ADDRESSING THE PSYCHOLOGICAL COMPLEXITY OF SCOLIOSIS BRACING

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INTRODUCTION: Bracing for adolescent idiopathic scoliosis (AIS) is an effective method of controlling curve progression. Because success heavily relies on following the wear schedule, adherence is frequently problematic. While decreased wear time can compromise the effectiveness of bracing, increased psychological stress can jeopardize the mental wellbeing of these braced scoliosis patients. Although the emotional effects of bracing have been heavily researched and documented, healthcare providers are not regularly initiating conversations to alleviate these effects. There are currently no clinical tools available to help healthcare providers address the psychological aspects of scoliosis bracing. Scolios-us was created to fill this void. Scolios-us is a web-based platform intended to empower scoliosis patients with the tools and resources they need to be successful brace-wearers.

OBJECTIVES: The first objective was to develop the Scolios-us website to meet the needs of AIS patients. The second was to collect feedback from orthotists and AIS patients to optimize Scolios-us for future use and studies.

METHODS: At the time of testing, the Scolios-us website consisted of six main pages: Home, Video, Blog, Resources, Research, and Discussion Board. The study consisted of two surveys – one taken by orthotists and one by AIS patients. Results were analyzed with descriptive statistics and a paired t-test.

Clinician Survey – Clinicians were recruited from the Spinal Orthotics Society site and O&P Listserv. English-speaking orthotists/orthotic residents were eligible. Subjects evaluated website design, contents, video, and feasibility of using Scolios-us as a clinical tool in a 16-question survey.

Patient Survey – AIS subjects were recruited at Baton Rouge Orthopedic Clinic. The inclusion criteria consisted of the following: AIS diagnosis, 10-17 years old, English-speaking, assenting, and receive parental consent. Subjects evaluated the video in a 10-question survey.

RESULTS:

Clinician Survey – The clinician survey produced an average of 29.5 responses on multiple-choice questions and 14.2 responses on free-response questions. Over 40% of the participants have been in practice for over 21 years, and 81.3% treat scoliosis patients frequently or very frequently. Respondents perceived the Scolios-us website as engaging, easy-to-navigate, and helpful for scoliosis patients. The video was perceived as the most helpful tool on the website, and subjects found it to be helpful and empowering. When asked for video improvements, two themes emerged: shorten the video and increase the diversity of the participants. The majority (60%) of subjects are extremely likely to recommend Scolios-us to patients.

AIS Patient Survey – Eleven female subjects with a mean age of 13.1 ± 2.0 years completed the survey. Subjects' feelings about bracing improved significantly after watching the video ($P=0.011$). Nearly two-thirds (63.6%) of participants reported that the tips, tricks, and advice shared in the video were very or extremely helpful, and 36.4% felt that the video was too long. When asked for improvements to the video, the theme of wanting more brace information emerged.

CONCLUSION: Overall, results support the continued use of Scolios-us to address the psychological aspects of bracing in AIS patients. Improvements have been made to optimize Scolios-us based on clinician and patient feedback. Although Scolios-us is still in its infancy, preliminary data suggest that it is encouraging a more holistic approach to scoliosis treatment by empowering scoliosis patients and stimulating conversations about the emotional effects of bracing.

INTRODUCTION

Adolescent idiopathic scoliosis (AIS) is a common condition affecting .47-5.2% of adolescents. Females are more frequently affected by AIS than males and often have more severe curvatures. Generally, curves less than 20 degrees are observed by the physician, while curves that surpass 20 degrees are treated with bracing.[1] Thoracic lumbar sacral orthoses (TLSOs) are a common conservative treatment used to manage AIS, with the goals of limiting curve progression and avoiding surgical intervention.

