

An Online Pilates Program for People with Hypermobility: A Pragmatic Clinical Trial Looking at Function, Interoception, Kinesiophobia, and Physical Activity Levels

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Purpose: This study evaluated whether an independent, online modified Pilates program alters function, interoception (internal body awareness), activity levels, and kinesiophobia (fear of movement) in people with symptomatic joint hypermobility.

Patients and Methods: This pragmatic clinical trial included and exercise group that did 8 weeks of modified Pilates and an 8-week waitlist control group. People with symptomatic hypermobility were asked to do an independent, online Pilates program designed specifically for people with hypermobility; each module was about 25 minutes, and participants were asked to do at least 3 days/week. Outcome measures included the Bristol Impact of Hypermobility (BioH), International Physical Activity Questionnaire (IPAQ), Revised Body Awareness Questionnaire (BARQ), and Tampa Scale of Kinesiophobia (TSK). Clinical Trial # NCT07118865.

Results: A total of 420 participants completed questionnaires at 8 weeks: 200 completed 8 weeks of Pilates and 220 were on a waitlist. The Pilates group demonstrated statistically significant improvements in BioH, BARQ, and TSK immediately after the intervention ($p < 0.001$ for each) and compared to the control group ($p < 0.001$ for each). Improvements in the Pilates group remained statistically significant at 6 months. IPAQ did not change for any group.

Conclusion: This online Pilates program for people with symptomatic hypermobility improved BioH, BARQ, and TSK, though changes were modest. The exercises did not improve IPAQ. Online exercise may provide a cost-effective way to encourage life-long activity in people with hypermobility. Limitations include the inability to monitor performance of the Pilates, high drop-out rates, and the inability to control for changes in other treatments patients may have received.

Plain Language Summary: We evaluated whether 8 weeks of an independently performed, online Pilates exercise program designed for people with symptomatic joint hypermobility could improve hypermobility-related pain, function, body awareness and overall activity level. We had 200 people in the Pilates group, who tried to do one of five 25-minute modified Pilates modules three times a week for eight weeks. We also had 220 people in a waitlist group who were able to start the Pilates after repeating questionnaires after an 8 week delay. Participants reported hypermobility-specific pain and fatigue-related function, body awareness, fear of movement, and overall activity levels. We found that hypermobility-specific pain and fatigue-related function, body awareness, and fear of movement improved in the Pilates group compared to the control group, but activity level did not change. Improvements were maintained at 6 months. Our conclusion is that an independent, on-line Pilates program designed for people with hypermobility may be beneficial and may provide a cost-effective way for people with hypermobility to engage in life-long exercise.



Keywords: hypermobile Ehlers-Danlos syndrome, hypermobility spectrum disorders, exercise, pragmatic clinical trial, symptomatic generalized joint hypermobility

Introduction

Hypermobility related disorders are common in patient-care environments.¹ In 2017, a new checklist was created to diagnose hypermobile EDS (hEDS), and the diagnosis of Hypermobility Spectrum Disorder (HSD) was created to catch people who had met the previous criteria for Joint Hypermobility Syndrome (JHS) but did not quite meet the criteria for hEDS.² Because of this diagnostic confusion, experts often describe the overall population as “Symptomatic Joint Hypermobility,” or SJH.¹⁻³ Although the most obvious presentation of SJH is generalized joint hypermobility, all connective tissue may be affected leading to widespread pain and systemic involvement.⁴

Musculoskeletal involvement is often associated with decreased strength, compromised body awareness or proprioception, and fear of movement that leads to decreased physical activity and deconditioning, which further exacerbates problems.^{1,5-8} Therapeutic exercise is considered one of the most effective treatment options in the improvement of pain and disability in symptomatic hypermobility. However, optimal type, frequency and intensity are not known.^{1,9,10} Individuals with symptomatic hypermobility often have movement disorders due, in part, to reduced proprioception,⁷ kinesiophobia or the fear of movement, and a reluctance to move due to the presence of chronic pain. The current study used the Tampa Scale of Kinesiophobia 11 to measure fear of movement,¹¹ the Bristol Impact of Hypermobility (BioH) questionnaire¹² to assess the impact of hypermobility, and The International Physical Activity Questionnaire Short Form (IPAQ) to measure physical activity.¹³

Mind-body exercises, such as Pilates, Tai Chi, and yoga are recommended for people with symptomatic hypermobility because these activities are typically gentle, foster relaxation, and improve body awareness.^{14,15} Pilates has substantial evidence supporting benefits for people with chronic low back pain,¹⁶ fibromyalgia¹⁷ and other chronic pain disorders¹⁸⁻²⁰ but only one single subject study on Pilates in people with hypermobility.²¹ There are several mechanisms by which mind-body movement training, such as Pilates, might be beneficial for people with symptomatic hypermobility. One is improved muscle strength and tone, which can stabilize hypermobile joints. Pilates differs from standard gym exercises in the emphasis on improved body awareness and coordination using slow, gentle, controlled movements, some of which use small props like balls and bands to improve sensory awareness.¹⁴ Pilates results in decreased kinesiophobia in patients with chronic low back pain²² and osteoporosis,²³ but has not been studied in symptomatic hypermobility.

