The lived experiences of teenage girls living with scoliosis and the effect of a peer support group, *Curvy Girls.*

A Qualitative Hermeneutical Exploration

by

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Abstract

Context: Scoliosis is an abnormal lateral curvature of the spinal column. Adolescent idiopathic scoliosis (AIS) is the most common type of scoliosis and affects approximately 1% to 3% of adolescents. AIS is more prevalent in females as they are ten times more likely to progress their spinal curvature requiring further treatment. The relationship between pain and idiopathic scoliosis has not been well documented and remains unclear in the literature. Evidence suggests that teenagers living with scoliosis could benefit from a support group. *Curvy Girls* is an international peer-run support group that aims to reduce scoliosis's emotional impact through education, mutual support, and self-empowerment. There is limited information on the lived experience of teenage girls living with scoliosis and the impact of peer-led scoliosis support groups.

Objectives: This study endeavors (1) to gain insight into the lived experience of teenage girls living with scoliosis and (2) to understand how the peer support group, *Curvy Girls*, has impacted their lives.

Approach: We interviewed sixteen members of *Curvy Girls* living with scoliosis. During these interviews, we explored the participants' journeys with scoliosis through four lenses: (1) personal, (2) social, (3) healthcare, and (4) peer support group – experiences. The interviews were transcribed verbatim, and these transcripts were then interpreted using applied philosophical hermeneutics, which fosters a philosophy of experience.

Findings:

I. Personal Lens: The narratives of living with undiagnosed pain revealed confusion, solitude, and loneliness. The impact of labeling the pain (i.e., an official diagnosis) led to relief in some cases or irritation in some other cases.

II. Social Lens: The concept of familiarity or unfamiliarity of scoliosis from their families, peers, and teachers may impact the acceptance of their condition and influence how they adapt to their social world.

III. Healthcare Lens: The stories of negative healthcare experiences and their impact on teenage girls are uncovered. When the healthcare professional disregarded their pain, the adolescent girls felt hopeless and misunderstood. The teenage girls wanted to be included in treatment decisions that may endorse autonomy and independence during adolescence.

IV. Peer support Lens: *Curvy Girls* provides a safe environment for these adolescent girls to engage. The power of sharing and communicating helps *Curvy Girls* members cope and feel a sense of belonging. *Curvy Girls* makes these teenage girls feel confident, empowered, and not feel alone.

Significance: An insight into these teenage girls' lived experiences allows for a better understanding of living with scoliosis and how a peer support group can help with this journey. This can promote collaboration between the teenage girls' and the medical field, allowing them to share their voices for designing adaptive services.

Résumé

Contexte: La scoliose est une courbure latérale anormale de la colonne vertébrale. La scoliose idiopathique de l'adolescent (SIA) est le type de scoliose le plus courant et touche environ 1% à 3% des adolescents. La SIA est plus fréquente chez les femmes, et elles sont dix fois plus susceptibles de progresser vers une forme plus sévère nécessitant un traitement supplémentaire. La relation entre la douleur et la scoliose idiopathique n’ayant pas été clairement documenté dans la littérature, elle demeure incertaine à ce jour. Les preuves suggèrent que les adolescents atteints de scoliose pourraient bénéficier d'un système de soutien. En effet, *Curvy Girls* est un groupe de soutien international qui s'efforce de réduire l'impact émotionnel de la scoliose grâce à l'éducation, au soutien mutuel et à l'autonomisation de ses membres. Peu d’information est disponible quant au vécu des adolescentes souffrant de scoliose et à l'impact des groupes de soutien qui leurs sont offerts.

Objectifs: Cette étude vise à (1) mieux comprendre l'expérience des adolescentes atteintes de scoliose et (2) à explorer l’impact du groupe de soutien *Curvy Girls* sur leur vie.

Approche: Nous avons questionné seize membres du groupe *Curvy Girls* vivant avec une scoliose. Au cours de ces entretiens, nous avons exploré l’expérience des participants à travers quatre lentilles: (1) personnelle, (2) sociale, (3) soins de santé et (4) expérience par rapport au groupe de soutien. Les entretiens ont été retranscrits textuellement, pour ensuite être interprétés en utilisant une philosophie herméneutique, favorisant ainsi une meilleure compréhension de l’expérience des participants.

Résultats:

I. Lentille personnelle: Le fait de vivre avec une douleur non diagnostiquée sollicitait confusion et solitude. Une fois le diagnostic posé, certains se voyaient soulagés, d'autres plutôt irrités.

II. Lentille sociale: Le degré de familiarité ou de méconnaissance des proches, notamment familles, pairs et enseignants, vis-à-vis de la scoliose a été démontré influent sur l'acceptation de la condition des participants, et leur capacité d'adaptation à l'environnement social.

III. Lentille des soins de santé: Les expériences de soins ayant été vécues négativement par les patientes sont soulignées. Lorsqu'un professionnel de la santé ne tenait pas compte de leur douleur, les adolescentes se sentaient désespérées et invalidées. Elles tenaient à être au cœur du plan de traitement et des décisions thérapeutiques, ce qui témoigne du développement de leur autonomie et de leur caractère indépendant.

IV. Lentille de groupe de soutien: Le groupe *Curvy Girls* fourni un environnement de confiance permettant aux adolescentes de s'impliquer dans le cheminement de leur diagnostic. Les pouvoirs de partage et de communication mis de l'avant ont aidé les membres de *Curvy Girls* à faire face à leur condition, et ont fait place à un sentiment d'appartenance. Le groupe de soutien leur a également permis de se sentir confiantes, autonomes et entourées.

Importance: Un aperçu des expériences vécues par ces adolescentes permet de mieux comprendre la vie avec la scoliose, et l'aide qu'un tel groupe de soutien peut apporter à leur cheminement personnel. Cela peut promouvoir la collaboration entre les adolescentes et le domaine médical, de même qu’offrir un moyen de faire entendre leurs voix dans le but d’innover des services mieux adaptés.

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I wish to express my deepest gratitude to my supervisor and mentor, Dr. Richard B. Hovey. Thank you for being incredibly supportive and allowing me to work along your side. Although half of my degree was spent virtually, you made me feel connected and involved. Your teaching style made me feel like a partner more than a student. Your collaborative ways of teaching piqued my curiosity and thirst for knowledge. You have opened my eyes to qualitative research and showed me the profound value of one's narrative. I am now a firm believer in patient and family experience and the immense significance it translates to health education, health promotion, and health awareness. I learned the difference between listening and hearing, healing and curing, and expressing and saying. I promise to transfer all this knowledge in my future endeavors. I can confidently say you have shaped me into a better collaborator, listener, and health advocate. Thank you for providing me an opportunity to grow.

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Contribution of Authors

Dr. Richard Hovey was the supervisory author and mentor of this research study. Dr. Richard Hovey and Dr. Marc O. Martel both acted as committee members and helped track my academic progress throughout the duration of my graduate studies. The candidate, Kristina Amja, wrote all sections of this thesis dissertation. Gillian Newman, a board member of Curvy Girls, publicized this research project to the *Curvy Girls* community for participant recruitment. The candidate worked closely with another fellow Master's-level student in Dr. Hovey's lab, Marie Vigouroux. The candidate and Marie Vigouroux completed recruitment, collected the data, and transcribed it. Marie Vigouroux, Dr. Hovey, Gillian Newman, and the candidate discussed the findings as part of data analysis. The candidate then interpreted the data and conducted a literature. All references, including the sample interview guide, ethics approval, and consent form, can be found in the reference and appendix sections.

Introduction

Situational Context

Contextualization is necessary as it situates the timing and setting of this study. The COVID-19 pandemic that started in the year 2020 has somewhat affected all of us, either directly or indirectly. It is important to note that this research study's recruitment began in March 2020. Most interviews occurred during the height of the first wave of the COVID-19 pandemic, between March 2020 and June 2020. The COVID-19 pandemic may have influenced the participants' perception of their scoliosis experience when interviewed at that moment in time; however, we are uncertain of this effect.

During my research inquiry, I explored the lived experiences of teenage girls living with scoliosis and the effect of a peer-run support group, *Curvy Girls*. My interest in scoliosis began when I heard Gillian Newman speak about scoliosis and pain during *RSBO Annual Research Day* held at McGill University, Montreal, Quebec, in 2019. Gillian Newman shared her lived experience with scoliosis and chronic pain. Her narrative sparked my interest in scoliosis and support groups.

Curvy Girls is an international network of peer-run support groups for girls living with scoliosis from ages 6-22 years old. *Curvy Girls* was founded in 2006 by Leah Stoltz, who was once a young girl searching for support within the scoliosis community. Leah Stoltz intended to connect with other girls living through a similar experience. *Curvy Girls'* mission statement is to reduce scoliosis's emotional impact by empowering girls through education, support, and acceptance. During the peer-run meetings, girls living with scoliosis share general advice – from clothing tips to advice on how to speak with the healthcare team (1).

Curvy Girls is a **peer-run** support group that girls living with scoliosis take the lead in facilitating a safe environment for potential meetings. Each leader is responsible for running a chapter representing their particular city or community. All leaders receive monthly training and support from senior members. In addition, leaders go through intensive training at the *Curvy Girls'* biennial conventions in Long Island, New York. Becoming a leader is entirely voluntary as this commitment demonstrates the will to be engaged and to actively engage with others as well. *Curvy Girls* leaders take a very hands-on approach and are responsible for planning and scheduling the meetings, answering any questions and concerns, and structuring discussion topics. During chapter meetings, the parents and the members break off into separate groups to allow for open and private conversations. This is beneficial for some parents because they receive additional support from other parents living through a similar experience. Parents share their concerns by discussing treatment options, doctor reviews, and various tips for supporting their children.

Curvy Girls has a website and can be found on multiple platforms (Facebook, Instagram, and Twitter). When one is looking for online support, *Curvy Girls* will appear on their search engines. An interested individual can reach out to members from *Curvy Girls*. *Curvy Girls* will provide them with the necessary resources, which can include joining an already existing chapter in their local community, starting a new local chapter, or assuming an advocacy role for scoliosis. The inclusion criteria to join *Curvy Girls* varies case by case. If a nonbinary or a male is looking for support, a board member will always provide resources and connect them to a past or current member. *Curvy Girls'* mission is to provide a safe and supportive space.

Curvy Girls has grown exponentially since 2006. Today, *Curvy Girls* has 114 chapters worldwide with 38 United States cities and 26 countries involved. Since 2006, *Curvy Girls* has supported thousands of families and continues to offer ongoing support, awareness, and education.

Rationale for the Inquiry and Objectives

> *Understanding is not only a cognitive but also essentially an* ***emotional project****.*
> *To understand in a medical meeting is essentially to be understanding. (2)*

From my perspective, life is expressed as a compilation of stories. Stories are a compilation of experiences, which are in turn a compilation of moments made up of a wide range of feelings. Feelings have a wide range of expressions from being happy, sad, stressed, cheerful, anxious, or neutral as all emotions are entirely valid. We can learn a lot from another person's lived experience as they are direct witnesses of those moments. How someone navigates through these series of compilations can vary from one person to another. Peer support groups are considered an essential aid when dealing with life-altering changes. The literature explains that belonging and engaging in a support group can help with the acceptance and coping mechanisms of one's lived experience. Yet, there is not much information in the literature regarding the mechanisms or intrinsic processes that occur within support groups.

Working Together when Facing Chronic Pain is a reference manual written by multiple health professionals and is designed for patients living with chronic pain. It strongly endorses the idea of engaging in a support group as part of the healing process. The testimonials in this book demonstrate the potential of support groups diminishing social isolation since people with chronic pain may rely on others like themselves for support and understanding of their life situation. This book explains that support groups are essential to promoting self-management treatment therapies for people in pain (3). However, few resources regarding peer support are listed in this reference manual. How can one access support-groups when information on how to access them is lacking? In short, the literature explains ***why*** support groups are beneficial, but there is little written on ***how*** these support groups work. Understanding the ***how*** can help grasp the foundational concepts that are transferable into practical sittings and help optimize the elements underlining support groups. This research study endeavours to understand ***how*** support groups, such as *Curvy Girls*, may function as well as shed light on the lived experiences of teenage girls living with scoliosis.

