A life askew: Understanding the lived experiences of *Curvy Girls* members

---

An Applied Philosophical Hermeneutic Exploration

by

Marie Vigouroux

Faculty of Dental Medicine and Oral Health Sciences

McGill University, Montreal

A thesis submitted to McGill University in partial fulfillment of the requirements

of the Master of Science Degree in the Faculty of Dental Medicine and Oral Health Sciences *the real teen girls, huddled on the subway*

after school, limbs draped over each other's shoulders

bones knocking, an awkward wind chime

and all of the commuters, who plug in their headphones

to mute the giggle, silence the gaggle and squeak,

not knowing where they learned to do this,

to roll their eyes and turn up the music

- Olivia Gatwood, "When I Say We That Are All Teen Girls" (1)

Table of Contents

Abstract

Introduction: Scoliosis in a condition where a curve develops in the spine. Adolescent girls affected by scoliosis are significantly more likely to require treatment such as bracing or surgery than their male counterparts. *Curvy Girls* is a peer support group for adolescent girls with scoliosis that allows them to engage with each other in a safe environment.

Objectives: This study endeavours to explore the lived experiences of adolescent girls with scoliosis who are *Curvy Girls* members and understand how this peer support group has affected their experience

Approach: Sixteen participants were recruited through a senior board member of *Curvy Girls*. Data was gathered through semi-structured interviews with open-ended questions, transcribed verbatim, and analyzed using an applied philosophical hermeneutic approach, a practice of uncovering insights from transformational conversation.

Findings: We found that participants perceived to have had their pain, feelings, or scoliosis treatments invalidated by friends, family members, educators, or healthcare professionals. We also found that the participants' sense of belonging to *Curvy Girls* did not depend on their level of involvement with the group, and that many of them displayed a strong sense of reflexivity and desire to 'give back' to the scoliosis community. Finally, we found that, if participants could make changes to *Curvy Girls*, they would extend its reach and scope through advertising and including peer support services for boys and non-binary adolescents.

Future Directions: These findings may help clinicians, healthcare professionals, and peer support organisations deepen their understanding of the perspectives of this specific population. This transformed understanding could lead to the instauration of care and services that are better

adapted to this population’s needs, resulting in lessening the burden of the condition on the individual and their support system.

Résumé

Introduction : La scoliose est une condition où la colonne vertébrale développe une courbe. Les adolescentes souffrant de scoliose courent un risque beaucoup plus important d'avoir besoin de traitements tels que porter un corset, ou nécessiter une chirurgie que les adolescents. *Curvy Girls* est un groupe de soutien par les pairs pour les adolescents souffrant de scoliose qui leur permet d'interagir entre elles dans un environnement sécuritaire.

Objectifs : Cette étude entreprend d'explorer les expériences vécues des adolescentes souffrant de scoliose qui sont membres de *Curvy Girls*, et de comprendre comment ce groupe de soutien par les pairs a affecté leur expérience.

Approche : Seize participantes ont été recrutées par une commissaire principale de *Curvy Girls*. Les données ont été recueillies via des entrevues semi-structurées composes de questions ouvertes, transcrites verbatim, et analysées utilisant une approche philosophique herméneutique appliquée, une pratique permettant de découvrir des observations à travers des conversations transformationnelles.

Résultats : Nous avons trouvé que les participants percevaient leur douleur, émotions, scoliose, ou traitements invalidés par leurs amis, membres de leur famille, éducateurs, ou professionnels de la santé. Nous avons aussi trouvé que le sentiment d'appartenance à *Curvy Girls* des participantes ne dépendait pas de leur niveau de participation avec le groupe, et que beaucoup d'entre elles démontraient une forte réflexivité et un désir de réinvestir leurs efforts dans la communauté de la scoliose. Finalement, nous avons trouvé que si les participantes pouvaient effectuer des changements à *Curvy Girls*, elles en élargiraient la portée et le cadre en publicisant le groupe et en incluant des services de soutien par les pairs pour les garçons et les adolescents non-binaires.

Directions futures : Ces résultats pourraient aider les cliniciens, professionnels de la santé, et els groupes de soutien par les pairs à approfondir leur compréhension des perspectives de cette population. Cette compréhension transformée pourrait mener à l'instauration de soins et services mieux adaptés aux besoins de cette population, et à la diminution de l'impact de la condition sur les individus et leur système de soutien.

Acknowledgements

The completion of this thesis would not have been possible without the guidance and support of Dr. Richard Hovey, my thesis supervisor. A gentle and inspiring educator, Richard ensured that I had the tools, knowledge, and skills necessary to complete this research project. He has taught me the importance of letting the narrative speak for itself and cultivated my curiosity. Through his unrelenting encouragement and patience, he helped me build the confidence and acceptance I needed to not only complete this project but imagine a future for myself that I didn't think possible. I will be forever grateful for his mentorship.

I would like to thank Ms. Kristina Amja, as we worked together to gather and process the data for our respective studies. It was an absolute pleasure and honour to work with her during my degree program. Her motivation, work ethic, and energy will keep inspiring me for years to come.

Moreover, this project would not have been possible without the generosity and candor of our research participants. It is a privilege to bring their narratives to light. Thank you to Ms. Gillian Newman for assisting us in recruiting them, and for sharing her powerful insights on their experiences.

Thank you to Dr. Marc O. Martel, as my professor, member of my advising committee, and graduate advisor for the Faculty's Research Day. His mentorship in these various settings has always been kind, supportive and enthusiastic.

Thank you to Ms. Nioushah Noushi and Mr. Veeresh Pavate, members of Dr. Richard Hovey's Hermes Research Lab. Their friendship and support, especially during this time of limited socialization was a constant comfort and a breath of fresh air.

Thank you to Dr. Jeffrey Myers, for encouraging me to return to school.

This project was possible thanks to the financial support of the Faculty of Dentistry and Dr. Richard Hovey through the Dr. E.T. & Mrs. Marjorie Bourke Award and the Graduate Excellence Award.

Last but not least, I wish to thank my son James, for being my North Star. The first fortune cookie he ever picked out said “You are the sun to those in need of light.” There is no better or more accurate description of my little gremlin.

Contribution of Authors

I wrote each section of this masters' level thesis under the guidance and supervision of Dr. Richard Hovey. Dr. Marc O. Martel acted as the second member of my advising committee. I worked with another masters' level student in Dr. Hovey's Hermes Research Team, Ms. Kristina Amja, and *Curvy Girls* senior Board Member, Ms. Gillian Newman, to create the recruitment material and recruit the research participants. Ms. Amja and I conducted the participant interviews, transcribed the interviews verbatim and anonymized the transcripts together. I performed a literature review with the help of librarian Mr. Martin Morris. I conducted the data analysis through regular meetings with Dr. Hovey and Ms. Amja. Any work used as a reference for this thesis is cited in the bibliography section of this document.

Introduction

COVID-19 Pandemic

It is important to situate this research project in time. Most of the participant interviews for this study were conducted during the height of the ‘first wave’ of the COVID-19 pandemic in Canada, which occurred from March 2020 to June 2020. The remaining interviews as well as the analysis and writing of this thesis were completed from July 2020 to August 2021, at which time the pandemic was still ongoing. This historic event undoubtedly affected the research of many research teams, and ours was no exception. I will discuss the ways in which the pandemic may have affected this study in the Limitations section of this thesis.

Research Interest

It is not unusual for hermeneutic researchers to have a personal connection to the topic they are researching. While I do not live with scoliosis or live with chronic pain, I wish to better understand how people live with chronic conditions and integrate them into their daily lives and identities. I have lived with post-traumatic stress disorder for fifteen years and still struggle to differentiate what is a symptom of my condition and what is personality trait, and whether this distinction matters given that it is a part of me regardless.

I began working alongside Dr. Richard Hovey in 2015 on a study examining the lived experiences of men living with chronic pain who were part of a peer support group. As a young woman living pain free, I was surprised to relate so deeply to the participants’ narrative of suffering and isolation. Their interviews made a strong impression on me, awoke a curiosity for the topic that I knew I had to investigate further, and revealed a desire to contribute meaningfully to the academic discussions surrounding the lived experiences of people living with chronic conditions like chronic pain.

Rationale

Scoliosis affects anywhere from 0.47% to 5.2% of the population, and 40% of people living with scoliosis report chronic back pain (2,3). While the pain mechanisms behind the presence of chronic pain in this population are not yet well understood, the experiences of people living with scoliosis combined with chronic pain persist (4). In adolescents, chronic pain can lead to negative outcomes such as decreased school attendance and social isolation, the impact of which can follow them into adulthood (5,6). Patient-facing literature encourages people experiencing chronic pain to join peer support groups (5). However, very little literature exists to justify this recommendation, and even less so when it comes to adolescents.

Curvy Girls is a peer support group for adolescent girls living with scoliosis that has existed since 2006 (7). Members of this peer support group have anecdotally reported positive outcomes from their engagement with the group. No research has been conducted on *Curvy Girls*, or the lived experiences of *Curvy Girls* members.

There is a need for research into the lived experiences of adolescent girls with scoliosis who engage or have engaged with peer support group *Curvy Girls*. Studying this population's experiences with scoliosis, pain, and their interactions with *Curvy Girls* could bring insight into the mechanisms of chronic pain support groups.

Objective

This study endeavours to explore the lived experiences of adolescent girls living with scoliosis who are current or past members of the peer support group *Curvy Girls*. Researchers placed focus on the participants' experience with chronic pain, their social life, experiences with health care, and *Curvy Girls*. This approach allowed for the collection of rich and ample data, leading in turn to findings that may guide future research as well as be applied in clinical and community settings. Indeed, the findings presented in this thesis may be of interest to tertiary care clinics such as multidisciplinary pediatric pain management clinics, and community peer support group organizations like *Curvy Girls*.

Review of Literature

Scoliosis

Scoliosis is a condition where a lateral curve develops in the spine (8). While there are different etiologies of scoliosis, namely idiopathic, congenital and neuromuscular, this study uses the term “scoliosis” as an umbrella term for any etiology or degree of the condition (8). Participants were not excluded depending on the etiology of their condition. Scoliosis affects an estimated 0.47-5.2% of the population with a female to male ratio of 1.5:1 to 3:1 (2). Adolescent girls affected by scoliosis are significantly more likely than their male counterparts to progress to a curve angle where treatment such as bracing or spinal fusion surgery is required (2).

There are proven and effective treatments for scoliosis such as bracing and, depending on the severity of the spinal curvature, spinal fusion surgery (9). However, both have important side effects that must be considered. While bracing is an effective way to slow down the progression of the spinal curvature, it is associated with decreased pulmonary function and psychological distress (10–12). Spinal fusion surgery straightens the spine and fuses the vertebrae together in order to correct the lateral spinal curvature and prevent further curvature (13). Recent research suggests that 15% of adolescents undergoing spinal fusion surgery will develop persistent postoperative pain (14).

There is a paucity of qualitative information regarding the lived experiences of adolescent girls with scoliosis. While some qualitative studies have endeavoured to explore the experiences of adolescents living with scoliosis, many of these studies focus on the physical and medical aspects of their experience, such as living with a “deformity”, or the experience of scoliosis-related surgery (15–17). Qualitative information is scarce when it comes to the day-to-day experiences of adolescent girls living with scoliosis, and comes from autoethnographic studies

(18,19). More qualitative research is needed to understand the specific lived experiences of this population, as their needs and trajectory through the condition are unique.

