Supporting Students with Endometriosis: A Canadian Perspective

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Table of Contents

Abstract

Endometriosis is a chronic disease in which endometrial-like tissue (similar to the tissue normally present within the uterus) begins to accumulate outside of the uterus, resulting in pain, reduced fertility, and pelvic mass growth (Becker et al., 2022). While research on endometriosis focuses on women, the current dissertation strives to also be inclusive of individuals born with a uterus but who do not identify as women; thus, gender-neutral terms will also be used throughout so as not to assume a participant's gender. No cure currently exists for endometriosis (Acién & Velasco, 2013; Björk et al., 2020). The condition affects approximately one in 10 individuals of childbearing age worldwide (Gambone et al., 2002), including both adults and adolescents (Ballweg, 2015). Individuals of all ages with endometriosis often experience depression, fear, and anxiety, as well as a decreased quality of life associated with the debilitating pain that the condition can cause (Friedl et al., 2015; Laganà et al., 2017). Individuals may further experience adverse effects on their daily activities, such as attending school or work. Due to the general lack of awareness of endometriosis and the social stigma surrounding menstruation, individuals are frequently uninformed of the symptoms associated with endometriosis or are unaware of the condition before their diagnosis (Seear, 2009). Individuals reporting symptoms of endometriosis may wait seven to 12 years before receiving a diagnosis (Agarwal et al., 2019; Singh et al., 2020; Soliman et al., 2017; Treloar et al., 2010). The first study presented in this dissertation is a scoping review of in-school supports (i.e., services, resources, academic accommodations, and practices available in schools) available worldwide for students experiencing any form of chronic pain. Articles were analyzed using a descriptive numerical summary analysis and a qualitative thematic analysis, following Arksey and O'Malley's (2005) scoping review framework. A total of 32 articles comprising 28 studies were included. The scoping review highlighted six themes relating to in-school support: knowledge, collaboration, in-school therapy, consulting school health professionals, building positive relationships, and academic accommodations. The in-school services were reported for students across various types of chronic pain, suggesting that the supports may be applicable to all students experiencing chronic pain. Barriers to implementing in-school supports included insufficient school resources and a need for education on chronic pain. The second study of this dissertation consisted of a mixed-methods research design in which an online survey was distributed to individuals who have experienced endometriosis while attending school to understand what types of in-school services might be beneficial. Gender theory, biopsychosocial theory, and the social-ecological modal of disability guided the development of the survey. Statistical analyses were conducted with the quantitative data, and a thematic analysis was conducted with the selected open-ended questions in the survey. One hundred and seventy-four participants provided responses to the survey. Participants reported experiencing stigma in the school setting. Several different types of in-school support were reported as necessary, and responses were consistent with the results from the scoping review. The results from Studies 1 and 2 further highlight the importance of supporting students with endometriosis and to consider the impact endometriosis has on students' lives, including in their school settings.

Keywords: chronic pain, in-school support, school, endometriosis

Résumé

L’endométriose est une maladie chronique dans laquelle des tissus similaires aux tissus normalement présents dans l’utérus commencent à s’accumuler à l’extérieur de l’utérus, entraînant ainsi de la douleur, une baisse de la fertilité et une croissance de la masse pelvienne (Becker et al., 2022). Alors que la recherche sur l’endométriose se concentre sur les femmes, la présente thèse s’efforce d’inclure également les personnes nées avec un utérus mais qui ne s’identifient pas comme des femmes, c’est pourquoi des termes neutres seront également utilisés tout au long de la thèse afin de ne pas supposer le genre d’un(e) participant(e). Il n’existe actuellement aucun remède contre l’endométriose (Acién et Velasco, 2013; Björk et al., 2020). La maladie touche environ une personne en âge de procréer sur 10 dans le monde (Gambone et al., 2002), y compris durant la vie adulte et l’adolescence (Ballweg, 2015). Les personnes de tous âges, atteintes d’endométriose souffrent souvent de dépression, de peur et/ou d’anxiété, ainsi que d’une diminution de la qualité de vie associée à la douleur débilitante que la maladie peut causer (Friedl et al., 2015; Laganà et al., 2017). Ces personnes peuvent aussi subir d’autres effets néfastes de l’endométriose lors de leurs activités quotidiennes à l’école comme au travail. En raison du manque général de sensibilisation et de la stigmatisation sociale entourant les menstruations, les personnes sont souvent mal informées des symptômes associés à l’endométriose ou ignorent la condition avant leur diagnostic (Seear, 2009). Les personnes qui signalent leurs symptômes à leur médecin peuvent attendre de sept à 12 ans avant de recevoir un diagnostic (Agarwal et al., 2019; Singh et al., 2020; Soliman et al., 2017; Treloar et al., 2010). La première étude de cette thèse est une recension de la littérature sur les sources de soutien (c'est-à-dire les services, les ressources, les aménagements scolaires et les pratiques disponibles dans les écoles) offertes aux élèves souffrant de toute forme de douleur chronique. Les articles ont été analysés à l’aide d’une analyse statistique descriptive et d’une analyse thématique qualitative, suivant la méthode de Arksey et O’Malley (2005). Un total de 32 articles comprenant 28 études a été inclus. La recension des écrits a mis en évidence six thèmes relatifs au soutien existant en milieu scolaire: les connaissances, la collaboration, la thérapie à l’école, la consultation des professionnels de la santé à l’école, l’établissement de relations positives entres les élèves et le personnel de l'école, et les accommodements en milieu scolaire. Les mesures de soutien à l’école ont été signalées pour les élèves souffrant de plusieurs types de douleur chronique, ce qui donne à penser que les mesures de soutien à l’école peuvent être universelles. Les obstacles à la mise en œuvre des mesures de soutien scolaire comprenaient l’insuffisance des ressources en milieu scolaire et le besoin d’éducation des élèves et du personnel de l’école sur le problème de la douleur chronique. La deuxième étude de cette thèse a consisté en un modèle de recherche à méthodes mixtes dans lequel une enquête en ligne a été distribuée à des personnes ayant été atteintes d'endométriose pendant leur scolarité afin de comprendre quels types de services scolaires pourraient être bénéfiques. La théorie du genre, la théorie biopsychosociale et le modèle socio-écologique du handicap ont guidé l'élaboration de l'enquête. Les données quantitatives ont fait l'objet d'une analyse statistique et les questions ouvertes sélectionnées dans l'enquête ont été soumises à une analyse thématique. Cent soixante-quatorze participants ont répondu au questionnaire. Les participants de la deuxième étude ont déclaré avoir été stigmatisés à l’école. Les résultats suggèrent que plusieurs différents types de soutien à l’école ont été déclarés nécessaires par les participantes ce qui réplique les résultats liés aux besoins de soutien des élèves vivant avec le douleur chronique identifié dans la première étude. Ces études soulignent également l’importance de soutenir les élèves atteints d’endométriose en mettant en lumière l’impact de l’endométriose dans la vie et en particulier lorsqu’elles étudient dans le milieu scolaire.

Mots-clés: douleur chronique, soutien scolaire, école, endométriose

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Contribution to Original Knowledge

The present dissertation makes several original contributions. First, the findings contribute to our understanding of how to support students with endometriosis in schools. In addition, it is the first Canadian study to examine in-school support needs for students with endometriosis. Specifically, in Study 1, a scoping review was conducted to explore the in-school support of students with chronic pain. Furthermore, the information about students with chronic pain was extrapolated to students with endometriosis. Research regarding endometriosis has been focused on understanding the cause of endometriosis, developing better diagnostic tools, and investigating the impact of endometriosis (Acién & Velasco, 2013; As-Sanie et al., 2019; Wróbel et al., 2022; Young et al., 2015). Second, despite researchers reporting that endometriosis impacts individuals in all aspects of their lives, such as medical, social, psychological, educational, and vocational (Gallagher et al., 2018; Le Roux et al., 2022; Wróbel et al., 2022; Zannoni et al., 2014), only seven studies have focused on endometriosis in educational settings. Of these seven studies, four were focused on raising awareness about endometriosis in the school setting. While raising awareness about menstrual health and endometriosis in the school setting is important, none of the studies explored which in-school support services are beneficial to students with endometriosis, despite students reporting the need for such support.

Given that endometriosis symptoms affect students' functioning in school, a setting where students spend on average 35 hours per week, it becomes clear there is a gap in the literature. Currently, no studies have investigated the variety of in-school needs of students with endometriosis, as the focus of the research so far has been limited to simply raising awareness about endometriosis in school settings. Thus, Study 2 is the first to examine the specific in-school needs of students with endometriosis, and the first to examine how endometriosis specifically affects students in Canada. Students with endometriosis in Canada have several in-school needs, and our findings provide data to aid in the development of evidence-based prevention and intervention strategies that are tailored specifically to the needs of students who have endometriosis.

Author Contributions

In the current dissertation, Jalisa Gittens is the principal investigator for both studies. As the principal investigator, Jalisa Gittens conceptualized and designed each study. As part of each study, Jalisa Gittens conducted the acquisition and interpretation of data, performed statistical calculations, and drafted the final manuscript.

For the first study, Dr. Ingrid Sladeczek (co-author of Study 1) advised on the conceptualization, design process, and contributed to the revisions. Gabrielle Dickner (co-author of Study 1) and Kevin Ah-Sen (co-author of Study 1) took part in study coordination, data acquisition, and manuscript revisions for Study 1. For the second study, Jalisa Gittens conducted the development of the survey and the recruitment of participants. The conceptualization, and data analysis were guided by Dr. Sladeczek (co-author of Study 2) and Dr. Danielle Groleau (co-author of Study 2). Furthermore, Dr. Groleau provided training on analyzing the qualitative data.

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List of Tables and Figures

Manuscript 1

Manuscript 2

List of Abbreviations

me	Menstrual health and Endometriosis
COVID-19	Coronavirus Disease 2019
EIQ	Endometriosis Impact Questionnaire

List of Appendices

Chapter 1: Introduction

Jordan (pronouns: she/her), a 16-year-old student, wakes up with pelvic cramps. She looks at her calendar and realizes that her menstrual cycle begins in a few days. She begins to feel nauseated and extremely bloated. While getting ready for school, Jordan frequently needs to stop and lie down, as the pain of the cramps goes through her spine down into her toes. Jordan has this experience every month before and during her menstrual cycle. She avoids telling her parents that she isn't feeling well, as her parents have told her that "menstruation is supposed to be painful." Jordan struggles to walk to the bus stop because of the pain.

At the age of 18, Jordan's pain during menstruation increases drastically, leading her to see a gynecologist. Jordan reports to her gynecologist that before and during menstruation, she experiences severe cramps, heavy bleeding, and back pain, feels nauseated and light-headed, frequently vomits, and has difficulty with bowel movements. The gynecologist says to Jordan: "take Midol during menstruation. I've reviewed your vitals, and you are fine." Jordan tries to talk to her classmates about her pain but gets called "weak"; her friends handle their menstrual cycles with mild discomfort. At the age of 21, the reported pain becomes severe to the point that Jordan often stays in bed.

Frustrated with the amount of pain she has and the number of days that she must stay home and miss work and school, Jordan begins to see several different doctors. Finally, a doctor agrees to an ultrasound and finds a large mass on Jordan's ovaries and around her pelvis, leading the doctor to conduct a biopsy on the growth. The biopsy results in a diagnosis of endometriosis. Jordan is happy to finally know what's going on but is also frustrated with how long it took to get a diagnosis despite years of complaining. Jordan begins exploring various treatment options, such as birth control.

The above vignette, a composite based on several studies (Cox et al., 2003; Emad, 2006; Facchin et al., 2015; Simoens et al., 2012) and personal stories (Endofound, 2019; SpeakENDO, 2020) from individuals with endometriosis, illustrates the physical and emotional experiences of adolescents and adults with endometriosis. Endometriosis is a gynecological disease associated with infertility and pain (Gidwaney et al., 2012). Individuals with endometriosis may experience depression, fear, anxiety, and a decreased quality of life associated with its debilitating symptoms. The difficulty of completing daily activities can adversely affect many aspects of life, such as relationships, school, and employment (Friedl et al., 2015; Gallagher et al., 2018; Lövkvist et al., 2016).

Women are not the only ones to face endometriosis; trans and non-binary individuals (who were assigned female at birth, but do not identify as a woman) also experience endometriosis. Approximately 3% of individuals assigned female at birth report an ambivalent gender identity, and 0.8% report having a gender identity that does not match their sex (Kuyper & Wijsen, 2014). Worldwide, endometriosis affects approximately one in 10 individuals of childbearing age, including both adolescents and adults (Gambone et al., 2002; Zhang et al., 2021). However, the experiences of trans and non-binary individuals with endometriosis may differ greatly from individuals who identify as women. Transgender individuals with endometriosis encounter distinct obstacles in healthcare environments, such as prejudice, poor comprehension of transgender health issues, and communication challenges. Such factors can have an influence on the diagnosis, treatment, and general handling of disorders such as endometriosis. In this regard, establishing transparent and sincere communication between the patient and their healthcare practitioner is crucial to appropriate care (Vallée et al., 2023).

Suffering from a gendered condition such as endometriosis when one does not identify with the associated gender creates additional stress when accessing medical treatment and support systems (Cook & Hopton, 2017; Higgins et al., 2019; Shim et al., 2020). The Endometriosis Network Canada has called for more inclusive language in the healthcare system (The Endometriosis Network Canada, 2020). The current dissertation recognizes the importance of inclusivity and will use gender-neutral terms along with words like *female*, *women*, or *girls*. However, when referring to participants in prior research, the authors' terms (whether gendered or not) will be retained.

As seen in the above vignette, students with endometriosis experience unique challenges. In one study, students with painful menstrual cycles were 28 times more likely to miss school than individuals without symptoms (Zannoni et al., 2014). In another study, students with painful menstruation reported a lower quality of life and difficulty with daily activities, such as completing schoolwork and attending social events and extracurricular activities (Bodén et al., 2013; Nnoaham et al., 2011; Soliman et al., 2017). Currently, endometriosis is not discussed in most sex education classes (Audebert et al., 2015; Shadbolt et al., 2013), leading to a general lack of awareness surrounding the condition. Thus, supporting students who are experiencing endometriosis in their educational environment is important.

Only seven studies have focused on individuals with endometriosis in the school setting (As-Sanie et al., 2019; Bodén et al., 2013; Bush et al., 2017; Gupta et al., 2018, 2021; Khan et al., 2022; Ramani Devi et al., 2021; Rusda & Rahman, 2019). A scoping review on in-school supports (i.e., school-based interventions and accommodations) for students with endometriosis thus could not be conducted due to the lack of studies. As chronic pain is one of the most common symptoms of endometriosis requiring intervention, reviewing research on supporting students with chronic pain can inform the current research on understanding how to support students with endometriosis.

The lack of general awareness about endometriosis means that individuals who potentially suffer from it may be unaware of the condition or its associated symptoms before diagnosis (DiVasta et al., 2018; Seear, 2009; Young et al., 2015). Moreover, individuals may be uncomfortable sharing information about their menstrual irregularities, as the topic can be regarded as taboo (Denny et al., 2011; Hawkey et al., 2017; Rubinsky et al., 2018; Seear, 2009; Shadbolt et al., 2013). Furthermore, individuals view their menstrual irregularities and suffering as normal symptoms to be endured. A lack of awareness about endometriosis and the taboo of discussing menstruation may thus delay one from seeking help (Cox et al., 2003).

The most effective current treatments for individuals with endometriosis include surgery, hormone therapy, pain medication, and emotional support (Nezhat et al., 2019; Opoku-Anane et al., 2020; Valle & Sciarra, 2003). Early identification and treatment may reduce or prevent pain, progression, and organ damage and preserve fertility (Brosens et al., 2013; Laufer, 2008; Liu et al., 2020); yet individuals with endometriosis encounter denial and neglect when reporting symptoms, leading to delayed diagnosis (Leroy et al., 2016). On average, diagnosis takes seven to 12 years (Treloar et al., 2010; Wróbel et al., 2022).

Furthermore, individuals with endometriosis report experiencing isolation, estrangement, and powerlessness, experiences that could be related to medical professionals failing to take their symptoms seriously (Emad, 2006). Systematic dismissal of endometriosis symptoms causes delayed diagnosis and treatment, as well as socio-emotional difficulties for individuals with the condition (Emad, 2006; Lövkvist et al., 2016; Nnoaham et al., 2011; Young et al., 2015). Early diagnosis and treatment are crucial for individuals with endometriosis (Young et al., 2015).

The current dissertation is divided into two studies. The first study comprises a review of the literature to ascertain current in-school supports available and implemented worldwide for individuals with chronic pain, as chronic pain is one of the most common and main symptoms individuals with endometriosis experience. In the second study, the overarching goal was to identify the specific needs of students with endometriosis (both current and former) via an online survey of their experiences. The retrieved in-school support services from the chronic pain scoping review were included in the online survey to understand if any of the in-school supports reported in the scoping review could be beneficial to students with endometriosis. The data gathered from both studies explore students' experiences with endometriosis to inform school-based guidelines on how to promote a greater understanding of endometriosis and how endometriosis impacts students.

Chapter 2: Literature Review

The following literature review outlines the importance of historical thinking and misconceptions about menstruation in the current perceptions of endometriosis, particularly in school settings. A comprehensive description of endometriosis and its epidemiology, along with a discussion of endometriosis's effects on an individual's quality of life, is presented. Three theoretical models are presented, which offers a lens to understand student's experiences with endometriosis and consider how in-school supports may be facilitated. Finally, an overview detailing the explicit research objectives of the conducted studies concludes the chapter.

Misconceptions About Menstruation

An important part of understanding endometriosis is recognizing the misconceptions and taboos surrounding menstruation. In her book *First Blood*, Sally Dammery (2015) discusses the history of menarche (i.e., the first appearance of menstruation). Two themes are relevant for understanding delays in receiving an endometriosis diagnosis: the historical perception of menarche as "dirty" and the ongoing lack of information concerning menstruation.

Historically, menstruation has been treated as a secret (Freidenfelds, 2009). Girls' education on menstruation is historically lacking, while boys receive little education on the topic (Chrisler, 2013). In addition, women report not communicating with men about menstruation for fear of being shunned or mocked (Chrisler, 2013; Freidenfelds, 2009; Hawkey et al., 2017; Johnston-Robledo & Chrisler, 2013). Thus, throughout history, menstrual health has been under-discussed and seen as shameful (Freidenfelds, 2009; Johnston-Robledo & Chrisler, 2013). Menstruation has been historically described as disgusting, and minimal knowledge of the menstrual cycle often deterred individuals from sexual activity (Johnston-Robledo & Chrisler, 2013; Rubinsky et al., 2018). Menstruation management was also perceived as a mystery. For example, in the 1940s, the process of using menstrual pads was not discussed; menstruating individuals have used pieces of cloth to manage their menstruation, washing and drying them daily, and promptly removing the pads from clotheslines to prevent others from knowing they were menstruating (Freidenfelds, 2009). The long history of the secret of menstruation continues into the present day, as review reported that adolescents revealed continued negative connotations surrounding menstruation (Chandra-Mouli & Patel, 2017).

Erving Goffman's theory of stigma suggests that stigma originates from the process of social labelling, and subsequent negative responses directed towards persons who possess specific features or attributes that are considered undesirable (Gibbons & Birks, 2016; Williams, 1987). Stigmatized individuals are frequently classified as other and associated with unfavourable stereotypes, resulting in unfair treatment and a decline in social standing (Gibbons & Birks, 2016; Williams, 1987). Internalizing negative attitudes can result in emotions such as shame, diminished self-worth, and self-blame.

Menstrual stigma comprises taboos and unfavourable attitudes and beliefs within society about menstruation. The consequences of experiencing menstrual stigma include silence, humiliation, embarrassment, and the reinforcement of negative preconceptions, which can hinder an individual's capacity to seek assistance and obtain necessary resources (Babbar et al., 2022; Johnston-Robledo & Chrisler, 2013). Additionally, menstrual stigma might restrict the availability of menstrual hygiene supplies, and impede access to education and healthcare services, as menstruation is regarded as a personal affair (Babbar et al., 2022). The stigma can also have an adverse effect on mental health, resulting in diminished self-worth, heightened anxiety, and depressive symptoms (Johnston-Robledo & Chrisler, 2013; Miller, 2019). To address the issue of menstruation stigma, healthcare professionals, and school staff must challenge prevailing social conventions. Implementing menstrual health education programs and fostering open conversation can create a more supportive and understanding atmosphere (Bush et al., 2017).

As endometriosis is a disease heavily influenced by menstruation, affected individuals may not be willing to discuss or share their symptoms openly. Furthermore, individuals may be unaware that their symptoms are unusual because they know little about how others experience menstruation (Johnston-Robledo & Chrisler, 2013; Miller, 2019). While awareness of menstruation and its management increases, the topic is still not openly discussed (Johnston-Robledo & Chrisler, 2013; Miller, 2019; Rubinsky et al., 2018). Several researchers have reported that individuals with endometriosis tend to hide their symptoms because of misconceptions surrounding menstruation and their lack of awareness of what is considered typical menstruation (Audebert et al., 2015; Johnston-Robledo & Chrisler, 2013; Rubinsky et al., 2018).

What is Endometriosis?

First described by Carl Von Rokitansky in 1860 (Rokitansky, 1860; Winterhager et al., 2009), endometriosis is a chronic, incurable gynecological condition causing debilitating pelvic pain (Harada, 2013). During normal monthly menstruation, hormonally active tissue found within the uterus—endometrial tissue—is shed through the vaginal canal. In endometriosis, endometrial-like tissue is found outside the uterus and is not evacuated during menstruation (Gidwaney et al., 2012). Without a way to exit the body, the tissue accumulates, causing inflamed areas, scarring of various internal organs, pain, infertility, and pelvic mass growth (Gidwaney et al., 2012). Chronic pelvic pain, heavy bleeding and fertility difficulties are the symptoms of endometriosis for which most affected individuals seek specialist evaluation and support (Abbas et al., 2012; Berkley et al., 2005; Bloski & Pierson, 2008; Facchin et al., 2015; Fourquet et al., 2010; Fuldeore & Soliman, 2017).

Endometriosis has a complicated history. Originally, it was thought to primarily affect individuals aged 30 to 40 years (Huntington & Gilmour, 2005). However, Goldstein et al. (1980) first reported the presence of endometriosis in adolescents and young adults in 1980. To date, there is no consensus on what causes endometriosis, as much is unknown about its epidemiology (Bloski & Pierson, 2008).

Symptomology

Common symptoms of endometriosis include painful and heavy menstruation, painful sexual intercourse, painful bowel movements, exhaustion, and infertility (DiVasta et al., 2018; Fuldeore & Soliman, 2017; Singh et al., 2020). Endometriosis is among the most common forms of pelvic pain. According to Singh et al. (2020), 20% of women in Canada who have severe chronic pelvic pain, and up to half (24%-50%) of infertile women may have endometriosis. Endometriosis pain has been described as intense, overwhelming, sharp, crippling, and horrific (Denny, 2004; Huntington & Gilmour, 2005; Jones et al., 2004). Physical disability associated with endometriosis is primarily the result of persistent pain, which limits occupational, social, and daily routine activities (Culley et al., 2013; Graham et al., 2019; Hållstam et al., 2018; Nnoaham et al., 2011).

Comorbidities

Endometriosis commonly co-occurs with other chronic disorders, including arthritis, irritable bowel syndrome, lupus, migraines, and osteoporosis (Ferrari-Souza et al., 2023; Karp et al., 2011; Surrey et al., 2018; Xue et al., 2021). Individuals with endometriosis also have a higher risk of developing ovarian cancer, breast cancer, endometrial and cervical cancer, and melanoma skin cancer (Aris, 2010; Kalaitzopoulos et al., 2020; Kvaskoff et al., 2021). Endometriosis is associated with social and psychological difficulties. For example, women with endometriosis experience higher levels of stress (e.g., irritability, feeling overwhelmed, and mental exhaustion) than healthy women (Carbone et al., 2021; Petrelluzzi et al., 2008; van Stein et al., 2023). In addition, researchers have reported that individuals with endometriosis have higher rates of depression, anxiety, and emotional distress than control groups and the general population (Chen et al., 2016; Fourquet et al., 2011; Friedl et al., 2015; Gambadauro et al., 2019; Simoens et al., 2012).

The association between endometriosis and mental health disorders is a persistent theme in the research. Cavaggioni et al. (2014) found a statistically significant difference between women with and without endometriosis in the prevalence of psychiatric disorders (54% and 18.6%, respectively), particularly mood and anxiety disorders. A review of psychological symptoms experienced by women with endometriosis found that 86% experienced depression, and 29% experienced moderate to severe anxiety (Koller et al., 2023). Other studies have found the prevalence of depression and anxiety disorders to be much lower within the general population: 27% for depression and 4.3% for moderate-to-severe anxiety (Chaman-Ara et al., 2017; Wang et al., 2017). Furthermore, a recent systematic review revealed a prevalence of 10% to 86% for depression and 10% to 79% for anxiety for women with endometriosis, while the global prevalence of depressive and anxiety disorders in women of reproductive age ranges from 4.5% to 7% and 5.5% to 6%, respectively (van Barneveld et al., 2022). Individuals with endometriosis are thus highly vulnerable to emotional and psychological disorders.

Prevalence and Population

Currently, the prevalence of endometriosis worldwide is one in 10, however, estimates vary by country (Ballweg, 2015; Ellis et al., 2022; Gambone et al., 2002). The accurate prevalence of endometriosis is a challenge to assess due to endometriosis often being untreated or misdiagnosed (Labinjo, 2020; Moradi et al., 2019; Sarria-Santamera et al., 2021; Singh et al., 2020). Prevalence of endometriosis appears to be similar across affected (menstruating) age groups (Fuldeore & Soliman, 2017).

About two-thirds of adolescent girls with chronic pelvic pain or dysmenorrhea (i.e., painful menstruation) have evidence of endometriosis (Janssen et al., 2013). Hirsch et al. (2020) conducted a systematic review on the prevalence of endometriosis in adolescents with pelvic pain. The review included a total of 19 studies involving 1,243 symptomatic adolescents. In all, 648 of 1,011 (64%) adolescents undergoing laparoscopy (i.e., a small incision to insert a laparoscope) were found to have endometriosis (Hirsch et al., 2020). Earlier menarche onset (i.e., the first occurrence of menstruation) and height (being taller) are associated with a higher risk of endometriosis (Aarestrup et al., 2020; Lu et al., 2023).

Endometriosis is not limited to individuals of one gender. For transgender and nonbinary individuals, accessing healthcare is a challenge. Kcomt (2019) reported that over half of transgender and non-binary individuals had difficulty accessing health services, and one in six had been denied healthcare because they were transgender. A gendered illness such as endometriosis increases barriers for transgender individuals in need of support, information, or treatment (Fox, 2014).

Gender-non-conforming individuals with endometriosis face barriers not only across the healthcare system, but also in support groups and online forums (Jones, 2016; The Endometriosis

Network Canada, 2020). For individuals with a misunderstood and frequently misdiagnosed illness, such as endometriosis, support groups and online forums can provide essential information, sympathy, and validation. Gender-non-conforming individuals may feel unwelcome or excluded in endometriosis support groups because of the exclusive use of gendered language (such as *female*, *woman*, *girl*, or even *endosister*, a term of solidarity in many groups). Gendered language can feel exclusionary to gender-non-conforming individuals with endometriosis.

Diagnosis

Early diagnosis and treatment of endometriosis can reduce the impact endometriosis has on physical, psychological, and social outcomes. On average, however, individuals with endometriosis experience a delay of between seven to 12 years before receiving a confirmed diagnosis (Pino et al., 2023; Rowe et al., 2019; Singh et al., 2020; Treloar et al., 2010; Wróbel et al., 2022). Individuals with endometriosis may be unaware that their experience of menstruation is atypical or feel hesitant to discuss their symptoms. Also, more conclusive symptoms (e.g., pelvic pain, heavy bleeding) may appear only in advanced stages of endometriosis (Gordts et al., 2020; Kuan et al., 2021; Mehmud et al., 2007). Ongoing negative connotations and stigma surrounding menstruation, as well as the resulting lack of general knowledge about endometriosis, have undoubtedly influenced the process and rate of endometriosis diagnosis, and contributed to diagnosis delays (Chrisler, 2013; Dahlqvist, 2018).

Furthermore, unlike other chronic health conditions (e.g., asthma, fibromyalgia), the development and cause of endometriosis are unclear, as the relationship between an individual’s symptoms and medical evidence (e.g., found in surgery) can be non-linear (Cousins et al., 2023; Whelan, 2007). Individuals may report several symptoms, but medical exams (including laboratory tests) may still provide no medical evidence supporting patients’ experiences

(Dunselman et al., 2014; Greene et al., 2016; Johnson et al., 2017; Whelan, 2007). Moreover, according to a recent survey conducted in France, researchers found that a quarter of general practitioners expressed a lack of confidence in their knowledge of endometriosis and its use in clinical practice (Roullier et al., 2021).

Even after a patient's symptoms are acknowledged by the healthcare system, endometriosis is difficult to diagnose. The gold standard for diagnosing endometriosis is laparoscopy (i.e., a small incision to insert a laparoscope) or laparotomy (i.e., incision several inches long to examine the abdominal organs; Duffy et al., 2014; Huntington & Gilmour, 2005; Mowers et al., 2016). Due to the requirement of invasive surgery, which is both costly and dependent on the presence of skilled surgeons, the process of diagnosis is not widely accessible worldwide. A call to action published in January 2019 by *The American Journal of Obstetrics and Gynecology* (Agarwal et al., 2019) suggests diagnosing endometriosis clinically, by examining symptoms, menstruation, and family history, rather than through surgery.

Certain types of endometriosis-related lesions can now be identified using less invasive methods. According to Kinkel et al. (2006), it is feasible to get a diagnosis of deeply infiltrating endometriosis with the utilization of either magnetic resonance imaging or transvaginal ultrasound, both of which offer a comprehensive view of the pelvic organs. Transvaginal ultrasounds are 78% to 98% sensitive and 90% to 100% specific for detecting nonovarian endometriosis when performed by sonographers with relevant training; however, diagnostic accuracy is decreased if imaging is not done by trained individuals (Johnson et al., 2017; Menakaya, 2015). Patients' access to imaging for endometriosis can be improved by increasing the number of experts available (As-Sanie et al., 2019; Grundström et al., 2018; Guerriero et al., 2016; Menakaya, 2015).

Further complicating the understanding of what causes endometriosis, a diagnostic laparoscopy is not always accurate, making surgical diagnosis an imperfect gold standard (Gratton et al., 2022). Endometriosis cannot be excluded simply because there are neither visible lesions nor positive histology, as hidden endometriosis has been documented (Nisenblat et al., 2016; Pascoal et al., 2022; Taylor et al., 2021). Relying on surgery to diagnose endometriosis may delay treatment (Taylor et al., 2021). Taking prescribed medication is not as risky as surgery; endometriosis should thus still be considered when there is clinical suspicion without a surgical diagnosis (Agarwal et al., 2019).

Medical history is important for accurate clinical diagnosis. Although pelvic pain is the most common symptom of endometriosis, it does not serve as a specific indicator since it is associated with multiple gynecological and non-gynecological conditions. Endometriosis can be distinguished from non-gynecological causes of abdominal and pelvic discomfort by paying special attention to cyclic bowel and bladder pain (Taylor et al., 2021). Menstrual pain progressing over time may be a sign of endometriosis, as this form of pain normally does not worsen with time. Finally, because nonsteroidal anti-inflammatory drugs typically provide relief from menstrual pain, these drugs failing to provide relief may also be a sign of endometriosis (Taylor et al., 2021).

Recently, there has been research on developing non-invasive methods of diagnosing endometriosis (Monnaka et al., 2021). The ENDO-miRNA (gene expression within endometrial tissue) study is the first prospective study to report a saliva-based diagnostic miRNA signature for endometriosis (Bendifallah et al., 2022; Dabi et al., 2023). Saliva-based diagnosis could improve early diagnosis through a non-invasive tool readily available by healthcare systems. For example, a saliva swab test to diagnose endometriosis has been used in France (Ferrier et al., 2023). Currently, the availability of the saliva swab test is limited as it's not available in Canada, and it is not provided free of charge. However, if the accuracy of the saliva swab test persists, such a novel technique can potentially reduce diagnostic delays. Nevertheless, it is important to note the absence of a cure would persist (Ferrier et al., 2023).