Interoception is the ability to perceive, interpret, and regulate internal body signals.^{24,25} People with chronic pain, including those with symptomatic hypermobility, demonstrate interoceptive deficits. Research shows that mind-body movement practices such as yoga, Tai Chi, and qigong benefit people with chronic pain and that the benefit is partially mediated by improvements in interoception.^{25,26} Pilates involves body awareness and retraining breathing patterns, introducing simple mindfulness and sensory awareness techniques that can have an instant calming effect and reduce anxiety^{14,27} Also, Pilates could enhance interoception through improving breathing patterns and inducing a calming response.¹⁴ The current study used the Revised Body Awareness Rating Questionnaire (BARQ) to assess interoception.²⁸

Research shows that there are many unmet healthcare needs among people with symptomatic hypermobility, including inadequate access to physical therapy and exercise,²⁹ even though these are considered cornerstones of management.^{1,15} Furthermore, healthcare costs are reported to be \$11,000-\$21,000 more in people with symptomatic hypermobility compared to people who do not have symptomatic hypermobility.³⁰ In particular, there is limited access to cost-effective, appropriate long-term exercise for this population. The Pilates program in the current study, which is available online and can be done when time, fatigue and pain permit, provides a potential solution to the lack of affordable, appropriate long-term exercise options for people with symptomatic hypermobility.

The aim of this study was to determine whether participation in an asynchronous online Pilates program designed for people with HSD/hEDS could alter function, physical activity, kinesiophobia, or interoception. We compared participants before and after 8 weeks of Pilates and at 6 months, as well as comparing the intervention and an 8-week waitlist control groups.

Methods

Study Design

This was a pragmatic trial comparing a waitlist control group to an intervention group. (Clinical Trials # NCT07118865, received 8/11/25) Participants who met the inclusion requirements and consented to participate completed a series of on-line questionnaires using SurveyMonkey™. Although the initial study design anticipated a total of 100 participants, we had over 1000 respondents within the first two weeks and modified the design to include a waitlist control group. The first 268 participants to complete the initial surveys were allowed to start the online Pilates program immediately after completing the surveys while the remainder completed baseline questionnaires again after 8 weeks then began the Pilates. All participants who completed 8 weeks of Pilates, either initially or after an 8-week wait, were included in the Pilates group and asked to complete the questionnaires after 8 weeks of Pilates. Participants who completed the Pilates program were also contacted 6 months after completing the program and asked to complete the questionnaires another time. All participants were given access to the Pilates program after the research ended. The study was approved by the Clarkson University Institutional Review Board and complies with the Declaration of Helsinki.

Participants

Recruitment has been previously reported in a study of qualitative outcomes of the exercise program reported here.¹⁹ Participants were recruited from September 2019 to April 2020 from Ehlers-Danlos Syndrome support groups and websites, including posting recruitment notices on the Ehlers-Danlos Society™ and The Hypermobility Syndromes Association™ websites. There was also snow-ball sampling from people who learned about the research and reposted or forwarded the announcement. All participants provided informed consent and were free to withdraw at any time. Participants had to be between the ages of 18 and 70, have one of the symptomatic joint hypermobility medical diagnoses. Since most participants were diagnosed before the 2017 diagnostic criteria were widely used in clinical practice, any of the pre-2017 diagnostic terms such as joint hypermobility syndrome were accepted, as well as HSD and hEDS. This was therefore a criterion sampling approach seeking participants with symptomatic hypermobility who were interested in doing Pilates. They had to be able to read and understand English and be willing to try to do Pilates exercises for 25 minutes 3 times per week. Exclusion criteria include medical restrictions or recent injuries that prevent participants from performing gentle exercise, and inability to safely stand for 10 minutes. Because people with symptomatic hypermobility often have comorbidities, we did not exclude them based on comorbidity, but only if people were unlikely to be able to safely engage in the exercise due to any injury or medical condition. Participants could be from anywhere in the world; we did not track nationality. For assessing adverse events, only, we included all participants who completed the 8-week survey, even if they did not do the Pilates at least 1 time per week, as adverse events might lead to people not doing the Pilates.

Data Collected

We collected the following demographic information: age, gender, years of symptoms, years since diagnosis, initial work status (nominal), and initial level of exercise (ordinal: none, less than 15 minutes, 15–30 minutes, or more than 30 minutes most days). Data collection was not blinded, as both participants and researchers knew whether participants were in the Pilates or waitlist group.

Primary outcome measure: The Bristol Impact of Hypermobility (BIOH) questionnaire measures the impact of hypermobility and its associated pain and fatigue. This is a 55-item questionnaire that asks about pain, fatigue, joint instability, function, self-efficacy and attitudes about having hypermobility. The BIOH is scored out of a total maximum of 360 points, with higher scores representing the more severe the impact.^{12,31} At the time of the study, it was the only outcome measure specifically validated for hypermobility-related conditions. Clinically significant change is reported to be 30.³²

Secondary outcome measures: The International Physical Activity Questionnaire Short Form (IPAQ) looks at measuring physical activity. This was used to determine if participation in Pilates allows people to become more active. It assesses physical activity at work, sport, and leisure time. It includes vigorous, moderate (“makes you breath somewhat

harder than normal”), and walking, but does not include gentle exercise such as the Pilates exercises in the study. The IPAQ is scored in terms of a continuous score in MET (metabolic equivalent of task) levels and a categorical score based on physical activity, low, moderate and high.³³