Bracing for AIS is an effective method of controlling curve progression. The BrAIST Study (Bracing in Adolescent Idiopathic Scoliosis Trial) is the most groundbreaking scoliosis bracing research in recent history. Published in 2013, this study showed the effectiveness of scoliosis bracing and the relationship between wear time and success. The study was forced to stop early because bracing was found to be so effective that encouraging patients to continue in the observation-only group without a brace was ruled unethical. In the bracing group, 90% of the subjects who wore their brace for 13 or more hours a day avoided surgery, demonstrating the importance of wear time adherence on success.[2] Because success relies so heavily on following the wear schedule, adherence is often problematic. According to a 2003 study, on average, patients wear their brace for 75% of the prescribed time, with younger patients being more adherent than older patients.[3] A more recent study reported that only 13% of its AIS subjects wore their brace for 14 hours or more, despite this study taking place at a highly experienced scoliosis treatment center.[4]

While reduced wear time adherence can compromise the effectiveness of bracing, increased psychological stress can jeopardize the mental wellbeing of these braced scoliosis patients. Adolescents with scoliosis are 40% more likely to develop suicidal ideations,

demonstrating the magnitude of the emotional impact of scoliosis.[5] While the diagnosis of scoliosis is concerning in itself, braced patients have revealed that bracing causes more stress than the actual diagnosis and deformity of scoliosis.[6] A 2017 study investigated the motivations for adherence in 39 female AIS patients, revealing that the desires to avoid surgery and prevent curve progression are the main reasons for adherence.[7] These stress-filled motivations further demonstrate that bracing not only impacts patients' physical bodies, but also affects their emotional states. Bracing evokes feelings of stress, anger, and shame, and braced patients suffer from poorer body image.[8-11] Although the emotional effects of bracing have been heavily researched and documented, conversations are not being consistently initiated by healthcare providers to alleviate these effects.[8-9] One study reported that "only 5% of those with scoliosis declared that they had opportunities to discuss their feelings and problems with health professionals, while 90% of them declared that they wanted to have more opportunities to do this."[9] This disconnect demonstrates the need for change in clinicians' approach to scoliosis care.

In addition to needing support from their healthcare team, AIS patients need social support. The majority of the subjects in the previously mentioned 2017 study reported that having peer support would likely increase the amount of time they wore their braces.[7] These results support findings from previous studies. When AIS subjects and their parents were asked what could be done to mitigate the psychological impact of initiating bracing, the most frequent recommendation was a support group for both the patients and parents.[12] Similarly, seeking social support is characteristic of adherent females.[13]

Although organizations, such as Curvy Girls and Higgy Bears & Friends, offer support for scoliosis patients, many go through the process unaware that scoliosis resources are available. Presently, there are no clinical tools available to help healthcare providers address the

psychological effects of scoliosis bracing. Scolios-us was created to fill this void. Scolios-us is a web-based platform intended to empower scoliosis patients with the tools and resources they need to be successful brace-wearers. It is based on the idea that young braced patients are better able to connect and communicate with fellow braced patients.[14] Consolidating external and internal resources into one website, Scolios-us aims to guide newly braced patients through the bracing process by giving them an authentic look into scoliosis bracing from the people who are living it. Instead of being the exception, these braced patients become part of the group, creating a social support network with the common goal of coping with and conquering scoliosis bracing.

RESEARCH OBJECTIVES

The first objective was to develop the Scolios-us website to meet the needs of AIS patients. The second was to collect feedback from orthotists and AIS patients in order to optimize Scolios-us for future use and studies.

METHODS

At the time of testing, the Scolios-us website consisted of six main pages: Home, Video, Blog, Resources, Research, and Discussion Board. The Video page housed the "Welcome to Scoliosis Bracing with Scolios-us" video, a 13-minute video featuring current and former brace-wearers speaking about their unique experiences with bracing. The main topics discussed include initial reactions, telling friends, daily routines, fashion advice, and words of wisdom. The Blog page consisted of blog posts from brace-wearers as well as from Scolios-us, while the Resources page housed scoliosis-specific resources and their websites. The Research page outlined influential bracing studies, and the Discussion Board page offered a space for brace-wearers to

connect with each other directly. The present study consisted of two surveys – one taken by clinicians and one by AIS patients.