The systematic dismissal of endometriosis symptoms before a diagnosis has been well documented, and a long delay before receiving a diagnosis means living with chronic pain for years (often up to a decade) without treatment (Agarwal et al., 2019; Johnson et al., 2017; Taylor et al., 2021). The psychological and social issues may be due to patients waiting seven to 12 years before receiving a diagnosis and living with endometriosis without support (Laganà et al., 2017; Nnoaham et al., 2011; Wróbel et al., 2022). More than 150 years after its discovery, endometriosis remains a complex, underdiagnosed, and misunderstood condition.

Treatment of Endometriosis

The goal of treating endometriosis is to reduce symptoms, effectively manage pain, and, in certain instances, enhance fertility. The treatment plan may differ depending on the severity of symptoms, the degree of the condition, and the individual's reproductive goals. Different methods for treating endometriosis are discussed below.

Medical and Surgical Options

Pain caused by endometrial tissue outside of the uterus is the most common and debilitating symptom. Medical treatments are often prescribed to alleviate pain, including anti-inflammatory drugs, narcotics, and hormonal treatments (e.g., contraceptives, and progestin therapy; Casper, 2017; Davis et al., 2007; Jensen et al., 2018; Laufer, 2008). Finally, individuals may seek opioids to manage their pain, a concerning choice given the high addictive potential (Poulos et al., 2019). As-Sanie et al. (2020) conducted a retrospective cohort analysis including

58,472 women with endometriosis, of whom 61.7% had filled an opioid prescription. The use of opioids to treat chronic noncancer related pain is a subject of debate and carries the potential for significant harm such as opioid abuse (Chiuve et al., 2021; Lamvu et al., 2019).

Surgical pain treatments are another endometriosis pain management option (Singh et al., 2020). Visible endometrial tissue can be destroyed with heat or surgically removed during laparoscopy. After the procedure, 87% of individuals report an improvement but not complete eradication of pain (Cavaco-Gomes et al., 2017; Duffy et al., 2014). A hysterectomy is another surgical treatment option, though typically a last resort, even for individuals with debilitating symptoms who do not want children.

A hysterectomy is considered only after other therapies have failed to treat the pain (Martin, 2006; Mowers et al., 2016; Rizk et al., 2014). Thus, while medical and surgical options are available to treat pain associated with endometriosis, most options come with complications. Which treatments are best will vary among individuals, and sometimes treatment is unsuccessful (Becker et al., 2017; Poulos et al., 2019; Rizk et al., 2014). Becker et al. (2017) conducted a systematic review and reported that up to 59% of endometriosis patients had continued pain after medical treatment.

Non-Medical Treatments for Pain

Other physical interventions have been successful in minimizing endometriosis-related pain. Physiotherapy, acupuncture, yoga, controlled breathing techniques, and muscular relaxation techniques are commonly used. Zhao et al. (2012) conducted a randomized control study to determine the effects of muscular relaxation training (including psychoeducation) on participants with endometriosis undergoing hormone therapy. Both groups showed statistically significant improvement in overall quality of life after 12 weeks of intervention ($p<0.05$). Participants who received the muscular relaxation training showed improvement in all quality-of-life domains (i.e., physical function ($M=28.75$, $SD=16.28$, $p<0.001$)., role limitation caused by physical problems ($M=31.45$, $SD=25.35$, $p=0.008$), body pain ($M=34.34$, $SD=18.47$, $p<0.001$), general health perception ($M=31.73$, $SD=17.12$, $p<0.001$), vitality-energy ($M=31.36$, $SD=18.41$, $p<0.001$), social function ($M=23.67$, $SD=23.39$, $p<0.001$), role limitations caused by emotional problems ($M=35.25$, $SD=22.13$, $p<0.001$), and mental health ($M=25.07$, $SD=18.26$, $p<0.001$), while the control group showed improvement only in physical ($M=14.71$, $SD=17.92$, $p<0.001$) and mental health ($M=25.07$, $SD=18.26$, $p<0.001$; Zhao et al., 2012). Also, participants who received muscular relaxation training experienced a statistically significant decrease in anxiety ($\eta_p^2=0.08$) and depressive ($\eta_p^2=0.08$) symptoms. The results are promising results for individuals who prefer non-surgical management of endometriosis-related pain.

Psychological Treatments

Individuals with endometriosis may struggle emotionally and psychologically from endometriosis-related pain and stress (Bloski & Pierson, 2008; Facchin et al., 2015; Nnoaham et al., 2011; Rubinsky et al., 2018). Van Niekerk et al. (2019) reviewed existing approaches and recommended cognitive behavioural therapy, acceptance and commitment therapy, mindfulness, and psychoeducation, as effective in treating emotional and psychological difficulties associated with endometriosis. Psychoeducation is an intervention where patients receive evidence-based medical and psychological information (i.e., causes, symptoms, prognosis, and treatments) to better understand a condition they have (Taylor-Rodgers & Batterham, 2014). According to a 2009 meta-analysis (Donker et al., 2009), psychoeducation can effectively reduce depression, anxiety, and other psychological disorders.

Recent studies provide further supportive evidence of the efficacy of psychoeducation (Morokuma et al., 2013; Reins et al., 2019; Wong et al., 2016). Individuals with endometriosis who take part in cognitive behavioural therapy, acceptance and commitment therapy, mindfulness, or psychoeducation show significant improvements in coping with pain and benefit from increased quality of life (i.e., health, satisfaction, comfort, and ability to enjoy daily activities; Sansom-Daly et al., 2012; Van Niekerk et al., 2019).

Endometriosis in Canada

According to Singh et al. (2020), the estimated prevalence of diagnosed endometriosis in Canada is 7.0%. Canadian women who participated in the study reported experiencing menstrual pelvic pain, fatigue, anemia, heavy bleeding, lower back pain, constipation, bloating, diarrhea, and anxiety or stress. Researchers reported a diagnostic delay of 5.4 years, implying an unmet demand for earlier identification of endometriosis in Canada (Singh et al., 2020). Furthermore, in a Canadian study (Levy et al., 2011), 27 participants treated at two gynecology clinics in Alberta and Quebec were included in a convenience sample. The study found endometriosis' societal cost in Canada was estimated at $5,200 Canadian dollars per patient per year, or an annual cost of $1.8 billion, based on data from medical and alternative treatments, work absenteeism, quality of life, and caregiver time (Levy et al., 2011). In Canada, the hospital cost associated with endometriosis was approximately $30 million per year (Chen et al., 2020).

Endometriosis Network Canada (a non-profit organization) has interacted with thousands of individuals who have been diagnosed with endometriosis and face difficulties in their physical and mental health (Wahl et al., 2021). Individuals diagnosed with endometriosis have instances when their symptoms have been dismissed by both their close acquaintances and healthcare providers, attributing their experiences to a normative aspect of femininity. Consequently, individuals have reported feelings of social isolation and despair, and in severe cases, have contemplated self-harm because of such circumstances (Wahl et al., 2021).

The availability of clinically qualified doctors for the diagnosis and treatment of endometriosis and pain-related diseases is limited or non-existent in locations in Canada, such as in the Northwest Territories (Wahl et al., 2021). In regions characterized by insufficient healthcare infrastructure and constrained finances, individuals without access to specialized professionals may have impactful repercussions, such as enduring persistent discomfort and requiring invasive surgical interventions like a hysterectomy. According to Canadian studies, diagnostic delays and ineffective treatment result in the following losses: loss of social ties, relationship breakdowns, dropouts, job losses, and the inability to have children (Chen et al., 2020; Singh et al., 2020; Wahl et al., 2021). Inadequacies in the current system are well-known to clinicians, patients, and their families (Wahl et al., 2021). The Canadian Institutes of Health Research Funding Decision Database revealed that endometriosis-related projects received only $7.3 million in the past 20 years, a mere $7.30 per person living with endometriosis in Canada (Wahl et al., 2021).

Patients frequently seek medical attention in emergency departments and consult with numerous physicians before receiving a diagnosis (Wahl et al., 2021). Waiting times can vary from three to nine months for an initial appointment and reach 12 months for surgery and interdisciplinary pain care (Wahl et al., 2021). Canadian healthcare can present challenges to some patients, leading patients to seek care abroad. Consequently, the Bucharest Endometriosis Center in Romania performs surgery on nearly 100 female and gender-diverse Canadians with endometriosis each year (Global News, 2022). According to a *Global News* article, patients' reasons for seeking care outside Canada include severe pain, lengthy wait lists for treatment, and having their complaints ignored by healthcare professionals (Global News, 2022).

Endometriosis and COVID-19

Given the data in the present dissertation gathered towards the conclusion of the COVID-19 pandemic, it is crucial to consider the contextual factors surrounding the influence of COVID-19, a worldwide pandemic of the coronavirus, on persons affected with endometriosis.

Kabani et al. (2022) found that approximately half of endometriosis patients infected with COVID-19 reported increased symptoms of dysmenorrhea (painful menstruation), dyspareunia (difficult or painful sexual intercourse), and dyschezia (straining or obstructed defecation). Most patients reported worsening pelvic pain, anxiety, depression, and fatigue (Kabani et al., 2022). Many non-urgent medical treatments and visits were postponed or cancelled during the pandemic to prioritize COVID-19 patients and limit the risk of infection (Ashkenazi et al., 2021). The delay in healthcare services led to a delay in diagnosing endometriosis (Handelsman et al., 2023; Keilmann et al., 2023).

Lockdowns, overburdened healthcare systems, and resource allocation to COVID-19 led to restricted access to routine treatments for endometriosis. The closure of health care services might also have hampered the provision of specialist care for endometriosis patients, causing treatment or follow-up visits to be delayed (Handelsman et al., 2023). For example, centers temporarily stopped offering outpatient appointments, diagnostic imaging for nonacute pelvic pain, endometriosis surgery, and fertility treatments (Kabani et al., 2022). A systematic review and meta-analysis of 17,799 patients (from 15 studies) found a decline of 47.2% in the availability of medical care, and increases of 49.3% in the prevalence of dysmenorrhea, 75% in anxiety levels, 59.4% in depression rates, and 68.9% in fatigue (Kabani et al., 2022).

Individuals who have endometriosis may have been experiencing chronic pain, exhaustion, and other symptoms, and additional extra stress, anxiety, and social isolation associated with the pandemic could have aggravated their disease and negatively affected their overall well-being (Handelsman et al., 2023). Although endometriosis does not increase susceptibility to COVID-19 infections, it could affect how COVID-19 symptoms present (Moazzami et al., 2021). COVID-19 can induce changes in endometrial tissue and affect the female reproductive system, such as the duration of the menstrual cycle and the length of bleeding (Jing et al., 2020; Lebar et al., 2022). Researchers have also reported that endometriosis is a risk factor for worsening of menstrual symptoms after receiving the COVID-19 vaccine (Edelman et al., 2022; Gilan et al., 2023; Male, 2021). However, additional research is needed to draw definitive conclusions regarding the impact of COVID-19 on endometriosis.

Effects of Endometriosis on Quality of Life

Facchin et al. (2015) examined the relationship between pain and quality of life in 110 patients with surgically diagnosed endometriosis of varying pain levels (from severe chronic pain to none). The study found patients with chronic pain had a poorer quality of life (i.e., loss of working ability, limitations on social activities, lack of understanding and support from others) because of the ongoing pain experienced, when compared to endometriosis patients with less or no pain. Similarly, other researchers have found that women with endometriosis report reduced quality of life, loss of work productivity, and higher absenteeism than individuals without the condition (Gao et al., 2006; Nnoaham et al., 2011). One study conducted in the United States reported that productivity loss accounts for approximately two-thirds of the annual cost ($12,419 per capita) of endometriosis’ effect on employers, patients, and the healthcare system (Simoens et al., 2012).

Gallagher et al. (2018) studied the quality of life of 567 adolescents and young adults (under 25 years) with endometriosis compared to their unaffected peers. Overall, earlier menarche and severe pelvic pain were associated with poorer physical and mental health-related quality of life among participants with endometriosis. Both adolescents and young adults with endometriosis experienced decreased quality of life compared to their healthy peers (Gallagher et al., 2018).

Adolescents with endometriosis reported poorer mental health, difficulty regulating their emotions, and feelings of social isolation compared to their healthy peers (Brosens et al., 2013; Le Roux et al., 2022). The studies described above are essential to understanding the effect of endometriosis on quality of life and productivity for individuals (including adolescents). However, despite adolescents spending a large proportion of their day in school, none of the above studies describe how endometriosis affects adolescents in the school setting, nor the interventions that are needed or recommended to support adolescents in schools.

Le Roux et al. (2022) conducted a mixed-methods study to examine the diagnostic and therapeutic process experienced by adolescent and young adult females with endometriosis, including aspects such as disease manifestation, challenges encountered during diagnosis and treatment, and subsequent effects on their overall well-being. Le Roux et al. (2022) reported that girls and women often begin their journey with treating endometriosis before diagnosis by engaging in self-directed care. Participants reported that healthcare professionals' and the general public's lack of knowledge postpones diagnosis, and that endometriosis affects all parts of anindividual's life (Le Roux et al., 2022).

Lack of Endometriosis Education

Ramani Devi et al. (2021) investigated college students' knowledge of endometriosis, focusing on symptoms, menstrual cycle patterns, genetic background, and predisposing factors. A total of 1,001 female students living in India were included in the study, of whom 53.7% had a familial background of cyclic menstrual pain, 69.3% experienced pelvic and abdominal discomfort, and 80.6% used non-pharmacological interventions for pain relief. Notably, 75.6% of participants did not understand the need to seek medical attention when experiencing persistent pain, as participants believed the pain was typical. Ramani Devi et al. (2021) highlighted the general population's lack of understanding of the symptoms associated with endometriosis, which forms an obstacle to receiving prompt medical intervention and contributes to delays in diagnosing and effectively managing the condition (Ramani Devi et al., 2021).

Ramani Devi et al. (2021) suggested that an awareness program should be provided to all female students at the start of adolescence, but did not provide suggestions regarding what form such a program would take. Ramani Devi et al. (2021) also did not suggest educating men about endometriosis. Educating only women about endometriosis and not men might further contribute to the stigma surrounding endometriosis (Reinhardt & Eitze, 2023). Finally, Ramani Devi et al. (2021) did not explore the importance of training school staff on endometriosis; they thus failed to hold school staff accountable for lacking knowledge of a prevalent condition like endometriosis and failing to support their students with this condition. Although awareness campaigns are important for raising public understanding and support, it is crucial to conduct comprehensive research addressing the diverse needs of students with endometriosis.

Khan et al. (2022) conducted a study from 2017 to 2019 to evaluate the understanding of menstrual pain and endometriosis among a cohort of female undergraduate students, nursing students, and medical students aged 19 to 24 years in Japan, Thailand, Lithuania, and Iran. Khan et al. (2022) found that undergraduates had the lowest amount of information about menstrual pain and endometriosis. The prevalence rates of cyclical pain among students were found to be 15.5% (undergraduate students), 4.6% (medical students), and 3.8% (nursing students), respectively. More than half of the participants coped with their endometriosis-related pain by either tolerating it or using non-prescription medicines.

Khan et al. (2022) found that a comprehensive educational program, including group discussions and lectures, enhanced understanding of menstrual pain and endometriosis. Participants who took part in such a program demonstrated a 3% to 60% increase in correct responses to factual questions regarding menstrual pain and endometriosis. However, the way in which the questions on the survey were worded could lead to and introduce bias by signalling the correct answer. For example, one question in the survey was written as “Endometriosis is not easy to cure: do you know?” Participants may have inaccurately reported that they did know the answer; the question would have been better worded as “Is endometriosis easy to cure?” The survey included misinformation, as there is currently no cure for endometriosis.

A further potential weakness is that Khan et al. (2022) only collected quantitative data, and thus did not explore themes of possible stigma. For example, the researchers reported that the percentage of students who would visit a gynecologist if they were experiencing menstrual pain remained low even after they received education about endometriosis (3.0% versus 2.1% before and after psychoeducation). The reasons that participants would not be motivated to seek a gynecologist could have been explored by collecting qualitative data such as responses to open-ended questions.

A lack of education exists regarding endometriosis and menstrual health in the school environment, as these topics are typically not included in sex education curricula (Schmitt et al., 2022; Simpson et al., 2021). Harper et al. (2023) surveyed adolescents in the UK and Belgium, asking participants to identify which sex and reproductive health topics they had learned in school. Less than 5% of participants reported having learned about endometriosis in school. The Menstrual Health and Endometriosis (*me*) program, developed by Endometriosis New Zealand in 1996, aims to improve adolescent knowledge of menstrual health and endometriosis (Bush et al., 2017). The program is integrated into the New Zealand secondary school curriculum, targeting objectives related to personal health, physical development, relationships, and healthy communities. The *me* program is addressed to 14–18-year-old male and female students in co-ed and single-sex schools, and aims to identify menstrual symptoms, raise awareness of endometriosis, improve physical, emotional, and social well-being, protect future fertility, and remove social stigmas (Bush et al., 2017). Program educators undergo comprehensive training, to help engage teenage audiences, on topics including interactive presentation skills, youth health services, and the treatment, management, and understanding of dysmenorrhoea (menstrual pain), endometriosis, and persistent pelvic pain.

The initiative had an effect, as awareness of endometriosis among students in Canterbury and Marlborough (New Zealand) increased significantly over the course of 17 years. The proportion of students familiar with endometriosis was less than 10% in both regions in 1998 and rose to 32% in Canterbury and 41% in Marlborough by 2015. The study is pivotal because it explores the longitudinal impact of an education program amongst secondary students. Bush et al. (2017) hypothesized that the program could promote an earlier diagnosis of endometriosis. However, Bush et al. (2017) did not explore ways students could be supported in school. The overarching goal of the *me* program is to raise awareness of endometriosis and its symptoms by educating students on typical and atypical menstrual symptoms. While the *me* program has created a template for psychoeducation about endometriosis in schools, awareness programs do not provide comprehensive support to students who are experiencing symptoms of endometriosis (Bush et al., 2017).

Due to endometriosis symptoms' wide-ranging and changeable nature, healthcare providers may dismiss an individual’s complaints (Hays, 2020; Rowe et al., 2019). Diagnosis is difficult and may require surgery and other specialized services (Agarwal et al., 2019; Singh et al., 2020). Early detection can offer relief to individuals with endometriosis. However, individuals experience delays in receiving diagnosis and treatment, forcing them to live with physical, psychological, and social consequences into adulthood. Only seven studies have explored endometriosis in the school setting, and researchers have not conducted studies on the various types of in-school support that students with endometriosis may require. The current dissertation addresses the gap in the literature on in-school support needs of students with endometriosis.

In-school supports refer to interventions and services offered within educational environments to assist students in achieving academic, social, and emotional success (Bettinger et al., 2013). Typical in-school supports consist of tutoring programs, Individualized Education Plans, resource support, behavioural support, counselling services, social skills groups, health and wellness support, accessibility support, and family and community engagement (Bettinger et al., 2013). In-school support can facilitate the inclusion of students with disabilities in the curriculum, assist in stress management, address interpersonal concerns, and promote the development of acceptable social interactions and behaviours among students. Providing in-school services is essential for establishing inclusive and nurturing learning environments that enable each student to flourish (Bettinger et al., 2013).

Endometriosis in the School Setting

Given the effect endometriosis can have on quality of life, including higher rates of absenteeism and lower rates of productivity in adolescents and adults (Gallagher et al., 2018), the impact of the condition on school functioning should be explored. Students with health problems are more likely to have difficulty participating in school activities and attending classes, and they perform worse academically than healthy students, as physical discomfort can hinder concentration and cognitive function (Lum et al., 2019; Pinquart & Teubert, 2012; Shaw et al., 2015; Spernak et al., 2006; Thongseiratch & Chandeying, 2020). Students with endometriosis-related chronic pain report difficulties attending school, completing schoolwork, and participating in school activities (Brosens et al., 2013; Moradi et al., 2019). One 15-year follow-up study found that 8.7% (n=137) of individuals with endometriosis postponed or discontinued their education because of their symptoms (Fagervold et al., 2009). Painful menstruation has resulted in 12% of adolescents missing school or employment (Zannoni et al., 2014).

Chronic pain and other endometriosis symptoms can result in fatigue, making it challenging for students to maintain consistent energy levels and concentration (Li et al., 2020). Students may struggle to keep up with classwork, homework, and exams (Bilir et al., 2020; Dharshini, 2021; Hailemeskel et al., 2016). Pain and other symptoms may make it difficult to engage in extracurricular activities important to their well-being, such as sports (Tadese et al., 2021; Troìa et al., 2021); students may also struggle to maintain friendships, contributing to feelings of alienation (Troìa et al., 2021).

Due to the difficulties presented by endometriosis, students may experience increased tension, anxiety, depression, and feelings of isolation (Balci, 2022; Bodén et al., 2013). Endometriosis often necessitates medical consultations, therapies, and possibly even surgery. Medical requirements can interfere with students' academic schedules and necessitate effective time and responsibility management (Gupta et al., 2021; O'Hara et al., 2019, 2021). Despite the negative effect that endometriosis has on students' health and well-being, only three studies to date (Bodén et al., 2013; Gupta et al., 2018, 2021) have explored the experience of students with endometriosis in school settings. However, researchers have failed to address the development of different types of in-school supports for students with endometriosis.

Bodén et al. (2013) conducted a study in Sweden to examine the extent and nature of school healthcare services provided to adolescent girls and young women diagnosed with endometriosis during their secondary (ages 13-15) and upper secondary (ages 16-19) school years. Participants were surveyed on current age, age of menarche, and onset of symptoms, and open-ended questions were asked regarding their experience of seeking support in the school setting. Only participants who had completed their education within the last 10 years were included in the study. A cohort of 23 female participants completed the survey; results showed they had experienced school absenteeism due to their symptoms, with some having been absent for a few days and others up to 70% of the academic year. In addition, of the 23 participants, only five participants were satisfied with the support provided by school nurses. While the five satisfied participants reported that nurses provided medication, empathetic consultation, and pain relief, such as transcutaneous electric neural stimulation (use of electricity to activate nerves to decrease pain), the remaining participants reported that they had not received the expected level of communication or treatment. Participants were also dissatisfied with the feedback given by the nurses, who were perceived as doubting their symptoms and not taking their concerns seriously. Some women reported their problems had been dismissed and not addressed at an early stage, indicating a need for improvement in services.

Bodén et al. (2013) suggested that school nurses could help young women be more comfortable discussing their intimate body functions, contributing to an earlier diagnosis and adequate support. Specifically, school nurses could discuss normal body functions associated with menstruation during group discussions, which can help young women bring up their experiences of menstruation during one-on-one discussions. Bodén et al. (2013) also suggested that school nurses could increase cooperation within the school and youth healthcare system by providing women with necessary services and increase awareness of the condition among school staff using age-appropriate materials such as pamphlets about endometriosis.

Bodén et al. (2013) provided important recommendations to highlight the role school nurses could play in supporting students with endometriosis. A strength of their study is that the researchers used a mixed-methods approach to explore participants' experience with school nurses; the inclusion of open-ended questions provided a more in-depth understanding of participants' experiences. However, Bodén et al. (2013) did not explore other school-based interventions to accommodate students with endometriosis.

School nurses can actively evaluate and treat the symptoms of endometriosis within the school setting. For example, school nurses can dispense medication, offer solutions for managing symptoms, and continuously evaluate the health of students. However, access to school nurses is limited (Gratz et al., 2023). In a survey, Willgerodt et al. (2018) reported that a third of schools do not have full-time school nurses. Several countries are currently facing a school nurse shortage (Gratz et al., 2023; Sanders et al., 2019). Exploring other school-based interventions that would benefit students with endometriosis is therefore crucial.

Another potential weakness of Bodén et al.'s (2013) study is that none of the participants were current students; thus, participants had to reflect on when they were in secondary school. Since the participants may have difficulty recalling events, obtaining feedback from current students could provide additional insight (Watson & McKinstry, 2009). In addition, because endometriosis is a condition with onset as early as elementary school age and can continue to affect an individual for the rest of their lives, it is important to explore the experiences and needs of students in different school settings (elementary, high school, college, and university). Finally, only 23 participants completed the survey. The results may not be generalizable to other students with endometriosis, given the small sample size.

Research has shown that social context can affect an individual's experience with endometriosis. Gupta et al. (2018) conducted a focus group study with male and female adolescents in New York City to investigate how perceptions of endometriosis can vary across social settings (e.g., home, school, peers) and how endometriosis symptoms can affect an individual's life. Groups of participants were presented with vignettes about an adolescent female with a specific set of symptoms suggestive of endometriosis in different social contexts, as well as discussion questions. Participants were asked to report factors they believed would influence the adolescent's experience with endometriosis in each context. Participants highlighted that the adolescents described in the vignettes might experience distrust of community health care providers, societal stigmatization of menstruation, peer stigmatization of endometriosis symptoms, and distrust of school health care providers. Participants also noted that the adolescents described in the vignettes may face a lack of endometriosis knowledge among peers and school personnel, inequitable gender norms, the invisibility of endometriosis symptoms, and the presence of negative attitudes about youth sexual activity that may hinder open communication between adolescents and their parents about painful sexual experiences (a common endometriosis symptom).

Interestingly, Gupta et al. (2018) did not directly explore the lived experiences of students with endometriosis, as none of the participants in the study had the condition; rather, participants had to put themselves in the position of a student with symptoms suggestive of endometriosis by reading vignettes. While Gupta et al. (2018) raised important concerns regarding stigma affecting students with endometriosis, they did not explore school-based interventions that would be beneficial for students. Consistent with other studies, Gupta et al.'s (2018) results suggest that stigma is a common experience for individuals with endometriosis; in other studies, up to 90% have reported being stigmatized, dismissed, and ignored at least monthly (Kocas et al., 2023; Seear, 2009; Sims et al., 2021). Future research should explore students’ needs and de-stigmatisation campaigns.

Gupta et al. (2021) conducted another study examining the frequency of social, academic, and work disruptions experienced by 468 college-aged (18 to 24 years of age) women with endometriosis symptoms and explored the relationship between disruptions and anticipated stigma. The survey found that symptoms suggestive of endometriosis were a frequent cause of disruption, including social (82.7%), academic (58.5%), and work disruptions (34.4%). Having experienced any of these forms of disruption was associated with a higher likelihood of anticipating stigma (discrimination, prejudice, or stereotyping directed towards the subject). However, Gupta et al. (2021) highlighted that more research is needed, as there is an unclear understanding of the relationship between life disruptions and anticipated stigma. The use of a mixed-methods approach may have provided more insight into the interaction between life disruptions and anticipated stigma. While Gupta et al. (2021) recruited participants with symptoms consistent with endometriosis, the diagnosis was not confirmed; it thus cannot be determined if the disruptions were due to endometriosis or other conditions with similar symptoms (Gin et al., 2022). Gupta et al. (2021) did not explore which types of interventions could be implemented at the school level to support students with endometriosis. Furthermore, they did not provide recommendations regarding how to reduce life disruptions and anticipated stigma for students who may have endometriosis.

Thus far, researchers have not explored different types of in-school supports and interventions for students with endometriosis. Implementing school-level interventions to assist students with endometriosis is crucial, as it has potential implications for early diagnosis, reducing stigma, improving academic performance and health literacy, and creating a supportive school environment (Mackenzie & Cohn, 2023; Zannoni et al., 2014). Timely interventions can help treat symptoms and prevent disturbances in academic and social settings (Bush et al., 2017; Shadbolt et al., 2013). Additionally, in-school support has the potential to diminish social disapproval and misconceptions, enhance scholastic achievement, foster knowledge about health, bolster psychological well-being, establish a nurturing atmosphere, and facilitate collaboration with medical professionals (Seear, 2009; Sims et al., 2021).

Implementing interventions to enhance awareness and understanding among individuals in the school community can foster the development of a more nurturing atmosphere (Randhawa, 2023; Simpson et al., 2021). Additionally, in-school support can help students stay involved in their education despite experiencing challenges with their health (Lum et al., 2019; Shaw et al., 2015). School-based interventions are needed to meet the needs of students with endometriosis and foster their academic achievement, health, and overall well-being within the school community (Gupta et al., 2021). Research on the gaps in services and needed interventions for students with endometriosis can create data for future initiatives, such as developing best practices, evaluating effectiveness, educating stakeholders, advocating for policy changes, and empowering students with endometriosis and their families.

Theoretical Frameworks

The current dissertation uses three different frameworks to conceptualize and develop a survey that explores the experiences of students with endometriosis and their beliefs and experiences with in-school support services. The chosen frameworks include gender theory, biopsychosocial theory, and the social-ecological model of disability, each of which is discussed in detail below.

Gender Theory

Gender theory can illuminate the social and cultural aspects of endometriosis, including its complicated diagnostic process. Gender theory emerged as a distinct academic field in the 20th century and has been influenced by sociology, anthropology, psychology, and philosophy (Beauvoir, 2023; Butler, 1999; Friedan, 2010). Gender theory, often known as gender studies, is an interdisciplinary field investigating the social, cultural, and political dimensions of gender. Social class and ethnicity are also considered dimensions of intersectionality beyond gender.

Gender theory investigates how gender roles, identities, and disparities are produced, perpetuated, and challenged (Annandale, 2013; Hare-Mustin & Marecek, 1988). The theory also highlights how women’s health issues, such as endometriosis, are frequently medicalized and pathologized, and how cultural expectations and conventions about femininity, reproduction, and women’s health affect the experience of those with such conditions. Gender theory explores how medical institutions may overlook women’s pain or other symptoms, resulting in delayed diagnosis, insufficient treatment, and a lack of research funding (Annandale, 2013; Hammarström & Hensing, 2018).

Endometriosis can affect anyone born with a female reproductive system; it has thus become associated with women’s gender identity (Culley et al., 2013; Mulé et al., 2009; Young et al., 2020). The discrimination against women in society results in a lack of research, diagnosis, and treatment for diseases and illnesses affecting women (Pinn, 2019; SteelFisher et al., 2019). Gender discrimination and the gap in healthcare research have negative consequences for girls, women, and other individuals born with female reproductive organs (Hoffmann & Tarzian, 2001). Gender theory provides an account of how gender stereotypes influence women’s health and how bias may go unrecognized. For example, the stereotype that women tend to exaggerate their issues could result in dismissing health concerns (Chen et al., 2008; Samulowitz et al., 2018).

McSweeney et al. (2005) discovered that some healthcare providers perceived female patients to be “time wasters,” dismissing specific symptoms as “irrelevant” and treating women patronizingly during consultations. Furthermore, women were told that they were “exaggerating” or that their symptoms were “all in their heads.” The condescending comments reflect stereotypes of women as attention seekers or hysterical hypochondriacs (Samulowitz et al., 2018).

A sociopolitical and cultural context is necessary to analyze the role of gender, as gender does not exist in a vacuum. Patients are treated differently based on their sex and gender, and male and female physicians behave differently, which can shape patients’ experiences (Maestre et al., 2021). Gender theory highlights the need for qualitative data in the current dissertation to explore the lived experiences of students with endometriosis.

Biopsychosocial Theory

The biopsychosocial theoretical framework is used in research involving chronic pain and diseases. The framework suggests that biological, psychological, and social interventions are more likely to be successful than interventions focused on one factor (Borrell-Carrió et al., 2004; Gatchel et al., 2007). The biopsychosocial model was first conceptualized by George Engel (1977). Fava and Sonino (2017) reported that Engel was motivated to create the biopsychosocial model, as he thought the biomedical model objectified individuals with an illness and ignored potentially important aspects of a patient’s emotional and social context.

Previous researchers have suggested that a biopsychosocial theoretical framework is the most suitable when working with individuals with chronic pain, as it affects all aspects of life (Berterö et al., 2019; Darnall et al., 2017; Gatchel et al., 2007; Liossi & Howard, 2016). Viewing endometriosis through a biopsychosocial lens acknowledges the experience as complex and multidimensional, involving intertwined biological, psychological, and social dimensions influencing the individual’s development and functioning. The current dissertation collected data on how endometriosis affected students across various aspects of life (i.e., psychosocial, sexual, employment, education, lifestyle, and fertility).

Social-Ecological Model of Disability

The current dissertation is further grounded in the social-ecological model of disability, complementing the biopsychosocial theoretical framework. In this model, disability is defined as a mismatch between a person’s competencies and the demands of settings and activities associated with participating in society (Shogren et al., 2018). A social-ecological model focuses on people’s strengths and support needs (Thompson et al., 2016). The goal is to determine what support the individual with a disability needs to successfully participate in the environment and activities (Shogren et al., 2018; Wehmeyer, 2013). Supports are resources and strategies that help promote an individual’s development, education, interests, and personal well-being (Wehmeyer, 2013). Supports include environmental modifications (e.g., removing barriers to access and participation) and efforts to mitigate discriminatory environmental demands, such as technological support to address environmental inaccessibility.