Chronic Pain and Social Isolation

In 2020, the International Association for the Study of Pain updated its 1986 definition of pain to: "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (20). This definition is accompanied by notes which include "[p]ain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors" and "[a] person's report of an experience as pain should be respected" (20). Chronic pain is defined as a "persistent or recurrent pain lasting longer than 3 months"; this definition, based on pain duration, allows for straightforward classification (21). Chronic pain has different classifications, namely musculoskeletal pain, visceral pain, headache, neuropathic pain, postsurgical and posttraumatic pain, cancer pain, and primary pain (21).

Adolescents who live with scoliosis are twice as likely to experience chronic pain than those who do not (22). In adolescents, living with chronic pain can disrupt school attendance and create social isolation (5). A 2010 systematic review conducted by Forgeron et al. concludes that adolescents living with chronic pain "have peer relationship deficiencies" (23). Additionally, studies have found that this population is subjected to pain-related stigma by medical professionals, education personnel, peers, and family members, and that 10% of adolescents report at least one experience of pain dismissal (24,25). These negative experiences have a lasting negative impact on the lives of the adolescents facing them. Indeed, a study evaluating the long term impact of experiencing chronic pain during adolescence found lower educational attainments, decreased vocational functionality, and social impairments in young adults 12 years after having experienced chronic pain in adolescence (6).

A recent phenomenological exploration of the experience of chronic pain in adolescent girls indicates that accepting chronic pain and meaningfully engaging in activities increases participants' perceived quality of life (26). More research needs to be conducted on how to minimize the social isolation experienced by adolescents living with chronic pain.

Peer Support Groups

Established in 2006, *Curvy Girls* endeavours to bridge the gap between health care and community. *Curvy Girls* is an international peer support group for teenage girls living with scoliosis that allows them to engage with each other in a safe environment (27). During their meetings, *Curvy Girls* members report feelings of isolation and frustration from the suffering caused by pain, bracing, and not being listened to by health care providers. Once the members become integrated within the support group, they experience a reduction in those negative feelings. These reports are anecdotal as the effects of peer support groups on adolescent girls living with chronic pain have not been explored academically.

A systematic review from 2001 on group interventions (including 'emotional support groups') for pediatric populations living with at least one chronic condition finds that "there have been no well-controlled studies of the psychological or physical impact of emotional support groups" for this population (28). A 2020 review of literature on support groups for adolescents living with chronic pain concludes that there is very little information available on the outcomes of peer support for this population (29). While some studies have found positive outcomes for specific peer support programs for youth with chronic illness and chronic pain, none of these focused on female adolescents with scoliosis (30,31).

Significance

Despite the existing evidence that scoliosis and its treatments can cause pain and chronic pain, some *Curvy Girls* members report feeling like their healthcare providers do not believe them when discussing pain. This feeling of not being believed hints that treatments, interventions, and interactions with this population can be optimized to better fulfill their needs.

There is very little research centring understanding the mechanisms of successful peer support groups (32). Current literature rarely attempts to analyse the strengths and limitations of peer support groups. This gap in knowledge leaves us with an important opportunity to better understand the inner workings of peer support. This study's findings could help clinicians and healthcare professionals deepen their understanding of patient perspectives, leading to the instauration of care and services that are better adapted to this population's needs.

Some *Curvy Girls* members also report social isolation from pain, bracing and the frequency of medical appointments. Additionally, some report a lessening of this social isolation once they join *Curvy Girls* and become active members. Yet, there is no research available as to why *Curvy Girls* has been successful at disrupting its members' social isolation. Understanding this success would allow for replication of this organizational model and implementation into various communities across the country.

Research Approach

Recruitment and Consent

Ms. Amja and I were assisted by Ms. Gillian Newman in our recruitment efforts. Ms. Newman is a *Curvy Girls* member, past chapter leader, and current senior board member. Since *Curvy Girls* members are often under 18 years of age, the organisation pays very close attention to the content published on their social media pages, and any information that reaches their members. Therefore, it was decided that all recruitment material would be drafted in conjunction with Ms. Newman and approved by the board of directors prior to being publicized.

The recruitment material (Appendix A) was published on Facebook, Instagram, and Twitter, with up to 2 reminders between March 14, 2020 and October 3, 2020. Ms. Newman also reached out to chapter leaders with information about the study on March 14, 2020 and April 1, 2020. Finally, Ms. Newman approached individual *Curvy Girls* members who she thought might be interested in participating in this study with general information.

Members who were interested would reach out by email to Ms. Amja, who would then either respond to the email herself or forward it to me. The responses were split evenly between Ms. Amja and me. In our respective responses, we would screen for eligibility, send the consent form (Appendix B), and answer any questions the participant or their parent(s) might have for us prior to the interview. Finally, we would obtain informed consent through the signature of the consent form. Participants who were above the age of 18 years would sign the consent form themselves. Participants who were under the age of 18 years would have their parent or guardian sign the consent form. The consent form also includes a space dedicated to capture assent of a minor.

Once informed consent was secured, either Ms. Amja or I would schedule a Zoom or phone interview time and date with the participant. In total, 16 participants were interviewed.

Inclusion Criteria

In order to be eligible to participate in the study, participants must:

1. Be 14 years of age or older
2. Identify as female
3. Currently be living in Canada
4. Be a past or current member of *Curvy Girls*
5. Speak English or French
6. Have had scoliosis for at least one year
7. Have had chronic pain for at least three months
8. Have signed or have a parent or guardian sign the informed consent form

Exclusion Criteria

People who were ineligible to participate in the study:

1. Were under the age of 14 years
2. Did not identify as female
3. Did not live in Canada
4. Never were a member of Curvy Girls
5. Did not speak English or French
6. Had not had scoliosis for over one year
7. Had not had chronic pain for at least three months
8. Had not signed the informed consent form or had not had their parent or guardian sign it

Research Ethics Consideration

This study (IRB Study Number A06-B44-19B) was originally approved by the McGill University Institutional Review Board in June 2019, and successfully underwent annual renewal in June 2020. The original approval documentation, as well as the renewal documentation is included respectively in Appendix C and Appendix D.

There were no known risks to this study. Had a participant become unable to continue with the interview, Ms. Amja or I would immediately have stopped the interview and ensured the participant was comfortable. This situation did not arise in any of our interviews.

Participants did not benefit directly from participating in this study. No compensation was offered.

Any personal information obtained during this study was kept strictly confidential. Interviews were conducted while the researchers were at home in closed rooms. Participant names and other identifying information was removed from transcripts and replaced with pseudonyms, and only the research team had access to identifiable data. This data was stored on the researchers' password-protected personal computers.

Participation in this research project was entirely voluntary. Participants were explained that they could refuse to participate or discontinue their participation at any time without explanation and without suffering any prejudice. No participant decided to discontinue their participation in this study.

One participant ("Riley") requested that some information she offered during the interview be excluded from the analysis. Another participant ("Neve") requested a copy of her interview recording. Another participant ("Taylor") requested that her mother be present during the interview. All requests were granted by the research team.

Data Collection

Once Ms. Amja or I obtained informed consent from the participant or their parent or guardian, we scheduled an hour-long interview with the participant at a time and date of their choice. The interviews could take place through video conferencing software Zoom, or by phone. All participants selected to participate by Zoom.

Sixteen interviews were held between April 15, 2020 and October 28, 2020. The shortest interview lasted 24 minutes, while the longest one lasted 103 minutes. The average interview lasted 61 minutes. All interviews were audio-recorded then transcribed verbatim. Interviews and transcriptions were split evenly between Ms. Amja and me. Only one interview was conducted in French ("Baelynne"). I conducted it and transcribed it myself. Since Ms. Amja and I are fluent in French, we kept the original French data, and only translated the quotes included in our respective theses.

All interviews followed the same semi-structured interview guide (Appendix E). Interview questions were planned in a "funnel" format with general, open-ended introductory questions announcing the theme of the upcoming prompting questions, which are more specific questions allowing for more complete information gathering. The introductory questions allowed participants to bring up any aspect of the question that is most important to them and discuss it in their own words. The prompting questions allowed participants to complete their original answers with aspects they may not have originally considered. The "funnel" in question is a metaphor for going from introductory questions and prompts such as "Can you tell me the story of how you were diagnosed?" as the wide mouth of the funnel, leading to specific questions and prompts such as "Do doctors/nurses believe you when you tell them you're in pain?" as the narrow tip of the funnel. Questions were formulated in a language appropriate and understandable to adolescent girls, in conjunction with Ms. Newman.

At the end of the interview, all participants were given the option to select a pseudonym of their choice to be used for de-identification of their data. Fourteen participants selected their own pseudonym while two left this choice up to the researchers.

Data Analysis

Applied Philosophical Hermeneutics

Much of the research performed in Faculties of Science and Medicine tends to adhere to specific and strict methodologies that are easily described and applied to collected data. In contrast, Applied Philosophical Hermeneutics is not defined as a methodology, but as a philosophical practice (33,34). This difference is not just one of semantics; it is fundamental to the way the data is approached and analyzed. Applied Philosophical Hermeneutics is guided by the research topic rather than adherence to a method (33,35). However, this does not mean that hermeneutic scholars process their data without direction, as explained by Moules et al.:

> *At the beginning of interpretive work, there is necessarily a deliberate showing of questionableness, intentionally allowing the topic to guide the direction of the character of the work. This questionableness, however, does not mean that we respond tentatively, but rather that we proceed attentively, recognizing that hermeneutics is a practice of meticulous scholasticism. (33)*

Applied Philosophical Hermeneutics requires that the researchers feel called to the topic, and be willing to challenge their existing views on said topic (33,36). Indeed, Davey explains that hermeneutic scholars endeavour to listen to participants speak of their lived experience of the topic at hand, and allow this encounter to be transformational (34). By proceeding as such, researchers engage dialogically with participants, letting the research interview become a time and place of mutual change for both the researcher and the participant (34).

This mutual change and transformation is referred to by Gadamer as a fusion of horizons (37). In the context of research, a fusion of horizons occurs when the researchers' theoretical understanding of a topic meets a participants' lived experience of the topic. This encounter may create friction, as the participant's lived experience may be different or even contrary to the researchers' existing understanding and, perhaps, prejudices (37). A fusion of horizons can happen through conversation between participant and interviewer, between text and researcher, and amongst researchers, so long as the researchers show up to the conversation or the dialogue ready and willing to go through a transformation (37,38). In other words, to engage with participants dialogically entails that the truth present in the participants' lived experience is indissociable from the transformational process that occurs when researchers allow that truth change them (34). Indeed, Davey concludes:

> *What hermeneutical consciousness aspires to do is to listen to the subject matters that speak through the other's voice for it is a shared concern or a shared subject matter that enables that consciousness to approach the other dialogically rather than dialectically. (34)*

Hermeneutic Circle

In this study, data analysis was conducted in accordance with the approach to the hermeneutic circle, as described by Moules et al. Researchers immersed themselves in the text, which in this case consisted of the interview transcripts of the participants (33). From reading and annotating the text, researchers saw compelling quotes emerge which were then organized by topic. Researchers selected the quotes based on their own understanding and preliminary interpretation, as well as relevance to the overall objective of the project. Once the quotes were collected and organized, the researchers met to discuss their findings. The conversation surrounding the participants' quotes as they relate to their own experience, to the other participants' experiences, and to the life-world of the researchers yields a transformation of the researchers' understanding and a Gadamerian fusion of horizons (37,39). Once the researchers discussed their findings, they inevitably returned to the text to extract any other quotes that may be of interest to them with this renewed understanding. The researchers' gentle motion from text to discussion continued throughout the analysis and writing stages of this thesis.

