, she experienced recurrent unilateral pulsatile headaches before and after undergoing corrective surgery for a brain tumour, also in high school. Academically, all participants self-reported having grade point averages of 3.6 or above (on a four-point scale) in both high school and college.

3.2 Data Analysis

This study used applied thematic analysis (Guest et al., 2012) to make predictions about the participants' schooling experiences in the light of their chronic pain. First, the author repeatedly read the original transcribed interview data and used keywords (e.g., musculoskeletal pain, migraine, fever, headache, abdominal pain, back pain, or general pain) to select the three female participants introduced above. Next, the author revisited the topics and discussed them further in a recursive cycle to ensure that the chronic pain data focused on the participants' high school experiences.

Then, the author keenly re-read the transcripts, intensely analysing the participants' diction and narratives to understand their viewpoints on schooling with chronic pain. Finally, using *NVivo*® Qualitative software, the author delineated aspects of chronic pain experiences and their impact on the participants' high school educations.

The author constructed codes to highlight significant words, phrases, and statements that participants made related to their schooling and chronic pain experiences; these codes were then organized into thematic categories. Finally, guided by deductive and inductive approaches, the data were isolated to uncover major structure elements, resulting in the categorization and delineation of significant themes (Guest et al., 2012). Therefore, the excerpts used in the study are retrospective accounts of high school incidents.

To achieve trustworthiness (Creswell, 2012), two hired independent inter-raters screened the themes based on predefined eligibility criteria (i.e., education, chronic pain, and disability) and then independently screened a sample of transcripts to verify and cluster themes, ensuring that they were representative of the participants' experiences (Golafshani, 2003).

4.0 Findings

This paper describes a series of interviews conducted with three female college students with disabilities with chronic pain about their high school educations. Thematic analysis revealed the topology of a significant theme–chronic pain influences an individual's meaningful schooling experience. The participants' chronic pain is linked to a primary disability or causal factors (systemic lupus, cerebral palsy, brain malformation) and secondary health issues related to diseases (e.g., juvenile rheumatoid arthritis), injuries, complications from treatments, and undiagnosed health conditions. As presented below, a wide range of effects stemming from chronic pain caused difficulties in participants' academic, behavioural, social, and emotional experiences.

4.1 Academic Problems

Chronic pain and related ailments and the effects of treatments and frequent hospitalizations caused erratic school attendance and limited engagement in learning, lowering the participants' academic rankings. Constant pain and hospitalizations forced them to miss many school days and fall behind content-wise. They also dealt with the side effects of medical treatments that impacted their academic functioning. Medications for pain and other ailments left them drowsy, tired, irritated, or nauseous, causing them to experience decreased attention spans and diminished learning abilities. As Karen reported, 'It is like, to me, being in school and being in pain are constants in my life . . . I ended up missing, like, 30 days of my [second year of] high school and then several months of my [third year]'. Although Karen graduated from high school in four years, immediately afterward, when her classmates were moving to college, she spent another year out of school being treated for spontaneous ailments he had never experienced before. Debra also reported missing many school days in high school because of debilitating migraines: 'My [third year] and [fourth year], I was really sick'. Migraines made it challenging for her to attend her morning classes, hurting her grades and dropping her class rank. 'I fell off my grade [i.e., her grades dropped] . . . because I missed every single day of that class . . . it was the a.m. class, and I didn't start school until 9 a.m. because I just could not make it to class with pain'. Similarly, Patricia reported missing many classes because of the side effects of her medications: 'Because I have chemo, sometimes getting up in the morning is unpleasant'.

4.2 Behavioural Problems

Chronic pain interfered with the participants' interactions with learning materials. They struggled to concentrate and engage in-class activities that required thinking, holding, or manipulating learning materials; moving, sitting, or standing; and collaborating with classmates for any significant length of time. They also experienced fatigue and immobility that limited their involvement in learning activities, such as test-taking, physical education, or laboratory work that required individual input and constant attendance. Certain activities triggered pain that made learning and performing to their full potential difficult—for instance, carrying weight (e.g., a bag full of books) triggered Debra's migraines. Once it had begun, the migraine could last for hours or days, making it difficult for her to participate in learning. Patricia, who frequently experienced inflammation, flares, fatigue, and rashes caused by exposure to sunlight, reported that she tired quickly from engaging in learning activities that required movement and the manipulation of learning materials.