Endometriosis can affect individuals’ ability to successfully engage with their environment by creating a mismatch between their ability and the needs of their environment (e.g., attending work/school, completing schoolwork or chores). Providing support for individuals with endometriosis could alleviate the mismatch. For example, individuals with endometriosis can be given a flexible schedule or the possibility of working from home to diminish the demands of attending work (Roomaney & Kagee, 2016; Stewart, 2019). Thus, a social-ecological model of disability is crucial in understanding how to support someone with a condition like endometriosis.

The social-ecological model of disability is divided into three components: personal characteristics and competencies, environmental factors, and support needs (Shogren et al., 2018). Applying the model explores various factors influencing human functioning, including personal characteristics (e.g., gender, race, age) and competencies (e.g., intellectual functioning, health conditions). Another key component of the model is the emphasis on examining possible environmental factors (e.g., physical, social, and attitudinal) that impact human functioning.

According to the model, appropriate support services can be identified only by understanding the demands present in an individual’s life. A social–ecological model assumes that people with disabilities are members of community environments, and, as such, deserve support to enable their full participation, self-determination, and quality of life in each environment (Shogren et al., 2018).

The current dissertation takes a biopsychosocial and social-ecological approach to understanding in-school support services for individuals with endometriosis, meaning the dissertation targets one social environment (school) in its analysis of the physical, psychological, and social support required to promote the full functioning of individuals with endometriosis. Gender theory contextualizes the gendered forms of stigma and dismissal that students may experience. In Study 2, participants were asked to complete the Endometriosis Impact Questionnaire (Moradi et al., 2019), which consisted of six dimensions: physical and social well-being (dimension 1); sexual and intimate relationships (dimension 2); fertility (dimension 3); finances and employment (dimension 4); education (dimension 5); and lifestyle (dimension 6). The dissertation adapts the social-ecological model of disability designed for individuals with intellectual disabilities (Schalock et al., 2010) by exploring the in-school support students (and former students) deemed necessary, as well as the support received.

By comparing the in-school support services students with endometriosis report needing with the types of support they have received, the researchers obtained information on the gap in services. Participants were encouraged to complete open-ended questions about their experiences of having endometriosis symptoms in school. Gender theory helped to conceptualize and provide a framework to understand the negative experiences and discrimination students with endometriosis face.

Scoping Review and Survey

School-aged individuals with endometriosis spend most of their days in educational settings, and endometriosis-related pain can impede school attendance, academic performance, and involvement in social activities (Seear, 2009). However, researchers have not yet extensively explored how schools support or could support students with endometriosis (Gupta et al., 2018). To our knowledge, only seven studies have explored endometriosis in the school setting. The focus of research has been on raising awareness of endometriosis in this setting, and while this is important, it is also crucial for schools to meet the needs of students who suffer from the condition.

The overarching goal of the current research is to understand the needs and experiences of students with endometriosis across Canada within an educational context. Providing in-school support for students living with endometriosis may improve their pain management, emotional well-being, and overall quality of life (Shaw et al., 2010, 2015). The primary objective of the dissertation is to improve in-school resources, potentially facilitating early detection and intervention measures. Furthermore, as late endometriosis detection affects an individual’s capacity to work and augments the cost of fertility treatment, early detection has positive economic implications for both the individual and the healthcare system (Fuldeore & Soliman, 2017; Soliman et al., 2017).

The research objectives were: (a) to investigate the available literature addressing current in-school support services (educational and otherwise) for individuals living with chronic pain; and (b) to increase understanding of the needs of students living with endometriosis. The dissertation comprises two studies. Study 1 is a scoping review of the available literature addressing in-school support to promote the learning of students living with chronic pain and draw inferences concerning in-school support services beneficial to students with endometriosis, as there is insufficient literature on supporting students with endometriosis in the school setting and as chronic pain is one of the most common symptoms for individuals with endometriosis. The possibility of conducting a scoping review on in-school supports for students who experience other symptoms like endometriosis, such as heavy bleeding, was considered; however, the research on students who experience heavy bleeding in a school setting is limited. Furthermore. conducting a review on symptoms such as heavy bleeding may not be as generalizable to the population of students with endometriosis, as chronic pain is a more common symptom of endometriosis than heavy bleeding (92.5% vs 75.0%; Hunsche et al., 2023). Study 1 was conducted as a part of a comprehensive examination and has been submitted for publication. In contrast, Study 2 explored the experience of students with endometriosis (former and current students) to better understand their in-school needs through a survey regarding their background, beliefs, and experiences with in-school support services, and the overall impact endometriosis has had on their lives.

Chapter 3: Scoping Review (Study 1)

Submitted for publication

In-School Supports for Students with Chronic Pain
A Scoping Review

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Abstract

Objectives: Students with chronic pain have reported difficulties attending school, completing schoolwork, and participating in school activities. The current scoping review aimed to understand and synthesize the types of in-school supports for students with chronic pain and to understand the barriers to or facilitators of implementing such supports.

Methods: The databases were searched using selected keywords. Articles were analyzed using a descriptive numerical summary analysis and a qualitative thematic analysis, following Arksey and O'Malley's scoping review framework. A total of 32 articles comprising 28 studies were included.

Results: The scoping review highlighted six themes of in-school supports: knowledge, collaboration, in-school therapy, consulting school health professionals, building positive relationships, and academic accommodations. The in-school supports were reported for students across various types of chronic pain, suggesting that the in-school supports may be universal. Barriers to implementing in-school supports included insufficient school resources and a need for chronic pain education.

Conclusion: The findings of the current scoping review have the potential to inform school staff and families of the types of support that could benefit students with chronic pain. However, randomized control trials should be conducted on the efficacy of in-school supports, as more evidence-based research for students with chronic pain needs to be undertaken.

Keywords: chronic pain, in-school supports, school interventions, school

The *International Association for the Study of Pain* has defined pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (International Association for the Study of Pain, 2017). Chronic pain, however, is defined as persistent pain experienced for three months or longer (Treede et al., 2015). Approximately 30% of the global population reports chronic pain (Jackson et al., 2016). According to Friedrichsdorf et al. (2016), chronic pain can affect individuals of any age, and the authors estimate that up to 20 to 35% of children and adolescents experience chronic pain worldwide. Individuals may experience chronic headaches, migraines, pelvic pain, abdominal pain, or other pain types (King et al., 2011).

The biopsychosocial theoretical framework is used in research involving chronic pain and diseases. The framework posits that interventions including biological, psychological, and social factors are more likely to be successful than one-factor (i.e., biological) interventions (Borrell-Carrió et al., 2004; Gatchel et al., 2007). The biopsychosocial model was first conceptualized by George Engel (1977). Engel was motivated to create the biopsychosocial model. He thought the biomedical model objectified individuals with illness and ignored potentially essential aspects of a patient’s emotional and social context (Fava & Sonino, 2017). Previous researchers have suggested that a biopsychosocial theoretical framework is the most suitable for working with individuals with chronic pain, as it affects all aspects of life (Berterö et al., 2019; Darnall et al., 2017; Gatchel et al., 2007; Liossi & Howard, 2016). Various strategies are needed to treat pain based on its biopsychosocial model. A multipronged approach, known as the "3P" approach, combines psychological, physical, or pharmacological. Children and youth with chronic pain can benefit from this approach in several ways, such as improving their mood, attending school, participating in activities, moving more easily, sleeping better, and spending time with their family and friends (Palermo & Law, 2015). When a child or youth exhibits symptoms of depression or anxiety, they are more likely to report higher pain levels. Thus, it is essential to focus not only on improving the severity of pain but also on how to return to valued activities.

Chronic pain can negatively impact an individual's quality of life (i.e., satisfaction with life and health), resulting in reduced energy and mobility and altered dynamics (i.e., impacts the ability to contribute in their role and puts strains on relationships) with family and friends (Hunfeld et al., 2001; Logan, Engle, et al., 2012; Palermo, 2012). Inactivity and isolation are known side effects of chronic pain, which can lead to loneliness, sadness, limited capacity, or inability to work or complete tasks (Henry, 2008). Chronic pain can negatively influence relationships with friends, partners, and family members (Gold et al., 2009; Hunfeld et al., 2001; Palermo & Eccleston, 2009). Individuals with chronic pain are more likely to develop depression, anxiety, moodiness, and low self-esteem than individuals without chronic pain (Eccleston et al., 2004; Fine, 2011; Tegethoff et al., 2015). Dominick, Blyth, and Nicholas (2012) conducted a cross-sectional survey in New Zealand with 12,488 participants (15 years of age and over) on the relationship between chronic pain and mental health conditions. Anxiety and depression were related to experiencing chronic pain, especially for individuals with arthritis and neck or back pain. Furthermore, chronic pain can result in economic consequences, such as loss of employment and healthcare expenditures (Fine, 2011).

As chronic pain can afflict youth and young adults, students with chronic pain are likely to present in classrooms around the world (Perquin et al., 2000; Zhang et al., 2015). Van Dijk et al. (2006) reported that 57% of school children (9-13 years old) reported experiencing at least one recurrent pain, while 6% were identified as having had or currently having chronic pain. Students with health problems are more likely than students without health problems to have difficulties participating in school activities and attending class, and they often demonstrate poorer academic performance (Shaw et al., 2015; Spernak et al., 2006). By third grade, children with poor health were found to score, on average, 8.55 points lower than their healthy counterparts on the Peabody Picture Vocabulary Test-Revised (PPVT-R), a tool to assess verbal language ability and, on average, 7.79 points lower on their reading and 5.72 points lower on their mathematic skills as assessed by the Woodcock-Johnson Psycho-Educational Battery-Revised (WJ-R), a tool to assess academic achievement (reading writing, and mathematics) (Spernak et al., 2006).

Logan et al. (2009) examined school functioning in adolescents with chronic pain presenting to a tertiary care pain program. In many cases, adolescents miss at least one day of school a week, experience a decline in academic performance, or report that pain interferes with school success. In a school-based sample, Vervoort et al. (2014) found that pain is associated with higher school absenteeism, higher pressure at school, and lower satisfaction. Serbic et al. (2021) conducted a scoping review on university students with chronic pain, revealing that students have poorer psychological, social, and academic functioning and quality of life than students without chronic pain. There were 18 studies included in the scoping review, but only two investigated the relationship between pain and academic performance. One study found that compared to students without chronic pain, students with chronic pain reported experiencing higher interference with schoolwork due to the effects of pain (Thomas et al., 1992). A second study found that among university students, more interference with academic functioning was predicted by higher levels of pain and disability (Serbic et al., 2020). Using the most recent United States national data, Groenewald et al. (2020) conducted a study to determine the association between chronic pain and school functioning among school-aged children (6-17 years). In multivariate analyses, children with pain were likelier to have low school engagement, be chronically absent, have school-related problems, repeat a grade, and be diagnosed with a learning disability. Matthews (2002) conducted a study with adolescents with chronic pain, which revealed that chronic pain had a negative impact on the school attendance of adolescents (absences ranging from 6 months to 3 years) and that adolescents perceived that having chronic pain disrupted their ability to interact with their peers.

Furthermore, Alsaggaf and Coyne (2020) conducted a systematic review of the impact that chronic pain has on adolescents' school functioning, which revealed that chronic pain has a negative influence on adolescents' school attendance, academic performance/achievement, academic competence, physical activities, and social functioning. However, four studies reported that students with chronic pain performed better academically than their healthy peers. Thus, there is a need for future research on the impact of adolescents' chronic pain on the full dimensions of school functioning.

The suggested treatments and interventions existing for youth with chronic pain, typically within a clinic or hospital setting, include pain education programs, acceptance therapy, and cognitive behavioural therapy (Serbic et al., 2021). However, several researchers have highlighted the need for school staff (e.g., teachers, principals, nurses, and school psychologists) to support students with chronic pain by being informed and involved in students' chronic pain management plans (Coakley & Wihak, 2017; Jones & Salamon, 2019; Palermo, 2012).

Unfortunately, school staff report being ill-equipped to manage students' chronic pain due to insufficient training, time, and collaboration with health professionals (Boutilier & King, 2013). Given the invisibility of chronic pain symptoms and a lack of education, teachers may dismiss students who report pain (Castarlenas et al., 2015). Students perceived support (i.e., increased sense of competence and autonomy) from teachers can act as a protective factor against the negative impacts of students’ chronic pain, particularly poor academic performance, school dropout and low school satisfaction (Vervoort et al., 2014). However, dismissal or disbelief of students’ chronic pain can increase the likelihood of students developing anxiety and depression and having difficulty attaining academic standards of performance (e.g., school attendance and schoolwork deadlines; Khan et al., 2015; Logan et al., 2007). Moreover, students experiencing chronic pain due to an unclear cause or condition may be even more at risk of judgment and dismissal (De Ruddere et al., 2016; Wakefield et al., 2018).

Providing in-school supports (i.e., services, resources, academic accommodations, and practices available in schools) for students with chronic pain may improve school functioning (e.g., school attendance and academic performance), pain management and prevention (Jones & Salamon, 2019; Logan, Simons, et al., 2012), and support students’ mental health (Shiu, 2010; Serbic et al., 2021). In-school supports could, for example, include academic accommodations, peer-support groups, pain management programs, and formalized collaboration between school staff, students and families, and clinicians (Wehmeyer, 2013). Identifying in-school supports that benefit students with chronic pain may be the first step towards developing support for students with endometriosis, a complex chronic pain condition with unclear etiology. However, synthesized literature on in-school support for students with chronic pain needs to be improved. Given the negative impacts of chronic pain on students, a scoping review of the types of in-school supports that could benefit students with chronic pain has been conducted. The current scoping review is part of a more extensive study to understand how students with endometriosis can be supported. A list of in-school support measures extracted from the scoping review will be included in a survey where participants with endometriosis will be asked whether an in-school support process (e.g., receiving instruction/information on healthy menstruation and endometriosis at school) is necessary and whether they have received such in-school supports.

The present scoping review aimed to search and summarize the literature on supporting students with chronic pain in the school setting. Therefore, the objectives of the current scoping review are (a) to identify the types of in-school supports implemented for students with chronic pain and (b) to understand the barriers and facilitators affecting the implementation of in-school supports.

Methods

A scoping review of the relevant quantitative and qualitative studies was conducted following Arksey & O'Malley's (2005) original five-stage scoping review framework, and more recent recommendations (i.e., to conduct the literature search through an iterative process) proposed by Levac et al. (2010) and the Joanna Briggs Institute (JBI) methodology for scoping reviews (Peters et al., 2020)were applied to augment the rigour of the findings. Arksey and O'Malley's scoping review framework aims to map all relevant literature to identify and synthesize the types of in-school support provided to students with chronic pain. The scoping review consists of five stages: (a) identifying the research question; (b) identifying relevant studies to answer each specific topic within the research question; (c) study selection; (d) charting data; and (e) summarizing and reporting of the results. The concepts, target population, and outcomes of interest from the existing evidence were reviewed and drafted into two main research questions for the present scoping review. The following research questions are being investigated to address the current objectives: (a) What in-school supports are provided to students with chronic pain? Moreover, (b) What are the barriers to and facilitators of implementing the reported in-school supports?

Identifying Relevant Studies

A scoping review of the existing literature on in-school support for students with chronic pain was conducted by consulting Medline, PsycINFO 1987-Present (Ovid), ERIC (ProQuest), and SCOPUS databases using selected keywords. The search time frame is from the earliest possible date within each database to gather the most information, from 1900 up to 2021. The search terms used during the search included:

1. *chronic pain/ or chronic illness/ or pain/*
2. *school* or boarding schools/ or charter schools/ or college/s or elementary schools/ or graduate schools/ or high schools/ or institutional schools/ or junior high schools/ or middle schools/ military schools / or nongraded schools/ technical schools/*
3. *school-based intervention,*
4. *school environment/ or academic environment/ or college environment/*
5. *2 or 3 or 4*
6. *1 and 5*

Keywords and eligibility criteria for the literature search were selected in consultation with McGill University’s librarian liaison to the Department of Educational and Counselling Psychology. The search terms were located after reviewing the indexing of 15 articles on supporting students with chronic pain within the school setting. The databases were searched on July 15, 2019, then an updated search on October 19, 2020, and the entire collection of articles was extracted, assembled and de-duplicated in Endnote X9 software.

Study Selection

The first, second, and third authors conducted the screening and data extraction process; they will be referred to as reviewers. The articles were divided amongst the three reviewers so that two reviewers screened all articles, and discrepancies were discussed until an agreement was attained. The research questions informed the eligibility criteria. During the first level of screening, titles and abstracts were screened to determine whether the articles met the inclusion criteria: (a) the article was peer-reviewed, (b) the article was written in English or French (due to limited resources for translation), (c) the author(s) included primary source data, (d) the author(s) discussed in-school supports for students with chronic pain, and (e) the author(s) discussed students with chronic pain, either persistent or recurrent. Articles were excluded if (a) the author(s) did not explicitly refer to pain as being chronic, recurrent, or persistent; (b) the findings were based on secondary source data; and (c) the article was qualified as grey literature (e.g., news reports and dissertations). Quantitative, qualitative, and mixed-method studies were included to consider different aspects of understanding how to support students with chronic pain.

The first-level screening was accomplished using Rayyan software (2016), a free, user-friendly online application that facilitates the screening of abstracts and titles. Rayyan software allows each reviewer to label an article as included or excluded. Rayyan blinds reviewers to each other’s responses until the selection process is complete; then, reviewers can remove the “blinding” process. The Rayyan software highlighted in red the articles that were in conflict. The reviewers then met to discuss their results and resolve discrepancies regarding which articles to include and exclude in the scoping review.

Data Extraction and Analysis

The extracted data was charted to determine trends in the results more easily. The data extraction was informed and adapted from Peters et al. (2020) for all studies (qualitative, quantitative, mixed-methods). The author(s), title, publication year, perspective, pain type, location, study design, the purpose of the study, and reported in-school supports (including their reported barriers and facilitators) were extracted from the included articles. Data extraction was completed independently by the first, second, and third authors, who compared extracted information to ensure consistency. Please see Table 1 for a description of the included articles. To articulate the scoping review results, two reviewers independently analyzed the data extraction chart and used thematic analysis to identify recurring themes in the data. Themes were established based on the frequency and the level of relatedness or independence of each recognized finding. Following this analysis, the reviewers met to compare their list of themes and worked collaboratively to collate, organize, and refine a finalized list of thematic results. Each article was charted independently by each reviewer; two reviewers would read each article and meet to verify the accuracy of the extracted data.

Consistent with Levac et al. (2010) recommendations, a descriptive numerical summary and qualitative thematic analysis were conducted. The descriptive numerical analysis summarized extracted information through numbers (i.e., percentages). To generate themes, a qualitative thematic analysis of in-school supports discussed was completed through data categorization, following Braun and Clarke's (Braun & Clarke, 2006) stages of thematic analysis, which, in short, consisted of generating codes and identifying themes. Two reviewers read through the in-school supports reported in each article and identified meaningful themes. The reviewers met virtually to compare their extracted themes. The results were then synthesized and interpreted according to the research objectives and questions.

Results

At first, 1,765 articles were extracted from the databases. An updated database search was conducted in October 2020 to determine whether any new articles had been published since the initial search. After this second search, 215 articles were extracted from the databases. In total, 1,876 articles were screened after de-duplication. During the second screening level, the entirety of each of the chosen 98 articles was reviewed, re-applying the inclusion and exclusion criteria to confirm eligibility.

Furthermore, the reference lists of each eligible article were reviewed to determine if any other relevant articles had yet to be retrieved during the literature search. Finally, 32 articles comprising 28 studies were included (four were based on the same data) and deemed eligible for analysis after completing the second screening (see Figure 1). The included articles were not critically appraised, as the purpose of the scoping review is to provide an overview of the available research evidence (Munn et al., 2018). Each category addresses the scoping review's overarching aims (i.e., supports in place, barriers, and facilitators). The findings of the current scoping review are presented as a descriptive numerical summary analysis and then as a qualitative thematic analysis. Next, based on the results of the analyses, facilitators of and barriers to in-school supports are also discussed.

Characteristics of the Included Studies

The most common study designs were quantitative (47%) and randomized controlled studies (28%), followed by qualitative designs (12.5%), and finally, mixed-method designs (12.5%). Some authors (19%) discussed the perspectives of various stakeholders (i.e., students, families, teachers, therapists, clinicians) regarding in-school supports for students with chronic pain, but most researchers (81%) studied the perspective of one stakeholder, with the most common perspective being that of students (75%). Finally, headaches were the most frequently reported type of chronic pain (32%). The educational settings analyzed were typically elementary to high school (96%), with only one study exploring university students' experiences (4%). Some studies aimed to determine whether a school-based intervention (i.e., therapy, education programs) or tool would effectively treat a specific type of chronic pain or educate students and staff about chronic pain (39%). Most studies (61%) were explorative in that the research aimed to analyze the perspectives and experiences of students with chronic pain and the various stakeholders involved with them.

Thematic Analysis

A thematic analysis was conducted with the in-school supports discussed in the 32 included articles. Several themes were identified, including knowledge, building positive relationships, consulting school health professionals, academic accommodations, therapy in schools, and collaboration. The following section will describe these individual themes in depth.

Knowledge. All included articles reported a theme of knowledge (i.e., information acquired through education). The authors of the included articles discussed information provision and the implementation of education programs regarding chronic pain and its management. Nilsson, Johnson, and Adolfsson (2016) suggested that transferring knowledge concerning a student’s chronic pain between health professionals and school staff is essential to ensure that stakeholders in the students’ lives are informed and work together to support the student.

Different types of educational programs that were implemented in schools were identified, such as the *Headache Tools to Stay in School*, the *Ergonomic Education Program*, and the *Pain Neuroscience Education Program* (Andias et al., 2018; Lazdowsky et al., 2016; Sellschop et al., 2015; Wager et al., 2018). The education programs implemented in schools were directed toward school staff or students. The student programs were designed to educate students with chronic pain and the general student population about personal practices that can be used to prevent and manage pain. For example, Andias, Neto, and Silva (2018) implemented a pain neuroscience education program for students with chronic idiopathic neck pain. In four sessions, students were instructed on the neurophysiology of pain, the differences between acute and chronic pain, and the brain’s ability to moderate pain experiences. Students were also taught how to perform safe neck exercises on their own. Overall, the researchers indicated that the exercises improved muscular endurance and reduced students’ perceived pain intensity in combination with pain neuroscience education.

The education programs for school staff were designed to educate staff about chronic pain and how to support students. For example, King, Boutilier, and MacLaren Chorney (2018) suggested that the usage of an e-health website called “Teaching Educators About Chronic Pain Project” (TEACh-Pain) for teachers would provide teachers with information on chronic pain and in-school support (i.e., classroom adaptations, facilitating the transition back to school, and relaxation). Teachers, parents, and students reported that such a tool would benefit teachers, as students and families reported that teachers had insufficient knowledge concerning chronic pain.

The lack of knowledge regarding chronic pain was recognized as a barrier to implementing in-school support. Teachers and school nurses had insufficient knowledge about chronic pain to help students in need (Bodén et al., 2013; Deacy & Morrison, 2015; Logan & Curran, 2005; Sellschop et al., 2015; Solé et al., 2018; Youssef et al., 2007). Healthcare professionals at the school level reported misconceptions and negative perceptions about chronic pain, which likely contributed to their misperceptions that students with chronic pain are less competent than healthy students or that students with chronic pain may lie about their pain (Solé et al., 2018). In addition, teachers and school nurses reported having insufficient information on the types of in-school supports that could be provided for students with chronic pain (Taras & Brennan, 2008).

Education (i.e., psychoeducation) was typically included as a first step in the therapeutic interventions for students with chronic pain so that students could learn what chronic pain is and how they can manage their pain.

Therapy in Schools. Another theme that emerged when synthesizing the in-school supports was the provision of in-school therapy to aid students in pain management (Larsson, Daleflod, et al., 1987; Larsson et al., 2005; Larsson, Melin, et al., 1987; Larsson & Melin, 1986; Passchier et al., 1990). Therapy was frequently discussed in the case of students with chronic headaches; however, Larsson et al. (2005) reported that students with different kinds of chronic pain would benefit from therapy in schools. All five articles reported that the therapy provided to students was based on cognitive behavioural therapy (CBT). A study by Larsson et al. (2005) included randomized controlled trials of 288 students from 10 to 18 years of age who experienced frequent headaches. Students were assigned to either therapist-administered relaxation, self-help (e.g., recording headaches in diaries), attention-control (e.g., group discussions on pain, education on pain, and being told to relax without being given any techniques), or school nurse-administered relaxation. Relaxation training for students consisted of education about headaches and relaxation, providing relaxation training techniques, and opening communication channels between students and school staff about pain.

Overall, students participating in relaxation therapy, mainly therapist-assisted relaxation, reported significant reductions in both the number of days that students experienced headaches and the intensity of their headaches. Barriers to providing therapy in schools were school absenteeism and dropping out of therapy, which Larsson et al. (2005) suggested were due to participants being less motivated to invest time and effort in treatment.

Building Positive Relationships. Several authors also discussed school staff creating positive relationships with students who experience various types of chronic pain and students developing a positive relationship with professionals (Adolfsson et al., 2018; Larsson et al., 1987; Larsson & Zaluha, 2003; Nilsson et al., 2016; Vaičiūnas & Šmigelskas, 2019; Vervoort et al., 2014). School health professionals reported that one way to create a positive relationship with students was by using humour and lay language that students can understand (Adolfsson et al., 2018). Moreover, Larsson and Zaluha (2003) reported that teachers should be supportive in their discussions with students with chronic pain and encourage students to continue working hard and doing their best despite the difficulties that they experience. Furthermore, students with chronic pain reported favouring teachers whom they perceived as supporting their sense of competency and autonomy and who provided them with appropriate support and feedback on their performance (e.g., encouragement regarding the work done and discussion with the student to find the best ways to help; Vervoort et al., 2014).

Academic Accommodations. Frequently reported academic accommodations consisted of providing students with chronic pain with minor to moderate in-school supports, such as using assistive devices (e.g., ergonomic chairs that improve chronic back pain), release from the regular classroom (e.g., by sending the student to rest in the nurse’s office), assignment extensions, reduction in course expectations, modified grading systems, adjustments to the number of weekly class hours, a second set of books for home, and restricting a student’s classes to the first floor (i.e., to avoid stairs that can further irritate chronic pain such as musculoskeletal pain). Extensive accommodations were also mentioned, such as permission to drop classes, sizeable reductions in the number of weekly class hours, or, in some cases, fully homebound instruction (Adolfsson et al., 2018; Deacy & Morrison, 2015; King et al., 2018; Logan et al., 2007, 2008; Nilsson et al., 2016; Simons et al., 2010; Spencer et al., 2018). Such accommodations allow students with chronic pain to participate better in the classroom. According to Lazdowsky et al. (2016) school nurses reported several barriers that they faced in implementing in-school supports, such as a lack of space or resources (e.g., not having space for students to rest or not being able to give snacks to high school students) as well as that some tools like the “Headache Tools to Stay in School” were too long to be used quickly in a school setting.

Consulting School Health Professionals. School nurses (the most consulted school health professionals) were frequently the first line of contact for students with chronic pain. School nurses reported recommending students take a nap and drink some water or tea and would sometimes provide an over-the-counter medication such as ibuprofen or acetaminophen (Larsson & Zaluha, 2003; Lazdowsky et al., 2016). When necessary, school nurses reported making suggestions for academic accommodations as well.

Furthermore, Taras and Brennan (2008) reported that school staff also benefited from consulting a school physician. The roles of a school physician included communicating directly with a student’s education team, recommending appropriate school health services, producing individualized school health plans (ISHP), and educating school staff on specific health conditions. The roles also included creating a communication system that facilitates a partnership between school staff and students’ physicians, assisting families with navigating the health system and observing students in the school and classroom setting to recommend accommodations (Taras & Brennan, 2008).

Collaboration. The final commonly reported in-school support was collaboration. Collaboration, or home-school collaboration, is defined as relationships between families and schools. Families and staff work together to optimize a students' outcomes (e.g., behavioural, emotional) (Cox, 2005). The authors stressed the importance of collaboration among all stakeholders in optimizing the student's wellbeing, which would require school staff to collaborate with families and health professionals outside of the school setting. The theme of collaboration was made especially salient in articles with authors who had adopted a biopsychosocial approach (i.e., considering biological, psychological, and social factors and their complex interactions) when working with students with chronic pain (Deacy & Morrison, 2015; King et al., 2018; Logan et al., 2007).

Furthermore, the lack of collaboration was described as a barrier to providing students with adequate support. Collaboration would allow school staff to gain insight into the types of in-school supports that would benefit students (Deacy & Morrison, 2015; Solé et al., 2018). Teachers and school nurses reported wanting to collaborate with physicians. However, they encountered numerous barriers, including family opposition to collaboration with physicians, time limitations, legal concerns regarding privacy, or their school policy did not allow for such a collaboration to take place (Deacy & Morrison, 2015; Logan et al., 2007; Logan & Curran, 2005).

Discussion

As discussed in the introduction, students with chronic pain experience difficulties (health, psychological, sociological) in various facets of their lives, including their school experiences (Gorodzinsky et al., 2011; Kashikar-Zuck et al., 2013). Thus, providing in-school support may improve students' school functioning and overall wellbeing (Logan et al., 2008). The current scoping review aimed to explore the types of in-school supports provided to students with chronic pain and define the facilitators of and barriers to implementing such supports.

Most studies did not report a theoretical framework, which is troubling, as frameworks provide valuable assistance to researchers when developing study methodology (Adom et al., 2018). The theoretical framework currently recommended when working with individuals with chronic pain is the biopsychosocial approach, which involves considering interactions between biological, psychological, and social factors, as chronic pain can impact all aspects of an individual’s life (Darnall et al., 2017; Gatchel et al., 2007). Previous researchers have also suggested that a biopsychosocial theoretical framework is the most suitable when working with individuals with chronic pain (Berterö et al., 2019; Darnall et al., 2017; Gatchel et al., 2007; Liossi & Howard, 2016).

The goal of the first research question was to explore the types of in-school supports that were provided to students with chronic pain. After conducting a thematic analysis on reported in-school supports, six themes emerged: knowledge, building positive relationships, consulting school health professionals, academic accommodations, therapy in schools, and collaboration. The six themes were discussed across different types of chronic pain, perspectives, countries, and years. However, the current scoping review did not uncover evidence for which in-school supports are most important or beneficial. None of the articles conducted randomized control trials of diverse school supports to determine if one type of in-school support is more beneficial within the context of students with chronic pain. In addition, researchers of two articles reported providing students with academic accommodations without describing the accommodations, which could be because the studies were not focused on the types of accommodations provided to students but on students’ and staff’s experience with dealing with students’ chronic pain within a school setting (Logan et al., 2007; Spencer et al., 2018). Without knowing the specific academic accommodations received and provided, there is no way to know which accommodations were most helpful or to implement similar accommodations in other school settings.

Jones and Salamon (2019) reported a need for more research on school-based therapeutic interventions for students with chronic pain. The current scoping review results further highlight the reported gap in research. The reported in-school supports were similar to existing guidelines on supporting students with chronic health conditions (i.e., diabetes, asthma, cancer), such as providing academic accommodations, collaborating with home and school, and building positive relationships between students and school staff. However, guidelines to support students with chronic health conditions do not emphasize providing therapy to manage and cope with chronic pain (Clay, 2004; Shaw et al., 2010).

Furthermore, school nurses were the most frequently discussed school health professionals that supported students with chronic pain. However, other school health professionals, such as school psychologists, were absent from the review. School psychologists are trained to monitor students' progress, develop, and implement evidence-based interventions, and facilitate collaboration between school and home, all of which would be beneficial when working with students with chronic pain (Forlin, 2010).

The second research question explored the barriers and facilitators school staff experienced when implementing in-school supports. Few researchers discuss the facilitators of in-school supports; however, having information about the student's chronic pain was seen as beneficial to identifying supports for the students. School staff faced several barriers, such as limited resources, time, training, knowledge, collaboration, and rigid school policies and administration. The reported barriers are common among stakeholders in various school settings working with diverse students, for example, students with developmental disabilities (Bettinger et al., 2013; Langley et al., 2010; Reinke et al., 2011). Thus, the reported barriers might be systemic issues that will require changes at the system level (i.e., school board, school system, school policies) because government funding ultimately determines what resources school boards can distribute to schools (Killoran et al., 2013; O'Day & Smith, 2016).