The Revised Body Awareness Rating Questionnaire (BARQ) measures body awareness and dysfunctional breathing patterns and was developed to assess body-mind treatment approaches. The BARQ includes 12 questions about body awareness, response to discomfort, breathing patterns, and physical response to stress. The BARQ may provide insight into the mechanism by which Pilates creates change, whether through improved body awareness, relaxation, effective breathing. The scores can range from 0–36 with the higher scores reflecting increased problems associated with body awareness.²⁸

The Tampa Scale of Kinesiophobia, short form (TSK-11), measures kinesiophobia, or fear with movement. This is an 11-question survey that asks about fear of movement and injury. The Tampa Scale of Kinesiophobia is one of the recommended Common Data Elements for hEDS. Scores range from 11–44 with higher scores indicating greater fear of pain, movement, and injury. A change of 4 points has been associated with clinically meaningful change.¹¹

Intervention

The intervention was briefly described in a study of qualitative outcomes of this exercise program.¹⁹ The modified Pilates intervention included a 5-module video series (“Strengthen Your Hypermobility Core”™) where each video lasted 25 minutes, including some resting activities so modules were not too vigorous or fatiguing for most people. The program was developed by a certified Pilates instructor (JDB) who specializes in working with hypermobile individuals, and the key modifications are listed in the [Box 1](#) and described in books about this modified Pilates approach.^{34,35} Participants were asked to try to complete 3 Pilates modules per week; 3 days per week was selected as it has been used in prior research into exercise for people with hypermobility,³⁶ and it seemed a reasonable balance between asking for a reasonable commitment from participants while still likely to be beneficial. Participants were encouraged to modify or omit activities that they felt unable to do safely and were allowed to contact the instructor for modification recommendations if not explicitly stated in the video. Participants in the exercise group received weekly emails encouraging participation and providing an opportunity to ask questions about the exercises. The control group were participants who were placed on a waitlist group depending on when they signed up for the study and they did not have access to the modules until they reached their second baseline at 8 weeks. [Supplement 1](#) includes more detail about the contents of the 5 Pilates modules.

Data Analysis

Missing data within outcome measures were managed as instructed for each measure, with imputation by the mean for remaining scores in that section. Data were summarized descriptively using means and standard deviations for normally distributed continuous variables; median and interquartile ranges for non-normally distributed continuous variables; and counts and percentages for categorical data. Data were inspected visually for normal distribution using box and whisker plots.

Box 1 Pilates Modifications Used in This Study

- Minimizes the number of position changes, as these can be stressful to hypermobile joints.
- Avoids breathing patterns that trigger excess tension in the core, but instead cues patients in how to integrate proper breathing with alignment and movement.
- Movements are slower to minimize fear of movement, improve body awareness, and to maintain joint stability during the exercises.
- Exercises are selected to minimize joint instability and stress on joints, starting in positions that provide more external stabilization.
- Cuing to avoid common errors that people with hypermobility often demonstrates when doing Pilates.
- Instructions provide increased cuing and information about sensory awareness and organization.

To address the skewed distribution of the metabolic equivalent (MET) data derived from the International Physical Activity Questionnaire (IPAQ), we employed the natural logarithmic transformation. This strategic adjustment aimed at reducing skewness in the data, significantly enhancing its conformity to a normal distribution. Such normalization was essential for the application of parametric statistical tests in our analysis.

Demographic data for the Pilates and Control groups were compared using independent *t*-tests for normally distributed data, Mann–Whitney *U*-tests for non-normally distributed data, and chi-square tests for categorical variables; significance was set at 0.05. Data were evaluated for satisfaction of criteria for inclusion in the analysis of variance (ANOVA). A separate 2 (group) x 2 (time) repeated-measures ANOVA was performed for the Bristol Impact of Hypermobility (BIOH), 11-item Tampa Scale for Kinesiophobia (TSK-11), Body Awareness Rating Questionnaire (BARQ), and log transformed MET from IPAQ questionnaire across the 8-week intervention period were assessed. Interaction effects were investigated once a significant main effect was observed. Mann–Whitney *U*-tests (for continuous variables) and Chi-square tests (for categorical variables) were used to compare those who completed 8 week surveys (Pilates and waitlist groups) with those who dropped out of the study. Post-hoc power analysis indicated that 98 subjects would be needed for an independent groups comparison with $p=0.05$ and $\beta=80\%$. The statistical significance threshold was set at $p<0.05$ and all analyses were performed using SPSS version 28 Statistical Packages for Social Science (Version 28; Armonk, NY, IBM Corp).

Results

Pilates Participation

In this study, a total of 671 individuals initially participated. However, of these, 220 participants were excluded from the analysis as they did not complete the necessary follow-up questionnaires. Of the 671 who completed initial questionnaires, 219 never started the Pilates even though they were given the opportunity, 125 set up an account but did not complete even a single module, 327 completed at least 1 module, 231 of those who started Pilates completed questionnaires at 8 weeks, and 31 individuals were withdrawn from analysis due to discontinuation of the Pilates classes or not doing at least an average of 1 class per week. Consequently, the final analysis was conducted with a cohort of 420 participants, comprising 200 individuals in the intervention group and 220 in the control group. Less than 1% of data were missing within surveys completed and used for analysis. [Figure 1](#) shows the flow of participants in the study.