By its nature, the hermeneutic circle demands that the researchers' understanding of different parts of the text inform their understanding of the whole text, leading them back to reflect upon the parts again, to re-consider the whole (33,39). Much like working on a jigsaw puzzle, our understanding of where each piece belongs changes our vision and understanding of the whole picture. This movement to and from the text, from part to whole, between the familiar and the unfamiliar is a generative process which allows the researchers to deepen their understanding of the topic at hand (33,36,39). The researchers' journey through the data brings about a changed understanding of the participants' experiences. It requires commitment from the researcher, and demonstrates one way to evaluate the rigor of the approach (33). To engage in hermeneutics and the hermeneutic circle is to surrender to change: "the assertion of a texts' alterity, the assertion of its own truth, and the process whereby that assertion brings us to a more truthful understanding of ourselves are bound together." (34)

Hermeneutic Wager

Another guiding principle in the data analysis of this study was Hovey's adaptation of Richard Kearney's hermeneutic wager (40). The hermeneutic wager is a tool for risk assessment and mitigation when it comes to health agency (41). For participants, being invited to tell their story as it relates to chronic pain, or in the case of this study, scoliosis, can allow them to transform some chaotic thoughts into catharsis (42). Having the opportunity to speak without being interrupted, with no further intention than to simply tell their story can bring forth a narrative that is disorganized and incomplete. Indeed, Hovey and Paul explain that participant narratives inevitably contain gaps, inviting the researcher to interpret those gaps using her own expertise and lived experience (43). These narrative gaps are the starting point of hermeneutic interpretation and the hermeneutic wager.

Kearney's hermeneutic wager posits that five main conversations guide hermeneutic exploration: imagination, humility, commitment, discernment, and hospitality (40). Adaptations of this wager have been used in various hermeneutic health research projects relating to Indigenous health promotion, synergistic research in medical education, adolescents living with chronic pain, to name a few (36,38,44). For this project, the hermeneutic wager was used in order to first *imagine* what the project could become; to allow all researchers and collaborators to come together and be open to the possibilities that lie in this project (36). The researchers practiced *humility* throughout this project, remembering to put their expertise to good use while leaving the title of 'expert' at the door (38). Once the project was defined by the team members, researchers *committed* to it, each taking on a certain level of risk by allocating time and other resources to its success (38). Then, the researchers engaged in a practical conversation to *discern* which possibilities imagined in a prior conversation are best suited for the project at hand (36). Finally, researchers were called upon to be *hospitable* to any outcome of the project, including potential setbacks or obstacles found along the way (38).

Research Findings

Our interviews yielded an immense amount of thoughtful narrative data. Given the structure of our interview guide, we collected information about the participants' experience of living with scoliosis in different spheres of their lives: social, educational, health care and peer support group. In this thesis, I will focus primarily on the participants' experience within *Curvy Girls*, their peer support group. First, I will contextualize the participants' experience with scoliosis in terms of the negative messages they receive from their friends, family members, educators, health care providers, or even themselves. Then, I will interpret the participants' experiences with *Curvy Girls* and how the peer support group affects their experience with scoliosis. Finally, I will go over the specific suggestions made by the participants to improve *Curvy Girls* and the experience and services they offer to adolescent girls with scoliosis. Given the hermeneutic nature and structure of this thesis, findings and discussion will be presented jointly in this section.

Dismissed and (not so) fragile

Living with scoliosis as an adolescent girl brings forth a wide spectrum of experiences. The clusters of experiences described below are opposites of each other: dismissal and perceived vulnerability. Most participants experienced at least one person in their life dismissing their pain, their condition, their need for accommodation, or their treatments as either unimportant or insignificant, going as far as calling it a need for attention. On the other hand, most participants also experienced at least one person in their life perceiving them as fragile and breakable due to their pain or their condition. These experiences, as different as they may be, co-exist within the life-world of the participants.

Dismissal

Participants experienced intense moments of dismissal from friends, family members, teachers, and healthcare professionals. Our interview guide (Appendix E) included a question about whether the participants had ever felt like the people around them did not believe that they were in pain. This question opened-up some thought-provoking conversations with our participants about other instances where they did not feel believed, instead feeling dismissed or invalidated. This section will explore these experiences as well as the participants' perceptions and emotional reactions.

During her interview, Milan explained that she had been mentioning her concerns about her appearance to her parents. Unfortunately, her parents dismissed her concerns about her hips, saying that her feelings were just the result of her being a teenager:

> *I kept commenting on my body and how it looked and oh like this is not normal and people around me thought I was over critical they're just like don't worry about it like she's just a teenager she's picking at herself for no reason just because she's insecure [...] I was like well you see what you want to see I see that my hips are clearly disbalanced so I'm going to feel insecure about it until its fixed I guess it kind of made me feel not taken seriously.*

Willow recalls a similar experience with her parents:

> *I was telling like my parents I was in pain, but I had bad posture, so they probably attributed it to that, or because of my shoulder problems. They were like "oh, that's probably why you have like a bump on your back, it's probably some weird muscle thing from your shoulder problem." It took a while before people... it's not like they didn't believe I was in pain, but they didn't think it was scoliosis.*

Baelynne also describes how she also had to advocate for herself to make sure her pain was taken seriously and investigated properly:

> *I'd talk about it to my parents. They're parents, they have so many other things to think about. When I would tell them my back was hurting, they'd tell me it was going to be okay. After, it was "no, but my back hurts." I think it took a few*

> *months for my parents to understand. I didn’t even know what it was. My back was hurting and I didn’t understand why it kept hurting. I wouldn’t stop repeating it and so they said “well, maybe you really have something.” For my parents, it took time specifically because we are young. After a few months, they said we’d go to the doctor.*

Milan, Baelynne, and Willow had to repeatedly voice their concerns to their parents before they were taken seriously and brought to seek medical advice. From the participants’ retelling, it seems like their respective parents were in denial that their child could be in a state of ‘unhealth’. This perceived denial can be interpreted as a belief that ‘unhealth’ or illness is something that happens to other people’s children. These parents’ immediate reaction to their children’s complaints was to delay seeking medical help, causing their children to remain in a situation of pain and discomfort that they perceived their parents not to take seriously. In his 2020 review on changing perspectives in pediatric pain care, Kenneth Craig explains that pediatric populations can learn to suppress pain expression when they perceive it to be socially undesirable (45). Children and adolescents who understand from their parents that their pain is not worth investigating can learn to mask their pain in order to feel accepted by their parents. Such a lack of parental validation can have serious consequences on adolescents. Adrian et al. found that parental invalidation can affect the likelihood of self-harm in adolescents, up to and including attempted suicide: “adolescents who experience invalidating responses from the environment may also respond by escalating emotions and behaviors in an attempt to be taken more seriously, creating a coercive cycle of interactions that fuel emotional reactivity and self-harm” (46).

Other participants described similar distressing experiences with healthcare providers. Evelyn explained that her primary care provider did not investigate her pain as a child:

> *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.*

When asked if she felt like her primary care provider took her seriously, she replied: "I kind of don't think so. I really don't, just given that they didn't take it seriously and that they didn't run any tests. I feel like they just trying to brush it off." Emily described a situation where not only her pain was not taken seriously, but she was also accused of being pregnant as a young teen:

> *We went to the hospital I was probably 13 or 14 and we were just telling the doctor how much pain I was in and how I was being so sick and my back was hurting so bad and he didn't really even talk to me he just accused me of being pregnant when I was 13 and I was like no... literally he wasn't listening to me it was so bizarre and so negative but it was just a side effect of all the medication that I was taking for pain killers. [...] 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 their questioning me"*

Caroline recalled how her surgeon repeatedly dismissed her concerns about her pain and her body, to the point where he felt it more appropriate to refer her to psychiatry instead of investigating her pain and her concerns:

> *He didn't care about my problems and stuff that was happening like internally. I would say "I can literally push my organ, that's not normal, I shouldn't be able to move it around." He didn't care. I would say "I'm having a hard time walking up the stairs in my house and I'm out of breath, that's not normal," "oh, it's not a problem." Until surgery, when it became a problem. I think the icing on the cake was at my six-week post-op appointment, I was in excruciating pain. They had to bring a stretcher out for me to lie down on. It was a mess. He told me my pain was in my head and I was making it up and he sent me to a psychiatrist. We met with the psychiatrist because we thought "counseling is great, why not, it could be*

> *helpful, we know my pain is real but maybe there's other things that I wanted to talk about." As soon as she saw the referring doctor, she was like "you are good, we get all of his patients here, you're fine." He's very notorious at the hospital for just not listening to patients and to what people's concerns are and minimizing. I think there's certainly an aspect if like ageism, looking down on children.*

Willow explained that she had a doctor claim that scoliosis does not cause pain:

> *I did have this one doctor, who was coming to me before I got my surgery, and he was not my normal doctor, he was some other guy. I don't know what he was there for, but he was just there. He 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." [...] I don't know if he was a specialized scoliosis doctor saying that, but I remember I felt really invalidated after.*

During her interview, Riley recalled that all her doctors had told her that scoliosis does not cause pain:

> *The thing with the doctors, they say scoliosis doesn't cause pain... All the doctors would say that [...] Honestly I didn't give it much thought I knew my parents understood and believed that I was in pain so I wouldn't give it much thought I just kind of moved on from what they think because I knew what I was experiencing... 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.*

Emily, Caroline, Willow, and Riley described experiences with health care providers where their concerns about their pain, condition, or body were dismissed, leaving them feeling invalidated. Willow especially, first had to convince her parents that she needed medical attention because she was in pain, only to have one of the physicians on her care team claim that scoliosis does not cause pain. She explains how this chain of events left her feeling "invalidated". By not taking her seriously, the healthcare professional eroded Willow's trust in them, and her trust in other healthcare professionals, as she mentioned further in her interview. At the time of the incident described, Willow was 16 years old, and relied on the adults in her life to provide her with care. She began feeling alienated when her parents did not immediately take her pain complaint seriously. This feeling grew after the incident with her physician. This left Willow with few options in terms of who she could report pain to, and still be believed.

While Willow's story is an unfortunate compound of not being believed by her parents, and then not being believed by her care team, Emily, Caroline, and Riley also experienced being invalidated by a healthcare professional. From the quotes presented above, we understand that the participants perceived the healthcare professional dismissing them as lacking empathy. Mommaerts et al. explain that there is no consensus on the meaning of 'empathy' in medicine (47). They go on to describe that a "profound belief" in the physician or the treatment is necessary for the patient to begin to feel "healed"; it is through the patient-physician relationship that the patient's condition can improve (47). Gadamer wrote that, medicine being both a science and an art, physicians who rely only on science to treat their patients are doing them a disservice by not using the full complexity of the tools at their disposal (48). In order to practice the art of medicine, not only the science thereof, physicians should attempt to understand the state of equilibrium in which individual patients feel at their best (48). In other words, physicians need to build a relationship with their patients in order to offer them the individualized tools and solutions they need in order to heal. The physicians mentioned in Willow, Emily, Caroline, and Riley's interviews did not attempt to learn about them, their stories, or their daily challenges. Instead, they relied solely on the science, or the mechanics of pain and scoliosis. Not being believed by their physicians left a negative impression on the girls and added stress and worry to their recovery and healing journey.