Limitations

Grey literature (e.g., reports, theses and dissertations, conference papers) is recommended for inclusion in systematic and scoping reviews, as it can provide complementary data that are not found in traditional sources of information (e.g., journals and books) and reduce publication bias (i.e., only reporting certain types of research; Paez, 2017). However, as grey literature typically does not go through a peer-review process, the quality of the articles can vary greatly (Saleh et al., 2014). As a quality analysis was not conducted for articles included within the current scoping review, grey literature was excluded.

Also, only articles written in English or French were screened, and articles in other languages were excluded during the first round of screening. Translators were unavailable for the current scoping review; thus, articles written in other languages were excluded.

Implications

The findings of the current scoping review have the potential to inform school staff and families of the types of support that could benefit students with chronic pain. Implementing in-school supports (e.g., education programs, relaxation therapy, academic accommodations) for students with chronic pain could ameliorate their ability to cope with pain and reduce school absenteeism and, in turn, improve their wellbeing and academic learning (Andias et al., 2018; Boutilier & King, 2013; Larsson et al., 2005; Logan & Curran, 2005). A universal guide for supporting students with chronic pain could be designed using information gathered from the current scoping review by extracting the in-school supports discussed and assessing their efficacy. Based on the scoping review, it is recommended that a guide should include collaboration, increasing knowledge about chronic pain, and academic accommodations; for example, a guide for school staff could include psychoeducation about chronic pain (i.e., prevalence, causes and symptoms, and how chronic pain impacts students functioning). Staff would also be encouraged to implement class-wide interventions such as discussions regarding chronic pain, breathing, and stretching strategies that could benefit the entire class and increase their understanding of chronic pain. The next focus of the guide should be on how to support students.

School staff are recommended to collaborate with students, parents/guardians, and healthcare professionals to develop an in-school pain management plan for the students. When meeting to discuss pain management, students with chronic pain should have the opportunity to explain their chronic pain and what typically helps them. A list of some in-school accommodations revealed in this review could be listed in the pain management plan, and decisions would be made as to which if any, accommodations are needed. Examples include time extensions on tests, stop-the-clock breaks, frequent breaks, a quiet space for a pain flare up and any other supports that may be beneficial. Other ongoing supports, such as individual therapy and meetings with the school nurse, could be discussed. Finally, school staff should be made aware of signs to look out for in students in pain. *Solutions for Kids in Pain* (2021) have recently created a guide for teachers on supporting students with chronic pain, including the essential elements mentioned above. However, the current review also emphasizes the importance of collaboration with other school staff and health professionals.

Furthermore, school staff at each school setting could implement additional specific in-school supports (e.g., using an adapted chair that provides additional back support for a student with severe chronic back pain) that correspond to the individual needs of students attending their school (within a set of universal guidelines and standards). Randomized control trials should be conducted on the efficacy of in-school support, as there is a lack of evidence-based research on in-school support for students with chronic pain. Future researchers may want to explore reported barriers in more detail to put resources, systems, and policies in place to help resolve bureaucratic hurdles.

Conclusion

In conclusion, this scoping review identified emerging literature on several in-school supports for students with chronic pain. The review highlighted the need for additional research on the efficacy of in-school support for students with chronic pain in a school setting. Various supports could be implemented, such as information sharing, building positive relationships, therapy, academic accommodations, consulting school health professionals, and collaboration between school, home, and health professionals. However, only five articles explored the efficacy of in-school supports (i.e., relaxation therapy and psychoeducation program) for students with chronic pain. Evidence-based research is still needed to determine the type of in-school support most beneficial for students with chronic pain. Future research should include randomized control trials.

Ethical Approval

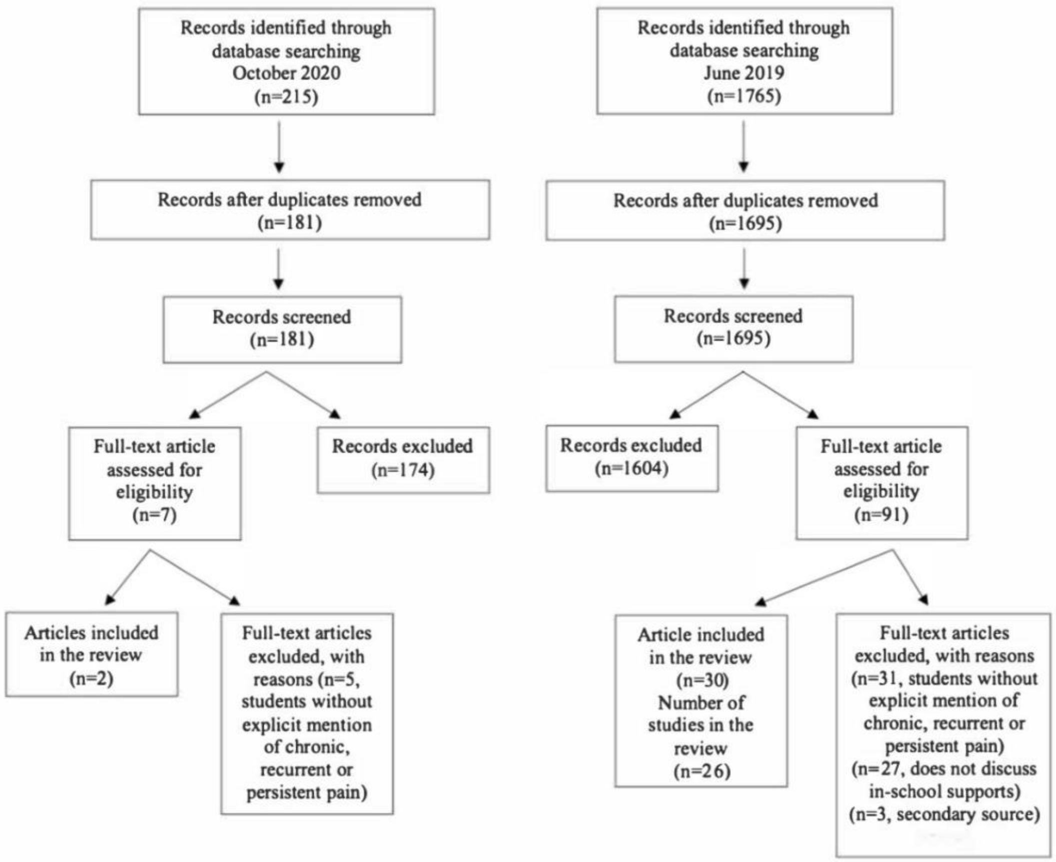
Procedures were not performed with human or animal participants in this article.

Informed Consent

Informed consent was not needed in this study.

Conflict of Interest

The authors have no conflict of interest.



TOTAL : 32 articles included in the review

Figure 1. PRISMA flowchart describing the study selection process

Table 1

Description of included articles

Author	Country	Study Design	Framework	Type of chronic pain	Perspective	Aim	Main Findings	Identified in-school supports	Themes of in-school supports discussed	Barriers/Facilitators (if any)
Adolfsson et al. (2018)	Sweden and South Africa	Qualitative	Not specified	Musculoskeletal pain via cerebral palsy	Clinicians, teachers, and personal assistants working with students between the ages of 3 and 21.	The aim of this study was to explore how health professionals manage pain in children with cerebral palsy in school settings.	Pain management was more focused on children's attendance than on their involvement. A difference between countries in terms of action-versus-reaction approaches was discussed.	Sweden: Keeping the child comfortable in school situations, prescribing technical aids, scheduling interruptions in schoolwork, and following up on children with severe disabilities. South Africa: Assistance from therapists and physiotherapist in attempt to treat, minimize, or eliminate the pain.	Therapy in schools, Consulting professionals, Academic accommodation Building positive relationships Collaboration	In South Africa, participants perceived it challenging to find means for informing parents about the child's needs.
Nilsson et al. (2016)	South Africa	Qualitative	Not specified	Musculoskeletal pain via cerebral palsy	Therapists, teachers, and personal assistants working with students between the ages of 3 and 21.	The goal of this study was to see how South African health practitioners respond to the demand for pain management therapies for children with cerebral palsy in school settings.	Professionals would probably be more effective at pain management interventions if they were given pain management education and had access to a prevention and follow-up program for children with cerebral palsy.	Assistive technology. To ease the pain, therapists used relaxing techniques such as massages and warm baths. A physician's prescription in order for nurses to provide medications. Distraction strategies such as joking with the child or attempting to get the child to focus on something else were tried. Educators employed positive reinforcement in the classroom to try to divert children's attention away from their discomfort and toward their academics. Emotional support and encouragement were offered.	Therapy in schools, consulting professionals, building positive relationships	Access to certain kinds of medication was difficult because of financial constraints. Lack of follow-up programs. The therapists had lots of knowledge and were willing to share it with the educators and class assistants to ensure better pain management and create good relationships between professionals and teachers.
King et al. (2018)	Canada	Mixed-Methods	Biopsychosocial	Unspecified chronic pain	Students, parents, and teachers.	The study's goal was to create and conduct preliminary usability testing on an eHealth education dissemination intervention aimed at providing educators with information on paediatric pain in the school setting.	The preliminary results of this eHealth intervention for educators were encouraging, indicating that it could be a valuable technique of disseminating and translating knowledge in the field of paediatric chronic pain.	Classroom adaptations (not specified), pain education for educators, interdisciplinary collaboration.	Academic accommodations, knowledge, consulting health professionals	Participant comments regarding website navigation and animation were all deemed to be major and, due to limited resources, it was not feasible to make the changes.
Logan et al. (2007)	USA	Quantitative	Biopsychosocial	Unspecified chronic pain	Teachers who work in middle schools or high schools.	The goal was to look into the elements that influence teachers' perceptions of chronic pain in pupils and how they respond to it.	The findings of this study show that situational factors such as the presence of documented medical evidence supporting the pain complaints and whether parents work cooperatively or	The teachers' judgements (or lack thereof) as a support that can help (or hinder) students with chronic pain.	Knowledge, consulting professionals, building positive relationships	Teachers were educated about pain but wanted to know more to help them help the children

							confrontationally with the school to address school functioning influence aspects of teachers' judgments of students with chronic pain and their responses to pain in the classroom.			
Logan et al. (2005)	USA	Qualitative	Not specified	Unspecified chronic pain	School teachers, administrators, school nurses, and guidance/mental health staff working in middle schools or high schools.	The goal of this research is to examine school personnel's understanding of adolescent chronic pain issues and to explore how healthcare and education systems may work together more effectively to address these issues.	Members of the focus group mentioned many challenges related to working with adolescents with pain in school (including high absence rates, wide individual variation in symptoms and impairments, balancing accommodations with school policies, attending to other students' needs, and dealing with parents).	In order to meet the social, emotional, health, and educational needs of students with chronic pain, school personnel cite a need for increased communication, education, and collaboration with healthcare providers.	Knowledge, collaboration	Not discussed
Solé et L. (2018)	Spain	Quantitative	Not specified	Unspecified chronic pain	Teachers and teachers in training working with preschool to university-level students.	This study aimed to examine teachers' and student teachers' reactions to children experiencing pain, to identify the most common challenges and resources associated with coping with them, and to assess whether their reactions differed according to their experience and gender.	The results show that coping responses were the responses endorsed the most by teachers and student teachers to children who experience chronic pain, followed by solicitous and discouraging responses.	The teacher's reaction to the student is seen as having a helpful or unhelpful effect on the student.	Consulting, building positive relationships, collaboration	Teachers want specific guidelines and knowledge about chronic pain and its effects on children. They would also like better collaboration with families and with healthcare professionals.
Vervoort et al. (2014)	Belgium	Quantitative	Self-determination theory	Unspecified chronic pain	Students from primary and secondary schools.	The study examined child and adolescent pain severity in relation to school functioning and the protective role of perceived teacher support of autonomy and competence.	A significant proportion of children and adolescents reported moderate to severe pain problems (i.e., about 14% were classified in the highest pain grade; grade III or IV). Furthermore, teacher support of competence appeared to buffer against the harmful effects of severe pain upon instances of bullying experiences at school.	Perceived teacher support	Building positive relationships	Teachers feel inadequately educated about how to work with students suffering from pain.
Wager et al. (2018)	Germany	Qualitative	Not specified	Unspecified chronic pain	Students in elementary school.	To date, no video-based education program on recurrent and chronic pain in general exists for use in the school setting. Therefore, this feasibility study was	This feasibility study presented the first evidence for the potential effectiveness of an 11-min educational movie on recurrent and chronic pain in increasing health literacy in adolescents.	This 11-minute educational film was divided into three parts: (1) general knowledge about pain, (2) pain development and maintenance, and (3) pain management strategies	Knowledge	Not discussed

						designed to test whether an educational movie has any effect on pain knowledge in students.				
Simons et al. (2010)	USA	Quantitative	Not specified	Unspecified chronic pain	Adolescents between the ages of 12 and 17.	To advance our understanding of social functioning in children with chronic pain, particularly how it relates to school impairments in this population.	Pain, physical limitations, somatic symptoms, and school impairment were significantly associated with lower social functioning scores. The relationship between adolescents' pain experience (i.e., pain, physical symptoms, physical limitations) and school impairment was mediated by their social functioning.	Social functioning within the school setting, accommodations to allow a student to participate in the classroom.	Building positive relationships, academic accommodations	Not discussed
Agoston et al. (2016)	USA	Quantitative	Not specified	Unspecified chronic pain	Students in high school.	The purpose of this study was to examine school functioning in adolescents with primary pain conditions, with juvenile idiopathic arthritis (JIA)-related pain, and with healthy peers with respect to school attendance, overall quality of life in the school setting, and school nurse visits.	In comparison to both adolescents with JIA-related pain and healthy peers, youth with primary pain conditions reported more school absences, a lower quality of life in school, and more frequent school nurse visits.	Nurse office visits	Consulting health professionals	Not discussed
Larsson et al. (2005)	Sweden	Randomized controlled study	Not specified	Recurrent headache/migraine	Students in high school.	This study examined the effectiveness and efficiency of various psychological treatments reported for a large number of adolescents, their effects on various features of recurrent headaches, and their long-term outcomes.	Researchers found that self-help and school-nurse-administered relaxation approaches were inferior to a therapist-administered relaxation approach.	A relaxation training program administered within a school setting can provide effective and efficient relief for adolescents suffering from long-standing and frequent headaches.	Therapy in Schools	Not discussed
Larsson et al. (1987)	Sweden	Randomized controlled study	Not specified	Recurrent headache	Students in high school.	The purpose of this study was to compare a therapist-assisted relaxation session with a self-help program to determine the maintenance effects of these procedures and to examine whether relaxation programs can be administered effectively to	The results indicated that the self-help approach was as effective as the therapist-assisted relaxation condition in reducing the students' headaches and that these findings were maintained at a 5-month follow-up evaluation	Therapist-assisted relaxation and self-help programmes were effective.	Therapy in schools	Not discussed

						students in a classroom setting.				
Larsson et al. (1986)	Sweden	Randomized controlled study	Not specified	Recurrent headache	Students in high school.	The purpose of the study was to compare two active treatment forms to the effects of regular contact with a professional person and systematic self-observation of the chronic headache symptoms.	The results of this study are comparable with those of previous studies on adults with chronic headaches who had been treated in clinical settings with an indication that these problems can be effectively treated in a school setting.	A school-based relaxation approach may be as efficacious as a clinically delivered treatment.	Therapy in schools	Not discussed
Larsson et al. (1987)	Sweden	Randomized controlled study	Not specified	Recurrent headaches	Students in high school	A particular goal of the present study was to find out whether self-help relaxation training would reduce headaches better than a problem-discussion condition.	This study indicates that a self-help relaxation program based on minimal therapist assistance can provide effective help for chronic headaches in adolescents treated in a school setting.	Minimal therapist-contact approach may be as effective as a therapist-directed program.	Therapy in schools	Not discussed
Larsson et al. (2003)	Sweden	Randomized controlled study	Not specified	Recurrent headaches	Students in high school.	In this study, the aim was to study Swedish school nurses' views on common health problems in school-aged children and their relationship to school level; the use of school healthcare among recurrent headache sufferers seeking help at the school nurse; causes of recurrence headaches in school-aged children; management and its efficacy for headache problems; and their current knowledge and formal education regarding tension-type headaches and migraines.	One of the most common complaints was headaches. Tension headaches were regarded as a more serious health problem than migraines. Recurrent headaches were attributed to various stressors, including family and peer problems.	Psychotherapy and relaxation training	Knowledge, Therapy in schools, consulting professional, collaboration	Not discussed
Lazdowsky et al. (2016)	USA	Study 1: Quantitative, Study 3: mixed-methods	Not specified	Chronic headache	Study 1: Parents, students (6-18), and school nurses. Study 2: School nurses working in middle or high school.	This study had two objectives: to confirm the need for a pediatric headache guide used by school nurses and to evaluate the use and acceptance of a headache-	Study 1 provided a clearer understanding of student utilization and perceptions of school nurse practices, emphasizing the perceived need for more resources for school nurses and acknowledging the	There is a need for more comprehensive, evidence-based guidelines, such as "Headache Tools to Stay in School," to be available to school nurses.	Knowledge, consulting health professions, building positive relationships, collaboration	School nurses could benefit from chronic and acute headache treatment and management education, and some recommendations are difficult to implement in a

						driven educational tool for school nurses.	possible gap between evidence-based practices and the healthcare available to students. Based on the results of Study 2, evidence-based resources like ‘‘Headache Tools to Stay in School’’ can help improve the quality of care students receive in school nursing offices.			school setting due to lack of space or resources (e.g., not having areas for students to rest undisturbed for a half-hour in a dark room or not being able to give them snacks) and the tool is too long to be considered a "quick" reference guide.
Passchier et al. (1990)	Amsterdam	Randomized controlled study	Not Specified	Recurrent headaches	Students in high school.	The purpose of the study was to analyze the effect of progressive relaxation training presented by a teacher on headaches and fear of failure. As well as school problems among school students.	There were no significant differences between both training groups (relaxation vs. placebo) in terms of headache frequency, duration, intensity, or psychological variables.	Relaxation Training	Therapy in schools	Not discussed
Bush et al. (2017)	New Zealand	Quantitative	Not Specified	Endometriosis	Students in high school.	This study seeks to report audit data from a menstrual health and endometriosis secondary school education program and to observe the age patterns of younger women presenting for menstrual morbidity care at a tertiary referral facility.	This study appears to be the first to demonstrate that consistent delivery of a menstrual health and endometriosis program in secondary schools may increase awareness of endometriosis and encourage young women to seek specialized healthcare services.	The “me” program delivery and students’ awareness of endometriosis increased.	Knowledge	Not discussed
Bodèn et al. (2013)	Sweden	Quantitative	Not Specified	Endometriosis	Adolescents with endometriosis between the ages of 10 and 15	The purpose of this study was to investigate the kind and level of support that women diagnosed with endometriosis in Sweden experienced from the school medical network and school nurses during their secondary and upper secondary school years, as well as how it impacted their quality of life.	Due to pain and abnormal bleeding associated with their menstrual cycles, young women were absent from school or missed extra-curricular activities. Because of their limited experience, some of the women believed these symptoms were normal and did not consult the school nurse.	Visiting school health services	Consulting health professionals	School nurses lack communication skills, lack knowledge on endometriosis.
Soderman et al. (2019)	Sweden	Quantitative	Not Specified	Dysmenorrhea	Adolescents between the ages of 16 and 20.	This study aimed to determine the prevalence of dysmenorrhea among adolescents and its impact on daily life.	Dysmenorrhea has a large impact on the lives of many adolescents in Stockholm, according to the study. The study cohort reported monthly pain in 89% of cases, and severe pain in 36% of cases.	Contacted and met with school nurses	Consulting health professionals, building positive relationships	Not discussed

Fay (1963)	USA	Quantitative	Not Specified	Menstrual related recurrent pain	Students in high school.	The purpose of this study was to report how many students from grades 7 through 12 had dysmenorrhea, what they knew about it, and what they did about it.	The majority of students reporting pain said that they took medications to relieve their symptoms; however, findings revealed that most did not consult a physician before taking medication.	School nurses should pay closer attention to cause of absenteeism among female students - urging them to seek medical attention if it is caused by dysmenorrhea. Also, counseling and incidental teaching.	Knowledge, therapy, consulting health professionals, collaboration	Not discussed
Sellschop et al. (2015)	South Africa	Randomized controlled study	Not Specified	Musculoskeletal pain	Students in grade 8.	This study examined the effects of a computer-related ergonomics intervention on posture and pain prevalence among grade eight learners in a school environment in Johannesburg, South Africa.	The results showed a sustained improvement in the postures of learners while using computers. There were significant reductions in the prevalence of musculoskeletal pain in the intervention group	Develop and implement a health promotion school program in ergonomics in the school environment.	Knowledge	Not discussed
Vidal et al. (2013)	Spain	Randomized controlled study	Not Specified	Lower back pain	Students in grades 5 and 6.	This study investigated the effects of a postural education program on school backpack habits related to low back pain in children aged 10–12 years.	According to the findings, a postural education program implemented in children can positively influence backpack habits that contribute to lower back pain.	School-based postural education program	Knowledge, collaboration	Not discussed
Deacy et al. (2015)	USA	Quantitative	Biopsychosocial	Abdominal pain	School nurses working in elementary, middle, and/or high schools.	In this study, school nurses were asked about their perspectives and practices regarding chronic abdominal pain	Children with abdominal pain are frequently seen by school nurses, and they primarily attribute the pain to psychosocial or behavioral issues (though they seldom consult with mental health professionals). School nurses also know relatively little about physiological factors that contribute to and classify abdominal pain.	Restroom breaks, encouraging dietary monitoring and/or modification, exercising, improving sleep hygiene, providing reassurance, making academic accommodations, and recommending supplements and referrals to other medical and behavioural health services.	Knowledge, academic accommodations, consulting professional, collaboration	Families opposed collaboration with mental health providers, time limitations, and legal concerns were barriers to collaboration. There was a lack of confidence in the understanding of chronic abdominal pain.
Youssef et al. (2007)	USA	Quantitative	Not specified	Abdominal Pain	School nurses.	The purpose of this study was to determine the need for educational programs for school nurses who commonly care for children with recurrent abdominal pain.	This study highlighted the current knowledge gap and the potential value of professional educational interventions. There is a high degree of receptivity among school nurses to learning, and those efforts are usually successful.	Consulting school nurses. Education on abdominal pain	Knowledge, consulting professionals, Collaboration	Not discussed
Andias et al. (2018)	Portugal	Mixed-Methods/ Randomized controlled study	Not specified	Chronic idiopathic neck pain	Students in high school.	The aim of this study was to assess the effectiveness of pain neuroscience education and exercise on pain intensity, pain disability,	The results suggest that an intervention of 4 weeks combining pain neuroscience education and exercise significantly improves the	An intervention consisting of pain neuroscience education and endurance exercises for the neck and shoulder regions can be delivered in a school setting.	Knowledge	Not discussed

						neck and shoulder muscle endurance, anxiety and catastrophizing among adolescents with chronic idiopathic neck pain.	endurance capacity of the neck extensors and knowledge of pain neurophysiology.			
Spencer et al. (2018)	Australia	Quantitative	Not specified	Chronic pain due to arthritis and chronic migraines.	Students in university.	This study aims to advance understanding of young people’s experiences of managing long-term health conditions and their perspectives on health and ill health at university by interviewing students with chronic health conditions.	Despite facing significant health challenges, young people seek to maintain a positive sense of health. To minimize disruptions to daily life, participants living with a (fluctuating) health condition had to constantly think about and manage the uncertainties of illness. This disruption was sometimes met with resistance as respondents downplayed how severe their illness was.	University and academic support services (supports weren’t specified), seeking support from teachers.	Academic accommodations and building positive relationships	Not discussed
Vaiciunas et al. (2019)	Lithuania	Mixed-methods	Not specified	Chronic specific-site (headache, backache, or stomach-ache) and multisite pain	Adolescents between the ages of 11 and 15.	The aim of this study was to describe and compare the prevalence of chronic specific-site (headache, backache, stomach-ache) and multisite pain in adolescents, to examine the patterns of chronic pain by age and gender, and to investigate effects on variations of chronic pain, as well as associations between pain and age. Finally, we explored how school related context can influence adolescents’ subjective health outcomes (specific-site and multisite pain).	School bullying, school demands, student satisfaction, and social support were the most relevant and independent factors associated with multisite somatic complaints among adolescents.	Active support from teachers and peers	Building positive relationships	According to the article, social support from family and good relationships between children and their teachers and classmates help to reduce perceived somatic complaints.
Randall et al. (2019)	USA	Quantitative	Biopsychosocial	Chronic specific-site and multisite pain	Parents and adolescents between the ages of 14 and 18.	The purpose of this study was to examine whether academic factors are associated with adolescent pain and somatic symptoms.	According to this study, adolescents in a high-achieving community report more somatic symptoms and pain if they are less engaged at school and if grades and outperforming peers are their primary focus.	Interpersonal relationship with peers and teachers	Building positive relationships	Not discussed

Taras et al. (2008)	USA	Quantitative	Not specified	Chronic pain due to back pain, hip pain, and abdominal pain.	Students in elementary, middle, and/or high school.	This study aimed to determine the type of medical diagnoses and circumstances that prompted schools to seek medical consultation and the response of the district medical consultant.	There was no single chronic condition, symptom, or healthcare need that predominated. To overcome hurdles schools faced when accommodating students with special healthcare needs, six types of school physician consultant activities were used.	Communication between the school physician consultant and the child's own physician. Educate school staff members about a particular health condition. The establishment of a system of continuous communication between school personnel and the child's physician. Assist the family in navigating the healthcare system; conduct an investigation of the school and classroom environment.	Collaboration, consulting health professionals, knowledge	Not discussed
Logan et al. (2008)	USA	Quantitative	Not specified	Chronic pain due to neck pain, migraine, headaches, abdominal pain, etc.	Adolescents between the ages of 12 and 17 and their parents.	The aim of this study was to describe school functioning among adolescents with a range of medically unexplained chronic pains, including school attendance and academic performance.	Results showed that chronic pain is associated with school absences, poor grades, and a perception by adolescents that pain interferes with their academic success.	School personnel (school administrator or guidance counsellor) completed a checklist reporting all accommodations implemented for the student in response to their pain problem. Examples include extensions on assignment deadlines, modified schedules, and individual tutoring.	Academic accommodations	Not discussed
Castarlenas et al. (2015)	Spain	Mixed-Methods	Not specified	Chronic pain due to neck pain, migraine, headaches, abdominal pain, etc.	Students in grades 7 to 11.	This study aimed to assess the expectations of students and teachers regarding children with chronic pain.	Participants believed that their teachers would provide more solicitousness, less discouragement, and more promotion of adaptive coping responses when they interacted with classmates with chronic pain in comparison with classmates without chronic pain.	Teacher education and training in how to best respond to children with chronic pain. Teachers getting to know their students	Knowledge and building positive relationships	Not discussed

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Bridging Text

In the first manuscript (Gittens et al., 2023, submitted), a scoping review of the literature was conducted to gather research-based information about existing in-school support options for students living with chronic pain, given that chronic pain is one of the most common symptoms of endometriosis and that there have been only seven studies of endometriosis in the education setting. From the scoping review, a list of in-school support services for students with chronic pain was compiled, which could also benefit students with endometriosis. However, as endometriosis is a gendered condition that involves menstruation, the needs of students who have endometriosis could differ from those of students who experience chronic pain from conditions that are not gendered or stigmatized by society. Further research is needed to understand the specific needs of students with endometriosis.

The diagnosis of chronic conditions that primarily affect only one sex (i.e., female), such as endometriosis, can be delayed compared to diagnoses of conditions that affect both sexes due to a lack of awareness or dismissive attitudes toward gender- or sex-specific symptoms (Rapp et al., 2022). Conditions that affect females often receive less research funding and treatment, leading to less well-developed treatment protocols (Mirin, 2021). Healthcare providers have reported a lack of specific training and sensitivity towards conditions affecting the female sex, leading to inadequate care, which can lead to higher healthcare costs through delayed diagnosis (Alcalde-Rubio et al., 2020). Chronic conditions that are associated with gender stigma present unique challenges related to societal perceptions, healthcare provider attitudes, and specific impacts on physical, emotional, and reproductive health.

For example, students with endometriosis have reported a need for hygiene products, and access to a washroom is exclusive to gynecological disorders (Gupta et al., 2021). Thus, the second study was conducted to understand the needs and experiences of students who have endometriosis, as the scoping review did not explore the needs of students who experience a gendered condition. Furthermore, qualitative data was collected in Study 2 to better understand the actual needs of students with endometriosis.

The results of study 2 focuses on real-life experiences, including beliefs about and experiences of in-school support for former and current students with endometriosis. Endometriosis is a gynecological condition that may require specific in-school support services that were not reported in Study 1, which focused on chronic pain stemming from a variety of conditions. Thus, the results in Study 2 are crucial to providing insight into the lived experiences of students with endometriosis in Canada and identifying the kinds of in-school support that students indicate they need.

Furthermore, this is the first Canadian study on the support needed by students with endometriosis. While studies that aim to understand the cause of endometriosis represent important contributions to medical knowledge, their findings do not ease the burdens of students currently suffering from endometriosis symptoms. The findings from Study 1 informed the potential types of in-school support that could benefit students living with chronic pain inclusive of endometriosis, Study 2 provides insight into which specific in-school support services were deemed necessary and which were received, to better understand the gap in support for students with endometriosis. Furthermore, the results from Study 2 address the overarching goals of the current dissertation, which are to understand the needs and experiences of students with endometriosis across Canada within an educational context.

A mixed-methods approach was applied to explore participants' experiences with endometriosis as well as the supports that are necessary and the supports that were received in the school setting. A thematic analysis was conducted on selected open-ended questions that were included the survey, and statistical analyses were conducted with the quantitative data. From the scoping review (Study 1), a list of in-school supports was extracted and compiled, referred to as the *In-School Support List*. The In-School Support List was included in Study 2 to provide participants' perspectives on which supports are necessary and which were received. Furthermore, the Endometriosis Impact Questionnaire (Moradi et al., 2019) was used in the survey to explore the physical, psychological, and social impact of endometriosis. In addition, the impact of endometriosis on sexual and intimate relationships, fertility, employment, education, and lifestyle were measured at each recall period (i.e., the last 4 weeks, the last 12 months, the last 1–5 years, and more than 5 years prior; Moradi et al., 2019). The results from Study 2 provide an understanding of the type of information to be included in guidelines for supporting students with endometriosis in Canada. Furthermore, participants in Study 2 highlight their own experiences of managing their endometriosis symptoms while in school, the need for support and the impact of stigma that is associated with menstrual health and endometriosis.

Chapter 4: Survey (Study 2)

A Mixed-Methods Approach to Exploring the In-school Supports and Impact of Endometriosis on the Lived-Experiences of Affected Canadian Students

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Abstract

Objectives: The three main objectives of this study were to: (a) explore and identify the in-school support needs of students with endometriosis; (b) understand the impact that endometriosis has on current students.

Methods: An online survey was distributed via online support groups to individuals who have experienced endometriosis while attending school to understand what types of in-school supports might be beneficial. A mixed-methods approach was used to identify and understand participants' experiences with endometriosis as well as the supports that were needed and received in the school setting. A thematic analysis was conducted with selected open-ended questions included in the survey, and statistical analyses were conducted on the quantitative data. One hundred and seventy-four participants responded to the survey.

Results: Participants reported that the most needed in-school supports included creating a plan with school personnel to outline procedures for when they are in pain or experiencing discomfort at school, academic accommodations, establishing a supportive relationship with a school staff member, and providing symptom-alleviating products like heat pads in the school setting. However, only about one fourth of participants received at least one support while in school. Thus, despite reporting in-school supports as necessary, participants did not receive support. The study further highlights the importance of supporting students with endometriosis and the negative impact that endometriosis has on their physical, psychosocial, sexuality, fertility, employment, lifestyle, and education.

Conclusion: Students with endometriosis reported that in-school supports, and education and awareness about endometriosis in school settings are needed. However, in addition to other in-school interventions and accommodations that students need, a gap remains in supports for students with endometriosis.

Introduction

Endometriosis is a chronic disease in which tissue similar to that normally present within the uterus begins to develop and accumulate outside of the uterus, resulting in pain, reduced fertility, heavy vaginal bleeding, and pelvic mass growth (Becker et al., 2022). No cure currently exists for endometriosis (Acién & Velasco, 2013; Björk et al., 2020). The condition affects worldwide approximately one in 10 girls, women, transgender and gender-diverse individuals born with a uterus (Gambone et al., 2002).