Literary Review

Scoliosis

Definition and Treatments

Scoliosis is a deviation in the typical vertical spine, which means an increase or decrease in the spine's natural curve's angulations (4,5). According to its etiology, scoliosis may be classified into three categories: (i) idiopathic, (ii) congenital, and (iii) neuromuscular (6,7).

The most common type of scoliosis is idiopathic (i), and its etiology remains poorly understood. Though, the role of hereditary or genetic factors in the development of idiopathic scoliosis has been widely suggested (8,9). Many factors weigh on the treatment approach for adolescent idiopathic scoliosis, such as growth maturity, sex, location of the curve, curve severity, and curve pattern (10). Some treatments include special bracing, physiotherapy, surgery, or a combination of these techniques (11,12). Idiopathic scoliosis is the diagnosis when other causes are excluded (i.e., congenital and neuromuscular scoliosis) (13,14). It can occur during infantile, juvenile, and adolescent years, depending upon onset age (7).

Congenital scoliosis (ii) is caused by prenatal malformations of the vertebra and ribs. Early surgical intervention is a suggested treatment for young patients (15).

Neuromuscular scoliosis (iii) can occur in children who have an existing medical condition (i.e., muscular dystrophy, cerebral palsy, and spina bifida) that impair the musculature supporting the spine. Neuromuscular scoliosis differs from idiopathic scoliosis by being more complex and accompanied by a higher complication rate for conservative and surgical treatment outcomes (16).

There are four common types of curve patterns seen in scoliosis: thoracic, lumbar, thoracolumbar, and double major, which occur both on the right and left sides (17). If scoliosis is left untreated or neglected, the curves may progress dramatically, creating significant physical deformity and possibly creating cardiopulmonary complications.

Prevalence of Scoliosis

Adolescent idiopathic scoliosis (AIS) affects approximately 1% to 3% of adolescents (18). AIS is the most common type of idiopathic scoliosis and is detected most commonly in children between the ages of 10 and 16 (19–22). It comprises about 80% of all scoliosis cases in the United States and has a strong female predilection (12,23). The difference in incidence between males and females is associated with the degree of curvature of the spine (24,25). As previously stated, AIS occurs more commonly in females (26,27). Females are ten times more likely to deviate their spinal angulation, which indicates that scoliosis in girls progresses to a higher grade of severity (18,26,28). Théroux et al. address the overwhelming predominance of girls with AIS up to almost 90% in some series (29). The spinal curvature's progression is why girls more commonly need treatment (24). The standard profile of one living with scoliosis is a tall adolescent girl in her teens with a convex right thoracic curve (25).

Scoliosis and Pain

A literature review suggests that the association of pain in idiopathic scoliosis has not been well documented and remains unclear. Traditionally, scoliosis has been defined as a non-painful condition. A debate regarding scoliosis took place in Rush Medical College in Chicago, Illinois, in March 1976 and argues that the association between scoliosis and pain is unclear, demonstrating the literature's ambivalence (30). Ramirez et al. describe in a retrospective study an incidence of 23% of patients living with AIS experienced back pain, but this finding was also similar in children living without scoliosis (31). It has also been suggested that idiopathic scoliosis in children is considered to be painless (23). For example, Reamy et al. explain that the presence of severe pain would be atypical for idiopathic scoliosis (24), and Horne et al. state that scoliosis rarely causes significant pain (28). Likewise, Agabegi et al. add that most adolescents with idiopathic scoliosis do not report significant pain (32).

Contrary to the previous idea that AIS was a painless condition in young people, several recent reviews point out that AIS can cause back pain in adolescents (33,34). Some studies demonstrate that pain is a constant complaint when treating scoliosis (14,35–38). Fekete et al. establish that almost 40% of adolescents living with idiopathic scoliosis complain about back pain (39). Accordingly, people living with AIS blame the presence of scoliosis as the cause of their back pain (40). A retrospective review of a random sample of 310 charts of AIS adolescents demonstrates that almost half of the patients (47.3 %) had chart-documented back pain. Similarly, Weinstein explains the back pain may arise in any patient with adolescent idiopathic scoliosis regardless of the spinal curvature size and/or location (41). Balagué and Pellisé conclude that back pain in adolescents is common, especially in girls, and there is no doubt that some AIS patients suffer from back pain (33). In brief, the relationship between AIS and back pain has been evaluated in multiple studies and leads to diverse conclusions leaving the literature scattered in this respect.

Scoliosis and Psychological Factors

Several studies report psychological factors playing an essential role in back pain in adolescents (42–44). Chronic back pain impacts the quality of life of adolescents living with idiopathic scoliosis (45). Consequently, AIS is associated with a significant negative impact on the quality of life and psychological functioning (46,47). Makino et al. address the relationship between back pain in AIS patients and their psychological background using Scoliosis Research Society questionnaires. They explain that psychological factors such as poor self-image and mental health are risk factors for chronic back pain (48). Furthermore, Makino et al. interpret that the psychological distress due to scoliosis in adolescent females could strongly relate to back pain (48). Also, scoliosis is suggested to be a risk factor for depression no matter what treatment the patient receives (49). MacLean et al. discover a significant period of stress and self-esteem change (88%) at the initiation of brace-wear in most patients living with scoliosis (50). Other studies suggest that people living with scoliosis perceive themselves to be less healthy than their peers and experience physical and social restrictions (51,52). Freidel et al. studied the health-related quality of life of 226 female patients living with idiopathic scoliosis (53). This study reveals that female scoliosis patients have a less positive attitude toward life, experience more physical barriers, have lower self-esteem, and are more likely to express depressive moods (53). In short, teenage girls living with scoliosis and pain go through many stressors and may benefit from external assistance such as peer support groups.

Peer Support Groups

Peer support is an essential adjunct to disease management that contributes to treatment adherence, lifestyle changes, sense of belonging, and rehabilitation management (54,55). Walker et al. explain that seeking social support, including peer support, may be a part of someone's personal journey towards a new identity and might influence their health outcomes (55). Social connectedness is described as having a personal sense of belonging to a group, family, or community that contributes to better health results (56). People living with a certain condition may experience uncertainty regarding their health treatments, social relationships, and identity apprehensions (57). Engaging in a peer support group might alleviate these uncertainties by connecting with others living through a similar experience. Brashers et al. examine how social support may facilitate or interfere with the management of uncertainty about health, relationships, and identity. They demonstrate how support from others living through a similar experience can assist in the following ways: exchange valuable information, provide instrumental support, facilitate skills development, give or receive acceptance or validation, and encourage perspective shifts (58). Peer support can help articulate and model effective coping techniques when experiencing illness.

In the context of a peer support group, the stories heard and told may carry the weight of shared experiences, the emotional influence of shared suffering, and an avenue for social learning (59). Schwieger et al. assess and compare the types of information that adolescents and parents seek in AIS online support groups on the National Scoliosis Foundation website (60). These findings suggest that adolescents and parents might not be receiving enough information from healthcare professionals and seek to exchange information from online support groups regarding the causes, progressions, and diagnosis of AIS as well how to live with scoliosis on a day-to-day basis. The findings from this study also suggest that adolescents might benefit from additional support and coping strategies regarding other adolescent experiences with AIS-related concerns (60). There is much evidence that peer support helps people living through hardship; however, little is understood about ***how*** peer support works. A literature review by Watson aims to reveal the mechanisms underlying one-to-one peer support relationships in mental health. Watson identifies five mechanisms relating to the process of peer support: use of lived experience; emotional labor; liminal position; provision of strengths-focused, social, and practical support; and helper role (61). Watson's peer support mechanisms are explained within a professional realm – between peer support workers and peer support seekers. *Curvy Girls* is a peer-run support group and, thus the members of *Curvy Girls* have little knowledge of these explained mechanisms. Therefore, it remains unclear ***how*** the process of peer support works.

Need and Purpose for the Study

The purpose of this research is to explore and expand the knowledge regarding teenage girls living with scoliosis. More specifically, we are interested in understanding the experiences of adolescent girls living with scoliosis who are members of *Curvy Girls* by uncovering what mechanisms underpin peer-led support groups. Our focus on peer-led support groups stems from the idea that these groups may help reduce scoliosis's emotional impact by empowering girls through education, mutual support, and acceptance.

In addition, the data obtained from this study will offer concrete directions towards future advancements of the *Curvy Girls* community, other adolescent-oriented programs or mentorship, and health care delivery services that others may develop in the future.

Methodology

Hermeneutics as a Philosophy and Research Approach

Philosophical hermeneutics fosters a philosophy of experience and practice of interpretation (62). It is a reflective and interpretive approach to understanding human experiences (63). The lessons learned from experiences extend beyond the norms of ratified methods. The philosophy of experience participates in a dialectic of mutual involvement and cultivates a sense of belonging to something larger than oneself (64). Friesen et al. explain that "experience" in this context refers to something that happens *to* us; an experience is lived and structured through consciousness and not accumulated by mastery or evidence (65). Hermeneutics is the art and science of interpretation that is constantly open to new insight (65). Davey explains that participation in research interviews enhances understanding by enriching our knowledge and offering doors to interpretation (64). Accordingly, the name *Hermeneus* refers to the messenger of the gods to humans, Hermes (66,67). Hermes conveyed messages between realms while enticing interpretation (62). In a likely manner, I am the messenger between the teenage girls living with scoliosis and the readers, while conveying my own interpretation. It must be noted as well that the readers also carry their own interpretation. Ricoeur, a French philosopher, states:

> *Experience [not only] can be said, it demands to be said. To bring it to language is not to change it into something else but, in articulating and developing it, to make it become itself (68).*

Narratives and stories are alive and have their own entity. However, this entity is malleable as every person carries their respectable interpretation. We are having a conversation about a topic; hence there is an ongoing movement with the text. To "move" conceptually requires acquiring new insights and broadening one’s perspective (69). Hermeneutical investigations as an applied research approach are described as the theory and practice of interpreting texts by cultivating our understanding of human experiences. The method of experience and reflection adds to our unique perspective. Gadamer emphasizes that dialectical movement exists between what we perceive and what we can interpret (62). Davey states that the achievement of understanding is challenging as it is the object of practice. He writes:

> *It is in the nature of conversation that its self-understanding changes. Conversation shows how an experience of change is part of understanding and demonstrates that, like itself, understanding has no end (64).*

Gadamer’s dialogical philosophical hermeneutics intends to unite the consciousness of conversations. Therefore, the researcher is attempting to understand the participant’s experience within the context of a community of experiences (70). Hence, a fusion of horizons occurs to achieve new ongoing understandings (62). A fusion of horizons also implies that interpretation is dynamic as one’s perspective is constantly changing as a function of time and new emerging experiences (64). Consequently, we are the product of all our collective experiences and wisdom. Based on Gadamerian hermeneutics, a fusion on horizons entails an expressive process that seeks the meaning of our and other people’s perspectives about a topic. Gadamer’s emphasis on horizons is linguistic; thus, there is an intimate and vibrant connection within dialogue (69). Moules et al. explain, “Our interpretive relationships in the world are dialogic: the world speaks to us, and most importantly, we listen to its address.” (62). Qualitative research intends to offer insight into lived experiences and explore meaning and context through conversation. Smith states that the writing is by *us*, but it is not about *us* (71). Interpretively, philosophical hermeneutics goes beyond colloquial concepts as it offers a way to grasp complex realities while finding novel avenues to understand human experiences. As Gadamer explains, “the job of philosophy is to clarify concepts, not to present a new body of knowledge through empirical research” (72).

Participant Recruitment and Consent

The following is a description of the steps that Marie Vigouroux (a MSc student studying a similar topic) and I took for the participant recruitment process:

1) Gillian Newman, our liaison to the *Curvy Girls* community, publicized this research project from March 14th, 2020, to October 3rd, 2020, through various platforms including email, Facebook, Instagram, and Twitter. The instructions explained that interested potential participants could contact the researchers via email or phone call to maintain a completely voluntary research participation.
2) When participants contacted us, Marie Vigouroux and I would screen the potential participants for eligibility and answer any questions or concerns. We kept track of the potential participants in an encrypted password-protected Excel workbook. We sent up to three reminders to the potential participants who initially reached out.
3) If potential participants met the eligibility criteria (see Inclusion Criteria below), we would send them the consent form in English or French (see Appendix C). If the participant was under the age of 18, we asked for a parent or guardian’s consent. If the participant was over the age of 18 (inclusive), we solely asked solely for their consent. Although the age

of majority by provinces or territory varies in Canada, we decided to choose the age of consent to participate in the province of Quebec, which is 18 years of age (73).