Pilates participants reported doing an average of 2.3 Pilates sessions per week, with 33.5% reporting 3 days/week and 27.6% reporting 2 days/week. Most participants (71%) reported being able to do the full 25 minutes Usually (31%) or Always (40.0%). Challenges that interfered with participants' ability to do the Pilates have been previously reported:¹⁹ the most common reasons cited were “personal issues”, “symptoms other than pain or fatigue,” “fatigue” and “not enough time”. Of participants who completed 8 weeks of the Pilates, 88.2% reported they were “Likely” or “Very Likely” to recommend the program to others.

Of the 251 participants who completed surveys after 8 weeks of Pilates (including those who withdrew or did not do the Pilates at least once a week), 17.1% reported some increase in pain or exacerbation of pre-existing problems that they attributed to the Pilates. About half of those individuals reported that the discomfort was transient or that they were able to modify or avoid specific exercises to eliminate the discomfort. Some of the adverse effects were not specific to this Pilates program, however. For example, some people stated that they were unable to sit or lie on their backs without pain. Other examples were more likely to be related to the Pilates movements, such as reports of shoulder, wrist, neck or hip discomfort during specific movements.

Demographics and Baseline Measures

Statistical comparison of all baseline variables (age, years since diagnosis, work status, current exercise, BIOH, TSK, BARQ, and IPAQ) between participants who completed the 8-week surveys (Pilates and waitlist control groups) and those who dropped out or never started showed no statistically significant differences except in age: the drop-out group had a slightly lower median age (36 years) compared to those who completed the 8-week follow-up (38 years), $p = 0.007$. The descriptive analysis of the demographics characteristics is shown in [Table 1](#). Age, gender, years of being diagnosed,

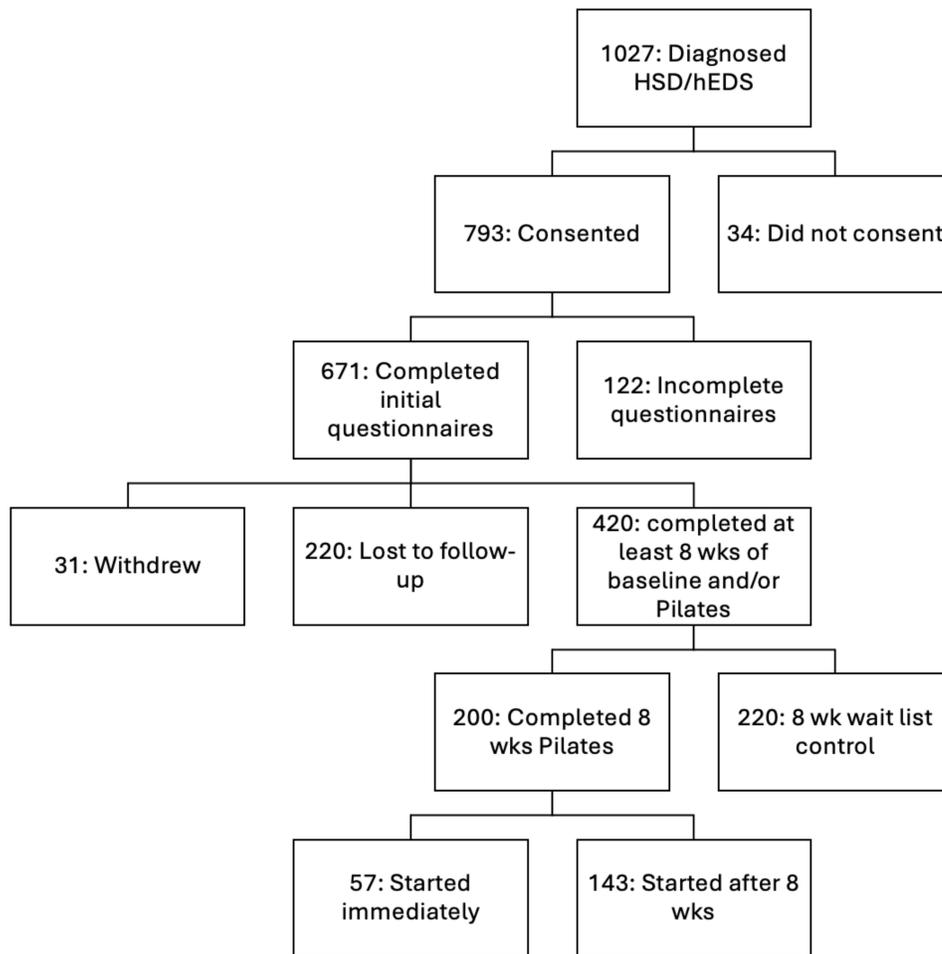


Figure 1 Participant flow. Participant flow, describing how potential participants were lost and how the Pilates and Control groups were created. **Notes:** Participant flow chart. 671 completed initial questionnaires, 420 completed 8 week follow-up questionnaires with 200 completing Pilates and 220 waitlist.

years of symptoms, work status and initial exercise level were not statistically different between Pilates and Control groups. [Table 2](#) summarizes the findings from four key outcome measures evaluated during the 8-week intervention period. The analysis reveals significant between-group differences in the BIoH scores and the BARQ scores as well as within group differences for BIoH, TSK, and BARQ. IPAQ showed no changes either between or within groups. [Figure 2](#) shows the mean values and 95% confidence intervals for each group for each of the outcome measures before and after

Table 1 Participant Demographics

		Pilates Group n=200	Control Group n=220	p value
Age - mean (SD)		39 (10)	38 (11)	0.354
Gender - n (%)	Female	195 (97.5%)	209 (95%)	0.212
	Male	2 (1%)	8 (3.6%)	
	Other	3 (1.5%)	3 (1.4%)	

(Continued)

Table 1 (Continued).