Individuals with endometriosis worldwide often experience depression (14.5%) and anxiety (29%), as well as a decreased quality of life (social life, mental health, sex life, and working capacity) associated with the debilitating pain that endometriosis can cause (Friedl et al., 2015). Individuals with endometriosis may further experience adverse effects on their daily activities, such as attending school or work. Due to the general lack of awareness about the condition and social stigma surrounding menstruation, individuals are uninformed about the symptoms associated with endometriosis or are unaware of the condition before their diagnosis (Seear, 2009).

Worldwide, individuals reporting symptoms of endometriosis may wait seven to 12 years before receiving a diagnosis due to the complexity of diagnosing endometriosis and the overall lack of knowledge regarding endometriosis (Agarwal et al., 2019; Singh et al., 2020; Soliman et al., 2017; Treloar et al., 2010). The stigma surrounding menstruation can normalize symptoms of serious conditions like endometriosis, leading to misdiagnosis and delayed treatment. Societal attitudes can also influence healthcare providers, causing a lack of awareness and understanding of symptoms (Gupta et al., 2021; Johnston-Robledo & Chrisler, 2013; Seear, 2009; Sims et al., 2021). Addressing this stigma and promoting open conversations about menstrual health are crucial for improving early detection and treatment, reducing diagnostic delays, and improving the quality of life for affected individuals. Individuals with endometriosis may be unaware of their atypical experience or feel hesitant to discuss symptoms with a clinician (Chandra-Mouli & Patel, 2017; Johnston-Robledo & Chrisler, 2013; Miller, 2019; Rubinsky et al., 2018). For example, Rowe et al. (2019) conducted a study in which health professionals in Australia recognized the constraints of their knowledge about endometriosis and reported misconceptions about endometriosis that lead to difficulties in providing optimal care. Enhancing the knowledge and collaborative care abilities of health professionals will improve primary care for endometriosis (Rowe et al., 2019).

Individuals with chronic pain due to endometriosis report a poorer quality of life, loss of working ability and productivity, limitations in social activities, higher absenteeism, mental health challenges, and a lack of understanding and support (Gao et al., 2006; Facchin et al., 2015; Nnoaham et al., 2011). Students with endometriosis who experience chronic pain struggle with attending school, completing schoolwork, and participating in school activities (Brosens et al., 2013; Gallagher et al., 2018; Moradi et al., 2019). Furthermore, once diagnosed, students with endometriosis may need medical consultations, therapies, and surgery, which can interfere with their academic schedules and require effective time and self-management skills in planning, decision-making, and carrying out tasks to manage their treatment (O’Hara et al., 2019, 2021).

To date, endometriosis research in school settings has mainly focused on raising awareness in schools (Bush et al., 2017; Khan et al., 2022; Ramani Devi et al., 2021; Rusda & Rahman, 2019). Only three studies have explored the effect of endometriosis on students in the school setting, but the researchers did not explore the type and development of in-school supports needed (Bodèn et al., 2013; Gupta et al., 2018, 2021). Bodèn et al. (2013) conducted a mixed-methods study on the experiences of 18- to 26-year-olds living in Sweden in regards to accessing healthcare services in secondary schools. The authors recommended that school nurses assist young women to feel more comfortable discussing their intimate body functions, which could contribute to earlier diagnosis.

Gupta et al. (2018, 2021) explored how social context (school, home, healthcare) can influence perceptions of endometriosis and how the corresponding symptoms affect individuals' living in the United States. Participants reported distrust of healthcare providers, societal and peer stigmatization, lack of knowledge of students and staff about endometriosis, and negative attitudes about sexual health (Gupta et al., 2018). The researchers highlighted the significance of social context in shaping adolescents' emotional well-being and experiences in seeking help. Societal stigma and inequitable gender standards influence the level of help provided to adolescents experiencing symptoms of endometriosis (Gupta et al., 2018, 2021). However, Gupta et al. (2018) did not explore the lived experiences of students with endometriosis, nor did Gupta et al. (2021) discuss how to help students (college, 18 to 24 years) and the school setting overcome stigma. The lack of awareness of endometriosis is an important service-related problem, as school staff may not understand the effect endometriosis has on students, potentially forming a barrier to providing appropriate support. While it is essential to raise awareness in school regarding endometriosis and to encourage consultation with school nurses, a need exists to identify what other school-based interventions, support, and accommodations are needed for students with endometriosis.

Recently, researchers and experts have called on schools to educate students and staff on endometriosis (Davey, 2018; Young, 2020). By taking a proactive rather than reactive approach, school staff can address students' differences and understand the types of accommodations that would benefit students with endometriosis (Saridoğan, 2016). Proactive support can diminish social stigma and foster a more nurturing environment for students with endometriosis (Seear, 2009). School staff need to know how to support students with endometriosis; a need thus exists to better understand the experiences of students living with endometriosis.

The present study is guided by the following research questions:

1. How has endometriosis impacted students (current and former students) in different aspects of their lives (physical, psychosocial, sexuality, fertility, employment, lifestyle, and education)?
2. Are there gaps in the in-school support services (including elementary, high school, college, and university) for current and former students with endometriosis in Canada?

Methods

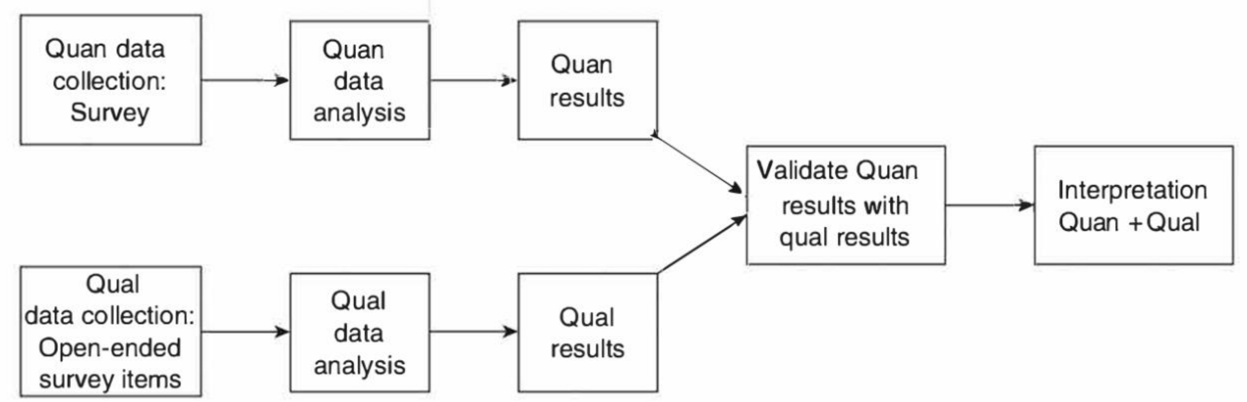
Theoretical Frameworks Used for Developing a Survey

The current study used gender theory, biopsychosocial theory, and the social-ecological model of disability to guide the development of the survey. Gender theory highlights the underrepresentation of women's pain and symptoms, leading to delayed diagnosis, insufficient treatment, and lack of research funding (Berterö et al., 2019; Darnall et al., 2017). To better understand the experiences of students, the survey included open-ended questions to explore possible experienced bias and stigma. The biopsychosocial model emphasizes the interplay of biological, psychological, and social factors in health and illness (Borrell-Carrió et al., 2004; Gatchel et al., 2007). The inclusion of the Endometriosis Impact Questionnaire (EIQ; Moradi et al., 2019), which explores how endometriosis affects students in various areas of their lives at different time points, provides a biopsychosocial viewpoint. The social-ecological model of disability aims to determine the support needed for individuals with disabilities to participate in their environment and activities, promoting their development and well-being (Shogren et al., 2018). Therefore, an In-School Support List was included for participants to select the supports that they deem necessary and identify the in-school supports they received. The In-School Support List was developed following a scoping review on students with chronic pain (Gittens et al., 2023; submitted).

A mixed-methods “triangulation design for validating quantitative data model” was used to enhance the validity of the analysis (See Figure 1; Creswell & Clark, 2007). The validating quantitative data model was used to confirm and enhance the quantitative results from a survey by incorporating open-ended qualitative questions in the survey. In this approach, both qualitative and quantitative data are gathered within a single survey. Although the qualitative questions are complimentary to the quantitative survey questions, the qualitative data offer insight into their lived experiences that can validate and enrich the quantitative findings (Creswell & Clark, 2007).

Figure 1

Validating Quantitative Data Model



Note. Reprinted from Creswell, J. W., & Clark, V. L. P. (2007). *Designing and conducting mixed methods research* (p. 63). Sage Publications.

Ethics Approval

The Research Ethics Board reviewed and approved the project as a part of the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (see Appendix E).

Participant Recruitment and Eligibility

Given the delay in diagnosing endometriosis, current students (aged 14 and older) and former students, defined as individuals who experienced endometriosis symptoms while in school but were diagnosed after leaving school, were recruited. Canadian students (aged 14 and older) and former students with diagnosed endometriosis were recruited through Facebook endometriosis support groups (e.g., Endometriosis Canada, Groupe d’entraide et de soutien Endométriose Québec), Reddit endometriosis support groups, and the Endometriosis Network Canada website. The endometriosis support groups were found through online searches.

The endometriosis support group organizers were contacted and asked for permission to share a flyer and a link to the survey with their members. Participants were then able to access the survey on LimeSurvey. Participants were asked to provide consent (English or French) online. Participants remained anonymous throughout the study. Participants were asked to complete background questions, respond to the in-school supports section, and then complete the adapted version of the Endometriosis Impact Questionnaire (EIQ; Moradi et al., 2019). The time commitment was approximately 25 minutes.

To determine the mean number of in-school support services reported in a population of students with endometriosis, with a 95% confidence interval of +/- .40 supports, Becker et al.'s (2002) in-school referrals and accommodations standard deviations (M=6.2, SD=2.8) were used to estimate the appropriate sample size, as determined by an a priori sample size analysis for descriptive studies (Hulley et al., 2013). Results of the analysis revealed that a minimum of 171 participants was needed. The inclusion criteria for the study were as follows: (a) living in Canada; (b) diagnosis of endometriosis; (c) age of 14 years or above; and (d) manifestation of endometriosis symptoms while attending school. In addition, to be eligible for inclusion in the survey analysis, participants needed to have provided responses up until the end of the in-school support section of the survey, rather than solely completing demographic information. Participant recruitment began in August 2022 and ended in May 2023.

Survey Development

Demographics and Background Information

The demographics and background survey included questions on participants' gender, education, and socioeconomic status, as well as multiple-choice and open-ended background questions related to endometriosis (e.g., "How long have you been diagnosed with endometriosis?" "How did you receive your diagnosis of endometriosis?"). The demographics and background section included questions about how the COVID-19 pandemic had affected participants (see Appendix B).

In-School Supports List

To better understand in-school supports that may be beneficial to students, the survey included a list of in-school support services extracted from a scoping review (Gittens et al., 2023; submitted) that was conducted to explore what types of in-school support services may be beneficial for students living with chronic pain, as chronic pain is the most common symptom for students with endometriosis. Participants were asked whether a described in-school support (e.g., receiving instruction/information on healthy menstruation and endometriosis at school) was necessary and whether they have received such in-school support.

The list consisted of 14 in-school support services: instruction/information on healthy menstruation and endometriosis at school, assignment extensions, adjustments to the number of weekly class hours, a second set of books for home, restricting a student's classes to the first floor (i.e., to avoid stairs), fully homebound instruction, consulting a school nurse, consulting a school psychologist, access to symptom-reducing products (e.g., heat pad), building a positive relationship at school with an adult supportive contact person aware of the endometriosis diagnosis, making a plan with school staff on steps to take when experiencing pain at school, locker close to the classroom, receiving therapy within the school to cope with endometriosis and school staff collaborating with a medical physician on how best to support students. The survey also included a comment section for participants to propose additional in-school supports.

Endometriosis Impact Questionnaire (EIQ)

The EIQ (Appendix C) is a questionnaire assessing the impact of endometriosis. The authors of the questionnaire approved its use in the current study (Moradi et al., 2019). The six dimensions of the EIQ consider endometriosis and its potential effect on physical and psychosocial (dimension 1), sexuality (dimension 2), fertility (dimension 3), employment (dimension 4), education (dimension 5), and lifestyle (dimension 6). Questionnaire items are presented as statements (e.g., "I experienced difficulty concentrating or focusing on my studies"). For each time point (the last 4 weeks, the last 12 months, the last 1-5 years, and more than 5 years prior) on the rating scale, participants were asked to choose one of the following for each statement: "*not at all true*" =0, "*a little true*" =1, "*somewhat true"* = 2, "*quite a lot true"* =3, "*very much true"* =4 or "*not applicable"* =9. The score for each dimension during each recall period was calculated by summing all relevant items and dividing by the maximum score for those items. The resulting score was then rescaled to a range of 0-100, with higher scores indicating a greater influence of endometriosis on that dimension and time. A 4-week recall period was added to assess the recent impact of endometriosis. Furthermore, the EIQ was translated into French by a native French speaker and then reviewed by a native French speaker.

Analysis

The following section is comprised of a statistical analysis of the quantitative component and a thematic analysis of the qualitative component of the current study.

Statistical Analysis

Descriptive statistics are reported for background variables (e.g., participant age, province). For the In-School Support List items, the frequency of responses for each item was reported as a percentage to understand the types of support participants deem necessary, have been received, and in which types of school settings. As the Endometriosis Impact Questionnaire was adapted to include the last 4 weeks as a reference period, the internal consistency reliability of each subscale was derived from a factor analysis using Cronbach’s alpha (See results section).

Fischer's exact tests were conducted to explore the association between participants reporting an in-school support as necessary and their receipt of such support. Furthermore, Mann-Whitney U tests were conducted to compare current and former students’ responses to the EIQ. SPSS (Version 31) was used to conduct the analyses. For each statistical analysis, a p-value of <0.05 was considered significant.

Qualitative Analysis

Certain sections of the survey included open questions that allowed designated space for participants to write their answers. A thematic analysis was conducted on the qualitative written responses (Braun & Clarke, 2006). First, the lead researcher reviewed and conducted a first read of all the participants' written responses and noted any themes that emerged in the data. Subsequently, the lead researcher read the responses repeatedly and noted any recurring ideas that emerged across the responses. The lead researcher consulted the third author on participants' responses and emerging themes. The recurring themes were added to a thematic coding tree, which was used to code responses. Thematic codes were created based on the themes that emerged from the qualitative data. When new themes arose, thematic codes were created, and previously assessed comments were reviewed again in an iterative process. Themes were then grouped under larger categories of themes. Upon completing the coding, thematic summaries were written for each major theme category.

The thematic analysis was conducted for each of the following open-ended survey questions:

1. Has the COVID-19 pandemic affected your experience with endometriosis? If so, please specify in the comment box.
2. Please use the comment section to specify what other in-school supports would be necessary or if you have any comments to add.
3. Please use the comment section to specify what other supports you have received or if you have any other comments to add.
4. If you have any comments, please include them in the box below.

Results

The results are organized into six main sections. The first section includes the participants' demographic background and attrition. The second section includes quantitative results of the *Endometriosis Impact Questionnaire* (EIQ; Moradi et al., 2019) outcomes. The third section includes a quantitative and qualitative analysis of outcomes for received in-school supports. The fourth section includes a quantitative and qualitative analysis of endorsed (i.e., deemed necessary) in-school supports. The fifth section includes an analysis of qualitative outcomes regarding participants' experience with COVID-19, and finally, the sixth section presents general comments of the participants.

1. Demographics and Attrition

Initially, 256 participants initiated the survey, hosted on LimeSurvey. However, 82 participants provided incomplete responses or did not meet the inclusion criteria, resulting in a final dataset of 174 responses. Among the participants who were excluded from the analysis (*n*=82), 27 participants did not provide any responses, 40 participants provided only demographic details, one reported the lack of endometriosis symptoms while in school, and one reported the absence of an endometriosis diagnosis. Additionally, 13 participants residing outside of Canada were excluded from the analysis. See Table 1 for participants' demographics.

For participants who passed the initial inclusion criteria, responses were included if participants provided responses through the end of the in-school support section (*n* = 42) or concluded the entire survey (*n* = 132), resulting in the final dataset of 174 responses. The language distribution reflected the diversity of the participants, with 85% completing the survey in English (*n* = 146) and the remainder in French (*n* = 28). Among the participants, 39 were current students, and 135 were former students who had experienced endometriosis symptoms during their time in school but were not currently in school. Questions with missing responses were noted to maintain transparency in the analysis process.

Table 1

Participants Demographics

Characteristic	All participants N (%)	Current students n (%)	Former students n (%)
Province			
British Columbia	12(6.9)	2(5.1)	10(7.4)
Alberta	20(11.5)	7(17.9)	13(9.6)
Manitoba	25(14.4)	1(2.6)	24(17.8)
Saskatchewan	5(2.9)	2(5.1)	3(2.2)
Ontario	60(34.5)	15(38.5)	45(33.3)
Quebec	37(21.3)	10(25.6)	27(20.0)
Prince Edward Island	0	0	0
Newfoundland and Labrador	9(5.2)	1(2.6)	8(5.9)
Nova Scotia	3(1.7)	0	3(2.2)
New Brunswick	2(1.1)	0	2(1.5)
Northwest Territories	0	0	0
Nunavut	0	0	0
Yukon	0	0	0
Prefer not to say	1(0.6)	1(2.6)	0
Age group			
14-17 years	3(1.7)	2(5.1)	1(.7)
18-24 years	26(14.9)	17(43.6)	9(6.7)
25-34 years	76(43.7)	11(28.2)	65(48.1)
35-44 years	55(31.6)	8(20.5)	47(34.8)
45-54 years	14(8.0)	1(2.6)	13(9.6)
Gender			
Female	166(95.4)	36(92.3)	130(96.3)
Male	1(0.6)	0	1(0.7)
Non-binary	3(1.7)	2(5.1)	1(0.7)
Transgender	1(0.6)	0	1(0.7)
Questioning	1(0.6)	1(2.6)	0
Prefer not to say	1(0.6)	0	1(0.7)
Missing	1(0.6)	0	1(0.7)
Social economic status			
Low	30(17.2)	7(17.9)	23(17.0)
Middle	119(68.4)	26(66.7)	93(68.9)
High	15(8.6)	4(10.3)	11(8.1)
Unsure	7(4.0)	2(5.1)	5(3.7)
Prefer not to say	2(1.1)	0	2(1.5)
Diagnosis by			
Pelvic exam	12(6.9)	7(17.9)	5(3.7)
Ultrasound	30(17.2)	3(7.7)	27(20.0)
Magnetic resonance Imaging	10(5.7)	2(5.1)	8(5.9)
Laparoscopy	81(46.6)	18(46.2)	63 (46.7)

Characteristic	All participants N (%)	Current students n (%)	Former students n (%)
Prefer not to say	8(4.6)	2(5.1)	6(4.4)
Other	33(19)	7(17.9)	26(19.2)
Other diagnoses?			
Yes	124(71.3)	28(71.8)	96(71.1)
No	41(23.6)	7(17.9)	34(25.2)
Prefer not to say	7(4.0)	4(10.3)	3(2.2)
Missing	2(1.1)	0	2(1.5)
Family member Diagnosed			
Yes	50(28.7)	13(33.3)	37(27.4)
No	77(44.3)	15(38.5)	62(45.9)
Unknown	47(27.0)	11(28.2)	36(26.7)

2. Impact of Endometriosis on Students: Quantitative Results

For the EIQ, as the last 4 weeks' recall period was included in the current study and not in the original EIQ, the internal consistency and reliability of each dimension at the 4-week recall period was derived from a factor analysis using Cronbach's alpha to test the reliability of the last 4 weeks' recall period. Aligned with the EIQ design, a Cronbach's alpha of ≥ 0.7 was deemed satisfactory (DeVon et al., 2007; Moradi et al., 2019). The first dimension (psychosocial, 33 items) resulted in a Cronbach's alpha of .936 (EIQ = 0.98) for the 4-week period. The second dimension (sexuality, 7 items) obtained a Cronbach's alpha of .806 at the 4-week time point (EIQ = .93). The third dimension (fertility, 3 items) revealed a Cronbach's alpha of .55, slightly below the acceptable range. The fourth dimension (employment, 11 items) obtained a Cronbach alpha of .93. The factor analysis of the fifth dimension (education, 6 items) resulted in a Cronbach alpha of 0.96. Lastly, the sixth dimension (lifestyle, 3 items) obtained a Cronbach alpha of .71, which was also deemed acceptable. Notably, only the fertility dimension fell below the satisfactory range, which could be due to the dimension only containing 3 items, and potentially influenced by the research's focus on students, for whom fertility concerns might be reduced due to educational pursuits. The EIQ scores for current students are detailed in Table 2.

Table 2

Current Students' Responses on the Endometriosis Impact Questionnaire

EIQ dimensions	Last 4 weeks	Last 12 months	1 to 5 years ago	More than 5 years ago
Physical-Psychosocial				
Mean ± SD	68.36 ± 20.82	74.90 ±18.66	74.94 ± 13.34	71.02 ± 16.75
Participants (n)[a]	30	30	30	30
Sexuality				
Mean ± SD	55.67 ± 23.05	58.86 ± 20.36	57.44 ± 21.32	60.41 ± 21.78
Participants (n)	25	25	25	22
Fertility				
Mean ±SD	73.33 ±30.82	73.08 ± 28.33	65.38 ± 27.27	48.46 ± 27.84
Participants (n)	13	13	13	13
Employment				
Mean ± SD	51.37 ± 28.33	54.83 ± 26.16	61.85 ± 24.78	52.45 ± 27.79
Participants (n)	25	23	24	22
Educational				
Mean ± SD	51.79 ± 28.73	55.79 ± 26.48	55.96 ± 25.17	55.67 ± 24.33
Participants (n)	27	28	28	28
Lifestyle				
Mean ± SD	31.38 ± 19.13	31.49 ± 16.80	34.94 ± 18.91	30.62 ± 15.28
Participants (n)	29	29	29	27

Note. [a] Number of responders for whom that dimension at that recall period was applicable.

The EIQ scores are calculated on a scale from 0-100; a higher score means a greater impact of endometriosis on that dimension of life. 0= minimum impact of endometriosis, as measured by the EIQ; 100= maximum possible impact of endometriosis, as measured by the

EIQ. Over four recall periods, the highest impact of endometriosis was on fertility, followed by the physical-psychosocial dimension, with the lifestyle dimension having the lowest impact. Examination of skewness and kurtosis values for each recall period across all dimensions indicated adherence to acceptable criteria. Despite the conformity to statistical benchmarks, the scores were assessed for normality with the Shapiro-Wilk test and normal Q-Q plots. The scores for the lifestyle dimension at the last 4 weeks and 12 months and the education dimension at the recall point of more than 5 years ago were not normally distributed. Given that the data was not normally distributed, a non-parametric test was conducted when comparing groups.

Participants' responses exhibited considerable variability, as indicated by the large standard deviations. Notably, the calculated standard deviations align with the scores reported by Moradi et al. (2019) in piloting the EIQ with 423 Australian women. The substantial standard deviations may be attributed to the individualized nature of the endometriosis experience, emphasizing the diverse impact that endometriosis has from one individual to another. The data were not transformed, as the non-normality is integral to the research, and transformation might result in loss of information (Bastow Wilson, 2007; Uchechukwu Marius, 2010).

For current students, endometriosis had affected their lives the most in the physical-psychosocial dimension over the last 12 months and the previous 1 to 5 years, while the lifestyle dimension consistently showed the least impact across all four time points. Generally, current students reported the lowest impact in the last 4 weeks, except for the fertility dimension, where the impact peaked, but caution should be taken as only 13 current students completed the fertility dimension. In the last 4-week recall period, endometriosis had the highest impact on fertility, followed by the physical-psychosocial dimension, with the least impact in the lifestyle dimension. Over the last 12-month recall period, endometriosis had the highest impact on the physical-psychosocial dimension, followed by the fertility and lifestyle dimensions. In the 1 to 5 years recall period, endometriosis had the highest impact on the physical-psychosocial dimension, with the lifestyle dimension experiencing the least impact. For the more than 5 years recall period, endometriosis had the highest impact on the physical-psychosocial dimension, followed by the fertility dimension. Overall, reported scores by current students on the EIQ varied greatly; but in general, students reported a score above 50 (moderate impact) in the physical-psychosocial, fertility, sexuality, employment, and education dimensions, and a score below 50 (mild impact) in the lifestyle dimension.

Skewness and kurtosis values for each recall period across all dimensions for former students were within the acceptable ranges. Assumptions of normality based on the Shapiro-Wilk test and normal Q-Q plots were assessed and were found to be non-homogeneous. As scores were not normally distributed, a Mann-Whitney *U* test was conducted to determine if there were significant differences between current students' and former students' responses on the EIQ. A *p*-value $<.05$ was considered statistically significant.

For former students, the scores reported on the EIQ suggest endometriosis symptoms have the highest influence on the physical-psychosocial dimension, recalled in the last 12 months, followed by fertility, recalled in the last 4 weeks (see Table 3). The lowest impact was on lifestyle across all four time points. Overall, the influence of endometriosis was lowest more than 5 years ago across all dimensions except for the lifestyle and sexuality dimensions, where the impact was highest. In general, current students and former students had similar trends in their responses. However, as expected, several former students reported the educational dimension as non-applicable in the last 4 weeks and last 12 months recall periods, as they were no longer in school.

Analysis of the Mann-Whitney U test (see Table 4) indicated current students had significantly higher scores than former students on the sexuality dimension in the last 4 weeks ($U = 783$, $p = 0.028$). Furthermore, current students had significantly higher scores on the sexuality dimension at the last 12 months’ recall periods than former students ($U = 764.50$, $p = 0.017$). In other dimensions and recall periods, current students’ and former students’ responses did not significantly differ ($p > 0.05$).

Table 3

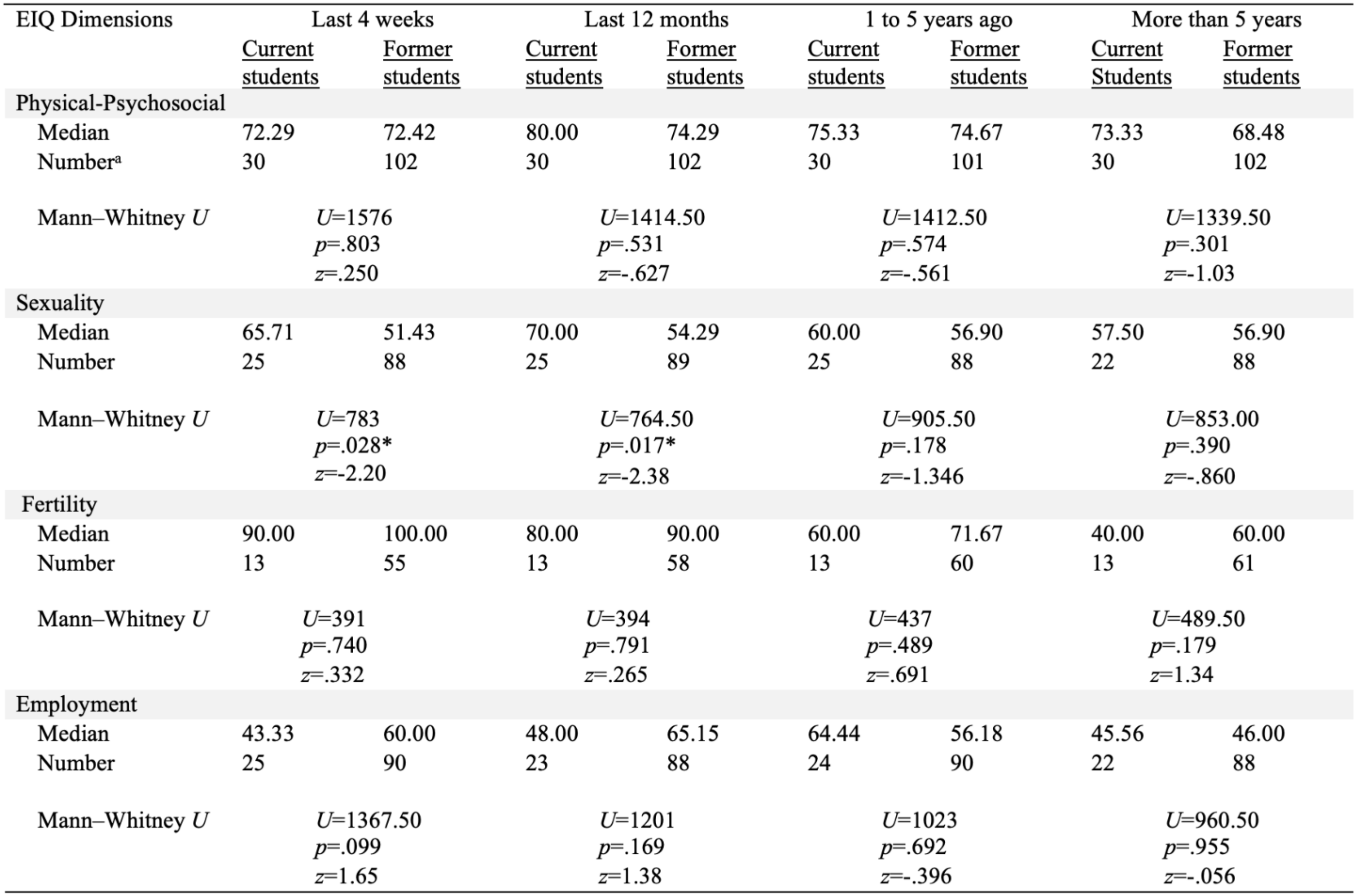
Former Students' Responses on the Endometriosis Impact Questionnaire

EIQ dimensions	Last 4 weeks	Last 12 months	1 to 5 years ago	More than 5 years ago
Physical-psychosocial				
Mean±SD	70.00±18.06	74.90±18.66	72.67±14.37	67.6±16.59
Participants (n)[a]	102	102	101	102
Sexuality				
Mean±SD	53.13±22.00	56.49±19.71	57.66±17.53	55.17±21.45
Participants (n)	88	89	88	88
Fertility				
Mean±SD	73.27±32.30	72.64±30.99	69.28±28.66	60.76±31.29
Participants (n)	57	58	60	61
Employment				
Mean±SD	61.56±28.10	63.71±26.87	59.48±23.84	52.79±26.43
Participants (n)	90	88	90	88
Educational				
Mean±SD	78.33±30.64	56.44±26.54	57.94±26.56	52.22±22.90
Participants (n)	2	6	42	87
Lifestyle				
Mean±SD	32.54±17.11	35.66±20.90	37.24±20.90	36.45±22.76
Participants (n)	92	93	93	92

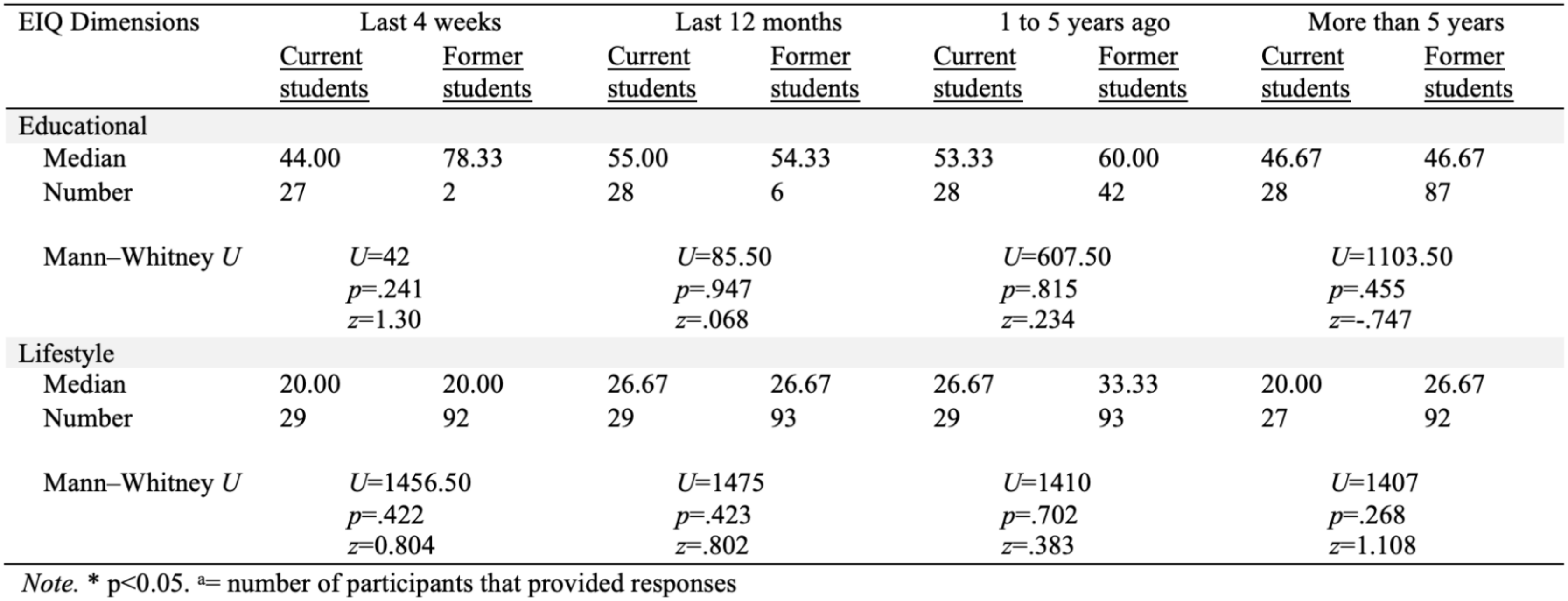
Note. [a]Number of responders for whom that dimension at that recall period was applicable.