4) Once we obtained informed consent, we booked an interview time that would take place via Zoom, an end-to-end encrypted video conferencing platform. McGill University provided the secure zoom license.

Inclusion Criteria

Individuals included in this study met the following criteria:

- were at least 14 years of age;
- current or past member of *Curvy Girls*;
- speak either French or English;
- currently living in Canada;
- living with scoliosis for over one year;
- living with pain for longer than three months; and
- had given informed consent to participate in this study.

Exclusion Criteria

Individuals excluded from this study met the following criteria:

- younger than 14 years of age;
- not a current or past member of *Curvy Girls*;
- not speaking either French or English;
- not currently living in Canada;
- not living with scoliosis for over one year;
- not living with pain for longer than three months; and/or
- had not given informed consent to participate in this study.

Research Ethics Consideration

This research study was conducted according to the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2014)*. We received approval through the McGill University Research Ethics Board in June 2019 and renewed our ethics approval in June 2020 (IRB A06-B44-19B).

Data Collection

Between April 2020 and October 2020, Marie Vigouroux and I interviewed 16 female participants with a mean age of 18.5, with the youngest participant being 14 years old and the oldest participant, 25 years old. Interviews were audio-recorded and conducted on Zoom, an end-to-end encrypted video conferencing platform secured by McGill University. Interviews lasted 55 minutes on average, with the shortest one being 24 minutes and the longest one, 104 minutes. We interviewed the participants using an open-ended semi-structured interview guide (see Appendix A) (74). Each interview was then transcribed verbatim without transcription software by either Marie Vigouroux or myself. We conducted 15 English interviews and one French interview. As Marie Vigouroux and I are both fluent in French, we translated passages from French transcripts only when including direct French quotes in this research dissertation. As required from McGill University Ethics Board, the transcriptions and audio will be destroyed seven years after completing this research project. All information collected during this study is kept confidential. A pseudonym protects the participants' identity. Only Marie Vigouroux, Dr. Richard Hovey, and I have access to the code linking the assigned pseudonym to the corresponding name. Participants' personal information will not be published or presented at scientific meetings.

Data Analysis

Moules et al. explain that a research study guided by the tenets of Gadamerian philosophical hermeneutics rarely has a fixed starting and ending point; however, if one has to allocate a starting point, it would be when the conversation of experiences unfolds (62). Gadamer states, "Hermeneutics begins when something addresses us" (75). Therefore, analysis began during research interviews as the process of conversating allows for one to be open and prepared to be guided by a topic (62). Bruns called the process of listening "reading with our ears" (76). Audio-recording is standard practice in hermeneutics research as the dialogue is transcribed verbatim, which captures the nuances from oral conversation to text (62). Transcribing the interviews of teenage girls living with scoliosis permitted me to fully engage in the text for a subsequent time. Moules et al. explain, "Engagement is an ongoing process that does not simply exist at the beginning of the interview."(62). Once the transcripts were written and annotated, I printed them and read the narratives several more times from a physical copy. As text became an object, it helped me emerge into the palpability of text more carefully.

Data analysis in hermeneutics equals interpretation. Moules et al. explain that hermeneutical research is different from other research approaches. It is divergent in nature rather than convergent; it is based on the understanding and interpretation of multiple phenomena rather than focusing on a single theme (62). Based on multifaceted engagement (i.e., interviewing, transcribing, reading, and re-reading the narratives), I developed interpretive conjectures as it is the foundation of my analysis. I highlighted some aspects of the narratives that resonated with me the most and chose to explore these findings. During my interpretation, I deconstructed and reconstructed the text as I questioned the health care system, family and friends' dynamics, and thought about new possibilities for better practice. Hermeneutical understanding of the text (such as narratives) is not concerned with the source of the stories; but instead, it targets understanding the meaning of the text. Gadamer explains:

> *When we try to understand a text, we do not try to transpose ourselves into the author's mind, but if one wants to use this terminology, we try to transpose ourselves into the perspective within which he has formed his views. But this simply means that we try to understand how what he is saying could be right (75).*

After my initial interpretations of my chosen findings, my research team entered the conversation and raised the interpretative analysis to another level by rigorous, reflexive, and communal attention to the narratives (62). Teamwork helps to provide a rigorous analysis by emerging various interpretations during these conversations. Accordingly, this shapes the hermeneutic circle of conceptualizing understanding and the ongoing process of interpretation. The hermeneutic circle is the "movement of existing understanding, or prejudice, into constructive interchange with another" and it is shaped by "each partial understanding or viewpoint that lends a new association to the topic and adds to its connectedness in the world." (62). In reading, re-reading, reflection, writing, and conversation, I recognized the particular and wrote my understanding about the topics generated in this process. I not only interpreted the text but the particulars of the material as well – the pauses, hesitations, and silences. The purpose of hermeneutical research is to bring understanding around a topic; however, the topics are not the participants but their voices and narratives that add to the topic in question. I endeavored to listen to what participants had to say regarding their experience living with scoliosis to expand my understanding of the phenomenon in conversation (62).

Finding #1: Personal Experience

Can anyone hear me?

Undiagnosed Pain Does Not Equal Invalid Pain

Historically, back pain in children and adolescents was considered unusual (37). The prevalence of back pain in this population has increased over recent years and has drawn attention from the healthcare sector (77,78). Nonspecific back pain is when there is no identifiable etiology for the pain (37). However, having little information about the etiology does not mean that the pain does not exist. It does not mean that the pain must be invalidated, unheard, or brushed off. It was initially believed that the majority of children and adolescents who experienced back pain had diagnosable pathologies; however, recent reports found that nonspecific back pain can be seen in up to 75% of adolescents experiencing back pain (79,80). Diagnosis is a theoretical construct by which health professionals attempt to explain their patients' problems. However, the absence of a diagnosis might disrupt and disregard the patients' concerns, leaving one isolated and confused.

One of our research participants, Emily, expressed:

> *It made me feel* ***very alone*** *because, of course no one really knows what you're going through but you… but then to have people who are supposed to help you not even acknowledge it… it made you feel really* ***stuck*** *because it's well then who is going to help me and stuff… it just made me feel very* ***helpless*** *and* ***very alone*** *and just* ***sad****, and it makes you feel "oh will I ever get better" and then you start to question "oh am I really having this pain am I making this up this person's a doctor, and they're questioning me".*

Emily felt unheard and alone. Her voiceless scream was characterized by uncertainty and confusion in the absence of a diagnosis and prognosis. According to Gadamer, the process of understanding carries with it the possibility of transformation (64). However, without understanding or acknowledging the pain, how can one be able to transform and carry on. Girls living with scoliosis that have yet to be diagnosed are occupying a "liminal space" in that they exist in-between two separate identities. "Feeling stuck", as Emily expressed, may situate her in this "liminal space".

Evelyn's pain was disregarded because chronic pain runs in her family history. Evelyn shared:

> *I've been expressing that I've been in pain since I was like 8 or 9 when I started doing gymnastics. They didn't really run any tests or anything; they just kind of said that because my family is known for having chronic pain, it's considered* ***normal****.*

The family medical history is not necessarily shared with the patient in question; however, it can guide the practitioner in the patient's management and care (81). Each person has their own entity and must be treated as a whole. The clinical model of Stewart et al. explains patient-centered care through four interactive components: (i) exploring the dimensions of disease and illness experience by unique perceptions, feelings, and ideas; (ii) understanding the whole person by life history, social support, and cultural context; (iii) finding common ground by stating expectations, goals, and roles; and (iv) enhancing the patient-doctor relationship by compassion, self-awareness, and transference (81). Evelyn was not the center of her care; her family as a whole was. Evelyn's pain was disregarded and normalized through her family's history. The concept of one's personhood comes into question here. Gadamer explains in his book *The Enigma of Health*:

> *The* ***loss of personhood*** *happens within medical sciences when the individual patient is objectified in terms of a mere multiplicity of data. In a clinical investigation all the information about a person is treated as if it could be adequately collated on a card index. If this is done correctly, then the relevant data will all uniquely apply to the person involved. But the question is whether the unique value of the individual is properly recognized in the process (63).*

Emily voiced:

> *They would tell me oh we don't know what's going on… in two months you'll see someone else… and it was like* ***what am I supposed to do*** *for the next two months of pain… at times I felt like they didn't really care…*

Having no diagnostic label may limit one's recourse to some sort of categorical identity. Emily seems to be expressing that she feels "lost" in the system. Her pain does not go away after the doctor's appointment. What is she supposed to do while waiting for the next healthcare professional? As proposed by Descartes, a mind and body dualism are culturally ingrained in the healthcare world (82). Emily goes back home with a similar pain she came to the medical appointment with. Person-centered care requires a balance between the subjective and the objective, a merger between the mind and the body (81). Olsson et al. studied the role of peer support in facilitating psychosocial adjustments to chronic illness in adolescence, and their study includes a personal testimony:

> *The diagnosis came after I had seen at least three doctors who threw their hands in the air and said, 'there is nothing wrong with her'. It came after many hospital visits and my arm becoming a living pincushion. […] I don't remember half the tests I had. All I remember was I felt like I was going insane.*
>
> *Every time test results came back; they would come back negative. While most people would say that was a good thing, for me, it was frustrating. I questioned myself. I wondered if I was a hypochondriac or if I was going crazy. While my illness is not terminal or visible, it has still affected my life (83).*

As Kingod et al. suggest, sharing stories became an important survival tool for some people living with a particular condition as writing in an online support group about their illness involved self-actualization when dealing with a disrupted identity (84). Engaging in a peer support group, such as *Curvy Girls,* might bridge that gap of this "liminal space" and speed up the process of unveiling the new, fused identities. A previous study examining the mechanisms of underpinning peer support explains that the liminal position provides an opportunity to revisit past experiences while reconnecting with them from a different position (61). *Curvy Girls* also allows one to express their personhood. During the *Curvy Girls* meetings, their family is not present; thus, one can feel like they are their own personal and validated being. Also, *Curvy Girls* can play a pivotal role in supporting one living between medical appointments.

Labeling Pain

Davey explains, "A word or concept is never solitary but resides within a web of associated meanings and uses." (64). The word or concept "diagnosis" held a different meaning for each participant. When we asked our research participants about their scoliosis diagnosis experiences, two avenues surfaced: a sense of relief or a sense of anger.

A Sense of Relief

A caregiver initiates the diagnostic process to label their child's condition (85). A diagnosis may help explain and understand the direction of treatment and care needed for the child. A sense of direction might alleviate some stress and gain control of one's condition. Research has shown that having a label eliminates the confusion related to the child's situation and enables families to access specialists' help (86). A diagnosis might help understand the particulars of one's life-world. Milan lived with unexplained back pain for a long time; thus, receiving a diagnosis provided her with some sense of relief:

> *It's something anybody can experience when they've had some sort of chronic issue for a really long time and they just don't know what it is, and they keep getting misdiagnosed… it's kind of like I finally know what this is, and I could* ***stop worrying.***

Moreover, some felt that their pain was not valid until receiving a diagnosis. Evelyn shared:

> *It made me feel like my pain* ***wasn't valid****. Over the years, I've just started to talk about it less and less. Now that there's actually a* ***diagnosis****, I can talk about it a little bit more because now people* ***believe*** *it.*

Evelyn's text demonstrates that her health professional had an enormous influence on her pain validity and recognition. One might isolate themselves when feeling unheard or voiceless regarding their pain. A formal diagnosis legitimizes the experience of one living with pain which can bring relief to the individual. Telford et al. explain that healthcare professionals hold an authority that imposes labels on people living with chronic illness, which has a strong significance for their sense of self-identity (87). Gadamer discusses:

> *Clearly, a diagnosis is a matter which belongs to science. However, the paradox remains that the doctor still has to ask the patient in what way he or she feels unwell. The condition of 'not feeling well' and the necessity for the doctor to question the patient directly testify to the fact that being ill involves a disturbance whose cause remains concealed (63).*

The disturbance, such as scoliosis and pain, might be concealed or hidden, yet it still exists. One's pain might not be believed until a formal biomedical diagnosis is received. Some participants expressed a sense of liberation when their diagnosis was brought to life. Their pain became this tangible entity with a name or a label. Girls living with scoliosis became believable and externally validated.