		Pilates Group n=200	Control Group n=220	p value
Years diagnosed with HSD/EDS - median [IQR]		3 [1–5]	3 [1–7]	0.230
Years ago began to have symptoms from HSD/EDS - mean (SD)		25.3 (12.7)	25.1 (12.80%)	0.876
Work Status - n (%)	Full time	59 (29.5%)	78 (35.5%)	0.783
	Disable, retired or unemployed	50 (25%)	50 (22.7%)	
	Part time	45 (22.5%)	44 (20%)	
	Homemaker only	24 (12%)	25 (11.4%)	
	Student	22 (11%)	23 (10.5%)	
Current Exercise - n (%)	No/invalid response	3 (1.5%)	2 (1%)	0.819
	No exercise most days	33 (16.5%)	42 (19.1%)	
	< 15 min on most days	63 (31.5%)	73 (33.2%)	
	15–30 min on most days	63 (31.5%)	68 (30.9%)	
	> 30 min on most days	38 (19%)	35 (15.9%)	

Abbreviations: HSD, Hypermobility Spectrum Disorders; EDS, Ehlers-Danlos Syndrome; IQR, Interquartile range; SD, standard deviation.

Table 2 Summary of Outcome Measures Before and After 8-week Pilates or Control

	Pilates Group				Control Group				Sig
	Baseline		8 Week		Baseline		8 Week		
	M	SD	M	SD	M	SD	M	SD	
BloH score	221.6	43.7	196.2	51.0	226.2	41.6	224.9	44.5	* †
TSK II score	26	6	24.5	6.2	28	5	26.8	6.8	*
BARQ score	23.5	5.2	20.8	5.2	24.1	5.1	23.6	4.9	* †
IPAQ score (log transformed)	6.26	1.10	6.42	1.05	6.39	1.07	6.30	1.07	NS
	Med	IQR	Med	IQR	Med	IQR	Med	IQR	
IPAQ score	495	[212.0, 1135.0]	594	[198, 1193.5]	495	[140.3, 1194]	433	[148.5, 1062]	NS

Notes: *Within-group differences ($p < 0.05$). †Between-group differences ($p < 0.05$).

Abbreviations: M, mean; SD, standard deviation; Med, median; IQR, interquartile range; Sig, significance; NS, nonsignificant; BloH, Bristol Impact of Hypermobility; BARQ, Revised Body Awareness Questionnaire; TSK II, Tampa Scale of Kinesiophobia; IPAQ, International Physical Activity Questionnaire MET score.

8 weeks of Pilates or waitlist control. Decreases in BloH, TSK and BARQ in the Pilates group indicate improvement while the Control group did not change.

Outcome Measures

Statistical analysis revealed a significant change in the Pilates group BloH total scores over time ($F(1417) = 66.996, p < 0.001$). The data also showed a statistically significant interaction effect ($F(1,417) = 53.677, p < 0.001$), indicating a difference, after 8 weeks, between the Pilates and Control groups. The calculated partial eta squared ($\eta^2 = 0.114$) value indicates a moderate to large statistical effect size in BloH comparing Pilates and Control groups over time.