Table 4

Comparison of Responses Between Current and Former Students on the Endometriosis Impact Questionnaire



EIQ Dimensions	Last 4 weeks		Last 12 months		1 to 5 years ago		More than 5 years	
	Current students	Former students	Current students	Former students	Current students	Former students	Current Students	Former students
Physical-Psychosocial								
Median	72.29	72.42	80.00	74.29	75.33	74.67	73.33	68.48
Number[a]	30	102	30	102	30	101	30	102
Mann–Whitney *U*	*U*=1576 *p*=.803 *z*=.250		*U*=1414.50 *p*=.531 *z*=-.627		*U*=1412.50 *p*=.574 *z*=-.561		*U*=1339.50 *p*=.301 *z*=-1.03	
Sexuality								
Median	65.71	51.43	70.00	54.29	60.00	56.90	57.50	56.90
Number	25	88	25	89	25	88	22	88
Mann–Whitney *U*	*U*=783 *p*=.028* *z*=-2.20		*U*=764.50 *p*=.017* *z*=-2.38		*U*=905.50 *p*=.178 *z*=-1.346		*U*=853.00 *p*=.390 *z*=-.860	
Fertility								
Median	90.00	100.00	80.00	90.00	60.00	71.67	40.00	60.00
Number	13	55	13	58	13	60	13	61
Mann–Whitney *U*	*U*=391 *p*=.740 *z*=.332		*U*=394 *p*=.791 *z*=.265		*U*=437 *p*=.489 *z*=.691		*U*=489.50 *p*=.179 *z*=1.34	
Employment								
Median	43.33	60.00	48.00	65.15	64.44	56.18	45.56	46.00
Number	25	90	23	88	24	90	22	88
Mann–Whitney *U*	*U*=1367.50 *p*=.099 *z*=1.65		*U*=1201 *p*=.169 *z*=1.38		*U*=1023 *p*=.692 *z*=-.396		*U*=960.50 *p*=.955 *z*=-.056	



EIQ Dimensions	Last 4 weeks		Last 12 months		1 to 5 years ago		More than 5 years	
	Current students	Former students	Current students	Former students	Current students	Former students	Current students	Former students
Educational								
Median	44.00	78.33	55.00	54.33	53.33	60.00	46.67	46.67
Number	27	2	28	6	28	42	28	87
Mann–Whitney *U*	*U*=42 *p*=.241 *z*=1.30		*U*=85.50 *p*=.947 *z*=.068		*U*=607.50 *p*=.815 *z*=.234		*U*=1103.50 *p*=.455 *z*=-.747	
Lifestyle								
Median	20.00	20.00	26.67	26.67	26.67	33.33	20.00	26.67
Number	29	92	29	93	29	93	27	92
Mann–Whitney *U*	*U*=1456.50 *p*=.422 *z*=0.804		*U*=1475 *p*=.423 *z*=.802		*U*=1410 *p*=.702 *z*=.383		*U*=1407 *p*=.268 *z*=1.108	

Note. * $p<0.05$. ^{a}= number of participants that provided responses

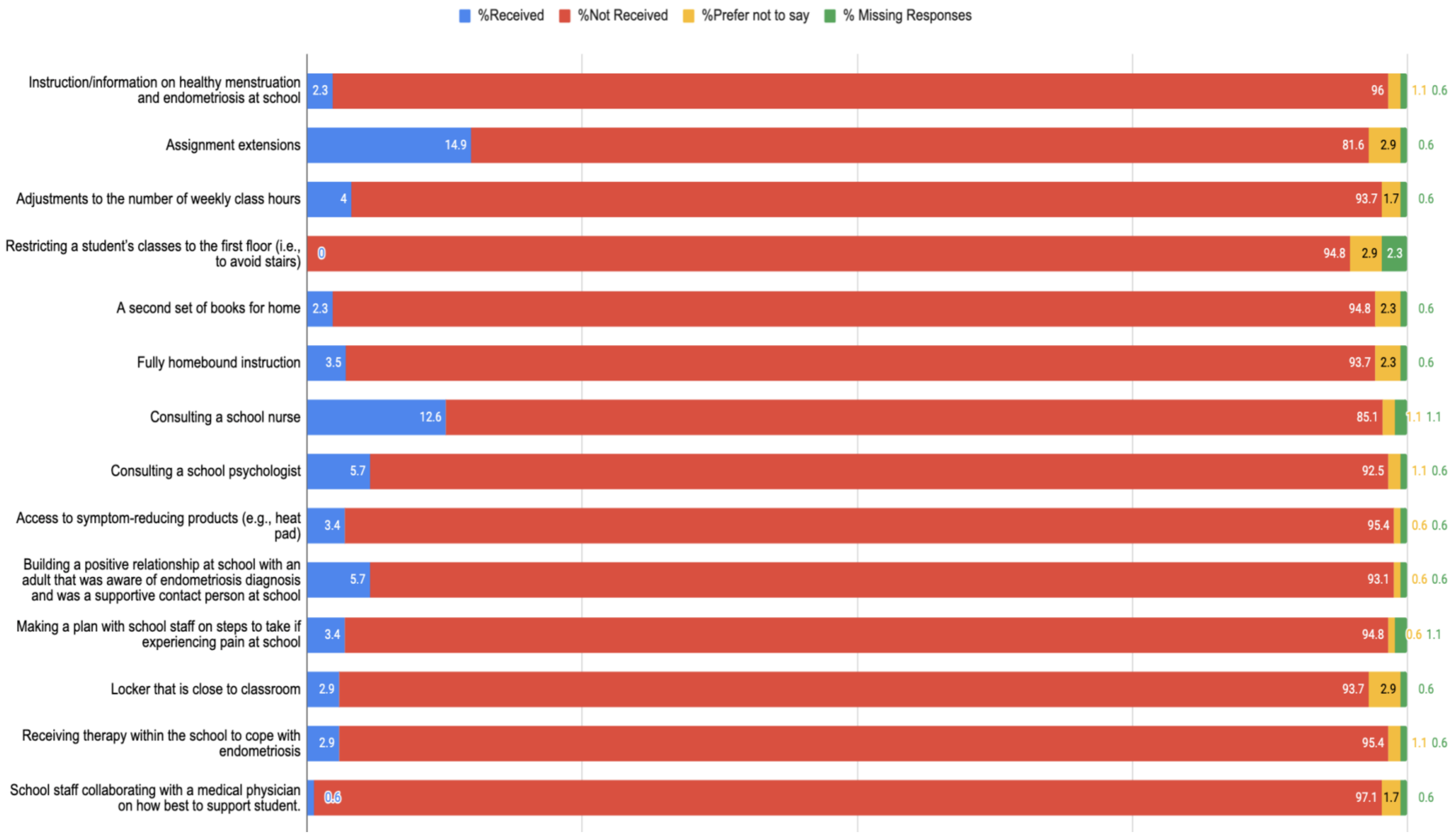
3. In-School Supports Received by Participants with Endometriosis: Quantitative and Qualitative Results

Quantitative Results

Participants were asked about receiving different in-school supports during their time in school (see Figure 2). Participants reported most frequently receiving assignment extensions and consulting a school nurse. Conversely, restricting a student's classes to the first floor (i.e., to avoid stairs) and school staff collaborating with physicians emerged as the support options least received by students. In general, most participants (69%) reported that they had not received any of the supports from the provided in-school supports list.

Figure 2

Types of In-School Supports Received by Participants



Qualitative Results

Few participants (6/48;12.5%) reported receiving some form of support from their school. Support included counselling services, extra time to complete work, consultation with a nurse, and access to class recordings when unable to attend class. One participant reported: "I had access to a school counsellor/therapist for my mental health issues both related and not related to endometriosis." (ID202). Close to half of the participants (20/48; 41%), reflected on the ways that not receiving in-school support negatively impacted their lives. Participants reported being stigmatized and told by school staff (i.e., teachers and nurses) that their pain was normal, leading to feeling dismissed. One participant expressed their experience with a lack of support:

> At university [approximately three years ago], there were many times the elevators were broken down and I could not take the stairs so I could not get to class. At the time, I was using a cane because my endometriosis pain was so bad. I later had to drop out of university and became bedridden until I had my first laparoscopy, where they found stage four endometriosis when I was 21. I also asked for presentation notes and slides to be sent to me from professors, and even though I was marked as a student with a disability, they refused and would not allow me to access the notes, so I would not know what was taught in those classes that I missed because I could not climb the stairs. I exclusively took public transportation to university, which was really hard on my body, and because I was a young person who looked totally fine on the outside except for the cane, I was repeatedly yelled at for taking up the disabled seating. (ID101)

Types of School Settings (Elementary, High School, College, or University) for In-School Supports Reported as Received

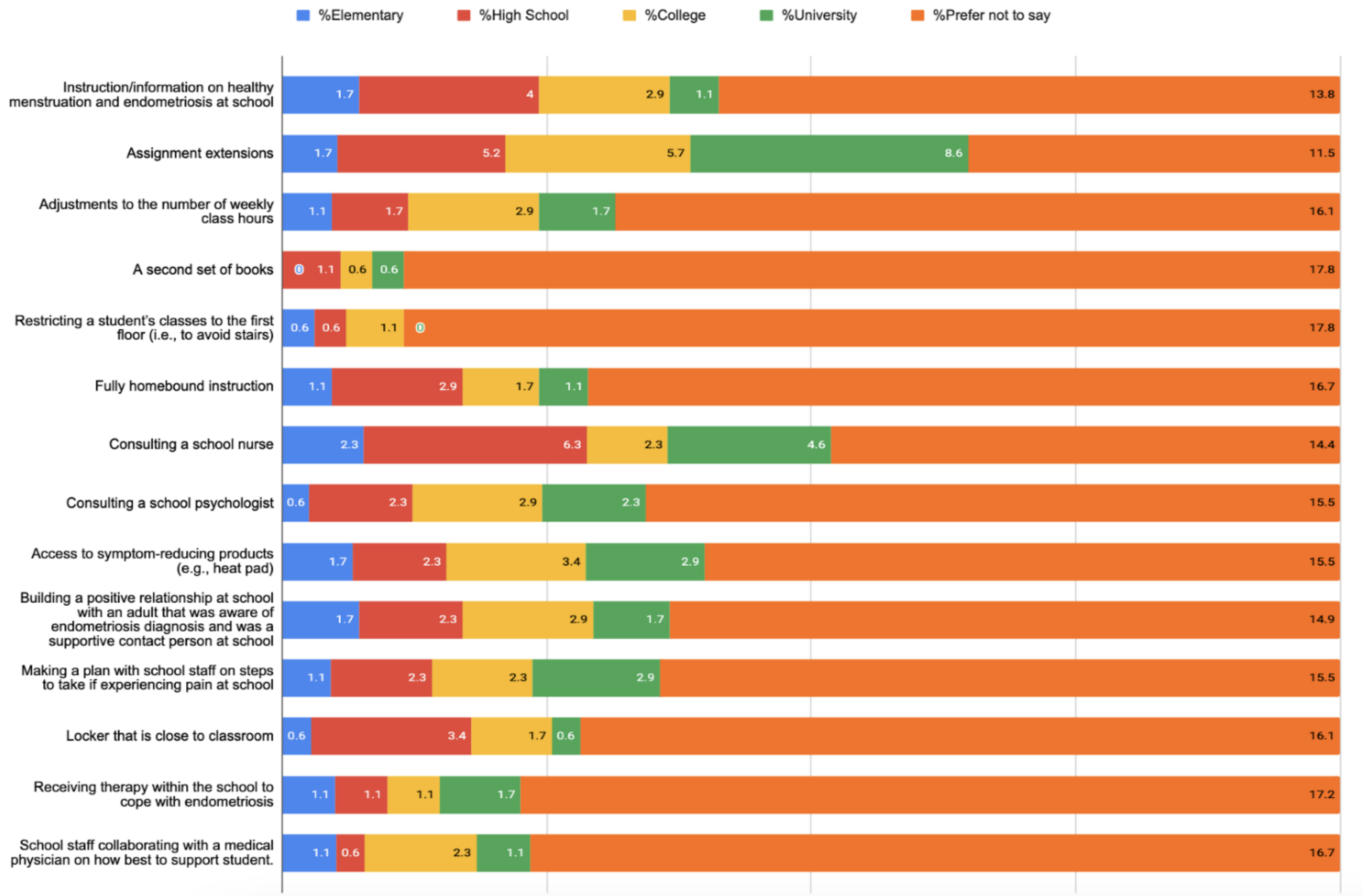
Quantitative Results

Participants were asked about the specific type of school setting where the listed in-school support services were received. In the overall analysis, elementary school emerged as the least frequently selected response. Extension of assignments emerged as the most reported in-school support received, a trend observed predominantly in university settings. Overall, 47/174

(27%) participants reported receiving at least one support in a school setting. Figure 3 provides a detailed description of participants’ responses. No qualitative results have been collected for this topic.

Figure 3

Types of School Settings for In-School Supports Received by Participants



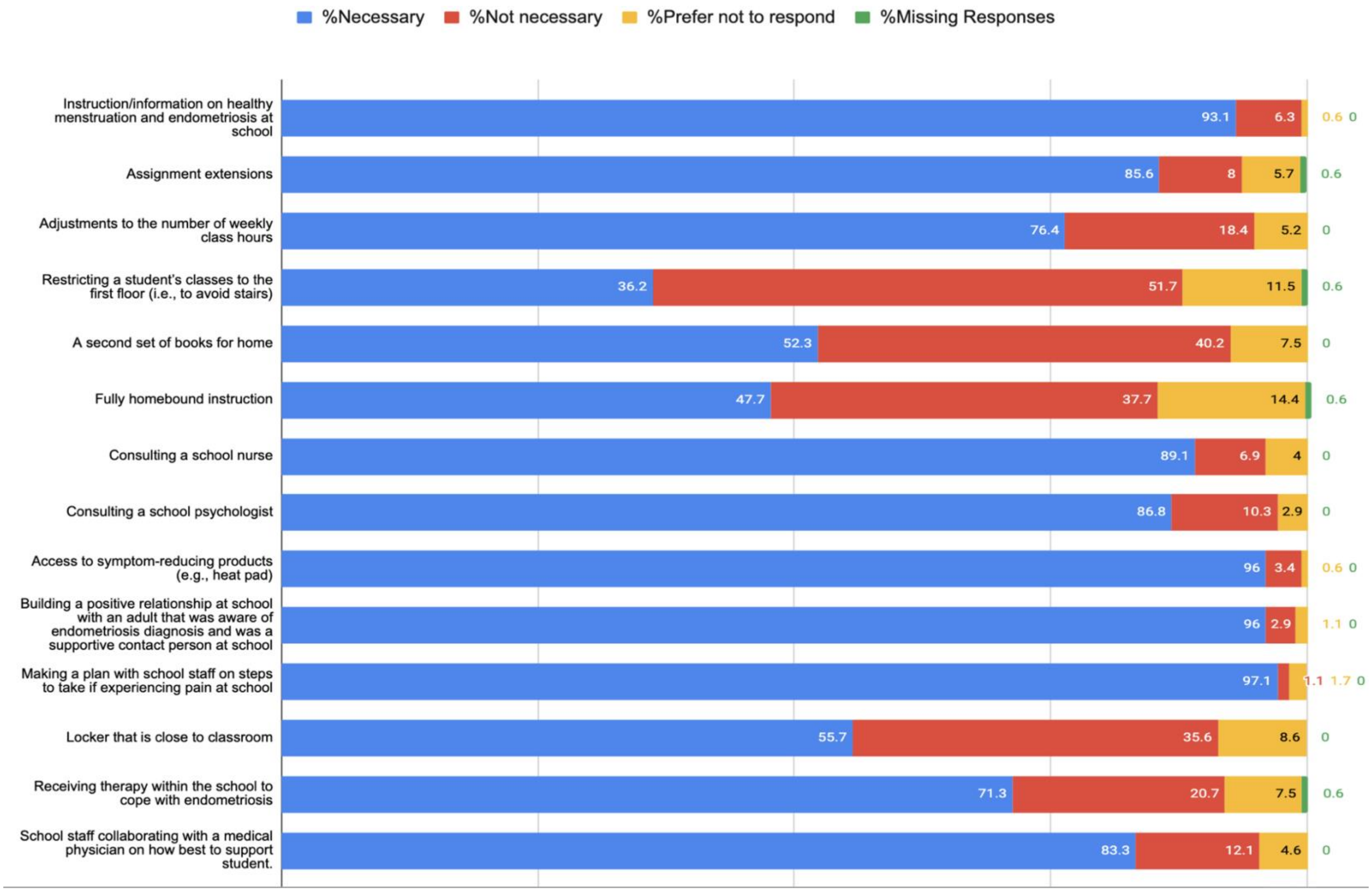
4. In-School Support Services Reported as Necessary: Quantitative and Qualitative Results

Quantitative Results

Based on the frequency of participants' responses to the in-school supports list, the most necessary support was making a plan with school staff on steps to take if they experienced pain while being in school (see Figure 4). As reported by participants, the least endorsed in-school support was restricting a student's classes to the first floor (i.e., to avoid stairs). Most (12/14) of the in-school supports were endorsed by more than 50% of participants, while only two in-school supports were reported by participants as necessary by less than 50% of participants (i.e., restricting classes to the first floor and fully homebound instruction).

Figure 4

Types of In-School Supports Reported as Necessary by Participants



Qualitative Results

Close to half of the participants (81/174; 46%) commented on the type of support needed for students suffering from endometriosis in school-based settings. Participants reported a need for increased awareness amongst students and staff of healthy menstruation and endometriosis, and that students with endometriosis should be validated and supported, which would have made a positive difference in their lives. A majority (62/81; 76%) also identified additional in-school supports they considered necessary that were not listed in the provided In-School Support List retrieved from the scoping review conducted by Gittens et al. (2023; see Table 5). In addition, two participants suggested that in-school supports should be provided without a doctor’s note or official diagnosis, and eight participants reported that supports should be provided with discretion and tailored to students’ needs. Furthermore, two participants specified that support should be provided for side effects of medication (e.g., nausea and fatigue).

Table 5

Additional In-School Supports Reported by Participants as Necessary

Supports	*n*
Access to snacks to help manage fatigue	2
Customized workspaces to be able to work in comfort (ergonomic) and have access to a washroom nearby	4
Access to the washroom while in class to manage excessive bleeding	12
Access to pain relief products when in pain	10
Access to hygiene products when menstruating to manage excessive bleeding	5
Priority class registration to choose classes that better align with student’s symptomology (e.g., choosing afternoon classes due to experiencing pain in the morning)	2
Priority seating to facilitate close access to an exit or washroom	1
Priority parking due to reduction in mobility	1

Access to healthcare services in school settings to manage symptoms and mental health	3
Permission to wear comfortable clothing such as sweatpants which provides comfort when bloated and in pain	1
Permission to refrain from activities such as gym class	9
Access to assignments ahead of time to allow to account for loss of productivity	1
Access to schoolwork if they could not attend school	2
A reduced course load to limit stress and anxiety	2
Allowing students to go home when in pain	4
Permission to complete tests in a distraction-free room as the toll that chronic pain takes can impact the ability to concentrate	1
Access to resource support to enhance students learning skills	2
A private room in which to lie down when feeling unwell	11
Access to audiobooks/audio textbooks to limit the number of books to carry	1
Note takers when being absent because of pain and fatigue	1
A limit on the number of exams per day to reduce fatigue	2
Flexible school schedules to accommodate medical appointments	2
In-school support groups to meet with other students with endometriosis	1
Access to virtual learning to make learning accessible even when not able to attend in-person	12
The ability to take breaks when experiencing pain to help manage pain	2
Access to elevators due to reduction in mobility	5
Flexibility in taking tests so that tests can be rescheduled due to a flare up occurring	5

In participants’ written comments, a minority (16/81;19%) expressed that their symptoms were dismissed by school staff and health care professionals and shared the importance of receiving validation and emotional support from school staff. One participant reported:

> I was told a painful cycle is normal and to just suck it up, so I did. If someone had cared to realize what was happening, I wouldn’t have had to wait until I was 30 to receive my diagnosis and gotten more beneficial treatment earlier. (ID036)

A total of 28/81(34%) participants discussed the need for school staff members and students to understand menstruation and endometriosis. One participant wrote:

> Teachers should be taught to recognize symptoms in their students, particularly those who have been taught to ‘tough out the pain,’ or ‘fake being fine.’ Sometimes ‘good’ students need intervention to take care of themselves and not feel guilt for leaving class in pain. (ID181)

Finally, a minority of participants (11/81; 13%) reflected on how receiving any listed in-school support may have changed their experience at school. For example, one participant stated:

> All of these supports would have absolutely enabled me to stay in school whilst going through my pain crisis due to endometriosis. If I had these things available to me, I would have been able to graduate on time and attend university. (ID190)

Types of School Settings (Elementary, High School, College, or University) for In-School Supports Reported as Necessary

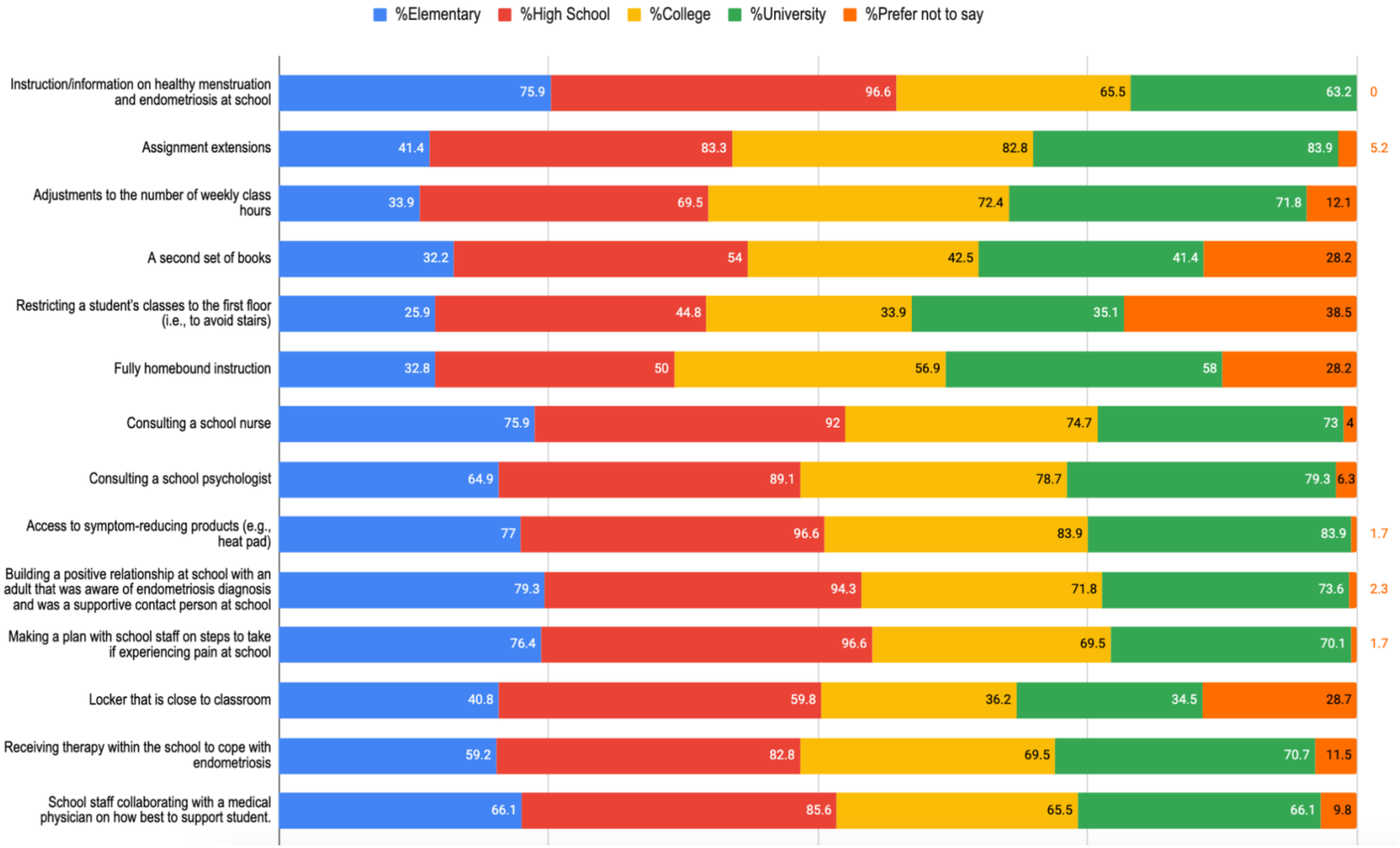
Quantitative Results

In general, participants reported the elementary school setting as needing the least in-school supports in comparison to high school, college, and university (see Figure 5). In an elementary school setting, participants chose “building a positive relationship at school with an adult aware of the endometriosis diagnosis and serving as a supportive contact person at school” as the most necessary in-school support. By contrast, participants identified “making a plan with school staff on steps to take if experiencing pain at school, receiving instruction/information on healthy menstruation and endometriosis at school, and access to symptom-reducing products (e.g., a heating pad)” as the most necessary supports across all settings.

Conversely, “restricting a student’s classes to the first floor (i.e., to avoid stairs)” emerged consistently as the least endorsed support in nearly all settings. In the college setting, participants selected “receiving assignment extensions” and “access to symptom-reducing products” as the most necessary in-school supports. Lastly, in the university setting, participants gave “receiving assignment extensions” the highest endorsement, whereas “a locker close to the classroom” received the lowest endorsement. No qualitative data was collected in relation to the type of support in different school settings.

Figure 5

Types of School Settings for In-School Supports Reported as Necessary by Participants



Relationship Between Support Perceived as Necessary and Actual Support Received

Quantitative Results

Fischer’s exact test analyses employing a phi coefficient (Φ) were computed to investigate the association between participants’ perspectives on the necessity of in-school support and the actual receipt of said support. Among the 13 Fischer’s exact tests analyses conducted, the Φ coefficients indicated no strong association between participants’ endorsement of in-school support necessity and the receipt of such support for 11 out of the 13 support services listed (see Table 6). There was a small (as indicated by the phi coefficient) but statistically significant relationship between reporting assignment extensions as necessary and receiving assignment extensions, $p = .047$, $\Phi =.160$. Participants who endorsed assignment extensions were more likely to have received such support. Furthermore, a small significant positive association was also found between reporting fully homebound instruction as necessary and receiving homebound instruction, , $p =.023$, $\Phi =.182$. Participants who reported fully homebound instruction as necessary were more likely to report receiving such support.

A chi-square goodness-of-fit test was performed to determine whether the proportion of participants who reported that their classes were not restricted to the first floor equally selected the support as necessary or not necessary. The distribution significantly differed between reporting the support as necessary or not necessary, X^2 (1) = 13.23, $p = <.001$. No qualitative results were collected on the relationship between received and necessary in-school supports.

Table 6

Comparison between participants reporting in-school support necessary and receiving the support

In-school supports		Received		Not Received		*Φ*	*p*
		n	%	*n*	%		
Instruction/information on healthy menstruation and endometriosis at school	Necessary	4	2.30	155	89.08	0.043	1.00
	Not Necessary	0	0	12	6.89		
Assignment extensions	Necessary	24	13.79	123	70.69	0.160	0.047*
	Not Necessary	0	0	23	13.21		
Adjustments to the number of weekly class hours,	Necessary	6	3.45	124	71.26	0.107	0.338
	Not Necessary	0	0	41	23.56		
A second set of books for home,	Necessary	3	1.72	86	49.42	0.071	0.622
	Not Necessary	1	.57	81	46.55		
Restricting a student's classes to the first floor (i.e., to avoid stairs).	Necessary	0	0	60	34.48	n/a	<0.001
	Not Necessary	0	0	107	61.49		
Fully homebound instruction	Necessary	5	2.87	76	43.68	0.182	0.023*
	Not Necessary	0	0	89	51.15		
Consulting a school nurse	Necessary	21	12.7	130	74.71	0.133	0.134
	Not Necessary	0	0	19	10.92		
Consulting a school psychologist	Necessary	8	4.60	140	80.46	-0.048	.626
	Not Necessary	2	1.15	21	12.07		

Access to symptom-reducing products (e.g., heat pad)	Necessary	5	2.87	159	91.38	0.036	1.00
	Not Necessary	0	0	7	4.02		
Building a positive relationship at school with an adult that was aware of endometriosis diagnosis and was a supportive contact person at school	Necessary	9	5.17	155	89.08	-0.074	0.349
	Not Necessary	1	0.57	6	3.45		
Planning with school staff on steps to take if experiencing pain at school	Necessary	6	3.45	159	91.38	0.033	0.834
	Not Necessary	0	0	5	2.87		
Locker that is close to the classroom	Necessary	3	1.72	92	52.87	0.016	1.00
	Not Necessary	2	1.15	74	42.53		
Therapy within the school to cope with endometriosis	Necessary	4	2.30	118	67.82	0.032	1.00
	Not Necessary	1	0.57	47	27.01		
School staff collaborating with a medical physician on how best to support student	Necessary	1	0.57	141	81.03	0.035	1.00
	Not Necessary	0	0	29	16.67		

Note. a= a chi-square goodness of fit test was conducted

5. Experience of Students with Endometriosis during the COVID-19 Pandemic: Qualitative Results

As the data collection occurred during the latter stages of various closures and restrictions prompted by the COVID-19 pandemic, information was gathered to ascertain the impact of the pandemic on individuals with endometriosis. Many participants (112/174; 64%) responded in the comments section of the survey regarding how the COVID-19 pandemic affected their experiences with endometriosis. The comments focused mainly on the effects of COVID-19 and vaccination on their gynecological health and the effect of pandemic-related confinement on their access to education and health care.

Challenges and facilitators to health care. A majority (89/112; 79%) of participants mentioned experiencing challenges accessing health care services during the pandemic, with eighty-eight participants (88/112; 78%) reporting delays in appointments and health services. One participant stated:

> I had to wait 3 years for my surgery due to surgical backlogs, despite daily disabling pain. My surgeons had no OR [operating room] access, all other treatment options failed, and they had no way to help me. (ID107)

Participants (24/112; 21%) also reported delays in receiving surgeries due to surgeries being put on hold during the COVID-19 pandemic (March 2020 to September 2022). Finally, two participants even resorted to travelling internationally to receive surgery due to delays in services in Canada. However, two participants with reduced mobility reported having access to virtual or phone appointments with their physicians, which improved service accessibility for them. For example, one participant stated.

> Medical appointments are much more manageable now that they’re virtual however wait times for treatment are much longer. (ID 122)

Health decline. A minority of participants (13/112;11%) stated they experienced declines in their health and challenges with coping with pain. For example, one participant commented: “Being at home a lot made me focus on my symptoms and pain more, [with] less distractions from it ” (ID30). The statement indicates the isolation of the pandemic led participants to a loss of access to coping mechanisms (e.g., physical activities, distractions) for pain, resulting in a decline in health. Furthermore, a minority (18/112; 16%) of participants conversely reported that the negative impacts of the symptoms on their lives and/or schoolwork were reduced due to the new flexible context of the COVID-19 pandemic. The pandemic offered flexibility in participants’ schedules to work from home and attend virtual classes and medical appointments. A participant stated:

> The ability to have flexible work hours due to the fact we were all working from home during the lockdown. I used that flexibility when needed when dealing with my endo pain. (ID206)

A few participants (9/112; 8%) reported adverse side effects from the COVID-19 vaccination, and changes in the menstrual cycle or heavy menstrual bleeding after contracting COVID-19. One example is a participant who reported: “[An] extremely painful period when sick with COVID-19. [I] bled heavier and pain was worse than usual. The next period was also worse than usual” (ID038).