A Sense of Anger

A diagnosis might provoke exasperating emotions. People living with a chronic illness or a disability may experience a shattering of self (88). This "shattering of self" might evoke anger at first as they grieve their old selves. Kubler-Ross developed a model of grief in which people transfer through. The five linear emotional adjustment stages are denial, **anger**, bargaining, depression, and finally, **acceptance** (89). Emily was experiencing many emotions. She needed to express them. She said, "I wish someone would have told me that **it's OK to be mad and to be sad and to be angry.**". Feeling and embodying emotions are considered a healthy way of coping with accepting a disability. Even though pain is an invisible condition, it impacts the whole person. A more profound sense of pain is that the body is not disconnected from the soul. Gadamer emphasizes that we, as living beings, are a unified organism rather than a collection of machinery. He writes:

> *The soul is not made up of parts as the body is made up of its various organs and members. As living things we are fully present in each of our different states or conditions. We are wholly taken up by anger, completely shaken by fear. We are not angry or fearful in just one part of the soul (63).*

Moreover, Evelyn felt like her diagnosis made her a vulnerable target. She said:

> *Growing up, I got teased a lot, just in general. So, I feel like that has definitely made me not want to be open about it. I fear getting made fun of again, especially now that there is something to make fun of. It's a **vulnerable target** basically.*

Likewise, Brenda felt like she was labeled “the girl with the disease”. She thought, “I was always the **outcast** that people tolerated because I had this disease but didn’t actually want to be my friend.” Telford et al. suggest that labeling occurs within social interactions as a negative identity is imposed on a person (87). Labeling an individual with a certain diagnosis can affect one’s self-stereotyping and sense of self (90). One is much more than a labeled disease as one is the product of all their collective experiences.

Evelyn claimed that her mental health struggled due to her chronic pain and diagnosis. She expresses:

> *I had to quit all those sports, and it became a **struggle** to function. Almost to it hurts to move around, it hurts to do certain things. It’s made my mental health a lot worse because I’m 18, and when I think of chronic pain I think of **older people**. Not like old, old, but older. It just feels like it’s going to **hold me back** for the rest of my life.*

Adolescents living with scoliosis deal with the typical physical, social, psychological changes of puberty; they also have the demands of scoliosis and chronic pain management. The anger of not being a “typical 18 years old” that Evelyn expressed establishes that living with scoliosis and pain is a full-time duty. Similarly, Neve expressed:

> *It’s almost like a cycle, or like a chess match where you always have to **think ahead**. That’s what I always felt. I had to predict what people were going to do, and what move they were going to make in order for me to feel OK.*

According to the narratives of teenage girls living with scoliosis, a sense of maturity is grasped very early on during their development and upbringing. Crossing the high school halls isn’t just a distant memory; they had to learn to navigate these crowded hallways without being pushed or tossed. Regardless of which avenue their scoliosis journey stumbled upon, a peer support group such as *Curvy Girls* offers a platform to discuss and normalize these feelings. Several studies described the importance of sharing experiences, precisely sharing profound emotions such as anger and frustration, enabling peers to build a sense of “normalcy” and connectivity with others who lived through similar experiences (91–93).

Finding #2: Social Experience

Having a social entourage equipped with certain knowledge can change one's experience before it even begins. Being familiar with a certain condition, such as scoliosis, might install assurance of navigating this encounter. However, being unfamiliar with scoliosis might first be a daunting space, as one needs to acquire new knowledge and relearn life with the added meaning of scoliosis.

Familiarity

According to Oxford Advanced Learner's Dictionary, the definition of familiarity is "the state of knowing somebody/something well; the state of recognizing somebody/something" (94). Being familiar with scoliosis might increase or enhance one's adaptability to cope with this condition.

Milan's social world was familiar with scoliosis. She said:

> *I felt really **supported** or really **understood** in my community or in my social ties because there's a lot of people that I know that have scoliosis, so I've always felt like they were able to **relate** to me and I was able to relate to them definitely on different levels.*

Knowledge is grasped when complex concepts are transformed into familiar notions. The anthropologist Peter Duerr reveals:

> *What is alien is supposedly understood when it is translated into familiar categories… Strangeness is alienated and resettled at home and thus neutralized. Things are understood as soon as it can be shown that we have always virtually understood them… (95).*

Mary was familiar with this world as her family holds a history of scoliosis. Mary's mother also works in the healthcare field, making it easier for Mary to navigate and discuss her concerns. Moreover, Emily was grateful for her supportive friends and mother that works in a common world:

> *I was lucky that I did have quite a few friends I felt* ***comfortable*** *talking to about it [scoliosis], then having a mother who works in the healthcare field… I did talk to her about it [scoliosis] a lot.*

A certain familiarity with the linguistic space and body of thought of scoliosis conveys self-stereotyping in a positive sense as it creates a sense of belonging, or as Gadamer would say, "feeling at home" (75,90). The horizon of understanding scoliosis has already begun when one is already familiar with the concept. One's lived experience will enhance or broaden that horizon of understanding. The idea of familiarity is borrowed from Heidegger's "Being and Time" which describes familiarity as "[knowing] its way about" (96). Dreyfus and Hubert explain that familiarity consists of "dispositions to respond to situations in appropriate ways" (97). Thus, being familiar with scoliosis before getting diagnosed might enhance one's reaction and compliance after getting diagnosed.

Unfamiliarity

A lack of familiarity with the scoliosis condition might evoke powerful emotions when diagnosed. Emerging into an unknown world is often an intimidating and lonely place. The process of adjusting and learning to live with scoliosis involves overwhelming fluctuations as it forces change to familiar life and vision of one's future.

Brenda expressed:

> *At first, I did feel completely **alone** because my family didn't know what scoliosis even was. My friends didn't know what scoliosis was.*

Caroline said:

> *I felt very nervous and definitely **alone** because I didn't know anyone who was experiencing this or had gone through this before.*

Emily said:

> *I was just shocked because I never heard about scoliosis especially in all of rural Manitoba… it's not really something that's talked about or a lot of people have… so I had no idea what it was… so on the way home I was looking up stuff about it and that just scared me more and I was just freaked out about everything that was going on and everything is **unknown**.*

Brenda, Caroline, and Emily share the common feeling of loneliness and uncertainty. An unfamiliar presence, scoliosis, has shaken the recognition of the familiar, which is the undisturbed reality of not being diagnosed. Davey explains:

> *We do not merely encounter the different but become different to ourselves because of that encounter. The hermeneutical experience of difference is not just a confrontation with the unfamiliar. It involves the recognition of the familiar having been rendered strange by the unfamiliar. We reside, it would appear, somewhere between our once and future selves (64).*

The transition between the two environments, familiar and unfamiliar, is bidirectional. The unknown, the gap between these two environments, can also be referred to as a "liminal space," as discussed in the first finding. The teenage girls living with scoliosis exist in-between two distinct identities, their old and new selves. Living in this “liminal space” is frightening, especially for teenagers. A peer support group such as *Curvy Girls* can support them between this gap while transitioning from one step to another. In addition, a peer support group might bring the unfamiliar to the familiar state. Seeking social support with peers going through a similar experience might alleviate strain on relationships with their family and friends. The participants did not want to worry about people in their surroundings; however, they still need to vent and talk about their illness experience. A support group outside the healthcare world and personal social world might normalize some feelings, empower one’s will to create a new self-identity. Baginsky explains that peers have greater credibility and approachability as they offer support outside formal or medical situations (98). The participants in Gidugu et al.’s study express that peer support provided them an opportunity to create normalizing relationships outside the healthcare world (91). A peer support group might help attain a redefined identity through sharing emotional identities, such as the loneliness felt in an unfamiliar environment.

Finding #3: Healthcare Experience

Do I Trust my Body or the Healthcare Professional?

Pain is an invisible condition, yet it is felt physically, emotionally, and socially. It is expressed through almost every outlet available – personal narratives, statements, poems, books, journals, music, dance, theater, drawings, paintings, etc. Pain is an individual experience, and it's specific to each person. Pain is difficult to grasp in a few words due to its multidimensional nature. Gadamer writes:

> *The patient is asked what is wrong, or, as we say in German, what it is that he or she feels to be '**lacking'**. The task, then, becomes that of locating what precisely is out of place. The entire vast apparatus of medical diagnosis today consists in attempt to identify just this. Here I am only describing what our language itself tells us. These are matters of real experience which we all encounter as human beings, doctors as well as patients (63).*

The relationship between scoliosis and pain is not well understood, as demonstrated in the literature review. Our research participants are witnesses and victims of this misapprehension of scoliosis and pain.

Caroline communicated:

> *But I also think that certain doctors didn't understand the **complexities** behind scoliosis and only really cared about the **biological** parts of the condition. […]*
>
> *He [doctor] told me my pain was **in my head** and I was making it up and he sent me to a **psychiatrist**.*

Willow said:

> *He [doctor] was talking about like '**oh, scoliosis shouldn't cause pain**;' I was like 'OK…' He just talked about how it shouldn't cause pain and he was like 'oh, if you're in pain, you should be pretty worried because it's **not normal** for scoliosis to cause pain.'*

An article by Speraw displays the moral disappointment occurring from health providers that focus solely on one's disease rather than one's personhood as a whole (99). These teenage girls' lived experiences clearly demonstrate that they are in pain. Why would one disregard one's suffering? Is it a lack of understanding, a lack of listening, or a lack of partnership? Gadamer emphasizes the importance of the connection of the scope of practice and human responsiveness of practice:

> *What we need to do is to learn to **build a bridge** over the existing divide between the theoretician who knows the general rule and the person involved in practice who wishes to deal with the unique situation of this patient who is in need of care (75).*

Emily felt like the healthcare professional dismissed her pain and made her feel invalidated. She said:

> *I had a lot of doctors that made me feel like nothing was wrong with me or kind of **shoved/pushed away my pain** so that was very hard.*

An experience is unique and deserves to be recognised as this is a person's lived reality. Invalidating one's experience is simply not acceptable. Riley expressed:

> *It was definitely interesting having doctors say that you're not actually experiencing that when you knew you were… so it's kind of having to like move*

> *on and understand that they're coming from a* ***medical point of view*** *but also, you're allowed to have your own feelings.*

To be patient-centered, the healthcare professional must empower the patient and share the power in the relationship (81). In making this shift, a partnership is formed. Gadamer discussed the significance of interpreting illness through the perspectives of both the medical practitioner and the person experiencing the illness. There is a need for patient involvement for healthcare professionals to best portray and treat the condition.

> *It is clearly a misrepresentation of the phenomenon to look at the concept of illness solely through the eyes of the doctor and from the standpoint of scientific medicine, and to think that medical knowledge is the same thing as the patient's insight into one's own illness is clearly not simply insight in the sense of knowledge of a true state of affairs, but rather, like all insight, it is something which is acquired with great difficulty and by overcoming significant resistance. […] The patient experiences his or her illness through the felt absence of something. What does this absence of something tell us; what does it tell us about that which is missing? It must occasion reflection. […] Often even the initial stages are closed off to such awareness. (64)*

Disregarding or brushing off one's pain can significantly impact one's mental state. People living with pain are witnesses of their own suffering. A person living with pain refers to "professionals" for help expecting some solutions or guidance. Théroux et al. document the prevalence and management of back pain in a retrospective review of a random sample of 310 charts involving the AIS population. Nearly half of these patients (47.3%) mention that they experienced back pain, however in approximately 80% (n=248) of the charts, no pain management treatment plan is documented (29). In addition, a study by Teles et al. explains that their large cohort population experienced back pain for more than one year (76.6%), and most of them reported daily pain (55.3%). These patients disclosed a lack of adequate pain management (45). Similar, two other studies investigating back pain and AIS fail to address pain management in the patients' treatment plans (31,100). This is very concerning as one's pain is not receiving adequate attention.

> *Without narrative acts, the patient cannot convey to anyone else what he or she is going through. More radically and perhaps equally true, without narrative acts, the patient cannot himself or herself grasp what the events of illness mean. And without telling about or writing about the care of a patient in a complex narrative form, the caregiver might not see the patient's illness in its full, textured, emotionally powerful, consequential narrative form (101).*

Where should one find answers if the people labeled to help might not help you? The National Institute of Arthritis and Musculoskeletal and Skin Diseases recommend joining a community or scoliosis support group to help a teen or a child cope with scoliosis and its treatments (102). A peer support group can act as a community to find these answers. *Curvy Girls'* mission is to effectively deliver a safe environment where all stories are heard, validated, and recognized.