[Systemic lupus] causes really, really bad fatigue . . . then all of these problems kind of contribute to learning issues because when you're tired and in a lot of pain, it's really hard to concentrate on what someone's telling you. So, right now, I would say that I'm doing relatively well because when I was first diagnosed, I was 16, and I went through a really, really big flare because no one knew what was wrong. (Patricia)

4.3 Emotional Problems

Troubling health complications and negative reactions from educators, peers, and family members toward participants' health conditions made their academics overwhelming and their lives distressing. For example, Debra's migraines made learning difficult, leaving her worried about her future.

Pain made Karen unhappy in high school, reporting that she had bouts of a strange ailment that doctors treated with medication, but the medication incapacitated her memory, mobility, and communication abilities to the extent that she was traumatized for months. She further reported that in her fourth year of high school, she had surgery to correct contractions in her arms and legs that caused her distress.

I was in so much pain – the surgery was supposed to help. It really didn't. So, I was miserable; I was in so much pain. … the first week of my [fourth] year, I snapped . . . my ankle . . . and then I could not tell what just happened. I could not breathe. And I was that way for seven months; it never stopped. . . . My body would start shaking. It was like small muscle spasms in my chest . . . like my lungs were shaking . . . [the] doctors didn't believe me. They looked for . . . what I've told them. And they thought . . . I might have contracted pleurisy. (Karen)

Patricia described how her peers and teachers were unable to comprehend and empathize with her pain.

My first symptom was pain, and that's a really difficult thing to pinpoint because there are so many different things that can cause pain. You can't see it or measure it. So, I was telling people that I'm in a lot of pain, and no one was able to gauge it. And it was a really big challenge. (Patricia)

The participants found it difficult to make appropriate decisions whether to continue with their schooling before their conditions were correctly diagnosed. It took about six months for Debra to be diagnosed with a brain tumour and two years for Patricia to be diagnosed with systemic lupus. Even Karen, who had cerebral palsy since childhood, had no precise diagnosis for sequelae of issues (i.e., a consequence of previous health issues). Meanwhile, the participants had to deal with family members, educators, doctors, and service providers who misunderstood and misjudged their health problems, behaviours, and feelings; these became pain triggers. While Debra's brain malformation remained undiagnosed, she was forced to deal with debilitating migraines and misjudgements that made schooling difficult. When Patricia grappled with symptoms of systemic lupus, her teachers attributed her academic struggles to inattentiveness.

I've had symptoms for almost my entire life, and 16 was when everything, like, blew up. . . . Even for probably eight months when I was 16, no one was really paying attention because everything I was explaining was pain . . . joint pain or abdominal pain or chest pain. (Patricia)

4.4 Accommodation Problems

Learning with chronic pain and without adequate accommodations in high school exacerbated the participants' struggles. Despite their disabilities and frequent chronic pain, participants could not get appropriate accommodations. While it took some time to get a correct diagnosis, Patricia and Debra did not qualify for special education services even after their conditions were correctly diagnosed. Patricia noted that, unlike in college, where the disability services office approved her accommodation needs, this was not the case in high school, both before and soon after she was diagnosed with systemic lupus.

So [at this university], that's a lot easier because I'm with the Office of Disabilities. But in high school, even after I was diagnosed, it was a really long process to get the disability form done. So, I just didn't. So, for [third year]and [fourth year], I had no accommodations. (Patricia)

4.5 Socialization Problems

The participants experienced fatigue and limited mobility, which bounded their involvement in social activities. In addition, frequent chronic pain and hospitalizations denied participants the opportunities to interact and build relationships with their peers and teachers. They also struggled to understand their health problems during their onset, making it challenging to explain their painful experiences to their loved ones; this led to a lack of support and social isolation. For example, unable to explain her circumstances to her teachers, Patricia reported feeling stressed about being in an unsupportive learning setting.

So, before I was officially diagnosed, even when I had the very big flair but . . . didn't have outward signs yet, the [teachers] didn't really react at all. I was just a regular student. And that's a problem because lupus isn't always visible, you know. . . . If I'm sitting in class, no one is going to be able to tell that I have a lot of pain or that I'm feeling really tired. (Patricia)

The invisible nature of chronic pain, lack of special education services, misdiagnoses, constant and inexplicable health problems, medical professionals' misinterpretations, teachers' and peers' misunderstanding, and participants' struggle to understand their body mechanisms all aggravated their academic problems, leaving them stressed, depressed, and confused. The difficulty they faced regarding sharing painful experiences with others also predisposed them to maltreatment, exclusion from learning activities, and academic and social failure.