Perceived vulnerability

Participants also experienced being perceived by friends, family members, and teachers as vulnerable, breakable or fragile. While some participants rejected this perception, others were concerned about being a “burden” to their loved ones. This topic was not prompted by any specific question in our interview guide. Instead, it presented itself organically in our conversations with the participants. This section will explore the participants’ experiences of being perceived as vulnerable by their loved ones or perceiving themselves as vulnerable.

During her interview, Kacey explained that her parents saw her as much more fragile than she felt. Her perception of her physical strength was greater than her parents’ perception. This mismatch led to exchanges like the one she describes here:

> *I was almost treated like a glass vase. Like I’m very fragile. Understandably, I have to be careful. I think that’s the only thing, not so much now, but at the beginning: “oh be careful, don’t do this.” Even now, actually, thinking about it and talking about it, when I do groceries, I literally put all the bags on my arms so I don’t have to do two trips. I can carry a bunch of heavy weight and not hurt my back. I don’t push myself when I’m carrying something. I know my limits. But “no, I’ll grab that for you.” I still get that from parents, which is normal, I think. [...] I think at first, I appreciated it. But now I’m 22. My parents are getting old if anything [laughs]. My dad has a bad back and he wants to carry everything. I just brush it off and I’m like “no, I got it,” stand my ground, like “I’m okay, I know how much I can carry.”*

Baelynne described a similar experience with her mother:

> *I think they’re more lenient about making me carry heavy things, even still today. If my mom sees me carrying a slightly heavy box, she says no. I can! I can carry the box! But for her, it’s “no, even if you can, you leave it there and your dad will do it for you.” For my parents, it can’t get worse.*

Both Kacey and Baelynne's experience share a tension between their own level of comfort and their parents'. Specifically, the girls describe feeling their parents underestimating their physical abilities. Similarly, when well-intentioned educators tried to spare Neve from carrying heavy things across school, she felt that they were treating her like she had fewer abilities, or lesser abilities than she estimated she had:

> *It's also when teachers found out I was in a back brace and they were like "hey can somebody take this box down to the third-floor classroom, two floors down?" I'd be like "oh I can," they'd be like "oh you shouldn't," and I'm like "oh OK so I probably just shouldn't volunteer for stuff that have physical requirement, because apparently people think I can't lift a box?" I'm capable because the brace isn't on my arms, it's on my torso. It was something that would embarrass me so much when a teacher would decline my offer over the fact that I have a disability, a physical disability. It was super embarrassing because I'm considered disabled, but I'm not. I do everything: I can go upstairs, I can run upstairs, I do that all the time when I'm late for school, I can carry boxes, I can carry very heavy things, I have a dog that's very heavy and I can carry him in a back brace. I can do so many things that everyone else can do in a back brace.*

Brenda echoed Neve's desire to be treated just like any other teenager at her school:

> *I would carry heavy books to class and people would ask me if I needed help and I was like "no I could carry my own books" it was little things like that... even teachers would be like "do you need a more comfortable seat, are you okay?" and I was like "I am just a normal student in your class don't treat me any differently..." it was little things like that that eventually got to me.*

Finally, Emily explains that having her parents treat her differently than before made her feel much "sicker" than she actually was, to the point where she almost felt like she was dying: "It was almost they were very cautious and kind of treating me like I was not different but kind of being more careful around me and stuff... I'm not going to say that they were treating me like I was dying or something, but it would make me feel that sometimes."

The experiences described by Kacey, Baelynne, Neve, Brenda, and Emily illustrate their frustration with their parents, educators, and friends when they attempt to spare the girls from any task they perceive as too physically intensive. Not being trusted in their capacity to accomplish these tasks, similarly to not being trusted in their pain complaints, comes with feelings of invalidation. The perceived message from these interactions, as Neve described, is that the people around them do not trust them with their assessment of their own limits and capacities. In addition to the frustration recounted by the participants, there is a real possibility that the girls might internalize the narrative of not being strong enough. Exploring the effects of labelling people as 'patients' even outside of healthcare situations, Hovey et al. explain that being labelled by others can cause a loss of identity, an "erosion of personhood", while internalizing the label (49). Transferring this idea to the participants, being labelled as fragile or unable to accomplish daily tasks could eventually lead them to believe this about themselves. It could therefore be useful to encourage parents and educators to use a relational model of autonomy when it comes to this population (50). Mackenzie and Stoljar write:

> *Relational autonomy perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. Thus the focus of relational approaches is to analyze the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency. (51)*

Instead of parents and educators unilaterally deciding that a task is too physically demanding for the girls, it could be beneficial for everyone involved to discuss it with them, and jointly decide on an outcome. Relational autonomy allows for the views of the adolescent and the adult(s) responsible for their well-being to be weighed and taken into account when making a decision (50). The premise of this model acknowledges that medical conditions of adolescents do not solely affect the adolescent with the diagnosis, but their close community in addition to the relationships the adolescents maintain with the members of this community. In order to feel like they belong in their community, they must feel at home within it (37). Shifting to a relational model of autonomy could allow other young women like Kacey, Baelynne, Neve, Brenda, and Emily to feel more at home, less othered by the people around them.

Evelyn, on the other hand, said she appreciated the softened attitude her friends adopted with her since her diagnosis. Her friends' new approach to her has been better adapted to suit her emotional needs:

> *I feel like they're a lot more... softer on me now. They approach me softly. I don't really know any other word to use for that [...] They'll be a lot more like nice. Our friendship is "satire-ish" almost. We'll make fun of each other, and now they don't poke fun at me. If anything, they just say nice things. [...] Before, I didn't feel like I was cared about, as I do require some kind of affection from my friends to feel cared about. Now that they actually give it to me, I think it has bettered our friendship for sure.*

This quote is noticeable because it is the only one collected throughout the interviews that viewed being treated differently as an improvement. In her assessment of the situation, Evelyn didn't focus on how her friends now perceived her, unlike Kacey who remembered feeling like a "glass vase". Instead, she turned her attention to the way her friends interacted with her: "softly". Both Kacey and Evelyn describe seemingly similar situations, but seen from vastly different perspectives, demonstrating that even in similar medical cases, patients require personalized approaches from their physicians (48). Knowing which approach to use for which patient demands that physicians build meaningful relationships with their patients. Evelyn's perspective also teaches us that there is a gift to be found in her condition (41). She extended empathy to herself and allowed for her friends' softness to care for her in the way she needed to be cared for. This self-empathy allows her to find the gift that comes with living with pain, and to feel more at home within her circle of friends (37,41,52).

Breaking the mold

While stereotypes of support groups perdure, *Curvy Girls* uses a novel, grass-roots approach to peer support. Prior to the COVID-19 pandemic, the organization was already using a mix of social media interaction and in-person local meetings to bring together adolescent girls with scoliosis. Members are free to choose their preferred level of interaction with the group, going from simply following the organization's official social media accounts on Facebook, Instagram, and Twitter, all the way to becoming a chapter leader and creating an in-person meeting group within their community. In this section, I will explore the different depths with which the participants engaged with *Curvy Girls*, and the importance of reflexivity and giving back.

Level of interaction

The finding that was most interesting to me due to my own pre-understandings was that participants expressed the same level of satisfaction and enthusiasm with *Curvy Girls* regardless of the nature of their interactions with the group. In this section, I will explore how the sense of belonging expressed by the participants was independent of their level of interaction with *Curvy Girls*.

Through a back and forth with the interviewer, Mary explained that she had only ever interacted with *Curvy Girls* through social media, namely Instagram and Facebook. This level of interaction suited her and allowed her to engage with her peers on her own terms:

> *Interviewer: Did you ever go to a meeting in person or via zoom?*

> *Mary: No, I seriously just looked at the Instagram page a couple years ago and was like "oh that's kind of cool, but..." I didn't really think about getting that involved...*
> *Interviewer: It was good to know that it was there to go back to when you were ready?*
> *Mary: Yeah.*
> *Interviewer: I get that feeling. So how exactly have you interacted so far in the past three weeks with this group?*
> *Mary: Not that much. I've been posting. There's a private Facebook group for all of the international leaders and then there's also one for anyone who wants to join the group or is a part of one of the groups. I - I've just been posting a couple of questions I had. A couple weeks ago, I was wondering when I would be able to like bike again because that's my main transportation in the summertime. I just like asking questions and also answering questions for the Facebook page.*

Emilie also described only ever interacting with *Curvy Girls* through social media. This interaction allows her to keep informed of the group's activities and imagine possible future interactions with the group:

> *Interviewer: So far, how have you interacted with people on there?*
> *Emilie: Not super closely. like I don't like to commit to something if I don't have the capacity for it. So I would say on Instagram, I'll keep up with what they're doing, and one day it would be fantastic to start my own branch.*

Similarly, Willow explained that she interacted with *Curvy Girls* exclusively on social media platforms:

> *Willow: I think I heard about it through my second physio, because my second physio was a scoliosis only clinic. I followed their page on Instagram, and they were always promoting it, like "oh this is a support group, we have one in Vancouver." They did like a bunch of little sessions. I was like "oh that's really cool, and cute play on words, you know, Curvy Girls." I remember going over to their page and I remember seeing a bunch of stuff, but recently there is no more Curvy Girls group in Vancouver where I live that I know of. I remember back when I had scoliosis and got my surgery, there was. But then they just stopped posting and now their account is gone. I still follow them on Twitter, the regular Curvy Girls and that's how I found this study.*

> *Interviewer: Have you ever gone to an actual meeting?*
> *Willow: No.*
> *Interviewer: How are you interacting with the group? You said you're following on Twitter...*
> *Willow: Yeah I followed them on Twitter and Instagram for a while. There were two leaders or girls running the page for the Vancouver one, and then I kind of talked with them a little bit about their experience but ever since their page hasn't been posting anymore, we haven't talked. We just shared experiences because they went to a school that's pretty close to where I live.*

Even amongst those participants who did attend in-person group meetings, the level of interaction varied. Caroline explained that some members prefer to interact by listening more than speaking:

> *I think that was a big lesson on how people are going to react differently to support groups and to that type of connecting emotionally. Some people aren't comfortable to, in a group, share their experience and some people are just naturally very shy, that's not for them. But that doesn't mean that they're not impacted by what's going on and it doesn't mean that they are passive. They're just expressing themselves in a very different way.*

Indeed, Riley described herself as someone who preferred listening to her peers in order to move forward with her daily life: "I wouldn't talk but even just sitting there and being at those meetings like changed my experience because I listened to other girls' stories I've listened to people taking positive spins on a challenge and I'd be completely inspired." On the other hand, Dawson explains that while she did not fully understand the purpose of the group during her first meeting, she eventually became a chapter leader:

> *My mom was online one day and she found the previous leader of the current group that I co-lead with someone else now, and she found it, and that's how we got involved. I talked to her and I started working with her, and I really liked it and then I became a leader and I think I got much more involved in it then I think I was before because my first gathering with the group I didn't entirely understand it at that time too.*

Finally, Caroline shared one of her experiences as chapter leader with a member who usually kept quiet during meetings and yet still benefitted greatly from them:

> *I remember leading a meeting and there was this girl, she was really young, who came to all these meetings. She never spoke. I'd never in my life heard her speak. We just put it off, maybe she's just not interested and her mom's maybe forcing her to come. I didn't make a big deal of it, we just we never asked her on the spot questions. One day, her mom pulled me over and she said "I hope you know that you've made a big impact on my daughter." And I said "oh really because I've never heard her speak before, I had no clue." And she said "she's very shy and she tells me she doesn't speak in the meeting but when she gets in the car on the way home, she does not stop talking through the whole ride home and she will say verbatim what every girl has said before her." She does all these things that all the girls mention, she's paying attention and she's actively able to discuss what they said and then put it into action.*

This finding surprised me. I had assumed that the depth and meaningfulness of the participants' experiences with *Curvy Girls* would be related to their level of involvement in the organization. For example, I thought that Caroline and Neve, who were both group leaders in their respective groups for many years, would have had a more transformative experience with the peer support group than Mary, Emilie, or Willow, who had only ever interacted with the group through social media. Instead, this study seems to indicate that participants engaging with *Curvy Girls* will have a meaningful experience regardless of the ways in which they engage with the support groups.