This is my Body, Talk to me Please.

Some of our research participants voiced that they were not part of their treatment care. Eliason and Richman describe adolescence's development tasks and how it is challenged by scoliosis. They explain that adolescents seek independence from adults (103). One living with AIS should be included in all treatment decisions to endorse the development of the adolescent's autonomy and independence level as well as increase treatment adherence (104).

Neve said:

> *I've had doctors explain my entire treatment plan with my parents. I wasn't even in the room. I would have to make it known that* ***this is my body****, and I would like*

> *to know what is happening so I can either agree or disagree with the treatment plan; I can either tell you that I would like to go forth with this treatment plan, or I would like to look for other options.*

Neve wants to be on the same wavelength as the healthcare professional. She said: "My mom, or my dad, or whoever is in the room with me is a secondary person running my medical care." She also expressed:

> *I've even had it where I would even tell my physicians that they had to talk to me, I would also ask my mom all the questions she had so that I could ask them. So that they were aware that they were having a* ***conversation with me****.*

Neve explains that she is primary in her care. She wants to be addressed and have a say in her treatment decisions. She wants to be heard as her body is being treated and manipulated. She is the one living with scoliosis and feeling her chronic pain. Davey explains that dialogical engagement is not often easy or comfortable. A willingness to be subject to the other's address and place one's self-understanding before the other's claims is required to reach fair engagement (105). A partnership between healthcare professionals and patients allows for a holistic healing approach. The French philosopher Michel Foucault reminds us, "one must become the doctor of oneself" (106). The patient, not the healthcare professional, is more intimately connected to the experience of illness:

> *The key to successful doctor–patient partnerships is therefore to recognize that* ***patients are experts*** *too. The doctor is, or should be, well informed about diagnostic techniques, the causes of disease, prognosis, treatment options, and preventive strategies, but only the patient knows about his or her* ***experience of illne****ss, social circumstances, habits and behaviours, attitudes to risk, values, and preferences.* ***Both types of knowledge are needed to manage illness successfully*** *(107).*

Caroline expressed:

> *In the beginning, I felt like everything was being done for me or to me, and I* ***wasn't really voicing*** *what my* ***concerns*** *were, what I was feeling. I think I was feeling very* ***frustrated*** *and very* ***uncertain*** *of what was happening. Things were moving so quickly because they had to make decisions and I just felt like it was a whirlwind experience. […]*
>
> *He [surgeon] didn't even look at you. He would talk to my parents the whole time, as if I'm not important even though* ***it's my body****.*

Emily said:

> *There is* ***no time*** *for people to even express how they're feeling and their concerns like it's just* ***in and out****… I guess if people actually had the time and there was more of a* ***safe environment*** *where you felt like you could actually have a conversation with the health care professional not just them tell you three things that you have to do and then you're out of there.*

Caroline and Emily express that their concerns were not addressed sufficiently by the healthcare professionals. Simmons and Scudds explain that the health professional is the main person talking during a medical examination as he or she explains the processes of diagnosis, directives, prescriptions, medications, and treatments such that there is "an objectification of the person and a blurring of personhood with a disease or illness" (108). Hovey and Paul explain that the patient's narrative has been reduced towards a charted yes-or-no checkboxes. The patient's story is rarely asked for (109). How can one heal another without knowing the patient's story? How can one feel involved in their care when they are not addressed? Hovey et al. describe that a person living with a chronic condition will feel empowered through active participation in the healing process (110). In addition, Donnelly et al. reinforce that generally the patient has little input into their scoliosis treatment decisions. A study demonstrates that having a voice in their own treatment decision for AIS substantially impacts treatment adherence for their bracing regimen (104). Furthermore, the involvement in support groups has also been identified as an effective strategy to improve adherence to long-term treatments (111).

Finding #4: Peer Support Experience

The Power of Sharing

Adolescence is a transitional phase between childhood and adulthood. Adolescent years are stressful for many teenagers, which is in part related to physical development, self-perception, and social relationships. During this time in development, most adolescents grow independent from their parents and associate with a peer group (103). Davison et al. explain that the experience of illness is profoundly a social one. Suffering prompts powerful emotions, hence, the desire to talk to others. Through interpersonal conversations, people living with a certain illness understand themselves in more meaningful ways (59).

Riley shared:

> *Especially with the teenage years, there's so many emotions so many insecurities already so adding the scoliosis on top of that can* ***be really hard… and what Curvy Girls does a great job of doing is making you feel not alone*** *and helping you take those challenges and finding a way to make your experience positive.*

Kaylie said:

> *Finding something like Curvy Girls helps so much especially if you're a young teenage girl like me just getting involved and finding more people like you and learning that you're* ***not alone****… it could help you a lot.*

Emily voiced:

> *You just felt so different and an* ***outcast*** *from everyone else because no one else is going through this and it was just* ***really painful*** *and then it's not just* ***physically painful*** *but the* ***emotional pain*** *of going through that especially as a young teenager when everyone is going through other stuff as well…*

Adolescence is a pivotal period as one gets to establish their social and personal identity. Providing these teenagers with opportunities to share and discuss how they feel, listen to other girls living through a similar context, and be actively involved in a social group can help them gain some control over their lives. In a study regarding social support for people living with HIV or AIDS, participants reported having another person to discuss with reduced stress or made their personal issues concrete. They also valued the affirmation and validation that others could provide through social support (58). Davey explains:

> *[…] sharing a concern with the other over certain subject matters allows, potentially, the other's viewpoint to question the adequacy of my own perspective, to illumine its limits, to expose its blind points, or to reveal its advantages. The process is mutual, for the perspective of the other is also exposed to my own. In either case, different perspectives can be enriched or become "more" by mutual dialogical exposure. The encounter can promote a mutual transformation of orientation toward a given subject matter (64).*

Experiential knowledge is only accessible to those living with particular chronic illnesses (84). By sharing similar experiences, people living with a certain condition can model each other a willingness to learn and grow. Mobilizing collective voices for the purposes of feeling mutual support has the power to protect, save, and transform one's painful experience. The neglected perspectives concerning life with scoliosis and pain can be heard and addressed in a peer support group such as *Curvy Girls.* In a qualitative study, Donnelly et al. describe that patients living with AIS reported they would like to have someone else in their class with a brace to not feel alone and isolated (104). Having someone in class with a similar condition might not be possible; however, joining a peer support group can easily address this matter. Kingod et al. state:

> *Peers exchanged knowledge that emerged from their own experiences of living with illness. This knowledge was not something that could be generated by health care professionals because it arose from* ***real-life experiences*** *and situations. Reciprocal exchange of experiential knowledge gave people a feeling of embodied control that supported them in daily illness self-management (84).*

This passage from Kingod et al. highlights the power of sharing experiences. Adolescents living with scoliosis need to feel some sense of "control" as they learn how to manage their pain at a young age. Consequently, adolescents want to relate and learn how to live with scoliosis on a day-to-day basis as it appears to be their reality. Schwieger et al. compared what type of information parents and adolescents living with scoliosis seek in an online support group. They reveal that parents seek material regarding the details regarding the causes and health conditions associated with AIS. However, adolescents exchange considerably more details about appearance-related concerns regarding AIS-related deformity and wearing a brace (60). As *Curvy Girls* is a peer-run support group, this provides a safe space to discuss adolescent-related interests. A peer-run program can be a powerful source for developing self-advocacy skills, a sense of normalcy, and acceptance towards their own challenges. Learning how to integrate scoliosis into their life while not overpowering it can be explained as "negotiating a partnership with the illness" (112). Hovey and Craig introduce a metaphor entitled "the dance", which explicates a transformative process of how one learns to live well with osteoporosis. They explain that in order to live well with osteoporosis, one needs to become a partner in this "dance" as opposed to being led by the disease (112). We can substitute osteoporosis with scoliosis as the "dance" can be transferred and represented with any chronic condition. A transformative process occurs when one learns to take control of their condition. *Curvy Girls* can represent the music in this "dance", leading and guiding the girls living with scoliosis towards their next crusade. The flow of music can ease them into the subsequent configuration of movements. In addition, *Curvy Girls* can also represent a rehearsal session of this “dance” as the girls living with scoliosis apply the knowledge and material acquired during the support meetings to their life scenarios. The power of sharing gives the opportunity to release and take control of one’s life-world.

Reflections of Support Offered by *Curvy Girls*

Curvy Girls has supported thousands of families by creating a safe community for teenage girls living with scoliosis. The peer support group raises scoliosis awareness, offers an opportunity for education, and gives a voice to teenage girls seeking help. Riley expressed, "*Curvy Girls*… it's definitely changed my life".

Figure 1: Curvy Girls influence in a Word Cloud

Definition of a Word Cloud

The word cloud content (Figure 1) is retrieved from our interview transcripts when discussing the experience of being a member of *Curvy Girls.* During the interviews, we asked our research participants to name three aspects that *Curvy Girls* helped them with (see Appendix A).

The Arts Multimedia Language Facility on the McGill University website suggested word clouds as a means of digital storytelling (113). Word clouds are "graphical representations of word frequency that give greater prominence to words that appear more frequently in a source text" (114). The text visualization data showcases the most salient findings. The word cloud was generated on the website (https://www.wordclouds.com/) (115). The size of the word is relative to the repetition of the word. The words included in the word cloud are the following: confidence (x6), solidarity (x6), support (x6), not alone (x5), acceptance (x3), connection (x3), empowering (x3), belonging (x3), togetherness (x2), community (x2), safe (x2), organization (x1), facilitator (x1), informative (x1), advocate (x1), outgoing (x1), balance (x1), and purpose (x1).

Word Cloud Interpretation

Firstly, I want to acknowledge the power that lies within words and their meanings. Gadamer writes in "Truth and Method":

> *Every word breaks forth as if from a center and is related to a whole, through which alone it is a word. Every word causes the whole of the language to which it belongs to resonate and the whole world view that underlies it to appear. Thus, every word, as the event of a moment, carries with it the unsaid, to which it is related by responding and summoning (75).*

Gadamer explains that every word highlights an underlying worldview and that words summons a totality of meaning from within (64). One expresses their truth with words which reflects the wholeness of an inner being. For Gadamer, words are documents of some collected underlying experiences (64). It can be seen that the three most prominent words highlighted in Figure 1 are "confidence", "solidarity", and "support". The Oxford Advanced Learner's Dictionary provides the following definitions:

Confidence = “the feeling that you can trust, believe in and be sure about the abilities or good qualities of somebody/something” (116)

Solidarity = “support by one person or group of people for another because they share feelings, opinions, aims, etc.” (117)

Support = “to give or be ready to give help to somebody if they need it” (118).

I find it important to contextualize these definitions to understand their meanings as they supplement our horizon of understanding. We can find a common thread among these three words as one needs the confidence to have the ability to support, which creates a network of solidarity. Watson explains that emotional honesty appears crucial within peer support relationships (61). One is seeking support while giving support, both standpoints fuse and the recovery process, which is unique to each person, takes place. *Curvy Girls* fuels this fusing point by engaging different perspectives and integrating unique experiences. The fusion of horizons occurs in a dynamic state as one’s perspective is constantly evolving towards a better understanding of their inner world (64). The desire for mutual solidarity and emotional support in relation to the day-to-day management of a chronic condition motivates patients to seek advice and inspiration among peers with similar illnesses (84). The lexicon illustrated offers an insight into the intricacies occurring in a peer support group. The words “not alone”, “acceptance”, “connection”, “empowering”, and “belonging” are visible in the word cloud, perhaps reflecting the long-term nature of conversational relationships. Similar to our findings, Høybye et al. reveal how women living with breast cancer felt empowered by conversating experiential knowledge (119). A consciousness of belonging and connection to a group results in feeling a sense of empowerment. When seeking support to manage an illness's uncertainty, some people adopt an *empowered* or *activist* identity to feel engaged and in control of their condition (58). The words “togetherness”, “community”, “safe”, “organization”, “facilitator”, “informative”, “advocate”, “outgoing”, “balance”, and “purpose” appear as minor terms, however these are also a part of the thread uniting “confidence”, “solidarity”, and “support”. I envision the words illustrated in Figure 1 as a staircase. Each step is a transformation leading to a better understanding of one's inner world. Each step is unique and personalized to the individual. One could go up and down the staircase while holding to the rail when needed. *Curvy Girls* can represent the supportive rail on this journey.