This discrepancy hindered the provision of essential support and made their learning environments hostile, again leading to lower social, physical, and academic performance.

5.0 Discussion

Three major concepts emerged from the participants' high school experiences with chronic pain: the impact of chronic pain on education, teacher-student discrepant views of ability, and the collaborative approach to pain management.

5.1 The Impact of Chronic Pain on Education

This study found that chronic pain negatively impacts adolescents' education and leads to academic, emotional, behavioural, social, and accommodation problems. The participants missed many school days and learning opportunities because of debilitating pain and frequent hospitalizations while dealing with teachers' and peers' misunderstandings of their disability and chronic pain. They also experienced stress and depression and struggled with academics as a result. Previous studies have shown that chronic pain reduced the QoL of children with spina bifida and juvenile arthritis (Büğüşan et al., 2018; Nery-Hurwit et al., 2018; Oppenheimer et al., 2018). In addition, children and adolescents with disabilities experience cognitive and emotional difficulties (Solé et al., 2016), functional limitations (Miró et al., 2014), academic problems (Tegethoff et al., 2015), social problems (Forgeron et al., 2010), sleep disruption (de la Vega et al., 2016; Gold et al., 2009), and low QoL (Araujo et al., 2014; Rabbitts et al., 2016). Consistent with previous studies of children and adolescents with disabilities with chronic pain, this study also provides further evidence that this group of individuals is vulnerable to low overall QoL (Berrin et al., 2007; Büğüşan et al., 2018) because, just like adult populations, they endure personal and societal burdens of chronic pain conditions (Kamper et al., 2016, 2017; Özge & Yalın, 2016).

Chronic pain and fatigue significantly interfere with adolescents' daily living activities, physical and social activities, and learning activities (Gold et al., 2009). Executive functioning is a composite of cognitive processes that control our emotions, behaviours, and thoughts in ways that allow us to navigate our environments to achieve our goals (Snyder et al., 2015). Chronic pain also interferes with executive functioning and predisposes adolescents to academic and social failures (Jastrowski Mano et al., 2020). Unmitigated chronic pain problems may also cause behavioural issues such as fear, stigma, aggression, or withdrawal; this can lead to bullying from peers without disabilities and further limit social adjustments, resulting in school phobia and consequently low academic performance or school failure. In their attempt to deal with their double disability (the chronic pain and its effects), adolescents are also vulnerable to developing internalizing problems (e.g., fearfulness, anxiety, guilt, social withdrawal) (Shelby et al., 2013). Those psychologically distressed may have little energy and no motivation to engage in learning, especially when the severity of pain makes concentration and involvement difficult (Gaultney et al., 2017). Moreover, their families are more vulnerable to breakdown because of emotional distress, overwhelming medical regimens (Nery-Hurwit et al., 2018), and significant direct and indirect financial costs in disability and chronic pain diagnosis and management (Groenewald et al., 2014) that adversely affect the child and teenage individual.

5.2 Teacher-Student Discrepant Views of Ability

The participants are on medication for various health issues (e.g., injuries, chronic pain, insomnia). Still, they have also developed personal pain relief strategies (e.g., distracting themselves from their pain by focusing on activities that make them happy, like studying, planning for college). Thus, they have different views about their abilities and the impact of chronic pain on their education from professionals and parents. They believe in their ability to succeed in life more than the professionals; are more optimistic about their lives than educators, peers, and parents; and remain hopeful even in the face of health crises. Previous studies have shown that students with disabilities have different perceptions about their functionality than their families and professionals, with the latter often having lower expectations than the former (Gaultneyet al., 2017). Chronic pain is an unpleasant experience, but that does not define the totality of the learners with disabilities' experiences. For example, the participants in the present study accepted their health conditions and felt increased happiness after their acceptance and moving to college. This is similar to Büğüşan et al.'s (2018) study, which revealed that learners with cerebral palsy rated themselves higher than their caregivers in the areas of happiness, ability to use extremities, ability to perform basic functional skills, participation in physical activities, and general functioning. Moreover, the academic successes of the present participants counter beliefs that children and teenagers with disabilities, including those with chronic pain, cannot handle a general curriculum (Maes et al., 2017; Özge & Yalın, 2016; Sexson & Madan-Swain, 1995).