This phenomenon might be explained in part through the lens of labelling and self-stereotyping. Available literature seems to agree that labelling and self-stereotyping can be either positive or negative, depending on the social context (49,53–55). Biernat et al. illustrate positive self-stereotyping using the example of fraternities and sororities: membership to these groups happen only through invitation, and members invest time into developing connections with other members (56). While sororities and fraternities may not be an entirely accurate parallel to peer support groups, they serve to understand that membership into these groups is desirable for its members. In other words, members of fraternities and sororities value their membership and association with the group. Likewise, participants in this study value their membership and association with *Curvy Girls*. They described both the undesirability of being labelled as having scoliosis, and the desirability of being part of a peer support group where membership is exclusive to people who fit relatively narrow criteria. The exclusivity of the membership renders the label of “member” desirable (56).

It appears then that the participants have positive feelings about their *Curvy Girls* membership, and that the way in which they choose to engage in that membership does not affect their overall positive feelings about the group or their experience with the group. It would seem that *Curvy Girls* membership takes the form of a classic “take what you need” poster you may find on the billboard of a café, presenting tags such as “confidence”, “inspiration”, “friendship”, “strength”, etc.

Reflexivity and giving back

Regardless of their level of interaction, participants enthusiastically described the benefits of belonging to *Curvy Girls*. Having experienced transformational learning, participants demonstrated deep reflexivity and a strong desire to give back to their community (41,57). This section offers insight into the participants’ transformational journey. The participants were not specifically asked about their reflexive process or any desire to give back to their community. Rather, participants brought up these topics of their own volution during the interviews.

During her interview, Milan explained that the experience of scoliosis is different for every person going through it. Recognizing this difference helped her contextualize her own experience as compared to other girls’: “I can be empathetic and I can listen to you but I cannot relate 100% to what you've been through that but I do have experience with interacting with people who have gone through that and that could be beneficial.” Emily echoed Milan’s words and generalized them: “We never really know what people are going through and the thing is everyone is going through something that's really affecting them and they just might not show it.” Dawson highlights the importance for adolescents with scoliosis to be able to find the narratives of other adolescents who have gone through a similar experience: “There's so many Wikipedia articles or medical journals of what goes on, but there's not many things that people explain what happened to them, and what they went through, and there's some people that just don't get it.”

The experience of being diagnosed with scoliosis and living with the condition is described by the participants as transformative. Their journey to accepting their condition and feeling at peace with it allows them to move from the liminal space of uncertainty into a new definition of themselves which integrates scoliosis as part of their identity (41,42,58). On the other side of liminality is a profound ability to reflect on themselves and their relationships with others in the world, as demonstrated by the quotes shared above. Self-reflection is a crucial skill to hone in the pursuit of emancipatory knowledge, which allows learners to think critically about the world around them (57). In order to make meaning of the world in which they live, participants had to reflect on their own role and place in this world, starting with understanding and making sense of their own lived experience (37). Milan, Emily, and Dawson display their own understanding of their relationships to others by discussing the limits of their understanding of others’ lived experiences. This deep understanding hints at the importance of being surrounded by peers, in this case other adolescent girls living with scoliosis, while in the liminal space of learning to live with a new diagnosis. Hovey describes this liminal space as “the time between the ‘what was’ and the ‘what is next’” and “a place of possibility, waiting, and not knowing” (41).

Existing literature about peer support operates under the assumption that it is beneficial but rarely attempts to explain its mechanisms (28). From this finding, we can hypothesize that peer support offers members an opportunity not only to share their stories and experiences, but also to hear and respond to other members’. This could allow members to develop self-reflection skills critical to their transformative process, as well as help them better understand the world and people around them through better understanding themselves (37,57). This renewed understanding, of both themselves and the world, could let members move with more ease from their previous definition of themselves, to a definition that includes scoliosis as an inherent part of that definition. Perhaps we could think of peer support as an approach to deal with liminality and come to terms with the ‘gift’ of their condition that is their deeper relationship with themselves and others around them.

For her part, Kacey expressed her desire to give back to the community that has brought her so much by raising awareness for scoliosis and using her own personal narrative as a platform during competitive beauty pageants:

> *The pageants really allowed me to gain more confidence in myself and to grow as an individual. I actually used scoliosis as my platform throughout the years to bring awareness of scoliosis and how common it is and how a lot of people don't really know what it is. It was a way to bring awareness to scoliosis.*

Brenda described a similar desire and explained that she uses social media as a platform to share her story with other girls living with scoliosis:

> *One big thing is my social media for example, I love posting about my scar and about my scoliosis, about the experience that I’ve gone through, my surgery because I know that a lot of girls who have gone through the same thing as me are*

> *petrified for going through surgery... so I want to be that rock that they can look up to and say okay I'm actually going to be okay after my surgery it's not going to be the end of the world it's not going to stop me from having the life that I've always wanted to have... it's little things like that I want to help other girls that have been going through the same thing as me... to persevere and knowing that they will be okay after this*

In her book "Understanding and Promoting Transformative Learning", Patricia Cranton outlines Mezirow's phases of personal perspective transformation:

> *- Experiencing a disorienting dilemma*
> *- Undergoing self-examination*
> *- Conducting a critical assessment of internalized assumptions and feeling a sense of alienation from traditional social expectations*
> *- Relating discontent to the similar experiences of others – recognizing that the problem is shared*
> *- Exploring options for new ways of acting*
> *- Building competence and self-confidence in new roles*
> *- Planning a course of action*
> *- Acquiring the knowledge and skills for implementing a new course of action*
> *- Trying out new roles and assessing them*
> *- Reintegrating into society with the new perspective (57)*

Kacey and Brenda's experiences relate to the later stages of this transformative process. They've both searched for new ways of being-in-the-world and decided to take on new leadership roles within their community, Kacey through speaking about her experience with scoliosis at her beauty pageants, and Brenda through social media. Actively practicing this new role, and acquiring the knowledge and experience that come with these new experiences has allowed them to reintegrate their community as mentors for other teenage girls living with scoliosis who are just entering the liminal space.

Leading the way

All participants had a positive experience with *Curvy Girls*, and none volunteered negative comments or even improvement suggestions unprompted. The research team had formulated a question in the interview guide in hopes of obtaining constructive criticism on how to improve the organization. Participants were asked what they would change to *Curvy Girls*, in a world with no limitation. While one participant chose not to answer the question and another said she wouldn't change anything, every other participant had suggestions that can be broadly classified into two categories: increasing access to the organization and expanding the scope of the organization.

Increasing Access

Citing their love and gratitude for the organization, participants suggested that *Curvy Girls* should be advertising and advertised more actively within the scoliosis community in order to increase accessibility. Participants wished that more teenage girls living with scoliosis would know about *Curvy Girls* and be able to participate, as it had brought so much to their lives. Many participants expressed a desire to share this gift with others in a similar situation. One participant suggested advertising campaigns in schools to reach out to as many teenage girls with scoliosis as possible.

In her interview, Milan explained: "I would like to come up with more efficient ways to, I don't want to say publicize… to make *Curvy Girls* more known so that more girls can reach out." Baelynne echoed her feelings: "I think it's something so good that it's not publicised enough. Why did I hear about it on Facebook? It's so important. Why would it only be on a few platforms? Why isn't it in schools?"

Kacey reminisced on her time as chapter leader and explained that videoconferencing software like Zoom would have been greatly useful to her at the time. Her chapter was located in a rural area, where population is sparse:

> *Thinking about this whole pandemic and how we were able to change school to online and having Zoom classes, if I were still a leader, I would've been able to... I was a leader starting 2014, and if I knew about this technology, maybe I would've been able to make a meeting with all those girls to be able to meet via webcam. Having meetings that way and getting them to do activities at their own home but getting together on Zoom.*

Similarly, Willow wishes she could access a local group for support. She explains that with increased popularity, *Curvy Girls* could open and support more chapters in currently underserved areas:

> *Obviously, I would want them to bring back the one that's closer to where I live. It was nice to have a closer community to where I was. This has nothing to do with Curvy Girls itself, but I kind of wish that it was a little bit more popular, because I feel like I'm the only person who knows about it for some reason. Where I am, none of my other friends with scoliosis know about it and I kind of wish that there was other ways to talk about it.*

Milan added that she had encountered multiple situations where prospective members would reach out to her, but never follow-up: "what has happened for me a lot is people reach out to me by email and then I respond, and I won't get a response back so I would kind of like to investigate why that is and to remedy that problem."

Through their perspectives, Milan, Baelynne, Kacey, and Willow are expressing their appreciation for the positive impact of *Curvy Girls* on their lives, and their enthusiasm at wanting to make this impact available to more girls who may be dealing with scoliosis. Their experience with the organisation has been so positive that they want to ensure that anyone who could benefit from *Curvy Girls* would be able to first access it. In Milan and Baelynne's view, access begins with ensuring that the organisation is promoted in formal spaces like schools and medical settings, allowing more people to find out about it. Participants are highlighting the need for collaboration between educational and medical settings, like schools and clinics, and peer support group organizations like *Curvy Girls*.

Kacey and Willow also bring in another layer of understanding of access: adding new modalities of attending 'in-person' *Curvy Girls* meetings, such as Zoom or other video conferencing software. They see this modality as a way to allow more girls, especially those living in remote areas, or areas with no established *Curvy Girls* groups, to attend the meetings and reap the benefits of these meetings. The role of the COVID-19 pandemic in precipitating the adoption of communication software in the context of healthcare and personal communication has been documented in several studies (49,59–62) The findings of this study suggest that it may also have played a role in precipitating this adoption in the context of peer support.

There is very little research aimed at better understanding online adolescent peer support groups. In his 2020 review of online group psychotherapy, Weinberg emphasises that there is a paucity of research in this field, but that the little research that is available seems to show that the benefits of online support and therapy groups are similar to those of face to face groups (62). Another study in patients with opioid use dependency found that patient engagement increased after implementation of online peer coaching, counseling, groups, and provider visits due to the COVID-19 pandemic (61). More to the point of the participants, Hirko et al. have found that the shift to telehealth forced by the COVID-19 pandemic may help address rural health disparities (60). While peer support groups may not fall within the umbrella of telehealth, it remains true that online access to *Curvy Girls* meetings, as pointed out by some of the participants, would allow members from rural regions to access the full range of services offered by the support group.

Finally, Milan's observation hints at other barriers for access that need to be further investigated. Indeed, if potential members reach out for support, but don't end up following through, there may be other factors at play. This may be feeling too shy to take part in a first in-person meeting, feeling too overwhelmed with the medical process, or other aspects of life like school, to devote attention to *Curvy Girls* membership, feeling like one may not need *Curvy Girls* after all, etc. Whatever these barriers might be, identifying them will help increase access to peer support groups like *Curvy Girls*.