Clinician Survey

Clinicians were recruited initially from the Spinal Orthotics Society webpage and subsequently from the O&P Listserv. The inclusion criteria included consenting certified orthotists or orthotic residents who speak English. Subjects were asked to evaluate the Scolios-us website design, website contents, "Welcome to Scoliosis Bracing with Scolios-us" video, and feasibility of using Scolios-us as a clinical tool in a 16-question survey. Eleven multiple choice questions produced an average of 29.5 responses, while five free response questions produced an average of 14.2 responses. Results were analyzed using descriptive statistics.

AIS Patient Survey

AIS subjects were recruited at Baton Rouge Orthopedic Clinic. The inclusion criteria included the following: confirmed AIS diagnosis, age between 10 and 17 years old, English-speaking, assent to the study, and receive parental consent. Subjects were asked to evaluate the "Welcome to Scoliosis Bracing with Scolios-us" video in a 10-question survey. The survey consisted of three demographic questions and seven questions specific to the video. Eleven female subjects with a mean age of 13.1 ± 2.0 years completed the survey. More than half (54.5%) of the subjects began bracing seven or more months ago prior to completion of the survey (Fig 1). Results were analyzed using descriptive statistics and a paired t-test.

RESULTS

Clinician Survey

Clinicians evaluated Scolios-us as a whole in a 16-question survey. Regarding the clinical expertise of the subjects, 43.8% have been in practice for over 21 years, and 81.3% treat scoliosis patients frequently or very frequently. Nearly two-thirds (63.3%) of respondents found the Scolios-us website to be very or extremely engaging, and 90% reported that the website was very or extremely easy to navigate. Over three-quarters (80%) of subjects found the website to be very or extremely helpful to scoliosis patients (Fig. 2). When asked for improvements to the design of the website, subjects provided many recommendations, but no theme emerged. Respondents perceived the video as the most helpful tool for scoliosis patients (Fig. 3). When asked for improvements to the content of the website, subjects again provided many recommendations, but no theme emerged.

In reference to the "Welcome to Scoliosis Bracing with Scolios-us" video, nearly two-thirds (64.3%) of respondents perceived the tips, tricks, and advice shared in the video as very or extremely helpful (Fig. 4). Nearly three-quarters (71.4%) of respondents found the video to be very empowering or extremely empowering for scoliosis patients who are new to bracing. Almost half (46.4%) felt that the video was too long, while the remaining participants felt that the video was a good length. When asked for video improvements, two themes emerged: shorten the video and increase the diversity of the participants. Regarding the clinical application of Scolios-us, 60% of respondents are extremely likely to recommend Scolios-us to scoliosis patients (Fig. 5). When subjects were asked about the likelihood of using Scolios-us in his/her office, 65.5% responded extremely or moderately likely.

AIS Patient Survey

Eleven female AIS subjects evaluated the "Welcome to Scoliosis Bracing with Scolios-us" video in a 10-question survey. When subjects were asked how they felt about bracing before

watching the video, 36.4% reported negative feelings, 9.1% reported positive feelings, and 54.5% reported neutral feelings. After watching the video, no subjects reported negative feelings, 36.4% reported positive feelings, and 63.6% reported neutral feelings (Fig 6). Subjects' feelings improved significantly after watching the video (P=0.011). When asked to describe the video in one word, subjects provided a variety of answers, presented in Table 1. Nearly two-thirds (63.6%) of participants reported that the tips, tricks, and advice shared in the video were very or extremely helpful (Fig 7). When asked about the length of the video, 63.6% felt that it was a good length, while the remaining 36.4% reported that it was too long. When asked for improvements to the video, the theme of wanting more brace information emerged.