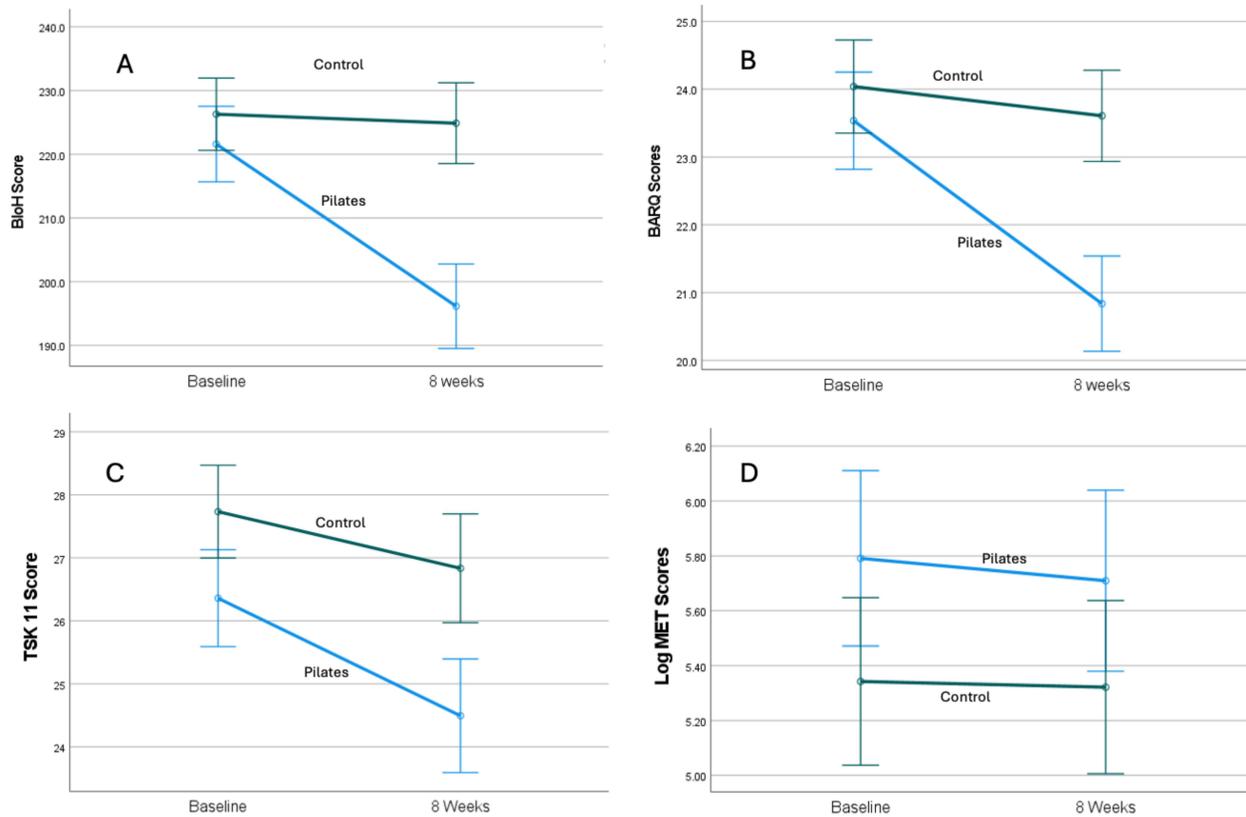


Figure 2 Baseline and 8-week outcome measures for control and Pilates groups. Estimated marginal mean and 95% confidence intervals of the four outcome measures before and after 8 weeks of Pilates or waitlist control. **(A)** Bristol Impact of Hypermobility (BioH). **(B)** Revised Body Awareness Questionnaire (BARQ). **(C)** Tampa Scale of Kinesiophobia (TSK-11). **(D)** International Physical Activity Questionnaire (IPAQ), presented as Log MET scores. **Notes:** Graphs for Bristol Impact of Hypermobility, Revised Body Awareness Questionnaire, and Tampa Scale of Kinesiophobia decreased for Pilates group while control group did not change. The International Physical Activity Questionnaire did not change for either group.

Statistical analysis of the TSK-11 score over time indicated a significant overall change ($F(1,416) = 22.469, p < 0.001$). However, the interaction effect between group and time, (F -statistic of $F(1,416) = 2.745, p = 0.098$; partial eta squared ($\eta^2 = 0.051$)), demonstrated a small effect size comparing Pilates and Control groups over time. Furthermore, the overall change of 1.5 points does not exceed the minimum clinically meaningful change of 4 points.¹¹

Statistical analysis of the BARQ scores showed a significant overall change over time ($F(1,416) = 50.268, p < 0.001$). Analysis of the interaction effect between the group and time (F -statistic of $F(1,416) = 26.366, p < 0.001$; partial eta squared ($\eta^2 = 0.109$)) indicates a large statistical effect size between Pilates and Control groups over time. Clinically minimum important change has not been reported for the BARQ. Statistical analysis of the log-transformed MET scores' changes across two measured time points did not reveal a significant overall change ($F(1,417) = 0.548, p = 0.709$) or difference between groups over time ($F(1,417) = 0.049, p = 0.824$).

Because the control group was on a waitlist and they were all given the opportunity to do the Pilates program at 8 weeks, there are no 6-month control data. Therefore, analysis was exclusively focused on the Pilates group to determine whether changes observed at 8 weeks were maintained over a 6-month period. **Figure 3** shows that BioH, TSK and BARQ all maintained benefits at 6 months, while IPAQ showed a decrease in activity at 6 months compared to baseline and 8 weeks.