Expanding the scope

Other participants suggested that the scope of the organization should be widened to organize more activities for members, as well as include non-binary teens, as well as boys. The participants who made this suggestion explained how beneficial *Curvy Girls* had been for them, and hoped that more teens, regardless of gender identity, could access this peer support group.

Brenda explained that she would love to see *Curvy Girls* become an organization for girls and boys with scoliosis:

> *Honestly I would change Curvy Girls to not be subjected to just girls because like I said, my little brother does have scoliosis as well and he did not feel comfortable going to Curvy Girls but he did obviously want a support group that he could not have because they do have Curvy GIRLS in the name.*

Mary echoed Brenda's thoughts, and added her concern that a gendered name might be limiting access from nonbinary children and teens:

> *The first thing is the name. I'm too new to make any suggestions, I need to get settled in before I would say anything. I think the name "girls" in the title might... There are a lot of guys with scoliosis, and I know that they apparently have a*

> *separate group for them. But I keep thinking about non-binary children, or how the name might turn people away. If the name were changed to something like Curvy Kids, I don't know how many more people could be helped. People who don't identify as nonbinary, don't identify as either gender, but still want to get support. I just think it's a great group but the name kind of limits the amount of people they can help.*

During her time as a chapter leader, Emily found herself wishing that she could organize more activities with her fellow *Curvy Girls* members.

> *I totally understand why they don't want you to be doing activities at your meetings but they don't want you to be going anywhere to do activities and stuff like that... just in general they don't want people to be spending money at meetings but I know at least from my group when I had the 3 members they all really wanted us to go and do stuff together and I had to be like "Oh no like we can't" and they'd be "well why" then I'd be "oh like in the rules like we're not allowed to" but I guess if they changed that... it's a different circumstance if you have a group of 20 people and you're like "OK everyone has to spend $20"... I think if everyone wants to do something and doing anything together helps build that bond and I think if everyone wants to and is willing then why not.*

Taylor joined *Curvy Girls* during COVID-19 and its associated physical distancing measures. She expressed her disappointment at not being able to interact with other girls wearing their brace out in public:

> *I don't know if it's different in our group, but I wish that our group did more activities together. So far we've only really met up at parks. I wish we did more things like hang out or go do fun things, which I guess is hard to do right now because of quarantine. I feel like it'd be nice to hang out with other girls and see them in their braces too. It's weird for me being in my brace in public still, and so I think it would help seeing other girls who are more used to it. It would make me feel less strange.*

Finally, Kaylie explains that she would love to be able to do activities with her fellow *Curvy Girls* members:

> *I’d probably change that in general we can't do a lot of stuff that's outside of scoliosis so I'd probably change that we can do more activities with our members like going swimming or like going rock climbing or something so we can get to know them as people but also as people with scoliosis.*

The reflections brought up by Brenda, Mary, Emily, Taylor, and Kaylie again point to a desire to extend the benefits from *Curvy Girls* to more people, and into different areas of the participants’ lives. Brenda and Mary explain that their experience with scoliosis is directly affected by their gender identity as girls or young women, and that other people with different gender identity might also need similar, targeted support. It bears repeating that *Curvy Girls* is a non-profit, grassroots organization, set up specifically to answer some of the unmet needs for support and socialization of girls living with scoliosis (7). As such, its members, mission, and resources are rightfully focused on meeting those unmet needs for that population. Additionally, it is worth mentioning that *Curvy Girls* offers a closed Facebook group dedicated to boys and non-binary children named *Curvy Kids*, amongst other less known resources available for this population. What Mary and Brenda are pointing out is that other populations, such as boys and non-binary children and teens living with scoliosis, might have similar unmet needs for socialization, support, and normalization. This attention to the unmet needs of others echoes the finding discussed earlier in this thesis under *Reflexivity and Giving Back*. Moreover, the participants’ desire to have more people benefit from *Curvy Girls* demonstrates how much they appreciate and value the experience they are gaining from the organization.

On their end, Emily, Taylor, and Kaylie express their wish to extend the positive experiences lived under the purview of *Curvy Girls* out into the world. They felt like socializing with other teenage girls with scoliosis in public spaces would be beneficial for them in helping them normalize their experience. Indeed, existing literature about children with physical disabilities explains that in order to feel included in the activity at hand, these children must feel legitimate in their participation and more importantly, be allowed to join safely (63). Joachim and Acorn remind us of the importance of considering stigma and normalization together in order to better understand the experiences of people living with chronic conditions (64). Furthermore, physical activity has been showed to be a normalizing experience for children and teens with physical disabilities, resulting in positive outcomes such as facilitating socialization with peers and fostering a sense of belonging (65). As such, the perspectives shared by Emily, Taylor and Kaylie can be taken as a need for adapted activities to take place within the community, where children and teens living with scoliosis or even other conditions could safely participate in these activities.

Overall, the findings presented in this thesis helps us better understand the lived experiences of adolescent girls living with scoliosis. The participants' narratives allowed us to conclude that *Curvy Girls* members benefit from membership in the peer support group and wish that more people in their demographic had access to a similar service. The group helps them cope with the daily challenges of living with their condition and helps them live a full life by connecting with others.

Conclusion

The primary objective of this study was to explore the lived experiences of adolescent girls living with scoliosis who are current or past members of peer support group *Curvy Girls*. Researchers centered participants' experience with chronic pain, their social life, experiences with health care, and *Curvy Girls*. As such, this study conducted a thorough exploration of the lived experiences of this population. Through the semi-structured interview format, which included a progression of open-ended questions going from general to more specific, participants were encouraged to discuss the aspects of their lives that were most salient to them. Allowing participants to speak freely, without strict time or subject constraint, empowered them to emphasize the experiences that were most meaningful to them, whether framed positively or negatively.

Implications

The findings presented in this thesis grant us a peek behind the curtain of a sometimes-invisible condition, as experienced by adolescent girls. Participants discussed their negative feelings toward feeling dismissed, both by medical professionals and their loved one, as well as the different ways in which they are perceived as vulnerable, particularly by their loved ones. This finding can be interpreted as a call from adolescent girls living with scoliosis to the adults in their lives to empower them to trust themselves, their bodies and their abilities. Encouraging this autonomy could address some of the negative experiences described by the participants during this study.

Participants also discussed the various ways in which they interacted with *Curvy Girls*, be it at in-person meetings or solely through different social media platforms, and their desire to give back to their scoliosis community. Some participants wished to bring more awareness to the realities of living with scoliosis, while others wanted to accompany newly diagnosed girls on their journey to accepting their condition. This finding highlights the need for peer support within the scoliosis community. It also highlights that peer support groups should offer several modalities of support, allowing members to choose how and how much they engage with the group. As these members are in situations where they feel like they have little control over their health, bodies, and relationships, having options in terms of how much interaction they wish to have with their support group could be appealing to potential members.

Finally, participants considered what changes could be made to the peer support group with which they are familiar that would improve the group overall. They identified ways of increasing access to and expanding the scope of the group, calling attention to the populations that are not primarily served by *Curvy Girls* but could still benefit from a support group, as well as other socialization needs left unanswered by *Curvy Girls* alone. While the prompting question that brought up this data focused on improvements to *Curvy Girls*, the improvements suggested by the participants indicated a need for more concerted efforts from professionals (health care workers, educators, and perhaps social workers) to address the unmet social and emotional needs of adolescents living with scoliosis.

Limitations

There are several elements of the hermeneutic approach that may be considered limitations when compared to quantitative research. For example, the sample size of sixteen participants may be considered small, indicating that the findings are not generalizable. While it is true that a sample size of sixteen participants is indeed small compared to quantitative studies relying on statistical analysis to derive results, interviewing sixteen participants hermeneutically on a topic that is important to them yields an immense amount of rich data. Applied

Philosophical Hermeneutics is not concerned with describing the behaviour of all (or most) individuals in a population as much as understanding the experiences of individuals within this population (37). This study does not imply that the lived experiences it describes are scalable to the entire population of adolescent girls living with scoliosis, simply that these lived experiences exist within the population.

Another example is that understanding exists on a temporal continuum: as we move through our life-world and expand our horizon of understanding, we continuously 're-understand' our experiences (37,48). This means that the data we collected captured the thoughts and understandings of the participants in a very specific moment in time, much like a metaphorical time-capsule. This also means that the analysis performed by the researchers is fixed in time. Given the time limits put on completion of a masters' degree, the researchers had to present the analysis they had completed within this specific time limit. We must be careful not to conclude that the analysis is incomplete, but that it can be continued through future research.

Additionally, as discussed in previous sections of this thesis, recruitment, data collection, and analysis were performed during the COVID-19 pandemic. It is difficult to estimate the exact effects of the pandemic on this study however, we noticed that recruitment presented its challenges. Potential participants trickled in slowly, and sometimes would not respond to us once we requested that they complete the informed consent form. We theorized that this may be because they were under the stress of living through a pandemic, in addition to the usual stress of their daily life. Perhaps these challenges were more related to the timing of the initial recruitment which started as the school year was winding down than to the pandemic, or perhaps they may have been the same had we completed recruitment and data collection before the pandemic started. There is no way to know this with certainty.

On the other hand, conducting data collection during the COVID-19 pandemic meant that the participants were already familiar with video conferencing software, since they had been using it for the purpose of attending school. This meant that the interviews ran smoothly, and that other than the usual small challenges associated with video conferencing like momentary ‘freezing’ of sound and/or image, we did not have to teach the participants how to use this technology. Therefore, the participants did not experience an additional technology-related stress when participating in the interviews.

Future Directions

This study and its findings shed some light on the lived experiences of adolescent girls living with scoliosis, and inevitably brought further questions about these experiences. As such, further research is warranted, particularly on the modalities of engagement offered by peer support groups and how they might affect members’ experiences with the support group, as well as the unmet social and emotional needs of adolescents living with scoliosis. As continued research unfolds, our understanding of the lived experiences of this population will expand, hopefully allowing for more comprehensive care and interventions which will help more adolescent girls living with scoliosis to lead fuller lives.

Bibliography

1. Gatwood O. When I Say That We Are All Teen Girls [Internet]. YouTube. 2018 [cited 2021 Sep 15]. Available from: https://www.youtube.com/watch?v=MHaCKwYCFZs

2. Konieczny MR, Senyurt H, Krauspe R. Epidemiology of adolescent idiopathic scoliosis. J Child Orthop. 2013 Feb;7(1):3–9.

3. Théroux J, Stomski N, Hodgetts CJ, Ballard A, Khadra C, Le May S, et al. Prevalence of low back pain in adolescents with idiopathic scoliosis: a systematic review. Chiropr Man Ther. 2017 Dec;25(1):10.

4. Balagué F, Pellisé F. Adolescent idiopathic scoliosis and back pain. Scoliosis Spinal Disord. 2016 Dec;11(1):27.

5. Curtis S, O'Donnell-Jasmin L, editors. Working together when facing chronic pain: a book designed for patients and written by their health professionals. Laval, Québec: Productions Odon; 2010. 388 p. (Working together).

6. Murray CB, Groenewald CB, de la Vega R, Palermo TM. Long-term impact of adolescent chronic pain on young adult educational, vocational, and social outcomes. Pain. 2020 Feb;161(2):439–45.

7. About [Internet]. Curvy Girls. [cited 2021 May 14]. Available from: https://www.curvygirlsscoliosis.com/about

8. Scoliosis [Internet]. American Association of Neurological Surgeons. [cited 2020 Dec 14]. Available from: https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Scoliosis

9. Asher MA, Burton DC. Adolescent idiopathic scoliosis: natural history and long term treatment effects. Scoliosis. 2006 Dec;1(1):2.