DISCUSSION

The fragility of adolescence should be taken into consideration when treating the AIS population. At this point in their lives, these patients desire independence from their parents, which is an important developmental goal specific to adolescence. However, once they begin bracing, their march toward independence is compromised, as they now must rely on their parents for transportation to and from additional appointments and potentially for brace donning. Friendships and romantic relationships become more difficult, all while navigating this "particularly sensitive stage of development that is highly susceptible to disruptive factors."[14] The decision to begin bracing is both life-altering and stress-inducing, yet healthcare providers are not consistently fulfilling these patients' need for emotional support.[6-11]

Results from the present study evince the potential for Scolios-us to satisfy these patients' unmet needs. Clinicians perceived Scolios-us as helpful, engaging, and empowering for scoliosis patients, and the majority answered that they are extremely likely to recommend Scolios-us to

scoliosis patients. At the very least, by recommending Scolios-us to patients, clinicians touch on the intangible side of bracing by describing what Scolios-us is and what it offers. Scolios-us not only allows clinicians to efficiently direct patients to scoliosis resources, but also may initiate deeper, emotionally-based conversations.

Similar to results from the clinician survey, results from the patient survey support the continued use of the "Welcome to Scoliosis Bracing with Scolios-us" video. Prior to watching the video, the majority of the AIS subjects had neutral or negative feelings about bracing. After watching the video, their feelings improved significantly, reaffirming the need for psychological support and validating the Scolios-us video as an effective approach. They found the video to be helpful, describing it as "relieving," "uplifting," and "encouraging." As with the clinician survey, some AIS subjects felt that the video was too long.

Due to the small sample size of both surveys, the generalizability of the results may be limited. Specifically, with the clinician survey, the majority of the subjects have been in practice for over 15 years, which may decrease the generalizability to newer clinicians. There also may be implicit bias present, as lead investigator is the creator of Scolios-us.

CONCLUSION

Overall, the results of the study support the continued use of Scolios-us to address the psychological aspects of bracing in AIS patients. Although Scolios-us is still in its infancy, preliminary data suggest that it is encouraging a more holistic approach to scoliosis treatment by empowering scoliosis patients and encouraging conversations about the emotional effects of bracing.

Since the completion of the clinician survey, improvements have been made to the website to better meet the needs of scoliosis patients. The biggest changes include the addition of several new resources and the creation of a Brace Information section. Data collection for the patient survey continues in an effort to collect more robust patient feedback. Future research includes determining the effect of Scolios-us on wear time adherence and on stress levels.

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TABLES AND FIGURES

“Relieving”	“Helpful”
“Useful”	“Descriptive”
“Cool”	“Inspiring”
“Encouraging”	“Enlightening”
“Uplifting”	“Different”
“Informative”	

Table 1: Words given by AIS subjects to describe the “Welcome to Scoliosis Bracing with Scolios-us” video.

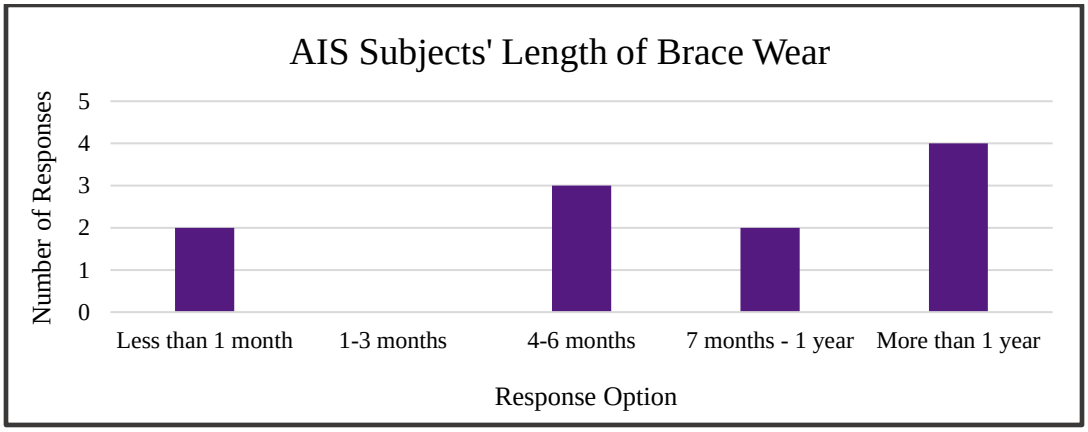

Figure 1: The above bar graph depicts the length of time AIS subjects had been wearing a brace at the time of the survey.