Discussion

Summaries of Findings

In the first finding, we received an insight into some personal experiences from girls living with scoliosis and pain. Before being diagnosed with scoliosis, some of our research participants lived with undiagnosed pain, which resulted in confusion, solitude, and loneliness. Having no identifying label for their pain made these teenage girls question their bodies and minds. A diagnosis is a theoretical construct by which health professionals attempt to label the patients' discomfort. However, the absence of a diagnosis might disregard the patients' discomfort, leaving one feeling isolated and alone. As back pain in children and adolescents was historically considered unusual, some teenage girls had to learn how to cope with their pain by themselves. Moreover, a diagnosis of scoliosis meant different things to different individuals; some felt a sense of relief while others were angry. Some participants felt reassured by their diagnosis as they have a sense of direction to their treatment plan and care. Others felt angry as they thought that scoliosis would hold them back for the rest of their lives. During the process of diagnosis and acceptance, teenage girls living with scoliosis occupy a "liminal space" in that they exist in-between two separate identities. *Curvy Girls* might alleviate some strain of this "liminal space" by offering a safe environment to discuss and feel a sense of normalcy of being a teenage girl living with scoliosis. The support group might help transition the adolescent girls living with scoliosis from the uncertainty of this "liminal space" to a safe and open space.

In the second finding, the social experience discussed the familiarity and unfamiliarity of scoliosis. If one's social network is familiar with scoliosis upon getting diagnosed, the teenage girls were not as frightened from their condition. Having little knowledge about scoliosis may be a daunting experience at first. The transition between these two realms can also be referred to as "liminal space", living in-between who they were and whom they may become. *Curvy Girls* can support these teenage girls transitioning from these two spaces. It brings the unfamiliar to the familiar state and surrounds them with others living through a similar experience.

In the third finding, we discussed the healthcare experience of teenage girls living with scoliosis. Pain is an invisible condition, yet it affects the whole individual. As the literature review reveals, the relationship between scoliosis and pain remains scattered. These teenage girls living with scoliosis are witnesses of this perplexity as not all health professionals acknowledge the pain with which the teenage girls live. In addition, some of our research participants revealed that they were not active partners in their own care. They wanted the healthcare professionals to include them in their treatment plans and form a solid and dynamic partnership (120). Dr. Charon explains the significance of providing space for personal narratives within the healthcare system:

> *Patients long for doctors who comprehend what they go through and who, as a result, stay the course with them through their illness. A medicine practiced without a genuine and obligating awareness of what patients go through may fulfill its technical goals, but it is an empty medicine, or, at best, half a medicine (101).*

In the fourth and final finding, we explored the effect of *Curvy Girls'* peer support group. Being a member of a peer support group offers the opportunity of sharing experiences and stories with people living through a similar context. Through interpersonal discussions, one might understand themselves in a more meaningful way. The neglected perspectives concerning life with scoliosis and pain can be heard and addressed in a peer support group. In addition, we asked *Curvy Girls* members to describe three aspects in which the support group influenced them, and the three most prominent words highlighted were "confidence", "solidarity", and "support". *Curvy Girls* provides a steppingstone towards a better understanding of one's life-world.

Study Limitations

The findings from this research study have to be seen in the light of some limitations as "[…] a part of the integrity of any research lies in recognizing and acknowledging that no one method provides all the answers and every method has strengths and limitations" (62).

A first limitation would be that the quality of the interpretations and analyses depends on the depth of the data collected. An intense life fluctuation characterizes a profound experience. In this study, teenage girls living with scoliosis live with a certain profoundness that distinguishes them from a typical girl going through adolescence. Gadamer explains that a profound experience is not momentary in nature but lingers upon the continuity of meaning (75). The quality of interviews is limited by the depth of conversations and the participants' willingness to discuss their profound experiences. The powerful nature of intense conversations is contingent upon the participants and the researcher's state of mind at that moment of time. Moules et al.

explain that “When the topic deals with human concerns and experiences, there is often emotion at play.” (62). It is important to be mindful of the reflexivity arising from the interviews.

Another limitation might be found in the context in which the study took place. Most interviews occurred between March 2020 and June 2020, highlighting the first wave of the COVID-19 pandemic. The COVID-19 pandemic may have altered the participants’ insight into their scoliosis experience when interviewed at that time. In addition, the COVID-19 pandemic required us to conduct the interviews virtually. Therefore, a face-to-face interview was not possible. I am not sure if that would impact the profoundness of the interviews; however, it is important to note that engaging virtually differs from engaging in person. The connection with the interviewee may be different virtually as all languages are not readily seen on camera (i.e., body language). Given the potential of that being a limitation, all participants were interviewed using the same platform, which harmonizes the extent of this restraint. While the virtual nature of the interviews is acknowledged as a limitation, it may also be considered a strength as the participants were from multiple geographic regions of Canada instead of just within one city or province.

Directions for Future Research

Hermeneutical research does not seek consensus but invites diverse interpretations to carry on the life of narratives and language. Future research should maintain the cycle of listening to another person’s voice to gain a unique insight into understanding the person’s experience behind a particular hardship. Moules et al. explain:

> *In one way, it is as though the interpretation cannot settle and rest in one’s own hands for, if it does, it stops growing, it stops being generative and fertile. It settles into a reified version of something without experiencing the life force and*

> *generativity of others and of the topic it needs to sustain it. When interpretations go out of our hands and into the hands of others, they situate themselves exactly where they are supposed to be – in movement and play, and we cannot even save the work from our own re-interpretation (62).*

Therefore, the narratives from people living through hardship should continue to be brought out into the light, reminding people to be aware, and remembering that we are the products of collective experiences. Future research should continue this dialogue of treating a person as a whole.

The intent of a hermeneutical research approach is not to generalize the findings to a greater population but to transfer the knowledge and gain insight to a deeper understanding of one's life-world. Inviting and presenting these narratives from teenage girls living with scoliosis serves to pin a reference for people living through a similar experience by allowing them to relate and validate their state of mind at any given moment. Moules et al. explain that "these kinds of stories are stories that need to be told and retold over time as a way for people to make sense and meaning of what they have undergone." (62). Future research should investigate if the acquired knowledge regarding peer support groups may be transferred to other chronic illness support groups that need to be further explored.

Conclusion

In this study, we endeavored to gain insight into the lived experiences of teenage girls living with scoliosis and to understand how the peer support group, *Curvy Girls*, impacted their lives. To acquire this knowledge, we conducted semi-structured open-ended interviews with 16 participants recruited from *Curvy Girls.* The interviews were based on philosophical hermeneutics, which fosters a philosophy of experience. Hermeneutical researchers work to understand the meaning of human experience that provides insight into the context of a daily reality of living with a certain condition. Teenage girls living with scoliosis often find themselves in a "liminal space", a rupture between their old and new selves, between the familiar and unfamiliar, and between their body and the health care professional. This tension between these two spaces may be a heavy load to carry alone. Through our participants' narratives, we learned that the peer support group, *Curvy Girls,* mobilizes collective voice into a transformation of communal learning. Engaging in a peer support group can ease the transition of the "liminal space". If we engage in the possibility of learning from each other, we open up to the possibility of engaging with people who have had experiences that we have not been witnessed. There is power and momentum in transformational learning if one is willing to seize it. We are proposing a reflective engagement beyond the biomedical discourse of diagnosis and treatment toward an inclusive meaning of treating a person as a whole.

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Appendix

Appendix A: Sample Interview Guide

Written by Marie Vigouroux, Gillian Newman, Dr. Hovey, and Kristina Amja.

1. Tell me about yourself.
    - Can you tell me the story of how you were diagnosed?
    - How did that feel? / How did you feel in that moment?
    - How has your life been since then?

2. Does scoliosis interfere with your social life? Friends, family, hobbies, colleagues, teachers…
    - Does it keep you from seeing your friends?
    - Do your friends treat you differently now than before?
    - Do your friends treat you differently than their other friends?
    - Does it make it harder for you to make new friends?
    - Does it keep you from doing things you like?
    - Do you usually tell people about it, or do you prefer to keep it to yourself?
    - How did it affect your family life?
    - Is it harder to do family activities?
    - Does your family treat you differently than before?
    - Does your family treat you differently than your siblings (if applicable)?

3. How was your experience with healthcare?
    - What kind of specialists or doctors did you see? (surgeon, social worker, psychologist, etc.)
    - Which one of the people you mentioned helped you the most?
    - How did they help you?
    - Can you tell me about your pain?
    - Do doctors/nurses believe you when you tell them you're in pain?
    - Can you give me an example of something that happened where someone didn't believe you were in pain?
    - How does it make you feel when doctors/nurses don't believe you?
    - How do you feel when someone asks you to rate your pain on a scale of 1 to 10?
    - What do these numbers mean to you?
    - What questions would you rather be asked to rate your pain?

4. How did you hear from curvy girls?
    - How long have you been a member?
    - What did you think a meeting would be like?
    - How was it actually?
    - Can you name the top 3 things that CG has helped you with? (Hone in on each)
    - In a world with no limitations, what would you change to CG?

5. Other general questions:
    - Age
    - Hobbies
    - Choice of pseudonym

Appendix B: McGill University Research Ethics Board Approval

McGill

Faculty of Medicine
3655 Promenade Sir William Osler #633
Montreal, QC H3G 1Y6

Faculté de médecine
3655, Promenade Sir William Osler #633
Montréal, QC H3G 1Y6

Fax/Télécopieur: (514) 398-3870
Tél/Tel: (514) 398-3124

CERTIFICATION OF ETHICAL ACCEPTABILITY FOR RESEARCH INVOLVING HUMAN SUBJECTS

The Faculty of Medicine Institutional Review Board (IRB) is a registered University IRB working under the published guidelines of the Tri-Council Policy Statement, in compliance with the Plan d'action ministériel en éthique de la recherche et en intégrité scientifique (MSSS, 1998), and the Food and Drugs Act (17 June 2001); and acts in accordance with the U.S. Code of Federal Regulations that govern research on human subjects. The IRB working procedures are consistent with internationally accepted principles of Good Clinical Practices.

At a full Board meeting on August 26, 2019, the Faculty of Medicine Institutional Review Board, consisting of:

Frances Aboud, PhD
Patricia Dobkin, PhD
Kathleen Montpetit, M. Sc.
Maida Sewitch, PhD

Joséane Chrétien, MJur
Sally Mann, M.S.
Roberta Palmour, PhD
Margaret Swaine, BA

Examined the research project **A06-B44-19B** titled: *What are the lived experiences and social implications of adolescents living with scoliosis and chronic pain*

As proposed by: Dr. Richard Hovey to ____________
Applicant — Granting Agency, if any