10. Weinstein SL, Dolan LA, Wright JG, Dobbs MB. Effects of Bracing in Adolescents with Idiopathic Scoliosis. N Engl J Med. 2013 Oct 17;369(16):1512–21.

11. Yagci G, Demirkiran G, Yakut Y. In-brace alterations of pulmonary functions in adolescents wearing a brace for idiopathic scoliosis. Prosthet Orthot Int. 2019 Aug;43(4):434–9.

12. Piantoni L, Tello CA, Remondino RG, Bersusky ES, Menéndez C, Ponce C, et al. Quality of life and patient satisfaction in bracing treatment of adolescent idiopathic scoliosis. Scoliosis Spinal Disord. 2018 Dec;13(1):26.

13. the American Academy of Orthopaedic Surgeons. OrthoInfo. [cited 2021 Apr 21]. Available from: https://orthoinfo.aaos.org/en/treatment/spinal-fusion/

14. Sieberg CB, Simons LE, Edelstein MR, DeAngelis MR, Pielech M, Sethna N, et al. Pain Prevalence and Trajectories Following Pediatric Spinal Fusion Surgery. J Pain. 2013 Dec;14(12):1694–702.

15. Carrasco MIB, Ruiz MCS. IDIOPATHIC ADOLESCENT SCOLIOSIS: LIVING WITH A PHYSICAL DEFORMITY. Texto Contexto - Enferm [Internet]. 2016 [cited 2021 Apr 14];25(2). Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072016000200310&lng=en&tlng=en

16. Honeyman C, Davison J. Patients' experience of adolescent idiopathic scoliosis surgery: a phenomenological analysis. Nurs Child Young People. 2016 Sep 12;28(7):29–36.

17. Jones K. Return to School Following Scoliosis Surgery: A Qualitative Analysis [Internet]. Mount Saint Vincent University; 2014 [cited 2021 Apr 14]. Available from: http://hdl.handle.net/10587/1696

18. Dailey KM. Chronic Pain and Complementary and Alternative Medicine: An Autoethnographic Chronicle Concerning Scoliosis and Disability Studies [Internet]. Prescott College; 2019 [cited 2021 Apr 14]. Available from: https://proxy.library.mcgill.ca/login?url=https://www-proquest-com.proxy3.library.mcgill.ca/dissertations-theses/chronic-pain-complementary-alternative-medicine/docview/2335279933/se-2?accountid=12339

19. Grantham W, Jespersen E, Płaszewski M. The end of being a straight child: an autoethnography of coping with adolescent idiopathic scoliosis. Disabil Rehabil. 2021 Jan 30;43(3):362–9.

20. Raja SN, Carr DB, Cohen M, Finnerup NB, Flor H, Gibson S, et al. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. Pain. 2020 Sep;161(9):1976–82.

21. Treede R-D, Rief W, Barke A, Aziz Q, Bennett MI, Benoliel R, et al. A classification of chronic pain for ICD-11. Pain. 2015 Jun;156(6):1003–7.

22. Sato T, Hirano T, Ito T, Morita O, Kikuchi R, Endo N, et al. Back pain in adolescents with idiopathic scoliosis: epidemiological study for 43,630 pupils in Niigata City, Japan. Eur Spine J. 2011 Feb;20(2):274–9.

23. Forgeron PA, King S, Stinson JN, McGrath PJ, MacDonald AJ, Chambers CT. Social Functioning and Peer Relationships in Children and Adolescents with Chronic Pain: A Systematic Review. Pain Res Manag. 2010;15(1):27–41.

24. Wakefield EO, Zempsky WT, Puhl RM, Litt MD. Conceptualizing pain-related stigma in adolescent chronic pain: a literature review and preliminary focus group findings. PAIN Rep. 2018 Sep;3(1):e679.

25. Defenderfer EK, Bauer K, Igler E, Uihlein JA, Davies WH. The Experience of Pain Dismissal in Adolescence. Clin J Pain. 2018 Feb;34(2):162–7.

26. Szwimer R, Widjaja M, Ingelmo P, Hovey RB. A Phenomenological Exploration of the Personal Implications of Female Adolescents Living With Chronic Pain. J Pediatr Health Care. 2020 Sep;34(5):470–7.

27. Mission Statement [Internet]. Curvy Girls. [cited 2020 Dec 14]. Available from: https://www.curvygirlsscoliosis.com

28. Plante WA. Review of Group Interventions for Pediatric Chronic Conditions. J Pediatr Psychol. 2001 Oct 1;26(7):435–53.

29. Tolley JA, Michel MA, Williams AE, Renschler JS. Peer Support in the Treatment of Chronic Pain in Adolescents: A Review of the Literature and Available Resources. Children. 2020 Sep 7;7(9):129.

30. Stinson JN, Lalloo C, Harris L, Isaac L, Campbell F, Brown S, et al. *iCanCope with Pain* ™: User-Centred Design of a Web- and Mobile-Based Self-Management Program for Youth with Chronic Pain Based on Identified Health Care Needs. Pain Res Manag. 2014;19(5):257–65.

31. Arnstein P, Vidal M, Wells-Federman C, Morgan B, Caudill M. From chronic pain patient to peer: Benefits and risks of volunteering. Pain Manag Nurs. 2002 Sep;3(3):94–103.

32. Cooper K, Wilcock S. The effectiveness of peer support interventions for community dwelling adults with chronic non-cancer pain: a systematic review: Int J Evid Based Healthc. 2013 Sep;11(3):214–5.

33. Moules NJ, McCaffrey G, Field JC, Laing CM, editors. Conducting hermeneutic research: from philosophy to practice. New York, NY Bern Frankfurt, M Berlin Brussels Vienna Oxford Warsaw: Lang; 2015. 214 p. (Critical qualitative research).

34. Davey N. Unquiet understanding: Gadamer's philosophical hermeneutics. Albany, NY: State University of New York Press; 2006. 291 p. (SUNY series in contemporary continental philosophy).

35. Yaffe MJ, Hovey RB, Rodriguez C. Use of patients' unsolicited correspondence to a family doctor to describe and understand valued components of a doctor-patient relationship: A Hermeneutics approach. BMC Fam Pract. 2019 Dec;20(1):136.

36. Hovey RB, Rodríguez C, Jordan S, Morck A. Synergistic Research in Medical Education: Some Philosophical Reflections. J Appl Hermeneutics. 2016 Jun 7;2016.

37. Gadamer H-G. Truth and method. First paperback edition.translation revised by Joel Weinsheimer and Donald G. Marshall. London: Bloomsbury; 2013. 623 p. (The Bloomsbury revelations series).

38. Hovey RB, Delormier T, McComber AM, Lévesque L, Martin D. Enhancing Indigenous Health Promotion Research Through Two-Eyed Seeing: A Hermeneutic Relational Process. Qual Health J. 2017;27(9):1278–87.

39. Grondin J. What is the hermeneutical circle? In: Keane N, editor. The Blackwell companion to hermeneutics. Chichester, West Sussex, UK: Wiley; 2016. p. 299–305.

40. Kearney R. Anatheism: returning to God after God. New York: Columbia University Press; 2011.

41. Hovey RB. The gift of pain with transformative possibilities. Patient Exp J. 2018 Apr 25;5(1):11–4.

42. Hovey RB. Cathartic narratives for chaotic thinking. Can Med Assoc J. 2016 Dec 6;188(17–18):E543–4.

43. Hovey R, Paul J. Healing, the Patient Narrative-Story and the Medical Practitioner: A Relationship to Enhance Care for the Chronically Ill Patient. Int J Qual Methods. 2007 Dec;6(4):53–66.

44. Szwimer R. Understanding the lived experiences of adolescents living with chronic pain: the implications of personal and social development [Internet] [Thesis]. [Montreal, QC]: McGill University; 2019 [cited 2021 Apr 27]. Available from: https://escholarship.mcgill.ca/concern/theses/6q182q53k

45. Craig KD. A child in pain: A psychologist's perspective on changing priorities in scientific understanding and clinical care. Paediatr Neonatal Pain. 2020 Jun;2(2):40–9.

46. Adrian M, Berk MS, Korslund K, Whitlock K, McCauley E, Linehan M. Parental validation and invalidation predict adolescent self-harm. Prof Psychol Res Pract. 2018 Aug;49(4):274–81.

47. Mommaerts J-L, Goubert L, Devroey D. Empathy Beyond the Conceptual Level: Core Nonspecific Factors of Psychotherapy. Perspect Biol Med. 2012;55(2):175–82.

48. Gadamer H-G. The enigma of health: the art of healing in a scientific age. Stanford: Stanford University Press; 1996. 180 p.

49. Hovey R, Pavate V, Vigouroux M, Amja K. A Reconceptualization of the Negative Self-Stereotyping of the Patient-Partner to the Introduction of the Patient Perspective Consultant. Perm J [Internet]. 2020 [cited 2021 May 5];24(5). Available from: http://www.thepermanentejournal.org/

50. Walter JK, Ross LF. Relational Autonomy: Moving Beyond the Limits of Isolated Individualism. PEDIATRICS. 2014 Feb 1;133(Supplement):S16–23.

51. Mackenzie C, Stoljar N, editors. Relational autonomy: feminist perspectives on automony, agency, and the social self. New York: Oxford University Press; 2000. 314 p.

52. Riess H. The Science of Empathy. J Patient Exp. 2017 Jun;4(2):74–7.

53. Hogg MA, Turner JC. Intergroup behaviour, self-stereotyping and the salience of social categories. Br J Soc Psychol. 1987 Dec;26(4):325–40.

54. Pickett CL, Bonner BL, Coleman JM. Motivated self-stereotyping: Heightened assimilation and differentiation needs result in increased levels of positive and negative self-stereotyping. J Pers Soc Psychol. 2002;82(4):543–62.

55. Sinclair S, Huntsinger J, Skorinko J, Hardin CD. Social Tuning of the Self: Consequences for the Self-Evaluations of Stereotype Targets. J Pers Soc Psychol. 2005;89(2):160–75.

56. Biernat M, Vescio TK, Green ML. Selective self-stereotyping. J Pers Soc Psychol. 1996;71(6):1194–209.

57. Cranton P. Understanding and promoting transformative learning: a guide for educators of adults. 2nd ed. San Francisco, CA: Jossey-Bass; 2006. 228 p. (The Jossey-Bass higher and adult education series).

58. Hovey RB. Living With a Trifecta of Pain and Cancer With Personal Reflections of COVID-19. J Patient Exp. 2020 Sep 9;237437352095687.

59. Sklar M, Reeder K, Carandang K, Ehrhart MG, Aarons GA. An Observational Study of the Impact of COVID-19 and the Transition to Telehealth on Community Mental Health Center Providers [Internet]. In Review; 2020 Jul [cited 2021 Aug 2]. Available from: https://www.researchsquare.com/article/rs-48767/v1

60. Hirko KA, Kerver JM, Ford S, Szafranski C, Beckett J, Kitchen C, et al. Telehealth in response to the COVID-19 pandemic: Implications for rural health disparities. J Am Med Inform Assoc. 2020 Nov 1;27(11):1816–8.

61. Langabeer JR, Yatsco A, Champagne-Langabeer T. Telehealth sustains patient engagement in OUD treatment during COVID-19. J Subst Abuse Treat. 2021 Mar;122:108215.

62. Weinberg H. Online group psychotherapy: Challenges and possibilities during COVID-19—A practice review. Group Dyn Theory Res Pract. 2020 Sep;24(3):201–11.