QoL is a person's perceived wellbeing in various aspects– psychological, emotional, social, economic, political, or physical (Oppenheimer et al., 2018). A combination of disability and chronic pain and their effects, such as fatigue and insomnia, lower the QoL of learners with disabilities (Araujo et al., 2014; Özge & Yalın, 2016).

Chronic pain and fatigue significantly disrupt daily life and negatively affect the QoL of children and adolescents with cerebral palsy (Berrin et al., 2007; Büğüşan et al., 2018; McKinnon et al., 2020; Ostojic et al., 2020). Often, however, the learners' academics and QoL are compromised when educators and peers hold different views about the impact of chronic pain on their education. Thus, valuing the input and knowledge of learners with disabilities with chronic pain is critical in instituting pain relief programs that support their schooling.

5.3 Collaborative Pain Management

Chronic pain management is complicated because of the aetiology of pain and the multifactorial factors related to pain (McKinnon et al., 2020). Thus, targeting personal and environmental factors that cause or trigger the chronic pain of students with disabilities is vital in its management (McKinnon et al., 2020; Ostojic et al., 2020). It is essential that a multidisciplinary team, such as an IEP team, routinely screens learners to identify chronic pain and provide appropriate interventions based on a biopsychosocial model of pain in order to tailor support to the full spectrum of the child's or teenager's health conditions and abilities (Logan et al., 2017; Ostojic et al., 2020). In addition, effort should be made to diminish fear of pain and nurture these children's and teenagers' positive qualities. Adopting pain management approaches can help to reduce anxiety, mitigate other pain triggers and their impacts, and curtail academic failure or social isolation.

The complexity of chronic pain – that it can be disabling and difficult to detect, understand, and treat– also makes collaborative pain management essential (Ostojic et al., 2020; Özge & Yalın, 2016). A shared pain management approach requires the input of the learners with disabilities and of people knowledgeable of the learner's academic and health conditions (Shiu, 2001) to address the demands of the learner, their family, and the environment (Nery-Hurwit et al., 2018; Palermo & Chambers, 2005) and to nurture positive attributes (e.g., confidence and self-discipline). The learners' input is critical in chronic pain management. As in Büğüşan et al.'s (2018) research, the present study reveals that the participants mitigated the psychological consequences of their health conditions by accepting them, causing them to be more hopeful about the future than their teachers. Oppenheimer et al. (2018) found that learners who acknowledged their chronic illness and minimized its psychological relevance had improved health related QoL than those who dismissed their illness, imagined it did not exist, had unrealistic expectations about it, or intellectualized and justified their illness to ease the pressure. Learners trained to accept their pain can develop personal initiatives to deal with triggers of pain in different situations (Pielech et al., 2017).

Equally, a collaborative effort ensures that educators work with service providers to improve learners' functional capabilities (Tauben, 2015). This is important, considering that children and adolescents commonly complain about chronic pain and its sequelae, such as fatigue (Gold et al., 2009; Ostojic et al., 2020), but professionals (e.g., educators) are often less keen to understanding their behaviours, learning abilities, and needs. This is a common occurrence even though chronic pain– and a sequelae of pain and disability (e.g., aphasia, ataxia, hemi- and quadriplegia)– significantly interfere with participation in learning and QoL (Gold et al., 2009). While the present participants managed to achieve a critical post-school outcome– successfully graduating from high school and moving to college– it came at a cost, as unmanaged chronic pain causes functional deficits and academic difficulties (Coakley & Wihak, 2017). Many children and adolescents with disabilities with chronic pain return to school without accommodations and must invest more in learning to compensate for missed time or classes and lost friendships.

Moreover, the lack of objective pain measurement instruments and the subjectivity of pain (Lee et al., 2017) often exposes them to unfair treatment. Educators assume the magnitude and impact of pain to be lower than the child or teenager reports. Therefore, teachers must understand the effect of chronic pain on students with disabilities and have strategies to mitigate their pain (Ostojic et al., 2020). As several studies reported, teenagers with chronic pain who receive appropriate support experienced improved psychological and behavioural effects that mitigated their pain conditions (Coakley &Wihak, 2017) and improved their school attendance, sleep, and social relations with peers (Fisher et al., 2014; Sokoloff et al., 2014). Professionals working with learners with disabilities with chronic pain should hold a positive view of pain management approaches and align them with learners' efforts to develop appropriate measures that promote their wellbeing (Chow et al., 2016). Unfortunately, considering the invisibility of pain and subjective judgement of pain, such support may not be readily available. This makes family members important elements of the chronic pain management matrix. Whole-family involvement in chronic pain management leads to successful schooling for the child and improved QoL for the family (Chow et al., 2016).