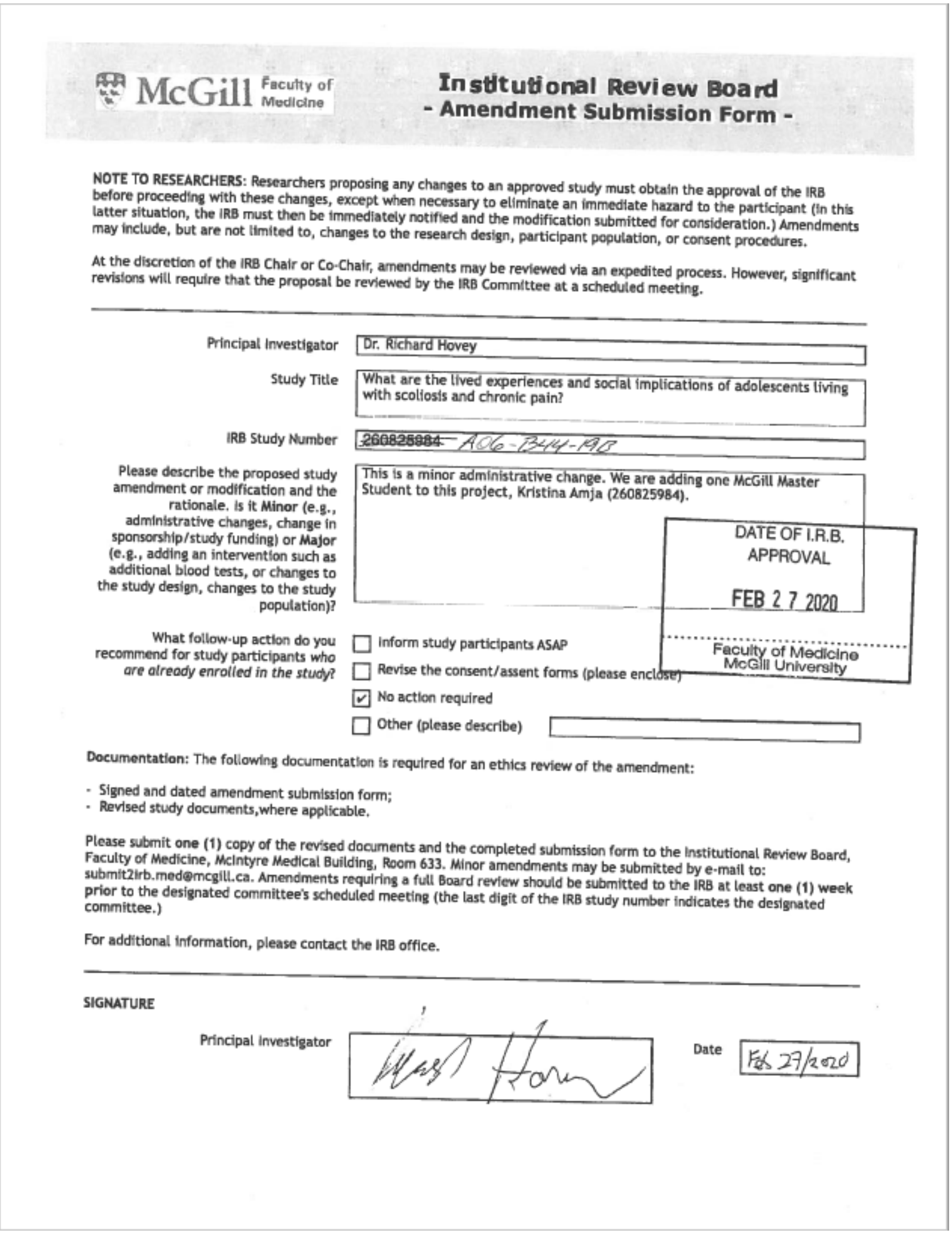
And consider the experimental procedures to be acceptable on ethical grounds for research involving human subjects.

August 26, 2019
Date

Chair, IRB

Dean/Associate Dean

Institutional Review Board Assurance Number: FWA 00004545



McGill Faculty of Medicine

Institutional Review Board - Amendment Submission Form -

NOTE TO RESEARCHERS: Researchers proposing any changes to an approved study must obtain the approval of the IRB before proceeding with these changes, except when necessary to eliminate an immediate hazard to the participant (in this latter situation, the IRB must then be immediately notified and the modification submitted for consideration.) Amendments may include, but are not limited to, changes to the research design, participant population, or consent procedures.

At the discretion of the IRB Chair or Co-Chair, amendments may be reviewed via an expedited process. However, significant revisions will require that the proposal be reviewed by the IRB Committee at a scheduled meeting.

Principal Investigator	Dr. Richard Hovey
Study Title	What are the lived experiences and social implications of adolescents living with scoliosis and chronic pain?
IRB Study Number	~~260825984~~ A06-B44-19B
Please describe the proposed study amendment or modification and the rationale. Is it **Minor** (e.g., administrative changes, change in sponsorship/study funding) or **Major** (e.g., adding an intervention such as additional blood tests, or changes to the study design, changes to the study population)?	This is a minor administrative change. We are adding one McGill Master Student to this project, Kristina Amja (260825984).
What follow-up action do you recommend for study participants *who are already enrolled in the study*?	☐ Inform study participants ASAP ☐ Revise the consent/assent forms (please enclose) ☑ No action required ☐ Other (please describe)

DATE OF I.R.B.
APPROVAL
FEB 2 7 2020
Faculty of Medicine
McGill University

Documentation: The following documentation is required for an ethics review of the amendment:

- Signed and dated amendment submission form;
- Revised study documents,where applicable.

Please submit **one (1)** copy of the revised documents and the completed submission form to the Institutional Review Board, Faculty of Medicine, McIntyre Medical Building, Room 633. Minor amendments may be submitted by e-mail to: submit2irb.med@mcgill.ca. Amendments requiring a full Board review should be submitted to the IRB at least **one (1) week** prior to the designated committee's scheduled meeting (the last digit of the IRB study number indicates the designated committee.)

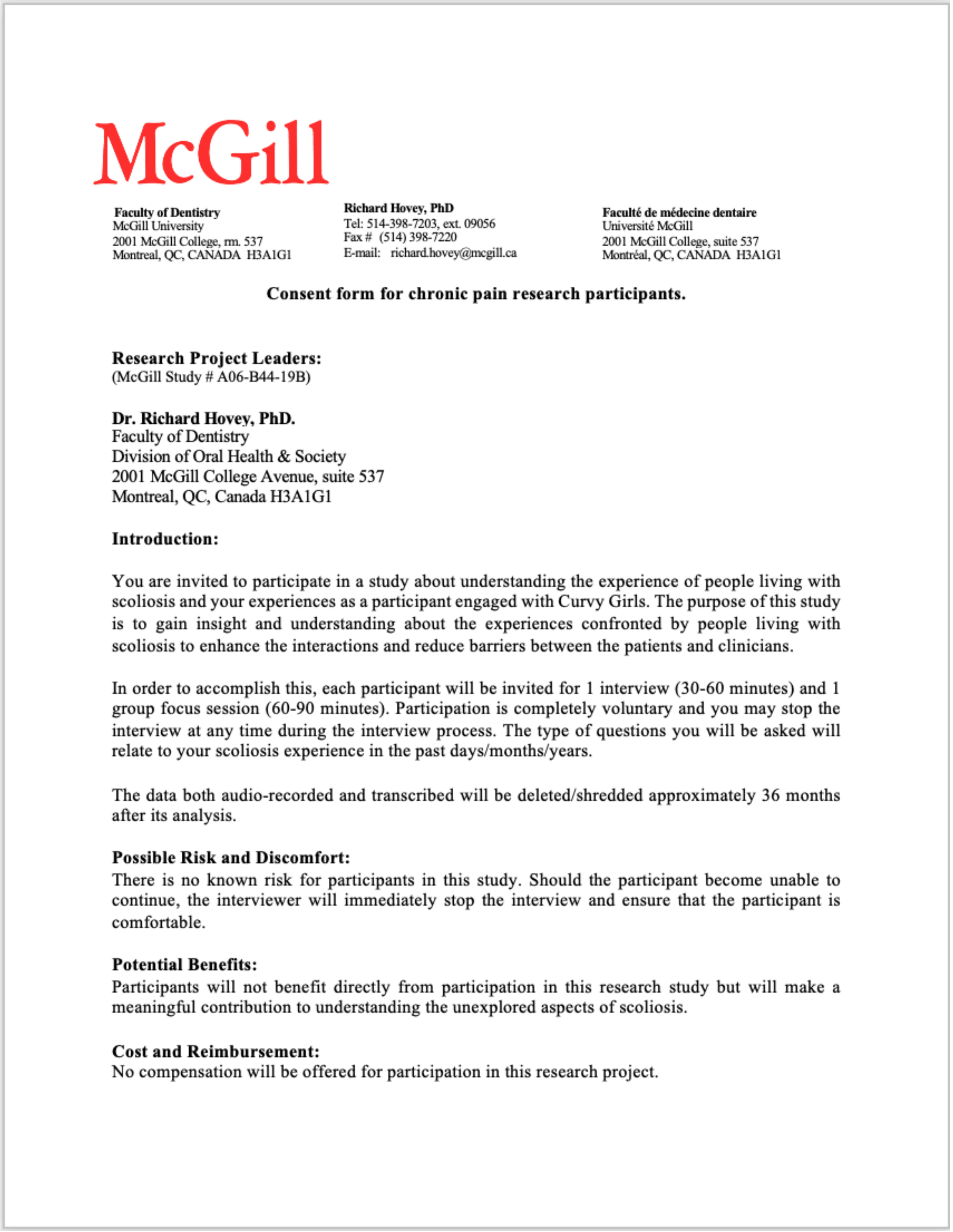
For additional information, please contact the IRB office.

SIGNATURE

Principal Investigator

Date Feb 27/2020

Appendix C: Example of English Consent Form



McGill

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Richard Hovey, PhD
Tel: 514-398-7203, ext. 09056
Fax # (514) 398-7220
E-mail: richard.hovey@mcgill.ca

Faculté de médecine dentaire
Université McGill
2001 McGill College, suite 537
Montréal, QC, CANADA H3A1G1

Consent form for chronic pain research participants.

Research Project Leaders:
(McGill Study # A06-B44-19B)

Dr. Richard Hovey, PhD.
Faculty of Dentistry
Division of Oral Health & Society
2001 McGill College Avenue, suite 537
Montreal, QC, Canada H3A1G1

Introduction:

You are invited to participate in a study about understanding the experience of people living with scoliosis and your experiences as a participant engaged with Curvy Girls. The purpose of this study is to gain insight and understanding about the experiences confronted by people living with scoliosis to enhance the interactions and reduce barriers between the patients and clinicians.

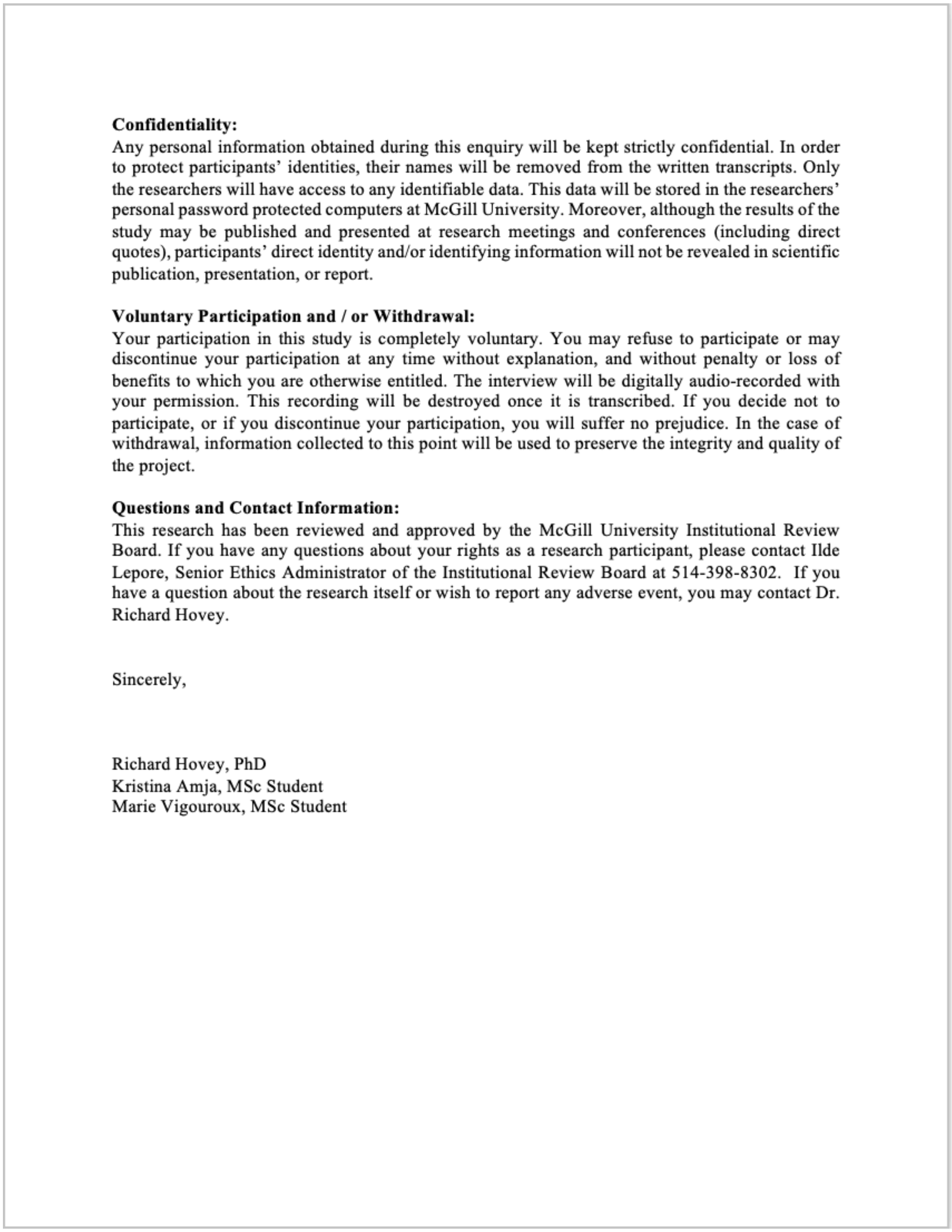
In order to accomplish this, each participant will be invited for 1 interview (30-60 minutes) and 1 group focus session (60-90 minutes). Participation is completely voluntary and you may stop the interview at any time during the interview process. The type of questions you will be asked will relate to your scoliosis experience in the past days/months/years.