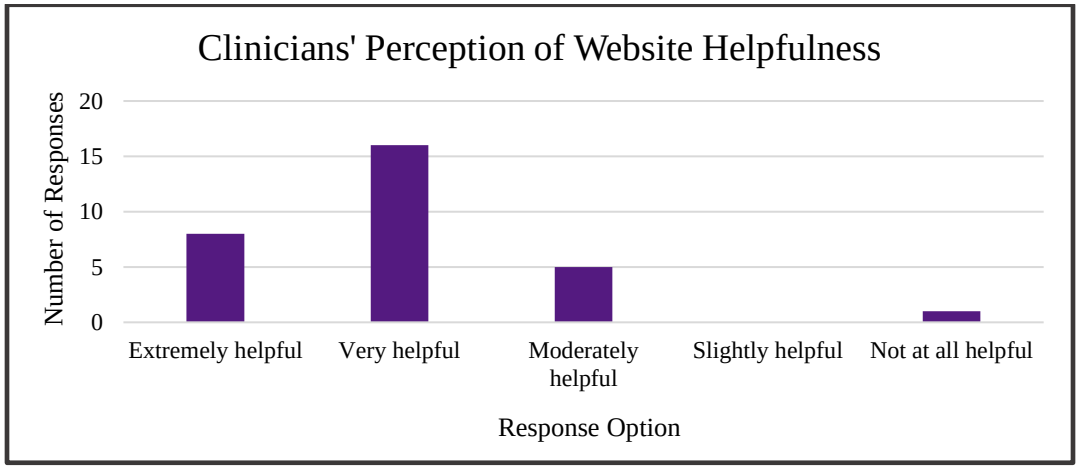

Figure 2: The above bar graph represents clinicians’ responses when asked about the helpfulness of the Scolios-us website.

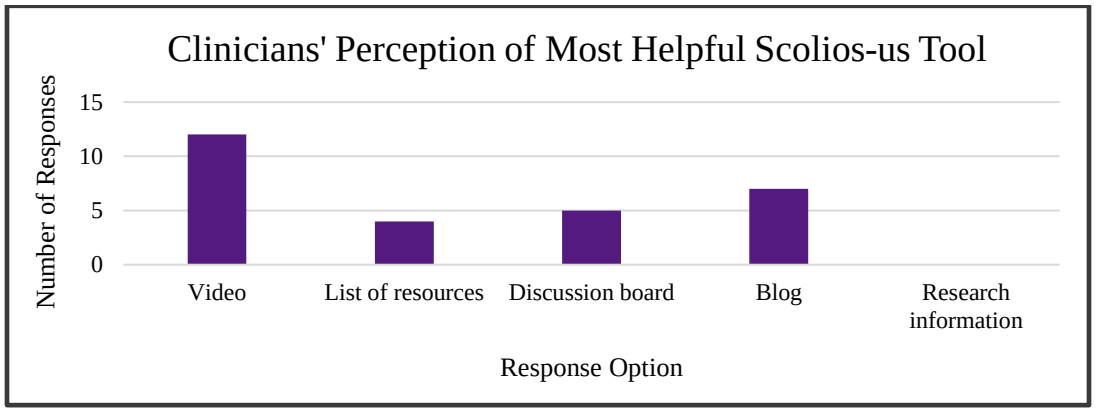

Figure 3: The above bar graph depicts clinicians' responses when asked which Scolios-us tool is the most helpful for patients.