Creating education opportunities for students with disabilities with chronic pain is indispensable. The participants in this study attended regular public schools, had access to the general education curriculum, and acquired positive traits (e.g., self-esteem, self-awareness) and repertoires (e.g., negotiation skills, persistence) to manage the demands of the high school system. These enabled their eventual transition to college amidst health crises.

However, they received little accommodation in high school, even while experiencing debilitating pain. This can be attributed to the bureaucratic nature of special education. Students must have a disability that negatively impacts their learning to qualify for special education services. It often takes several tests– stretching over days, weeks, months, or years– to diagnose an illness, categorize and label the student, and offer them special education services. During this time, a student is exposed to misjudgement and discrimination that often derails their schooling (Maes et al., 2017). However, educators can mitigate chronic pain by creating safe learning environments that increase social and academic participation and student belonging.

6.0 Conclusion

This study aimed to understand the impact of chronic pain on high school education from the viewpoint of students with disabilities who are now attending university. The findings show that chronic pain is a common condition in adolescents with physical and developmental disabilities; further, the negative impacts on their education are more significant when peers, family members, and professionals (e.g., educators, doctors, and therapists) are unaware of the causes and impacts that chronic pain has on schooling. The findings also shed some light on the high school education process of students with disabilities with chronic pain. Like their peers without disabilities, students with disabilities with chronic pain are easily invigorated when valued, accepted, and supported in caring and welcoming learning settings. Therefore, the lives of adolescents with disabilities with chronic pain should be normalized in all realms, especially by their teachers and families. Their schooling should be prioritized, and they should be held to a high academic standard and be provided with challenging learning experiences, just like students without disabilities, so that they can participate in learning to their abilities and grow and develop as per their potential. Whether pharmacologic or nonpharmacologic, it is also critical that pain management plans utilize a collective approach to mitigate internal and external pain triggers, encourage self-management strategies, and create a vast network of social support.

While this study demonstrates that students with disabilities with chronic pain can succeed academically when provided with said opportunities and support, it also reveals that they still face obstacles to participating in high school learning and achieving post-school outcomes. Thus, the creation of supportive learning settings requires that stakeholders in education develop pain-mitigating strategies that address the institutional barriers that often exacerbate the physical, social, emotional, and academic demands and triggers of chronic pain. Also critical is the ability of the students, families, educators, and other professionals to use chronic pain management approaches to help them manage and cope with their situation and support personalized school re-entry plans to ensure continued schooling.

These study findings should be interpreted in the light of certain limitations. First, the sample was limited to cross-sectional subjective data used to analyse disability, chronic pain, and high school education relationships. Thus, data from a small sample population are not representative of all undergraduate students with disabilities with chronic pain. Second, the chronic pain data of undergraduate students with disabilities focused on their high school years, and no medical records were required to prove their accounts because of privacy policies. Third, all participants were Anglo-American females from middle-class families; they were from the same city with the same healthcare system and attended the same university. Consequently, more studies with larger and more diverse groups are needed to understand the impact of chronic pain on the education of learners with disabilities at all levels of schooling– pre-kindergarten through college– and understand the interplay of the multiple factors (e.g., economic, social, language, cultural, structural) that affect the education of students with disabilities with chronic pain.

Nevertheless, the study findings have several educational implications for creating learning opportunities and chronic pain management for high schoolers with disabilities with chronic pain. The participants' experiences can contribute to pain management needs and the reformation of education systems. For example, teachers, doctors, and therapists could collaborate with students with disabilities with chronic pain, their families, peers, and people in their social networks to collectively implement pain management that supports the students' participation in school and community activities, improving their QoL.

Declarations

The author had no financial or other conflicts of interest.
This study was approved by the relevant Institutional Human Subjects Review Board.

This study and manuscript were solely conducted and written by the author. However, I acknowledge the input of two hired independent inter-raters who screened and verified the coded ideas and themes during thematic analysis.

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