The data both audio-recorded and transcribed will be deleted/shredded approximately 36 months after its analysis.

Possible Risk and Discomfort:
There is no known risk for participants in this study. Should the participant become unable to continue, the interviewer will immediately stop the interview and ensure that the participant is comfortable.

Potential Benefits:
Participants will not benefit directly from participation in this research study but will make a meaningful contribution to understanding the unexplored aspects of scoliosis.

Cost and Reimbursement:
No compensation will be offered for participation in this research project.



Confidentiality:

Any personal information obtained during this enquiry will be kept strictly confidential. In order to protect participants' identities, their names will be removed from the written transcripts. Only the researchers will have access to any identifiable data. This data will be stored in the researchers' personal password protected computers at McGill University. Moreover, although the results of the study may be published and presented at research meetings and conferences (including direct quotes), participants' direct identity and/or identifying information will not be revealed in scientific publication, presentation, or report.

Voluntary Participation and / or Withdrawal:

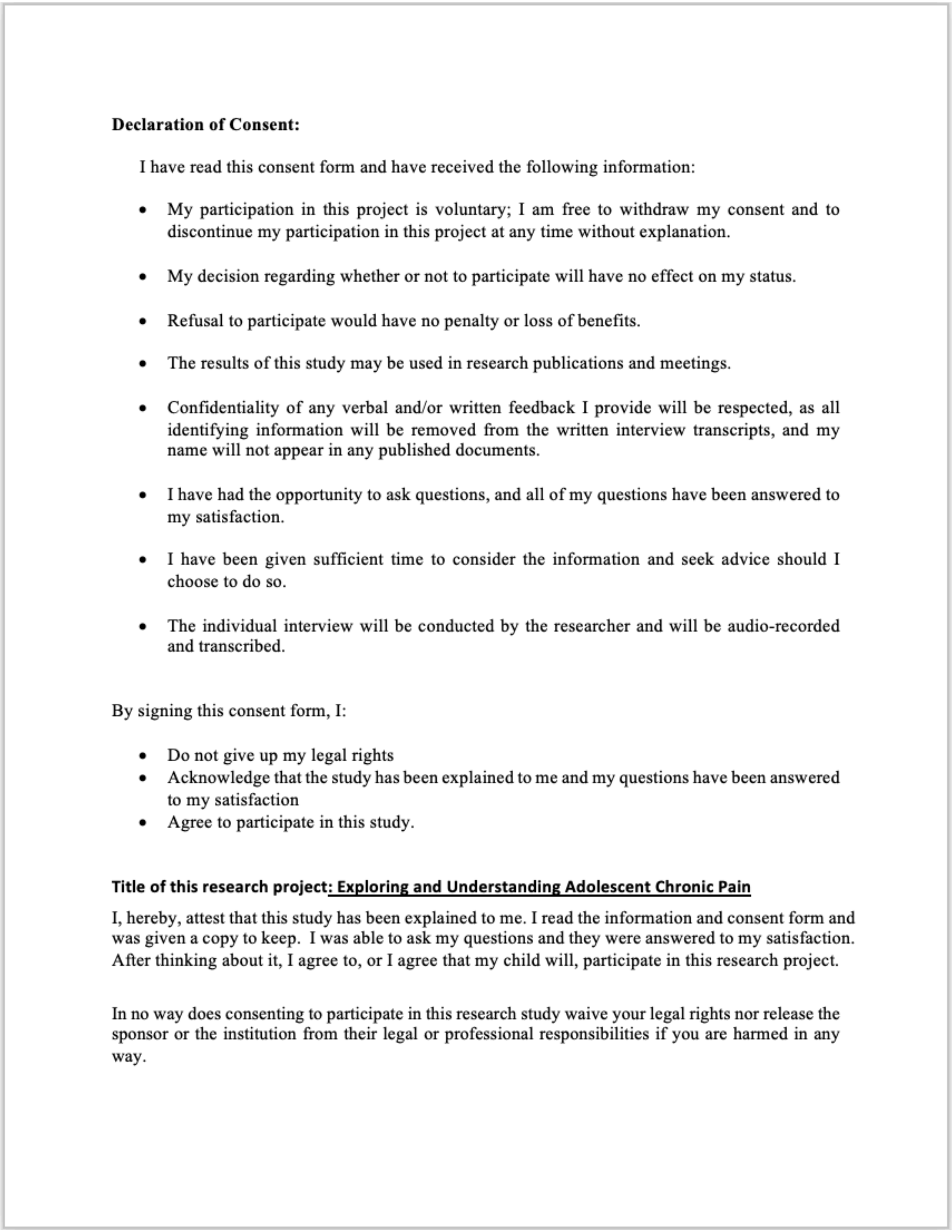
Your participation in this study is completely voluntary. You may refuse to participate or may discontinue your participation at any time without explanation, and without penalty or loss of benefits to which you are otherwise entitled. The interview will be digitally audio-recorded with your permission. This recording will be destroyed once it is transcribed. If you decide not to participate, or if you discontinue your participation, you will suffer no prejudice. In the case of withdrawal, information collected to this point will be used to preserve the integrity and quality of the project.

Questions and Contact Information:

This research has been reviewed and approved by the McGill University Institutional Review Board. If you have any questions about your rights as a research participant, please contact Ilde Lepore, Senior Ethics Administrator of the Institutional Review Board at 514-398-8302. If you have a question about the research itself or wish to report any adverse event, you may contact Dr. Richard Hovey.

Sincerely,

Richard Hovey, PhD
Kristina Amja, MSc Student
Marie Vigouroux, MSc Student



Declaration of Consent:

I have read this consent form and have received the following information:

- My participation in this project is voluntary; I am free to withdraw my consent and to discontinue my participation in this project at any time without explanation.

- My decision regarding whether or not to participate will have no effect on my status.

- Refusal to participate would have no penalty or loss of benefits.

- The results of this study may be used in research publications and meetings.

- Confidentiality of any verbal and/or written feedback I provide will be respected, as all identifying information will be removed from the written interview transcripts, and my name will not appear in any published documents.

- I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction.

- I have been given sufficient time to consider the information and seek advice should I choose to do so.

- The individual interview will be conducted by the researcher and will be audio-recorded and transcribed.

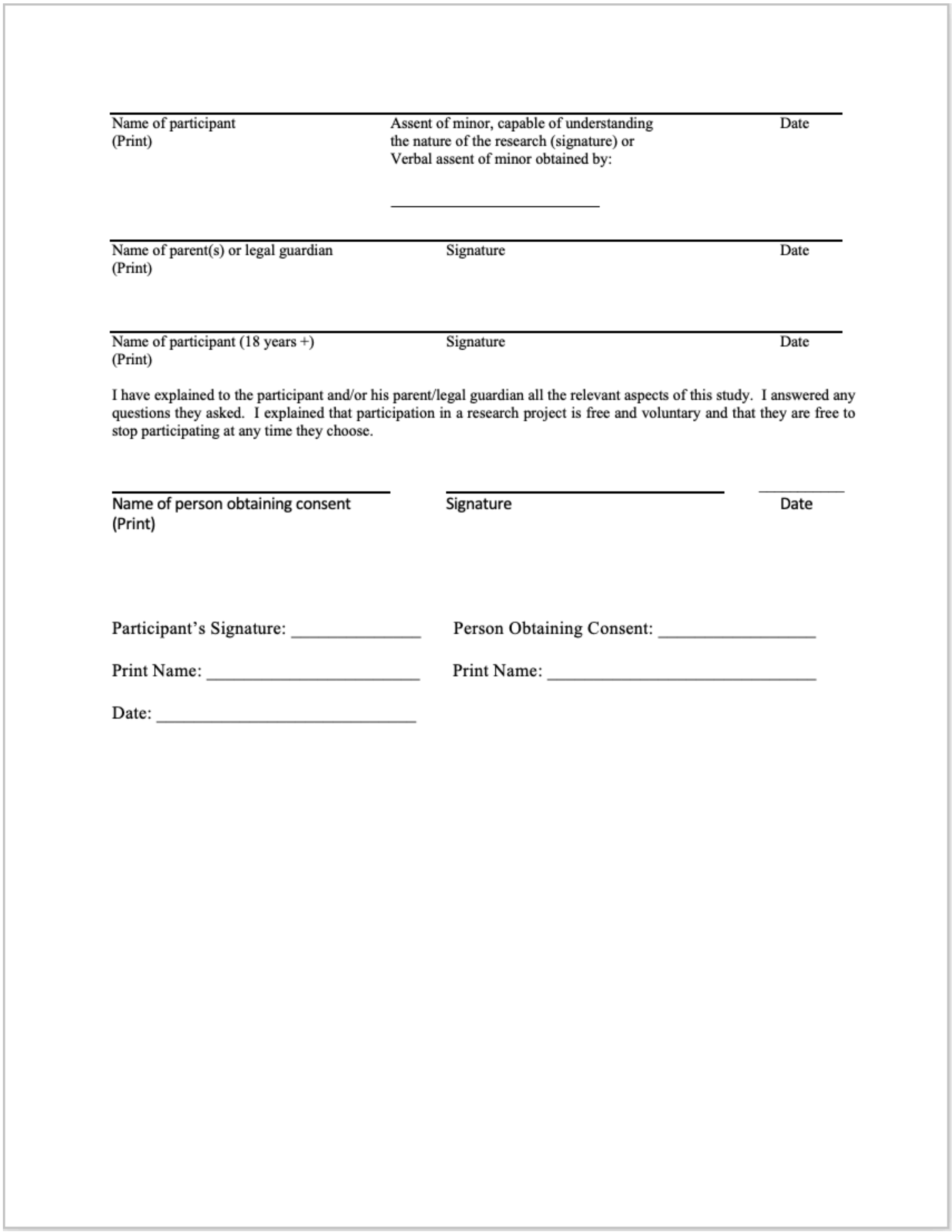
By signing this consent form, I:

- Do not give up my legal rights
- Acknowledge that the study has been explained to me and my questions have been answered to my satisfaction
- Agree to participate in this study.

Title of this research project<u>**: Exploring and Understanding Adolescent Chronic Pain**</u>

I, hereby, attest that this study has been explained to me. I read the information and consent form and was given a copy to keep. I was able to ask my questions and they were answered to my satisfaction. After thinking about it, I agree to, or I agree that my child will, participate in this research project.

In no way does consenting to participate in this research study waive your legal rights nor release the sponsor or the institution from their legal or professional responsibilities if you are harmed in any way.



Name of participant (Print)	Assent of minor, capable of understanding the nature of the research (signature) or Verbal assent of minor obtained by: ________________________	Date
Name of parent(s) or legal guardian (Print)	Signature	Date
Name of participant (18 years +) (Print)	Signature	Date

I have explained to the participant and/or his parent/legal guardian all the relevant aspects of this study. I answered any questions they asked. I explained that participation in a research project is free and voluntary and that they are free to stop participating at any time they choose.

Name of person obtaining consent (Print)	Signature	Date

Participant's Signature: ______________ Person Obtaining Consent: ________________

Print Name: ______________________ Print Name: ____________________________

Date: ____________________________