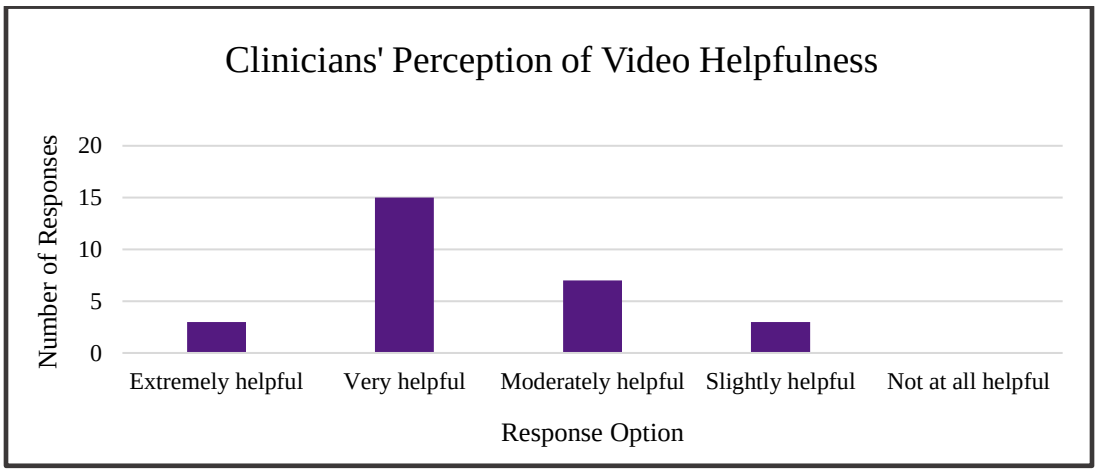

Figure 4: The above bar graph demonstrates clinicians' responses when asked about the helpfulness of the "Welcome to Scoliosis Bracing with Scolios-us" video.

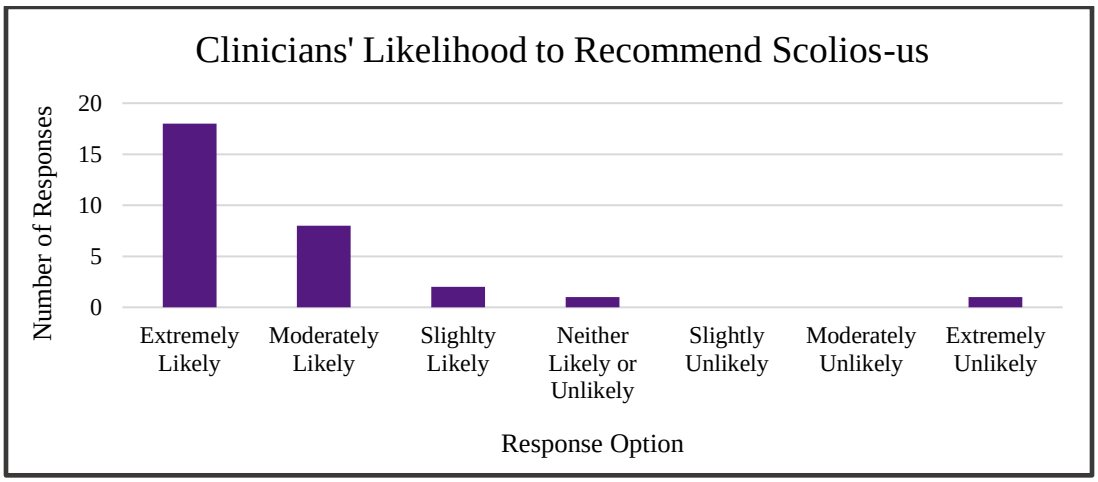

Figure 5: The above bar graph represents clinicians' responses when asked to rate their likelihood to recommend Scolios-us to patients.