6. Comments from Participants Regarding the Survey: Qualitative Results

At the end of the survey, close to half of the participants (14/32; 43%) were thankful for the study and were reflective on their own experiences in the school system:

> Thank you for researching this disease and working towards a higher standard of understanding for those affected. I think if I was met with understanding and compassion for my symptoms while in school, I may have even completed my schooling. (ID214)

Seven participants (7/32; 22%) reported community awareness of endometriosis as essential for early diagnosis and treatment. One participant stated:

> There needs to be earlier intervention and diagnosis for people with uteruses, as I ended up infertile after 24 years of no treatment because every doctor (male and female) that I saw never once suggested I have endometriosis (even though they[doctors] did comment that I had ‘chocolate cysts’ but never did/said anything more other than it will go away on its own), or [they] shook me off saying that I’m ‘too young’ to have anything wrong with me. (ID119)

The above participant’s response reflects the impact of untreated endometriosis, which several other participants shared. Three participants discussed the possible monetary impact of endometriosis. For example, one participant stated:

> I require excision surgery, but there are no qualified surgeons in Canada who are able/willing to do this surgery. Thus, I manage my symptoms by taking the birth control pill continuously (I haven’t had a period in 10 years) while I contemplate spending $30,000 to get surgery done in Romania. This is another large amount of money that I have had to pay out of my own pocket. (ID261)

Two participants expressed worry for their loved ones who might also have endometriosis and experience the same difficulties and delays that they did before receiving a diagnosis and treatment. Three participants reported using alternative treatments, including cannabis and psychedelics, to help them cope with chronic pain from endometriosis symptoms. Participants also believed some alternative treatments should be covered by Canada’s universal, publicly funded health care system.

Discussion

Overall, students’ responses suggest that endometriosis moderately affects students’ physical well-being, psychosocial well-being, fertility, sexuality, employment, education, and mildly affects their lifestyle. The results are consistent with several other studies reporting that endometriosis considerably affects individuals, including their physical health, emotional well-being, relationships, and quality of life (Facchin et al., 2015; González-Echevarría et al., 2019;

Roomaney & Kagee, 2018). Endometriosis requires comprehensive management involving medical, surgical, and psychological interventions to address the multifaceted nature of the condition and its implications. Given the high prevalence of endometriosis (10%) among girls, women, and individuals born with a uterus and the effect it has on various aspects of life, it is important for staff working in different settings (medical, work, and school) to be knowledgeable about how to support individuals with endometriosis.

Participants with endometriosis were and remain victims of stigma in the school setting, in part due to the ignorance of school staff regarding endometriosis, what constitutes typical and abnormal menstruation, and taboos around discussions of menstruation. Due to ignorance regarding menstrual health and endometriosis, students' chronic pain and their needs linked to severe bleeding were dismissed. Despite students reporting a clear need for in-school supports to better aid their well-being and functioning in a school setting, only one fourth of participants received support. The lack of support for students with endometriosis received in the school setting is consistent with other studies on women with endometriosis who report being stigmatized in clinical/hospital, employment, and social settings (Gupta et al., 2021; Hays, 2020; Seear, 2009).

The results of this study are also consistent with gender theory; as endometriosis is a gendered condition, research on women's health has reported women experiencing stigma and being dismissed when they report experiencing chronic pain and atypical menstrual bleeding (Kocas et al., 2023), suggesting the presence of broader gender biases throughout the healthcare industry that are also reflective of a gender bias in society. The lack of support in school-based settings further highlights the stigmatization faced by girls, women, and individuals born with a uterus who have endometriosis. Following Goffman's work on stigma, Knaak et al. (2017)

highlighted that a lack of awareness, lack of skills, negative attitudes, and workplace stigma can create barriers to accessing services and a decline in the quality of services in healthcare. Knaak et al. (2017) have suggested that a method to remove the barriers to accessing services and improve the quality of healthcare services is by reducing stigma. To reduce the stigma around endometriosis in schools, schools should discuss menstrual health and endometriosis education, use an empathetic approach with students, provide support resources, dispel myths regarding menstrual health and endometriosis, engage parents, open discussions with students, and provide flexible accommodations (Gupta et al., 2018, 2021; Mackenzie & Cohn, 2023; Randhawa, 2023; Randhawa et al., 2021; Seear, 2009; Simpson et al., 2021; Sims et al., 2021). By applying the above strategies, educational institutions can play a pivotal role in diminishing stigma and creating a more inclusive atmosphere for students with endometriosis.

When individuals are provided with psychoeducation on a subject, such as endometriosis, they develop a deeper understanding of its indications and symptoms, resulting in increased awareness (Khan et al., 2022). Students (and former students) in the current study reported psychoeducation as one of the most needed supports, which is similar to students with chronic pain, as there is a lack of awareness about healthy menstruation and endometriosis among students and school staff (King et al., 2018; Solé et al., 2018). Furthermore, academic accommodations were also highlighted as being crucial to supporting students with endometriosis. Some of the academic accommodations reported as necessary in the qualitative data, such as taking tests in a quiet room and additional time for tests, are similar to the in-school support services reported as being beneficial for students with learning difficulties and chronic health difficulties (Brown et al., 2020; Lipka et al., 2019; Lovett & Nelson, 2021).

Insufficient support from schools for students with endometriosis can have substantial repercussions on their academic achievements and physical and mental well-being. A lack of support can result in academic interruptions, heightened absenteeism, adverse mental-health consequences, lack of access to accommodations, social isolation, and missed opportunities (Audebert et al., 2015; van Barneveld et al., 2022; Wróbel et al., 2022). Students may encounter elevated levels of stress, anxiety, and social isolation, which could result in the development of depression or other mental health disorders (Audebert et al., 2015; van Barneveld et al., 2022; Wróbel et al., 2022). A lack of support support might worsen physical health issues, including heightened pain and fatigue (Agarwal et al., 2019). School staff have the legal and ethical responsibility of ensuring a secure and encouraging learning environment for every student, including those with chronic health conditions, such as endometriosis. Hence, educational institutions must acknowledge the distinct requirements of individuals with endometriosis and establish policies that foster inclusiveness, comprehension, and assistance.

Implications

The following section will discuss the implications of the current study for human rights, the COVID-19 pandemic, and school policy.

Human Rights

Participants emphasized the importance of obtaining permission to use restroom facilities, access to menstrual hygiene products, and having the choice to refrain from participating in activities (i.e., physical education) when suffering from pain due to symptoms related to endometriosis, which raised concerns about basic human rights in school settings. In Canada, individuals with debilitating endometriosis are protected from discriminatory practices by human-rights charters and legislation (Canada, 2013), specifically the Canadian Charter of

Rights and Freedoms and The Canadian Human Rights Act (Constitution Act, 1982), which are Canadian laws put in place to maintain human dignity, health, and well-being and to protect and accommodate individuals with disabilities. To create a welcoming and inclusive learning environment, educational policies have to meet the needs of students who have been diagnosed with endometriosis. Educational policies that adhere to the requirements of students diagnosed with endometriosis to foster a supportive and inclusive academic setting. Such regulations can effectively contribute to the equitable provision of academic opportunities for students with endometriosis (As-Sanie et al., 2019; Fernley, 2021). Furthermore, access to education is indeed a fundamental human right, which further highlights the importance of ensuring that students with endometriosis have access to education (As-Sanie et al., 2019; Fernley, 2021).

Barriers

While the barriers to implementing in-school support services were not explored in the present study, supporting students with endometriosis in educational settings might be difficult due to multiple barriers that need to be addressed, including a lack of knowledge of endometriosis, social disapproval of discussions of menstrual health, late identification and diagnosis of endometriosis by healthcare professionals, and a lack of financial resources (Bodén et al., 2013; Márki et al., 2022; Randhawa et al., 2021; Zannoni et al., 2014). To overcome these obstacles, raising awareness and understanding and implementing academic accommodations is crucial. Training for school staff on endometriosis is needed, including an overview of the condition, treatment options, in-school support options, pain management, and legal considerations. An increased awareness about endometriosis and how to support students can help school staff collaborate in fostering students' well-being and school functioning (Angelhoff & Grundström, 2023; Bodén et al., 2013; Fagen et al., 2010).

COVID-19

The qualitative results underscored both the positive and negative effects of the COVID-19 pandemic on the participants. Healthcare systems worldwide experienced disruptions because of the overwhelming focus on the management of COVID-19 cases (Handelsman et al., 2023). Non-urgent medical interventions, including ones related to the diagnosis and treatment of endometriosis, were also affected by delays or cancellations. Participants reported that the COVID-19 pandemic increased creativity and flexibility in accommodating students, while such accommodations were not readily available before the pandemic. The transition to online learning and socializing has highlighted deficiencies in school and employment settings and presented opportunities for innovative solutions that are now recognized as feasible.

Consistent with the results of the current study, recent research has shown an increasing cohort of women who have documented notable alterations in their menstrual cycles, which are categorized as abnormal uterine bleeding, after receiving the vaccine or contracting COVID-19 (Edelman et al., 2022; Issakov et al., 2023; Male, 2021; Oliver, 2020). As endometriosis is closely intertwined with menstruation, any changes to the menstrual cycle due to COVID-19 could further exacerbate endometriosis symptoms.

School Policies

The current study can inform school policies to better support students with endometriosis. The implementation of flexible attendance standards can provide students diagnosed with endometriosis the opportunity to effectively manage their symptoms without the added burden of adhering to strict attendance requirements (Mastrangelo & Turnbull, 2022). The flexibility can be advantageous for students experiencing chronic pain, who are apprehensive about potential repercussions for their non-attendance in class. Academic accommodations such as assignment extensions, modifications to class schedules, and designated quiet spaces have been found to help students with learning or attention difficulties to focus and complete their coursework (Baker & Scanlon, 2016; Florell & Strait, 2020). Academic accommodations might help students effectively manage their academic responsibilities while accommodating their health requirements. Nevertheless, it is imperative to underscore the unique requirements of every student.

Future Directions

Future research should focus on how to close the gaps in providing students with endometriosis with in-school support by exploring which kind of services could improve their quality of life, emotional well-being, pain management, and education attainment (Agarwal et al., 2019; Bush et al., 2017; Ramani Devi et al., 2021). A website could be created to make the study's results accessible to school staff, allowing them to adjust support based on individual needs by selecting the forms of support most applicable to and beneficial for each student. Also, a randomized controlled trial could be conducted to determine the most effective in-school support services for students with endometriosis with a focus on endometriosis education and support services, such as academic accommodations (Ali et al., 2022; Ramani Devi et al., 2021; Randhawa et al., 2021). The trial should consider the efficacy of in-school support and the perspectives of stakeholders to understand the facilitators of and barriers to implementing such support.

Strengths and Limitations

The study used a mixed-methods design to understand the experiences of students with endometriosis in the educational setting. The qualitative component uncovered participants' lived experiences, while the quantitative component provided evidence of broader patterns regarding participants' responses to a list of in-school supports that was extracted from a scoping review (Gittens et al., 2023; submitted). While the study focused on the perspectives of students with endometriosis, it did not include the perspective and experience of stakeholders, such as families, school staff, or mental health professionals, who may have different views on ways to support students with endometriosis.

Another limitation of the present study is the length of the survey, which was approximately 25 minutes. Researchers suggest that a survey should be between 10 to 20 minutes to reduce the response burden (the effort required to complete a survey) and can potentially lead to fewer completed surveys and lower response rates (Galesic & Bosnjak, 2009; Rolstad et al., 2011; Yan et al., 2020). Forty participants attempted to respond to the survey, but stopped after providing the background information, which could be due to the length of the survey. Furthermore, only participants who self-reported being diagnosed with endometriosis were recruited, which could be interpreted as a limitation due to the delay in diagnosis for most individuals with endometriosis (Singh et al., 2020; Soliman et al., 2017; Surrey et al., 2020).

The current study may have selection bias, where the demographics and interests of participants may be skewed, limiting the generalizability of the survey results (Bethlehem, 2010). Participants may have specific characteristics or interests, which can also limit the external validity of the survey findings (Elston, 2021). Additionally, participant recruitment through online support groups may have excluded potential participants who are not in the groups. The results of the current study, however, are consistent with results from other studies (Bodén et al., 2013; Moradi et al., 2019).

Conclusion

Participants in the current study reported that endometriosis moderately affected their physical well-being, psychosocial well-being, fertility, sexuality, employment, and education. Participants overwhelmingly reported that most of the supports provided on the In-School Support List were necessary and identified additional supports as needed. Despite the clear need for support, current and former students were not adequately supported in school.

The current study is the first to explore the experiences of students with endometriosis in school-based settings and their various in-school support needs. The results of the current study emphasizes the importance of a supportive school environment, involving multiple stakeholders like students, parents, teachers, school staff, and healthcare professionals. The study highlights an urgent need for in-school support for Canadian students with endometriosis, as students are not being supported in their schools. Participants had stigmatizing experiences while in school, with some experiences involving human rights issues, such as a lack of access to washrooms, hygiene products, and education. The dismissal of their symptoms and the corresponding stigma experienced in the school setting are also reflections of the stigma seen in healthcare settings, which contributes to delays in diagnosis and access to treatment. The educational, healthcare, and corresponding human-rights issues need to be addressed by policymakers, stakeholders in education and healthcare settings, and future researchers.

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Chapter 5: Discussion

The rationale and goals for Study 1 and Study 2 are presented in this chapter, followed by a comprehensive discussion of the results obtained from both studies, including an analysis of the original contributions made by each study. Implications are examined in the chapter's final section, and future research directions derived from the findings are explored.

Rationale and Objectives

The current dissertation emphasizes that endometriosis is a complex and frequently misunderstood medical condition (Johnson et al., 2017). Endometriosis can be difficult to diagnose due to the wide range of its symptoms (Sims et al., 2021). Endometriosis is commonly misdiagnosed and understudied, resulting in a lack of understanding about endometriosis among the general population and healthcare providers (As-Sanie et al., 2019).

A lack of understanding and misdiagnosis of endometriosis can result in delayed diagnosis and inadequate symptom management, decreasing an individual's quality of life as untreated chronic pain can lead to low energy levels, affecting daily activities and relationships. Emotional distress can result from anxiety, depression, and other mental health disorders (Pino et al., 2023; Simpson et al., 2021; Wróbel et al., 2022). Endometrial tissue outside the uterus can produce inflammation, scarring, and adhesions, which interfere with reproductive function, making conception difficult. The disorder's chronic nature, as well as the difficulty in regulating its symptoms, can have a detrimental influence on mental health, relationships, work/school productivity, and overall quality of life (Pino et al., 2023; Simpson et al., 2021; Wróbel et al., 2022). Due to the invisibility of endometriosis, students may feel alienated or unsupported (Bodén et al., 2013; Gallagher et al., 2018; Gupta et al., 2021). Students may have difficulty finding peers who can relate to their circumstances, or a support network understanding of their difficulties. Social isolation can increase the condition’s emotional burden and impair students’ general well-being and school functioning (Bodén et al., 2013; Gallagher et al., 2018; Gupta et al., 2021). In a study by Gupta et al. (2021), 58.8% of college students with symptoms suggestive of endometriosis reported that endometriosis affected their functioning in school, causing students to miss school, preventing them from participating in activities due to pain, and creating symptoms that were dismissed by school staff.

Seven studies published between 2013 and 2022 specifically focused on the topic of endometriosis in an educational environment (Bodén et al., 2013; Bush et al., 2017; Gupta et al., 2018, 2021; Khan et al., 2022; Ramani Devi et al., 2021; Rusda & Rahman, 2019). Four of the seven studies aimed to increase endometriosis awareness among students in school settings. The remaining three studies focused on exploring students’ experiences with endometriosis concerning the availability and experience with school health services. However, the seven studies failed to explore the diverse in-school needs of students with endometriosis. Thus, to better understand how a school setting could support students with endometriosis, a scoping review (Study 1) was conducted of in-school support for students with chronic pain, given that chronic pain is a primary symptom of endometriosis. Following the scoping review, a survey study (Study 2) was conducted to understand the experience of students with endometriosis in the school setting and the impact that endometriosis had on various aspects of their lives.

Results of Studies 1 and 2

The scoping review of in-school supports for students with chronic pain (Study 1) revealed six distinct themes: knowledge, fostering positive relationships, seeking guidance from school health experts, implementing academic accommodations, providing therapy inside school settings, and promoting collaboration among stakeholders. The results of the survey (Study 2) revealed diverse types of in-school interventions and accommodations considered necessary by individuals with endometriosis who experienced symptoms while in school. The results of the scoping review were consistent with the survey study's results in emphasizing the importance of having information about endometriosis available. Overall, the results of the current investigation indicate that Canadians with endometriosis reported several in-school supports as necessary; still, only 27% of participants had received at least one support while they were in school.

The research findings indicated a diverse set of essential in-school support needs. In line with findings reported in other studies (Bodén et al., 2013; Bolt et al., 2011; Bush et al., 2017; Logan & Simons, 2010), certain forms of support have been reported to be beneficial for students with chronic pain were similarly useful for students specifically affected by the chronic pain resulting from endometriosis. According to the participants in Study 2, the most crucial support within the educational setting was a contingency plan created in collaboration with school staff, outlining the essential procedures to be taken when the student experiences discomfort at school. Establishing constructive rapport with a knowledgeable adult who is aware of the student's endometriosis diagnosis and serves as a supportive point of contact within the school setting, as well as the availability of symptom-alleviating supplies such as heating pads, were identified as essential by more than a half of participants.

According to the participants' reports, one of the least essential forms of in-school support was the restriction of a student's courses to the first floor (to prevent the use of stairs), which may not be feasible, as students typically have classes in different classrooms and on different floors. Like students who experience chronic pain, students (current and former) in Study 2 also identified psychoeducation on endometriosis as an essential form of support (King et al., 2018; Solé et al., 2018). The uniformity in students’ stated need for in-school support may stem from the necessity of addressing chronic pain for all students, regardless of the specific kind of pain.

The results of Study 2 identified in-school supports previously unreported in other chronic pain research, such as unrestricted access to restroom facilities and access to menstrual hygiene products. The novel finding might be attributed to the lack of focus of previous research on conditions calling for the availability of restroom facilities and hygiene products. Furthermore, participants in Study 2 reported that their symptoms were dismissed in the school setting and that they experienced stigma. The results are comparable to research on endometriosis in healthcare and employment settings, which reported that the concerns of individuals with endometriosis were dismissed (Gupta et al., 2018, 2021; Mackenzie & Cohn, 2023; Randhawa, 2023; Randhawa et al., 2021; Seear, 2009; Simpson et al., 2021; Sims et al., 2021). As a result of social stigma about menstruation and women’s health, the general population, including healthcare professionals, tend to minimize or disregard the symptoms experienced by girls, women, and other individuals with endometriosis (Miller, 2019; Seear, 2009; Sims et al., 2021). The dismissal of students' symptoms might result in the postponement of diagnosis, insufficient treatment, or a general disregard for women’s health issues (Seear, 2009). Additionally, the social disapproval associated with menstrual disorders and women’s reproductive health can impede their access to suitable medical treatment and assistance for their condition (Sims et al., 2021). The dismissal and social stigma faced by individuals with endometriosis are indicative of a wider trend of gender-based discrimination in both healthcare and society.

Implications

The following section discusses the implications of the current dissertation for the COVID-19 pandemic, human rights, barriers to schools' integration of in-school services, and the stigma of victim-blaming. The section finishes with recommendations for staff training.

COVID-19 Pandemic

Future researchers can explore whether participants' responses to additional in-school services were affected by the COVID-19 pandemic, as several participants suggested online or hybrid schooling as a possible accommodation and intervention to implement. The scoping review conducted on students with chronic pain (Study 1) neither discussed nor reported on online schooling or a hybrid model of schooling, perhaps due to the COVID-19 pandemic's increasing creativity and flexibility in accommodating students. Prior to the pandemic, such interventions were not readily available. According to participants, the COVID-19 pandemic had a positive effect on individuals who could benefit from flexible scheduling, online schooling, or hybrid schooling options. The rapid transition to online and distance learning, socializing, and therapeutic activities has brought to light deficiencies in infrastructures (school, employment, healthcare), while presenting possibilities for developing innovative and inclusive solutions (Long et al., 2021).

Human Rights

Participants commented in the survey (Study 2) on the lack of certain in-school supports in the comment sections of the survey, suggesting a concern about the violation of basic human rights. For example, participants reported needing to wear comfortable clothing, to be allowed to access the bathroom, and be exempted from certain activities when in pain due to endometriosis symptoms, suggesting that their basic rights might not be respected in academic settings.

Furthermore, participants described facing discrimination in their school settings due to their endometriosis symptoms. In Canada, individuals living with debilitating endometriosis are protected by human-rights charters and legislation designed to prevent discrimination and ensure equal treatment for all citizens. The Canadian government states that:

> According to the traditional bio-medical approach, disability is viewed as a medical or health problem which prevents or reduces a person's ability to participate fully in society. In contrast, the social approach views disability as a natural part of society, where attitudes, stigma, and prejudices present barriers to people with disabilities, and prevent or hinder their participation in mainstream society. (Human Resources and Skills Development Canada, 2013)

Such charters and laws uphold the rights and dignity of individuals with disabilities, including those with chronic health conditions such as endometriosis. Some key human-rights charters and laws protecting individuals with endometriosis in Canada include the Canadian Charter of Rights and Freedoms and The Canadian Human Rights Act (Constitution Act, 1982).

Incorporating respect for menstrual needs and gynecological conditions, such as endometriosis, in schools should not depend solely on the voluntary initiatives of school boards and school staff. Instead, it should be recognized as part of the government's duty to defend fundamental human rights (Babbar et al., 2022). Schools should seek to address and challenge the social stigma often associated with menstruation. Doing so will promote the inclusion of those who menstruate. A shift in attitudes about menstruation from being seen negatively to being viewed positively would further help girls, women and individuals who menstruate to live to their potential and honor their human rights (Riley et al., 2020).

Barriers

Unfortunately, despite participants in Study 2 reporting that in-school support from the provided list was necessary, only one fourth of participants had received any support while in school. Probable reasons for the gap between the services needed and those received, as described in Study 1, could be students' difficulty with self-advocacy, a lack of school resources, or a lack of education on menstrual health. Researchers have reported that individuals with endometriosis must become skilled in self-advocacy to receive services (Bergen et al., 2023; Debolt, 2023; Rodriguez, 2022; Woolf & Bie, 2022; Young et al., 2020; Zale et al., 2020). While Study 2 did not explore the reported barriers to receiving in-school support, future studies need to explore possible barriers to implementing such forms of support for students.

Educators and school personnel may be unaware of endometriosis and its effect on students (Ali et al., 2022). The lack of endometriosis awareness can lead to a failure to recognize and address the unique requirements of students with endometriosis. Peers, teachers, and even healthcare professionals may judge, disbelieve, or discount endometriosis symptoms, thereby creating an environment unsupportive of the needs of those with endometriosis and making it difficult for students to seek treatment or even disclose their concerns (Márki et al., 2022).

While researchers have not directly studied school staff's awareness of endometriosis, a lack of awareness has been reported among healthcare workers (Carneiro et al., 2020). Educational institutions may lack resources and support services specifically designed for students with endometriosis, including a lack of school psychologists, counsellors, or healthcare specialists who can offer specialized assistance (Gittens et al., 2023; Logan et al., 2007, 2012). A lack of financial resources may also limit the availability of supports, such as sufficient school staff or quiet rest areas (Gittens et al., 2023).

Stigma

Less attention has been given to the social variables influencing the well-being of individuals with endometriosis (Kocas et al., 2023). Stigma, defined as a socially unacceptable attribute, includes perceived, experienced, and self-stigma components (Goffman, 1986).

Perceived stigma refers to an individual's perception of how society views them, while *experienced stigma* refers to actual stigmatization and discrimination (Goffman, 1986). *Self-stigma*, often manifesting as feelings of shame, blame, hopelessness, and guilt, is the emotional experience of the adverse effects of stigma (Goffman, 1986). Stigma is linked to mental well-being factors, such as hopelessness, depression, suicidal thoughts, limited social support, low self-esteem, and overall life dissatisfaction (Gupta et al., 2018, 2021; Mackenzie & Cohn, 2023; Randhawa, 2023; Randhawa et al., 2021; Seear, 2009; Simpson et al., 2021; Sims et al., 2021).

Although attempts have been made to combat the social stigma around menstruation by increasing menstrual health education, menstruation is often still depicted negatively in society (Johnston-Robledo & Chrisler, 2013). The stigma surrounding women's health in healthcare settings can stem from various sources, including gender bias, cultural taboos, the medicalization of women's bodies, reproductive health stigma, intersectional stigma, and lack of research and education about women's health (Gibbons & Birks, 2016; Knaak et al., 2017; Ostrach et al., 2017). Gender disparity marginalizes individuals who menstruate, while restricted access to education reinforces misunderstandings about menstruation and endometriosis (Sims et al., 2021). Stigma can be worsened by the insufficient availability of feminine hygiene products and sanitation facilities (Miller, 2019). Having open discussions regarding menstruation and reproductive health can effectively combat unfavourable beliefs about menstruation (Miller, 2019). Endometriosis faces the same stigma as menstruation, as it is associated with menstruation (Sims et al., 2021). Addressing stigma in healthcare settings requires systemic changes, such as implementing comprehensive training programs for healthcare providers, promoting gender-sensitive and culturally competent care, fostering open communication between healthcare providers and patients, and implementing policies and initiatives that prioritize women’s health research, education, and access to quality care (Knaak et al., 2017; Nyblade et al., 2019). Reducing the stigma in healthcare for women’s health would also reduce the stigma that women and other individuals born with a uterus may face in other settings.

Participants in Study 2 reported being stigmatized in the school setting. Chronic pelvic pain, fatigue, and menstrual irregularities are often invisible, leading to skepticism and disbelief from peers and teachers (Gupta et al., 2021; Johnston-Robledo & Chrisler, 2013; Miller, 2019; Seear, 2009; Sims et al., 2021). Menstrual-health taboos and discomfort about discussing endometriosis further contribute to its stigma. The perception of chronic pain being normal can invalidate one’s experiences and feelings, further exacerbating the stigma of the condition. If healthcare settings and school settings do not address the stigma that individuals with endometriosis face, dismissal of students’ experiences could continue, as well as the negative effects on students’ well-being and disruptions in their education (Gupta et al., 2021; Sims et al., 2021).

Victim Blaming

Participants in Study 2 reported that they were considered weak or too sensitive due to having difficulty managing debilitating menstrual pain. Victim blaming in relation to endometriosis may arise due to misunderstandings or biased judgments about endometriosis (Ballweg, 1997; Cole et al., 2021). Victim blaming occurs when individuals, including health care professionals, attribute the symptoms of endometriosis to variables like stress, increased sensitivity to pain, or emotional issues rather than recognizing and addressing the physiological cause of the symptoms (Cole et al., 2021). Victim blaming can lead to delayed diagnosis, inadequate treatment, and emotional distress and contribute to the stigmatization of individuals with endometriosis (Wischmann & Ditzen, 2023). Endometriosis is a legitimate medical condition with well-defined diagnostic criteria and established treatment protocols. Dismissing symptoms or implying that the pain is faked or exaggerated can worsen feelings of isolation and frustration and contribute to stigma (Hays, 2020).

Staff Training

The negative interactions that participants in Study 2 reported experiencing with school staff highlight the need for school staff to be trained on endometriosis and how to support students with endometriosis. The implementation of endometriosis training among school staff is crucial for establishing an atmosphere that is supportive of students with endometriosis (Gupta et al., 2018, 2021). Westin et al. (2024) evaluated the effect of a brief educational intervention regarding endometriosis on staff at a healthcare centre. Westin et al. (2024) reported an increase in knowledge about endometriosis among the participating centres at follow-up. A training program should describe endometriosis, including its prevalence and typical symptoms (Roullier et al., 2021). The implications for school functioning, psychosocial consequences, available treatments, provisions of accommodations and support, strategies for effective communication, and pain management should also be included (González-Echevarría et al., 2019). Finally, training materials should be regularly updated and disseminated to school staff. Through the implementation of training programs, staff members can develop their understanding of the various obstacles encountered by students diagnosed with endometriosis (Bodén et al., 2013; Roullier et al., 2021).

Guidelines for Supporting Students with Endometriosis in School

The information gleaned in the current dissertation, combined with information from a support guide on chronic pain (Kids in Pain, 2023) and a brief guide for youth with endometriosis (Center for Young Women's Health, 2020), provides vital information about the type of material to include in a prospective guide for students with endometriosis. Individualizing support for students with endometriosis is necessary because, as revealed in Study 2, the experience of endometriosis can vary greatly among individuals.

School Policies

Flexible attendance policies would allow students with endometriosis to manage their symptoms without the pressure of having to leave home for school. Both students with endometriosis and students with other forms of chronic pain fear being penalized for not attending class; thus, they go to school even when in severe pain (Logan & Simons, 2010; Zannoni et al., 2014). In Study 2, participants reported a need for flexible attendance policies. For example, students could be granted excused absences for medical appointments, trips to the hospital, or for not feeling well. The development of additional means by which they could obtain the content covered in class, such as online resources or recordings, would be helpful. Furthermore, it is recommended that sex education classes be updated to include menstrual health and endometriosis education for students.

Endometriosis Education

Endometriosis awareness and education were among the most reported supports needed, suggesting that educating staff and students about endometriosis is important. Previous studies have developed educational material (e.g., Bush et al.'s (2017) *me* program, what about *me?*) to teach students about endometriosis in schools, but the material focused on endometriosis knowledge, not on how schools can support students with endometriosis (Bush et al., 2017; Simpson et al., 2021). Thus, endometriosis education could be a first step in supporting students, given that the current dissertation's results reveal a need not only for students to be educated about endometriosis but also for staff members to receive education. A program could be adapted and implemented to provide teachers and students with pertinent information regarding menstrual health and endometriosis.

Collaboration

Collaboration and communication among students, their families, teachers, and support staff must be established. A lack of communication can lead students with endometriosis to experience a sense of disconnection from their teachers and peers, which can impact their school functioning and future opportunities (Rubinsky et al., 2020; Wischmann & Ditzen, 2023). Hence, communication and collaboration would facilitate providing students with endometriosis with the required support and accommodations (Cox, 2005; Deacy & Morrison, 2015; King et al., 2018). Students would benefit from being invited to share their challenges, needs, and any necessary accommodations for their school experience with school staff. Frequent check-ins with a go-to person might be helpful to address issues and ensure that the needs of the students are being met (Logan et al., 2007; Logan & Simons, 2010; Wahl et al., 2021). Keeping lines of communication open with the student's healthcare providers is important to guarantee a cohesive strategy for treatment (Cox, 2005; Deacy & Morrison, 2015; King et al., 2018).

Academic Accommodations

Given that participants in Study 2 reported several academic accommodations as being necessary, students with endometriosis would benefit from their school's student accessibility centres (centres in schools that facilitate the implementation of academic accommodations for students) or disability-support services to receive academic accommodations (Handelsman et al., 2023). Students would benefit from having access to calm and quiet areas where they can go to relax or manage their symptoms if necessary. During the school day, having designated locations where students can speak to staff and take breaks is recommended. Furthermore, although resources may be limited in schools, it is recommended that students with endometriosis have access to counselling services or support groups to help address the potential issues endometriosis may pose for their emotional well-being and mental health.

Receiving academic accommodations may make it easier for students to concentrate on class materials rather than having to worry about trying to keep up with their classwork when experiencing discomfort or exhaustion (Baker & Scanlon, 2016; Florell & Strait, 2020). Academic accommodation could include extended deadlines for tasks, altered class schedules, additional time for tests, or access to quiet locations for resting if required. Moreover, for students whose symptoms interfere with regular classroom attendance, flexible learning conditions might allow students to manage their coursework while meeting their health needs. However, it is essential to emphasize the individual needs of each student, as discussed by participants in Study 2, who highlighted that endometriosis could present and affect each student differently; some students may have fewer symptoms, while others may experience many symptoms and debilitating pain. Thus, treatment and care should be tailored to each student.

Implications for School Psychologists

The current dissertation has implications for school psychologists who want to be involved in supporting students with chronic illnesses (Barraclough & Machek, 2010; Forlin, 2010; Jones & Salamon, 2019; Shaw et al., 2015). While students in Study 2 (current and former) reported several in-school supports as being necessary, very few received any support, indicating that there might be important barriers to implementing or accessing such support. The role of a school psychologist in Canada is described as conducting psychological and psychoeducational assessments and consultations, developing and evaluating prevention programmes, providing supervision and training, and conducting research (Montreuil, 2016).