63. Spencer-Cavaliere N, Watkinson EJ. Inclusion Understood From the Perspectives of Children With Disability. Adapt Phys Act Q. 2010 Oct;27(4):275–93.

64. Joachim G, Acorn S. Living with Chronic Illneww: The Interface of Stigma and Normalization. Can J Nurs Res. 2016 Apr 14;32(3):37–48.

65. Taub DE, Greer KR. Physical Activity as a Normalizing Experience for School-Age Children with Physical Disabilities: Implications for Legitimation of Social Identity and Enhancement of Social Ties. J Sport Soc Issues. 2000 Nov;24(4):395–414.

Appendices

Appendix A: Recruitment Material

“Hey Canadian CG members!
I have an amazing online opportunity for you to get involved with!

I am helping out with a study about scoliosis and Curvy Girls. We are looking for people to share their experience with scoliosis over video call. It’s a super simple way to get involved in research without the time commitment!

If you are Canadian and 14 years or older, please feel free to email Kristina.amja@mail.mcgill.ca to learn more!

Stay safe everyone!!”

“Dear Canadian Curvy Girls,

I am working with two awesome students at McGill University in Montreal to create a study on scoliosis! We are looking for girls to share their experience and how scoliosis has impacted them. This is a great way to get involved in research and to raise awareness about the impact of scoliosis. It is all online so not to worry!

If you are interested in participating, please email Kristina.amja@mail.mcgill.ca!

** Participants must be Canadian citizens or permanent residents and must be 14 years or older***”

Appendix B: Consent Form

McGill

Faculty of Dentistry
McGill University
2001 McGill College, rm. 537
Montreal, QC, CANADA H3A1G1

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 Collège, 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 egngagment 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-recoded and transcribed will be deleted / shredded approximately 36 months after its analysis.

Possible Risk and Discomfort:

There is no known risk for the participants who will participate 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: Exploring and Understanding Adolescent Chronic Pain

I have been explained what will happen on this study. 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.

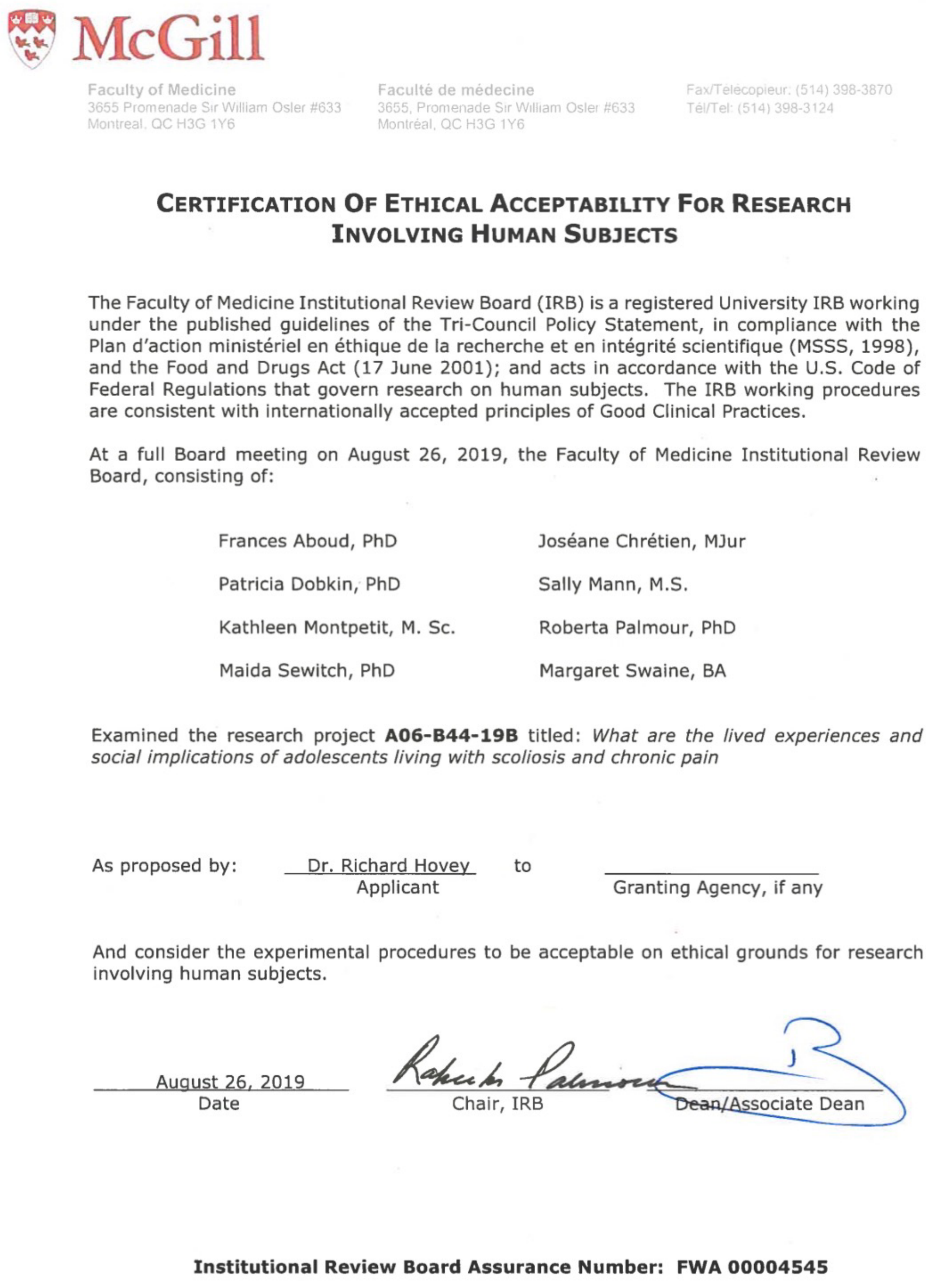
Name of person obtaining consent (Print)	Signature	Date

Participant's Signature: _______________ Person Obtaining Consent: __________________

Print Name: ________________________ Print Name: _______________________________

Date: ______________________________

Appendix C: IRB Ethics Approval Certificate



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	Joséane Chrétien, MJur
Patricia Dobkin, PhD	Sally Mann, M.S.
Kathleen Montpetit, M. Sc.	Roberta Palmour, PhD
Maida Sewitch, 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.

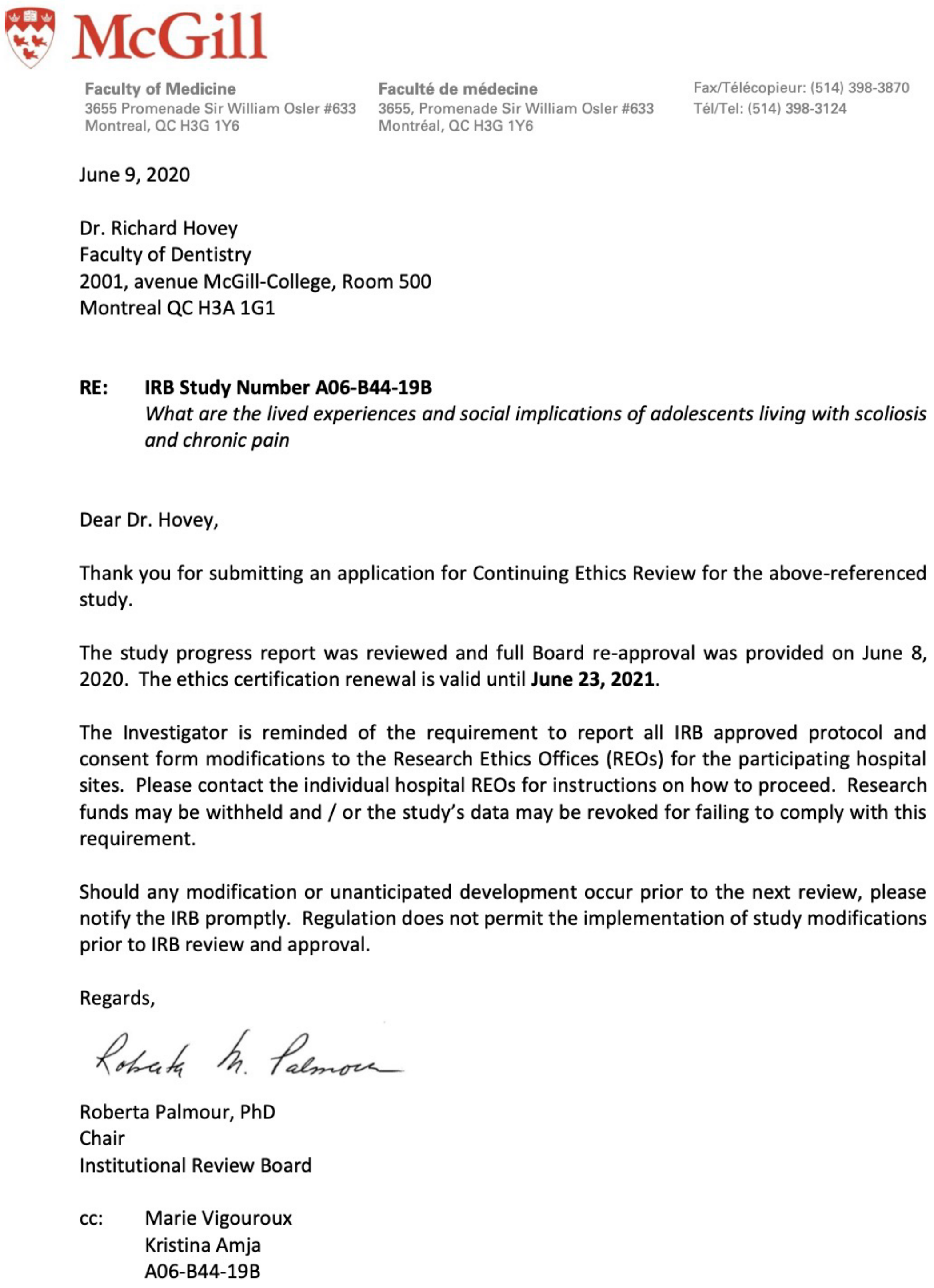
August 26, 2019
Date

Roberta Palmour
Chair, IRB

Dean/Associate Dean

Institutional Review Board Assurance Number: FWA 00004545

Appendix D: IRB Ethics Renewal



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

June 9, 2020

Dr. Richard Hovey
Faculty of Dentistry
2001, avenue McGill-College, Room 500
Montreal QC H3A 1G1

RE: IRB Study Number A06-B44-19B
What are the lived experiences and social implications of adolescents living with scoliosis and chronic pain

Dear Dr. Hovey,

Thank you for submitting an application for Continuing Ethics Review for the above-referenced study.

The study progress report was reviewed and full Board re-approval was provided on June 8, 2020. The ethics certification renewal is valid until **June 23, 2021**.

The Investigator is reminded of the requirement to report all IRB approved protocol and consent form modifications to the Research Ethics Offices (REOs) for the participating hospital sites. Please contact the individual hospital REOs for instructions on how to proceed. Research funds may be withheld and / or the study's data may be revoked for failing to comply with this requirement.

Should any modification or unanticipated development occur prior to the next review, please notify the IRB promptly. Regulation does not permit the implementation of study modifications prior to IRB review and approval.

Regards,

Roberta M. Palmour

Roberta Palmour, PhD
Chair
Institutional Review Board

cc: Marie Vigouroux
Kristina Amja
A06-B44-19B

Appendix E: Interview Guide

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