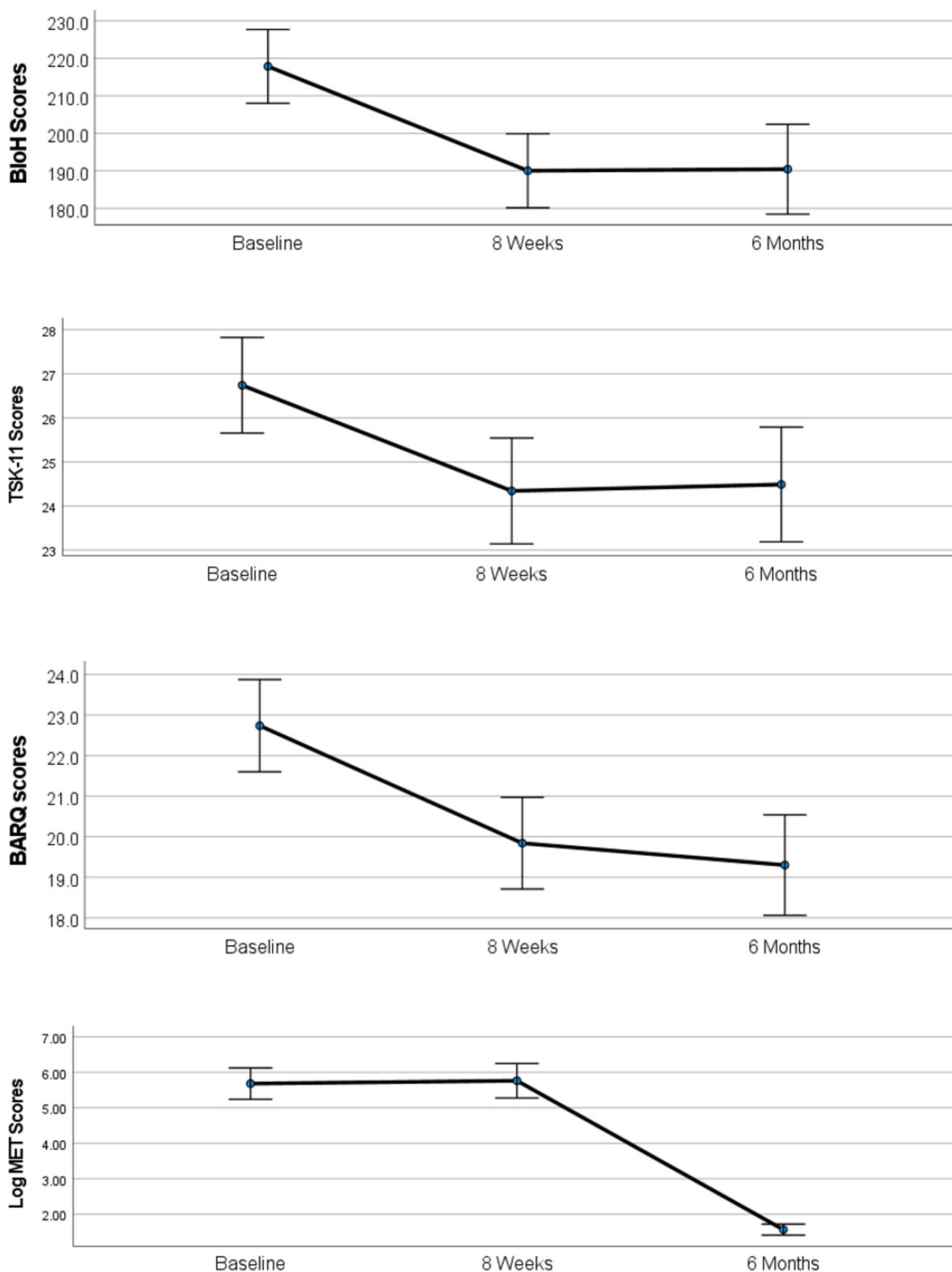


Figure 3 Baseline, 8-week and 6-month outcome measures. Estimated marginal means of the four outcome measures and their 95% confidence intervals in the Pilates group across the 6-months intervention period. Bristol Impact of Hypermobility (BloH). Revised Body Awareness Questionnaire (BARQ). Tampa Scale of Kinesiophobia (TSK-11). International Physical Activity Questionnaire (IPAQ), presented as Log MET scores.

Notes: Graphs at 6 months show maintained improvement for Bristol Impact of Hypermobility, Revised Body Awareness Questionnaire and Tampa Scale of Kinesiophobia. International Physical Activity Questionnaire decreased at 6 months.

Discussion

The current pragmatic clinical trial demonstrated that an 8-week online video-based modified Pilates program designed for people with symptomatic hypermobility can improve function and body awareness (BARQ) and decrease the impact of hypermobility, pain and fatigue (BIOH) and kinesiophobia (TSK). Furthermore, improvements were maintained 6 months after completing the Pilates, though we cannot know that improvements at 6 months were due to the Pilates. Our change of 25.4 points in BIOH was slightly below the 30 points proposed for clinically meaningful change.³² Only one other published study has used the BIOH as an outcome measure for a clinical intervention; that small study had only 11 participants in the 4-month intervention arm and reported a change of 31.7 points.³² It is likely that the many uncontrolled variables contributed to variability in outcomes. Also, because the BIOH has 55 questions resulting in 360 points, it is possible that the number and wide range of questions may dilute changes observed in response to a relatively short-term intervention. We did not use select portions of the BIOH, such as just the pain or functional questions, as those subscores have not been validated. The change in TSK-11 was also below the reported Minimum Detectable Change and was not likely to be a meaningful effect, indicating that changes in fear of movement probably did not mediate improvements from doing Pilates. In spite of the modest changes in outcome measures, 88% of the Pilates participants said they were “Likely” or “Very Likely” to recommend the program to others.

Physical activity, as measured by IPAQ, did not appear to change in response to the Pilates program. It is important to note that the IPAQ includes only walking as light intensity exercise. Since the focus of Pilates is body awareness, motor control, stability and strength rather than aerobic fitness, the IPAQ might not have captured increased gentle exercise such as Pilates. Another possibility is that people unconsciously maintain a constant activity level that is comfortable for them. Finally, the IPAQ has been criticized for limited reliability and validity in patients with chronic illness.^{13,37}

Although Pilates has been recommended for people with hypermobility,^{8,14} this is the first large-scale report of outcomes in this population. The Pilates program in this study was specifically developed for people with hypermobility, emphasizing body awareness and motor control while avoiding positions that would stretch joints. The instructions also included “watch points” for common mistakes or problems hypermobile people might have. A qualitative analysis of participants doing modified Pilates program found that having exercises specifically designed for people with hypermobility helped them to feel safe.¹⁹ The current study therefore adds to the body of research showing that Pilates is beneficial for people with chronic musculoskeletal conditions, fibromyalgia, and lumbar instability.^{17,18,20,22,38,39} Only one study has looked specifically at Pilates in three hypermobile children and found it effective.²¹ Another study found that standard spinal stabilization exercises using principles similar to Pilates improved pain and trunk stability.³⁶ Research has also shown that the functional improvements in chronic low back pain seen with Pilates are partially mediated by improvements in kinesiophobia,^{40,41} consistent with our finding of decreased kinesiophobia. Another study found that mind-body exercises in general, including Pilates, can decrease pain and disability, and improve quality of life and mental health.³⁹ A qualitative analysis of facilitators, barriers, and perceived outcomes provided specific recommendations for further improving online exercise programs for this population.¹⁹