School psychologists can play an important role in providing endometriosis assistance to students in educational settings. School psychologists can help students identify and assess endometriosis (by screening and making a referral to a physician); collaborate with teachers, parents, and healthcare professionals to learn more about the student's endometriosis symptoms and specific educational accommodations necessary for their success in school; and help develop and implement Individualized Education Plans (IEPs; Forlin, 2010; Shaw et al., 2015). IEPs detail the adjustments, alterations, and support services needed to ensure the student's academic achievement and access to education.

Students with endometriosis may have emotional concerns, such as stress, anxiety, or depression, because of endometriosis-related symptoms (González-Echevarría et al., 2019; Koller et al., 2023). Counselling services from school psychologists can help students cope with their feelings, develop appropriate stress-management strategies, and build resilience. School psychologists can also establish support groups or refer students to other mental health experts when necessary (Van Niekerk et al., 2022).

School psychologists with crisis intervention training can help coordinate and develop emergency plans specific to the student's needs (Jones & Salamon, 2019). School psychologists can advocate for students with endometriosis by raising awareness among school staff, parents, and the greater school community; helping clarify stereotypes about the disease and educating stakeholders about its effect on a student's educational experience; helping establish a welcoming and inclusive environment for students with endometriosis by raising awareness and empathy; and assisting students with endometriosis by applying their understanding of mental health, assessment, intervention, and teamwork (Barraclough & Machek, 2010; Forlin, 2010; Jones & Salamon, 2019). However, similar to other school healthcare professionals, access to school psychologists is limited in Canada as a single school psychologist frequently covers several schools (Finn, 2016; Jordan et al., 2009).

Future Directions

In general, more research is needed on the topic of students with endometriosis and how to support students with endometriosis. The results from Study 1 (scoping review) highlighted the lack of researchers conducting studies to demonstrate the efficacy of school intervention and support for students with chronic pain or endometriosis. Researchers have reported that in-school support for students with learning difficulties and neurodivergence can increase their quality of life, academic success, and symptoms of anxiety and depression (Baker & Scanlon, 2016; Florell & Strait, 2020; Lovett & Leja, 2013). Thus far, researchers have not explored the efficacy of school-based interventions for students with endometriosis.

Future researchers can improve evidence of the efficacy of in-school supports for students with endometriosis by conducting a randomized controlled trial focused on the effectiveness of in-school support on students with endometriosis. Group comparisons (between the intervention group and a waitlist control group) could be used to determine whether the intervention affects the factors known to be associated with endometriosis, such as: (a) perceived self-efficacy; (b) the use of coping strategies (e.g., diverting attention, reinterpreting pain sensations, ignoring pain sensations, praying and hoping, catastrophizing, or increasing activity levels); (c) quality of life (e.g., the experience of body pain, general health status, vitality, social and emotional functioning, and mental health); (d) knowledge of endometriosis; and (e) symptoms of anxiety and depression. The delay in diagnosing endometriosis, however, may cause recruitment challenges for researchers, as finding students with a confirmed diagnosis of endometriosis in elementary and high school may be difficult. Given the current diagnosis delays for endometriosis, it may be best to conduct research on college or university students or screen students for symptoms suggestive of endometriosis.

Furthermore, in Study 2 (survey study), participants reported negative experiences with school staff. There is currently no available research on school staff perspectives on supporting students with endometriosis. Logan et al. (2007) explored the school staff's perspectives on supporting students with chronic pain, revealing important concerns about school staff not being equipped to support students with chronic pain. A similar study should also be conducted for students with endometriosis to better understand school staff's knowledge about endometriosis, perspective on supporting students with endometriosis, and the barriers and facilitators to implementing school-based interventions for students with endometriosis.

Chapter 6: Conclusion and Summary

The primary objective of this dissertation was to understand the needs and experiences of students diagnosed with endometriosis throughout Canada within an educational setting, including elementary and secondary school, college, and university. The aims were to: (a) examine the existing literature on in-school support services (educational and other types) for individuals with chronic pain; and (b) enhance comprehension of the requirements of students with endometriosis. To address the objectives of this dissertation, two studies were conducted.

Study 1 highlighted six primary domains of support for students living with chronic pain in schools: knowledge, collaboration, in-school therapy, consultation with school health specialists, the development of positive relationships, and offering academic accommodations. The study analyzed the provision of in-school support for youth suffering from various types of persistent pain, suggesting that these programs may be relevant to all students. The barriers to implementing in-school assistance were insufficient school resources and school staff’s lack of awareness and education on chronic pain.

Study 2’s aim was to gain a deeper understanding of the effects of endometriosis and the specific support needs of these students within an educational setting. Different forms of in-school support were deemed essential and aligned with the findings of the scoping review. The study emphasized the significance of helping students with endometriosis and the influence of endometriosis on the participants’ lives. Furthermore, the gap in services was highlighted by participants’ identifying several necessary supports, but only one fourth of participants reported having received support while in school.

An awareness of healthy menstruation and endometriosis in educational settings continues to be needed; academic accommodations, however, were also reported as critical.

Participants reported being stigmatized, which is consistent with previous research on individuals with endometriosis who experience stigma at work and in healthcare settings. Thus, individuals with endometriosis appear to be stigmatized across various settings, which is problematic, as experiencing stigma can cause negative impacts on mental health, lost opportunities, social isolation, and disruptions to work and schooling (Kocas et al., 2023).

The current dissertation advances the literature on endometriosis in the school setting. Endometriosis can substantially affect the lives of school-aged individuals, as it often causes pain that hinders their ability to attend school, do well academically, and participate in social activities (Seear, 2009). Nevertheless, how schools support or could potentially assist students with endometriosis has not been thoroughly explored by researchers (Gupta et al., 2018). Only seven studies have investigated endometriosis in the context of schools. The research has concentrated mainly on enhancing endometriosis awareness within the educational environment. While it is indeed imperative to increase awareness, it is equally vital for schools to address the requirements of students afflicted by this condition adequately.

The dissertation has extended previous findings of stigma in the school setting and provided clear examples of what types of support students with endometriosis report as being necessary. Furthermore, the results from the dissertation highlight the stigma that students with endometriosis face and the effect that the stigma and lack of support perpetuate. For example, students (and former students) reported school absenteeism, discontinuing their studies, mental health issues, a loss of schoolwork productivity, social isolation, and missed opportunities. The current investigation uncovered several in-school practices that could be put into place that would create a school culture and environment that reduces stigma toward students with endometriosis.

Implications for Practice

Given the importance of creating a school environment that reduces stigma and supports students with endometriosis, school staff and policymakers should seek to foster an educational setting that is open to dialogue regarding endometriosis, menstrual health, and respecting the human rights of students. The lead researcher of the current dissertation can collaborate with organizations like Action Canada and the Sex Information & Education Council of Canada (SIECCAN) to advocate for the importance of including menstrual health and endometriosis education in sex education classes. Such changes, however, may only be implemented if school staff are given the resources to be trained on endometriosis and how to support students with it.

The students (current and former students) in Study 2 reported that if policies are put in place in schools to foster an environment that is empathetic and understanding of endometriosis, it could potentially lead to earlier diagnosis of endometriosis and reduce the negative effect of endometriosis symptoms on students. Finally, school psychologists may be well positioned to support students with endometriosis, given their expertise in intervention and consultation.

Summary

The current dissertation contributes to the burgeoning research on supporting students with endometriosis in the school setting and creating a school environment that respects students’ rights to education and healthcare and reduces endometriosis stigma. Findings from this research continue to underscore the stigma that women experience regarding their health and the critical need to support students with endometriosis. The study provides guidance for future research on students with endometriosis.

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APPENDIX A

PARTICIPANT CONSENT FORM
SUPPORTING STUDENTS WITH ENDOMETRIOSIS: A CANADIAN PERSPECTIVE

Dear Participants:

We are pleased to share this information regarding a research project exploring the current impact of endometriosis on students and how they can be supported. This project is being conducted by Jalisa Gittens, Doctoral Candidate, and Dr. Ingrid Sladeczek in the Faculty of Education at McGill University. Given your experience with endometriosis, your involvement in this project will be invaluable towards gaining insight into the impact of endometriosis and how to support students with endometriosis.

Description of the Project: Endometriosis is a chronic condition that can impact individuals assigned female at birth as early as eight years old. In an attempt to gain a comprehensive understanding of the needs of students officially diagnosed with endometriosis in Canada, this study will identify the in-school supports that can be used to facilitate the learning of students with endometriosis in Canada and how endometriosis impacts their lives. Given the delay in diagnosis of endometriosis, retrospective responses will also be gathered to be able to include individuals that had experienced endometriosis symptoms while in-school but only received an official diagnosis later in life.

Study Procedures: The study will be completed through McGill Lime Survey. Should you agree to participate in this study, you will be asked to fill out a questionnaire to provide information about yourself and the impact that endometriosis has had on your life, and your experiences with endometriosis in the school setting, specifically regarding in-school support. This questionnaire should take approximately 25 minutes to complete. Please note that you may refuse to answer any questions on the questionnaire. There are no right or wrong answers to any of the questions, so please respond according to your feelings and experiences about how endometriosis has affected your life.

Potential Risks and Benefits: There are limited anticipated risks involved in participating in this study. The benefit of participating includes contributing to the research on in-school supports for students with endometriosis. However, some questions in the survey may cause psychological distress and discomfort, particularly questions relating to living with endometriosis. If you feel that you may become distressed as a result of discussing your endometriosis, please consider not participating in the study. If you do experience distress, please contact Ms. Jalisa Gittens at jalisa.gittens@mail.mcgill.ca or consult the following resources for support:

https://www.crisisservicescanada.ca/en/looking-for-local-resources-support/ or https://cmha.ca/find-help/if-you-are-in-crisis/

Furthermore, the results of this study will be utilized at a later stage of the project, which involves the implementation of a guide on how to support students with endometriosis. Your valuable participation will contribute towards a better understanding of the impact of endometriosis on students' lives and better meeting the needs of students with this condition.

Withdrawal from Study: Given the fact that participation is anonymous, once you submit your responses it can't be withdrawn.

Confidentiality: Please note that your participation in this study is confidential and anonymous. All completed electronic questionnaires will be kept in a password- protected OneDrive folder only accessible to the research team supervised by Jalisa Gittens and Dr. Ingrid Sladeczek. No identifying information will be used in any oral or written presentation of the results. Only combined data from all the questionnaires will be reported. Once you complete the questionnaire, you will be brought to another page where you can provide your email for contact concerning participation in later studies or would like to receive the results of the studies, the researchers will know your identity but will not be connected to your responses on the questionnaire.

Thank you kindly for considering participation in this important project. To get involved, please sign below. Should you have any questions, please feel free to contact Jalisa Gittens at jalisa.gittens@mail.mcgill.ca.

If you have any ethical concerns or complaints about your participation in this study and want to speak with someone not on the research team, please contact the McGill Ethics Manager at 514-398-6831 or Lynda.mcneil@mcgill.ca.

Sincerely,

Jalisa Gittens, MA	Ingrid Sladeczek, PhD

Doctoral Student/Project Coordinator McGill University, Department of Educational and Counselling Psychology jalisa.gittens@mail.mcgill.ca (514) 398-4908	Associate Professor McGill University, Department of Educational and Counselling Psychology (2019) (514) 398-3450

CONSENT TO PARTICIPATE IN PROJECT

By clicking the "Next" button and proceeding to the following page, I certify that:

- I have read all the information provided in the consent form and understand that the study will be conducted for research purposes only.
- I understand that my participation is voluntary, and I can withdraw from the study at any time prior to submitting the completed survey.
- I am voluntarily giving my consent for my participation in the current study.
- I have been notified that all the information that I provide will remain confidential.
- I understand that my consent is implied by the submission of the completed survey.

Submitting your study responses indicates that you consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities.

Please save or print a copy of this document to keep for your own reference.

Do you give your permission to be contacted in the future by a Sladeczek Research Team Member regarding your willingness to participate in future research studies related to endometriosis? If yes, please provide your email below.

☐ Yes ☐ No

APPENDIX B

Background Information

- Have you been diagnosed with endometriosis?
  ☐Yes
  ☐No
- Are you a person who has or has had a uterus?
  ☐Yes
  ☐No
- Are you 14 years or older?
  ☐Yes
  ☐No
- Do you live in Canada??
  ☐Yes
  ☐No
- What is your age?
  ☐14-17 years
  ☐18-24 years
  ☐25-34 years
  ☐35-44 years
  ☐45-54 years
  ☐55-64 years
  ☐65-74 years
  ☐75 years or older
  ☐ Prefer not to say
- Which gender do you identify with most?
  ☐ Male
  ☐ Female
  ☐ Transgender
  ☐ Genderqueer/ Non-Binary

  ☐ Questioning or unsure of gender identity
  ☐ Prefer not to say

- Are you currently a student?
  ☐ Yes
  ☐ If yes, what grade are you in?
  ☐ No
  ☐ Prefer not to say

- If you aren't a student, how long ago have you been out of school? ________
  ☐ Prefer not to say
  ☐ Not Applicable

- If you aren't currently a student or you are a student currently working, which of the following best describes your current occupation:
  ☐ Employed for wages
  ☐ Self-employed
  ☐ Out of work and looking for work
  ☐ Out of work but not currently looking for work
  ☐ A homemaker
  ☐ Retired
  ☐ Unable to work
  ☐ Prefer not to say
  ☐ Other:________________

- What is the highest level of formal education that you have completed?
  ☐ No schooling completed
  ☐ Primary school
  ☐ Middle school
  ☐ Some high school, no diploma
  ☐ High school graduate, diploma, or the equivalent
  ☐ Some college credit, no degree

☐ College degree/ CEGEP degree
☐ Trade/technical/vocational training
☐ Associate degree
☐ Bachelor’s degree
☐ Master’s degree
☐ Professional degree
☐ Doctorate degree
☐ Prefer not to say

- What is your socioeconomic status? (Perceptions of your social position relative to others based on income, educational attainment, and occupational prestige.)

☐ Low
☐ Middle
☐ High
☐ Prefer not to say

- In which province/territory do you currently live?

☐ Alberta
☐ British Columbia
☐ Manitoba
☐ New Brunswick
☐ Newfoundland and Labrador
☐ Northwest Territories
☐ Nova Scotia
☐ Nunavut
☐ Ontario
☐ Prince Edward Island
☐ Quebec
☐ Saskatchewan
☐ Yukon
☐ Prefer not to say

COVID-19

Has the COVID-19 pandemic affected you? If so, How?

Endometriosis-related background information

- How long have you been diagnosed with endometriosis? ________
- How did you receive your diagnosis of endometriosis?
  - ☐ Pelvic Exam
  - ☐ Ultrasound
  - ☐ Magnetic Resonance Imaging (MRI)
  - ☐ Laparoscopy
  - ☐ Other
  - ☐ Prefer not to say
- How many years ago did you first experience symptoms of endometriosis? ________
- How many endometriosis-related surgeries have you had since being diagnosed with endometriosis? ________
- What are the 3 worst endometriosis symptoms you have experienced? *Please check 3 items.*
  - ☐ Pelvic Pain
  - ☐ Digestive Problems / Gas
  - ☐ Nausea / Vomiting
  - ☐ Diarrhea / Constipation
  - ☐ Excessive bloating (water retention)
  - ☐ Heavy bleeding and/or clotting
  - ☐ Irregular periods
  - ☐ Bleeding or spotting between periods
  - ☐ Painful bowel movements

  - ☐ Painful urination
  - ☐ Severe migraine headaches
  - ☐ Sudden mood swings / Uncontrollable crying
  - ☐ Lower back pain and/or leg pain
  - ☐ If you are sexually active – Painful sex
  - ☐ Other: please specify ________________
  - ☐ Other: please specify ________________
  - ☐ Other: please specify ________________
  - ☐ Prefer not to say ________________

- What medications (pharmaceutical, herbal, nutritional) do you currently use to manage your pain? ______________ ☐Prefer not to say

- What treatments (e.g., meditation, massage, exercise, hot water bottle, etc.) do you use to help manage your pain?____________ ☐ Prefer not to say

- Do you have any previous or current physical and/or mental health diagnoses?
  - ☐ Yes (please specify)___________
  - ☐ No
  - ☐ Prefer not to say
- Have any of your family members been diagnosed with endometriosis?
  - ☐ Yes (please specify)____________
  - ☐ No
  - ☐ Unknown
  - ☐ Prefer not to say
- If none of your family members have been diagnosed with endometriosis, have any of them experienced endometriosis symptoms?
  - ☐ Yes (please specify)_________
  - ☐ No
  - ☐ Unknown
  - ☐ Not applicable
  - ☐ Prefer not to say

APPENDIX C

Endometriosis In-school Supports

I am answering the following questions based on (please check one):

☐ Currently being a student

☐ Retrospectively (no longer a student but was a student who had endometriosis symptoms while in school)

The following is a list of in-school supports. **Which of the following are beneficial to supporting students with endometriosis?** *Please check one in each row to indicate whether or not these supports are necessary*. In the "Other" section, please specify what other supports would be necessary. Please use the comments section if you have any comments to add.

In-school supports	This support is necessary	This support is not necessary	Prefer not to respond
a) Receiving instruction/information on healthy menstruation and endometriosis at school			
b) Receiving academic accommodations such as:			
1. Receiving assignment extensions			
2. Receiving adjustments to the number of weekly class hours,			
3. Receiving a second set of			

books for home,			
4. Restricting a student's classes to the first floor (i.e., to avoid stairs).			
5. Fully homebound instruction			
c) Consulting a school nurse			
d) Consulting a school psychologist			
e) Access to symptom-reducing products (e.g., heat pad)			
f) Building a positive relationship at school with an adult that was aware of endometriosis diagnosis and was a supportive contact person at school			
g) Making a plan with school staff on steps to take if			

experiencing pain at school			
h) Locker that is close to classroom			
i) Receiving therapy within the school to cope with endometriosis			
j) School staff collaborating with a medical physician on how best to support student			
Other: please specify			
Comments:			

The following is a list of in-school supports. **Which of the following did you receive while being a student with endometriosis?** *Please check one in each row to indicate whether or not you have received these supports*. In the "Other" section, please specify what other supports would be necessary.

In-school supports	**I have received this support while in school**	**I have not received this support while in school**	**Prefer not to respond**
k) Receiving instruction/information on healthy menstruation and endometriosis at school			
l) Receiving academic			

accommodations such as:			
6. Receiving assignment extensions			
7. Receiving adjustments to the number of weekly class hours,			
8. Receiving a second set of books for home,			
9. Restricting a student's classes to the first floor (i.e., to avoid stairs).			
10. Fully homebound instruction			
m) Consulting a school nurse			
n) Consulting a school psychologist			
o) Access to symptom-reducing products (e.g., heat pad)			
p) Building a positive			

relationship at school with an adult that was aware of endometriosis diagnosis and was a supportive contact person at school			
q) Making a plan with school staff on steps to take if experiencing pain at school			
r) Locker that is close to classroom			
s) Receiving therapy within the school to cope with endometriosis			
t) School staff collaborating with a medical physician on how best to support student			
Other: please specify			
Comments:			

APPENDIX D

Endometriosis Impact Questionnaire (63-item EIQ)

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We appreciate you filling out all dimensions to help us complete this important study.

Instructions: We ask you to complete the EIQ questionnaire by placing in every box the number which best describes how much endometriosis has affected your life over three time periods (last 12 months, 1 to 5 years ago and more than 5 years ago).

0 = Not at all
1 = A little
2 = Somewhat
3 = Quite a lot
4 = Very much
9 = Not applicable, was not relevant to you during that time period (e.g., did not have endometriosis in that time period or question is about the effect of endometriosis on working, and you did not work in that time period)

Example:		
Because of My Endometriosis:Last 12 months	**1 to 5 years ago**	**More than 5**
years ago Q1.I had severe period pain.1	**3**	**4**
Q2.I found it difficult to care for my child.0	**4**	**9**

This participant's answer for question 2 shows they did not have any children more than 5 years ago (9), then they had a baby 3 years ago and "Because of their endometriosis" they found it difficult "Very much" (4) to care for their child, but during the last 12 months the participant has not had this problem at all (0). Some dimensions of the EIQ may not be relevant to you, so you could skip to the next dimension.

Dimension 1. Physical Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 = Not applicable, was not relevant to you during that time period (e.g., did not have endometriosis at that time or question is not relevant to you)

Because of My Endometriosis:

		Last 4 weeks	**Last 12 months**	**1 to 5 years ago**	**More than 5 years ago**
Q1.	I had severe period pain.				
Q2.	I had pelvic pain between my periods.				
Q3.	I had heavy bleeding with periods.				
Q4.	I had irregular spotting or bleeding between my periods.				
Q5.	I felt tired more than usual.				
Q6.	I spent time in bed or lying down due to pain (e.g., period, or pelvic pain).				
Q7.	I had trouble sleeping.				
Q8.	I felt that my energy levels have decreased.				
Q9.	I had difficulties carrying out normal daily activities (e.g., shopping, driving).				
Q10.	I had to decrease my involvement in exercise or sport.				
Q11.	I was bothered physically by the side effects of medical or surgical treatment/s.				
Q12.	I was concerned about weight gain (e.g., due to less activity caused by pain or as a side effect of treatment).				
Q13.	I thought about having a hysterectomy (removal of uterus) to treat my symptoms.				

Dimension 1. Psychological Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 = Not applicable, was not relevant to you during that time (e.g., did not have endometriosis in that time or question is not related to you)

Because of My Endometriosis:

		Last 4 weeks	Last 12 months	1 to 5 years ago	More than 5 years ago
Q14.	I felt depressed.				
Q15.	I felt uncertain because of the unpredictable nature of endometriosis and its symptoms.				
Q16.	I felt uncertain about the effectiveness of my treatment/s.				
Q17.	I experienced mood swings (due to my symptoms/pain or treatment side effect).				
Q18.	I felt nobody understands how I feel.				
Q19.	I felt less self-confident.				
Q20.	I was unhappy about my appearance (e.g., due to weight gain, surgery scar/s).				
Q21.	I felt my identity has been disrupted as an individual, caregiver, partner, etc.				
Q22.	I felt embarrassed (e.g., symptoms at workplace, school, explaining to employers, colleagues, or teachers).				
Q23.	I felt jealous (e.g., of others who have no pain or have had children or pain-free sex).				

Q24.	I felt worried that my symptoms would get worse.				
Q25.	I was worried about the effect of endometriosis on my future plans.				
Q26.	I felt annoyed about the amount of painkillers I have had to take.				
Q27.	I had feelings of defeat or hopelessness (e.g., not being able to deal with this disease anymore).				
Q28.	I was concerned about overuse or accidental overdose of painkillers.				
Q29.	I was not able to control my life as I would like.				

Dimension. Social Impact of Endometriosis (Questions marked are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 = Not applicable, was not relevant to you during that time (e.g., did not have endometriosis in that time or question is not relevant to you)

Because of My Endometriosis:

		Last 4 weeks	**Last 12 months**	**1 to 5 years ago**	**More than 5 years ago**
Q30.	I reduced participation in social events like attending parties or going out with my friends.				
Q31.	I decreased my leisure activities (like hobbies or going on holidays).				
Q32.	I had problems with my relationships with other people (e.g., because of my mood swings or pain).				
Q33.	I felt isolated.				

Dimension 2. Sexual and Intimate Relationships Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 = Not applicable, was not relevant to you during that time (e.g., did not have endometriosis in that time or you were not sexually active or partnered in that time)

If all the following questions about “Sexual and Intimate Relationships Impact" are not relevant to you (never been sexually active or did not have endometriosis when you had sexual relationships), please tick the box and go to the next dimension.

Because of My Endometriosis:

		Last 4 weeks	**Last 12 months**	**1 to 5 years ago**	**More than 5 years ago**
Q34.	I had pain during or after sexual activity.				
Q35.	I had bleeding or spotting during or after sexual activity.				
Q36.	I avoided sexual activity.				
Q37.	I experienced strain in my relationship with my partner/s.				
Q38.	I was not able to maintain long-term relationships with my partner/s.				
Q39.	I was not satisfied with my sex life.				
Q40.	I had thoughts about being single due to sexual difficulties (e.g., pain or bleeding) or fertility issues.				

Dimension 3. Fertility Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 = Not applicable, was not relevant to you during that time (e.g., did not have endometriosis in that time or question is not relevant to you)

If all the following questions about "Fertility" are not relevant to you, please tick the box, and go to the next dimension.

Because of My Endometriosis:

		Last 4 weeks	Last 12 months	1 to 5 years ago	More than 5 years ago
Q41.	I found it difficult to become pregnant.				
Q42.	I was worried about my fertility.				
Q43.	I had regrets about not being able to have a child/more children.	]			

Dimension 4. Employment and Financial Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 = Not applicable, was not relevant to you during that time (e.g., did not have endometriosis in that time or did not study in that time)

If all the following questions about "Employment" are not relevant to you (never worked or did not have endometriosis when you were working), please tick the box, **answer only Question 54,** and go to the next dimension.

Because of My Endometriosis:

		Last 4 weeks	Last 12 months	1 to 5 years ago	More than 5 years ago
Q44.	I had difficulty pursuing my preferred career.				
Q45.	I experienced limitations in what I can do at work.				
Q46.	I reduced my working hours.				
Q47.	I took time off work.				
Q48.	I experienced difficulty concentrating or focusing on my work.				
Q49.	I think that I missed out on job promotions.				
Q50.	I was afraid of losing my job.				
Q51.	I had to change or give up my job.				
Q52.	I had a reduction in my income.				
Q53.	I felt that I was unable to reach my career goals.				
Q54.	I experienced financial hardship (due to the cost of diagnosis or treatment medications, surgery, infertility, or lost job opportunities).				

Dimension 5. Educational Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 =Not applicable, was not relevant to you during that time (e.g., did not have endometriosis in that time or did not study in that period)

If all the following questions about "Educational Impact" are not relevant to you (did not have endometriosis when you were at school/university), please tick the box and go to the next dimension.

Because of My Endometriosis:

		Last 4 weeks	Last 12 months	1 to 5 years ago	More than 5 years ago
Q55.	I took time off school/studies.				
Q56.	I experienced difficulty concentrating or focusing on my studies.				
Q57.	I did not complete my study requirements on time.				
Q58.	I missed school/university exams.				
Q59.	I needed more time to complete schooling/studies (e.g., extensions, re-enrolment).				
Q60.	I felt that I was unable to reach my educational goals.				

Dimension 6. Lifestyle Impact of Endometriosis

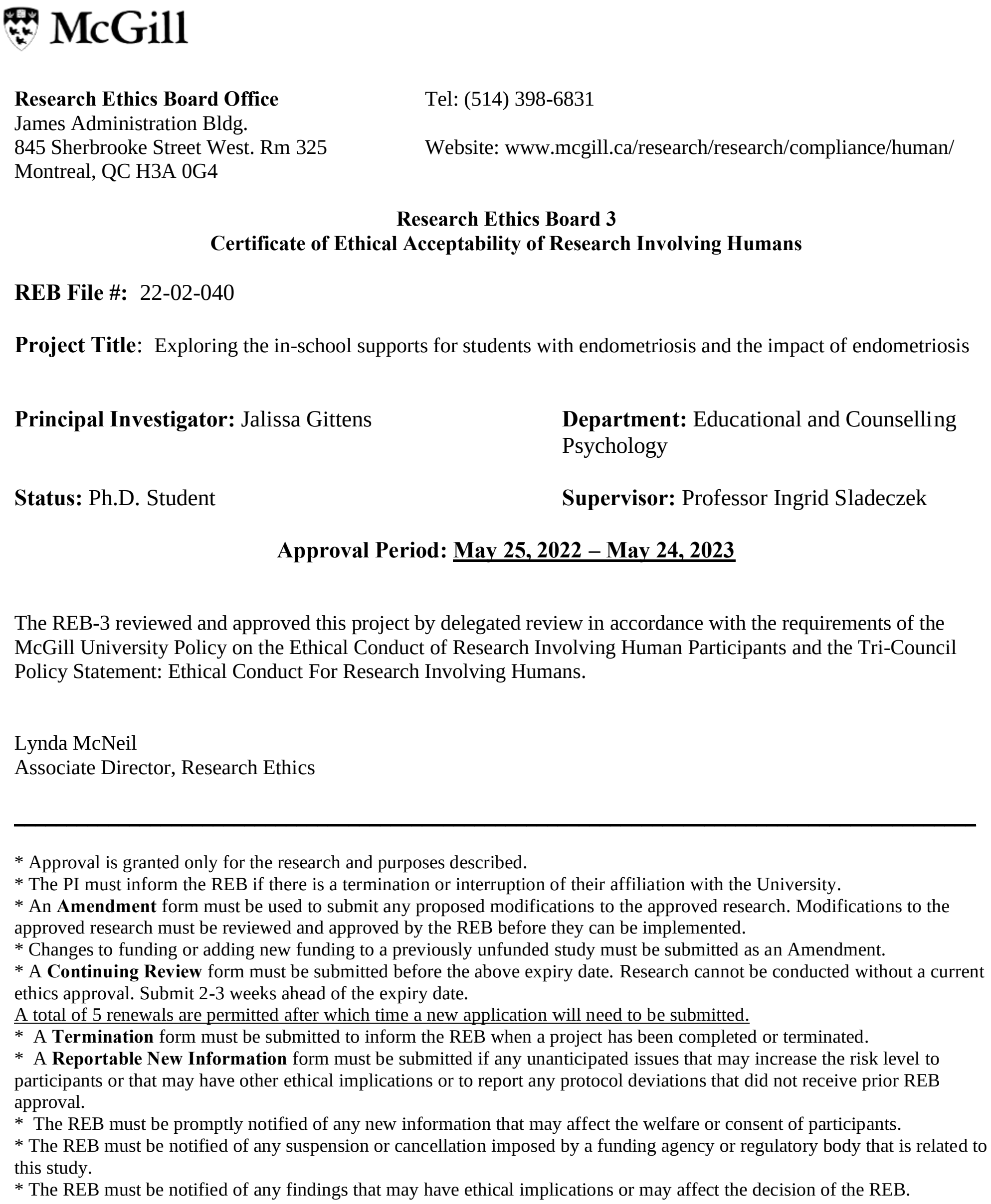
Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all 1 = A little
2 = Somewhat 3 = Quite a lot 4 = Very much
9 = Not applicable, was not relevant to you during that time (e.g., did not have endometriosis in that time or question is not relevant to you)

Because of My Endometriosis:

		Last 4 weeks	Last 12 months	1 to 5 years ago	More than 5 years ago
Q61.	I consumed alcohol to help me cope (e.g., with my symptoms or feelings).				
Q62.	I smoked cigarettes (tobacco) to help me cope (e.g., with my symptoms or feelings).				
Q63.	I used other illicit substances or drugs to help me cope (e.g., with my symptoms or feelings).				

APPENDIX E



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Research Ethics Board 3
Certificate of Ethical Acceptability of Research Involving Humans

REB File #: 22-02-040

Project Title: Exploring the in-school supports for students with endometriosis and the impact of endometriosis

Principal Investigator: Jalissa Gittens

Department: Educational and Counselling Psychology

Status: Ph.D. Student

Supervisor: Professor Ingrid Sladeczek

Approval Period: May 25, 2022 – May 24, 2023

The REB-3 reviewed and approved this project by delegated review in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Participants and the Tri-Council Policy Statement: Ethical Conduct For Research Involving Humans.

Lynda McNeil
Associate Director, Research Ethics

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* Approval is granted only for the research and purposes described.
* The PI must inform the REB if there is a termination or interruption of their affiliation with the University.
* An **Amendment** form must be used to submit any proposed modifications to the approved research. Modifications to the approved research must be reviewed and approved by the REB before they can be implemented.
* Changes to funding or adding new funding to a previously unfunded study must be submitted as an Amendment.
* A **Continuing Review** form must be submitted before the above expiry date. Research cannot be conducted without a current ethics approval. Submit 2-3 weeks ahead of the expiry date.
A total of 5 renewals are permitted after which time a new application will need to be submitted.
* A **Termination** form must be submitted to inform the REB when a project has been completed or terminated.
* A **Reportable New Information** form must be submitted if any unanticipated issues that may increase the risk level to participants or that may have other ethical implications or to report any protocol deviations that did not receive prior REB approval.
* The REB must be promptly notified of any new information that may affect the welfare or consent of participants.
* The REB must be notified of any suspension or cancellation imposed by a funding agency or regulatory body that is related to this study.
* The REB must be notified of any findings that may have ethical implications or may affect the decision of the REB.