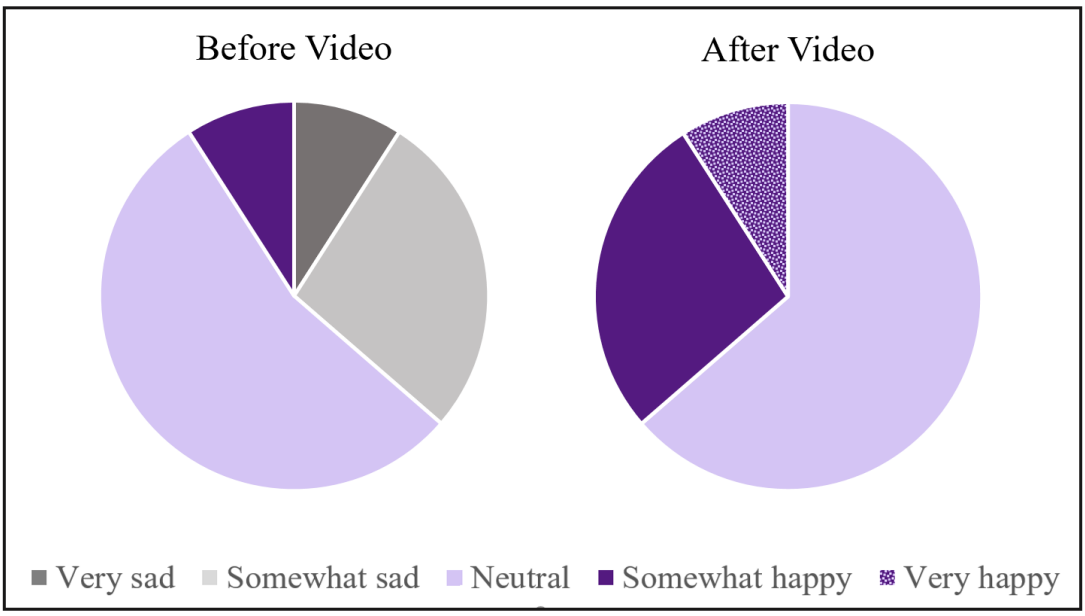

Figure 6: The above pie graphs compare AIS subjects' feelings about bracing before watching the "Welcome to Scoliosis Bracing with Scolios-us" video versus after.

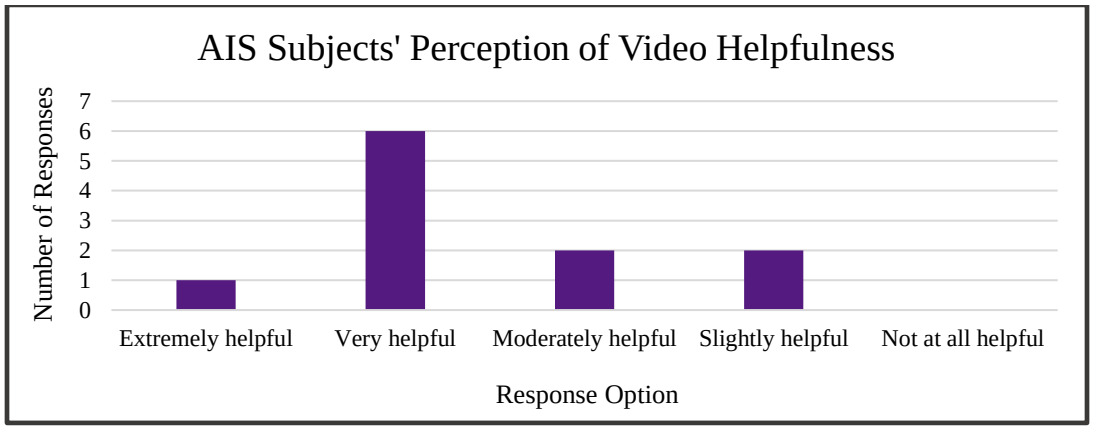

Figure 7: The above bar graph displays AIS subjects' responses when asked about the helpfulness of the "Welcome to Scoliosis Bracing with Scolios-us" video.