The Pilates program used in this study was provided online with asynchronous access, which could potentially provide a cost-effective option for exercise in this chronic condition. The asynchronous format made the exercise program more accessible, particularly to people with limited access to healthcare resources and during the COVID-19 epidemic. No other studies have reported use of online Pilates in this format. One study found that individual, real-time Pilates telerehabilitation was effective for people with multiple sclerosis; they proposed that body awareness and kinesthetic sense could be improved using the online format.⁴² Another study found that small group real-time online Pilates could also be effective for improving strength and decreasing low back pain during pregnancy.⁴³ Extensive qualitative feedback about the strengths and limitations of our Pilates program is reported elsewhere.¹⁹

About 17% of all people who attempted the Pilates in this program reported some discomfort that they attributed to the Pilates, though some were non-specific issues such as discomfort lying down or sitting. Based on descriptions of the specific issues reported, these appeared to mostly be typical flares for these individuals when they try new activities and, to our knowledge, none of the adverse effects were severe. About half of people reporting any adverse event stated that they were able to modify or omit exercises, or that they adapted to the demands so that they could continue with the

program without further problems. Standardized and unsupervised exercise is more likely to be problematic in causing flares in this vulnerable population. Future exercise programs should be more easily customized to avoid specific positions or joint movements. Also, it might be helpful for vulnerable populations such as those with symptomatic hypermobility doing independent exercise to be monitored by movement specialists.

The pragmatic clinical design was both a strength and limitation for this study. It was a strength in that the intervention was implemented in a realistic manner where participants were not 100% compliant with the goal of performing the exercises three times a week, and researchers were not able to completely control how the exercises were performed. Participants were allowed (and encouraged) to modify or omit exercises that might not be appropriate for them. Although many options were provided within the videos, participants might have made other changes. This variability decreased researcher control but was similar to how people are likely to use an online exercise program and improves external validity.⁴⁴ Another strength of the study is the large sample size. Although participants were not assigned randomly to the Pilates and waitlist groups, the two groups were very similar at the outset. The wide age range of participants may have added variability to our outcomes, but is a strength in that the results are applicable to a wide range of ages who would be interested in participating in this type of exercise.

One of the primary limitations is the large fraction who did not start or continue the Pilates intervention or complete follow-up surveys: 32.6% of people who completed initial surveys never set up an on-line account for the Pilates, and another 18.6% set up an account but did not complete even one module, suggesting that many people had hoped to do the Pilates, but did not. Ultimately, 61% of people who did at least one session of the Pilates completed the 8 weeks and completed the final surveys. Prior research found that only 46.2% of subjects completed 8 weeks of online exercise with more dropping out if they started after a 4-week delay;⁴⁵ therefore, our drop-out rate is not unusual for independent online exercise. Multiple factors contributed to our loss of participants. Participants reported that the greatest challenges to doing the Pilates were personal issues, symptoms other than pain and fatigue, fatigue, and time (see Russek, 2025¹⁹ for more detail about challenges reported in doing this Pilates program). We also lost some initial participants to follow-up due to Email servers blocking our emails, which were sent (blinded) to multiple participants and might have been blocked as potential spam. Response rate improved when we emailed fewer individuals at one time. High drop-out rates raise the concern of self-selection bias, but this is the same self-selection that would affect people choosing to do this type of exercise program. We therefore chose to use Per Protocol analysis rather than Intent To Treat analysis, since our goal was to determine effects of actually doing this modified Pilates program.⁴⁶ Post-hoc analysis revealed that, other than age, there were no significant differences in any variables (demographics, work status, initial activity levels, or any of the outcome measures) between those who completed the 8-week surveys and those who were lost to follow-up. This suggests that the high dropout rate is not likely to have led to systematic bias; when bias is minimal, Per Protocol analysis is considered valid.⁴⁶

Another limitation is that almost 98% of participants were women. However, this likely reflects the higher prevalence of symptomatic hypermobility in women and perhaps the likelihood that women would seek out Pilates as a form of exercise. Next, the exercises were unsupervised, so we cannot know exactly what participants did and they likely did not all do all of the exercises. However, as noted above, this reflects how such interventions are applied in the real world, improving external validity of the study. Also, we were not able to monitor or account for changes in other medical interventions, including medications or other treatment approaches. Finally, the study began before COVID-19 caused widespread lockdowns, illness, and significant stress. The lockdowns increased interest in participating in the research as this provided access to exercises that could be done at home. However, other aspects of COVID might have altered outcomes, such as increasing stress or decreasing overall activity.

Future research should use more controlled methods to minimize variability in the population and use of the exercise program. Cost-benefit analysis would also provide valuable information about potential benefits of online exercise instruction for people with chronic conditions such as symptomatic joint hypermobility, as other studies have reported economic benefits to online exercise instruction.⁴⁷

Conclusion

In conclusion, this pragmatic clinical trial provides evidence that a video-based online modified Pilates program developed for people with symptomatic joint hypermobility can decrease the impact of hypermobility, pain and fatigue, improve function (BioH) and body awareness (BARQ) and that improvements can be maintained 6 months after completing the Pilates. While changes were statistically significant, they were modest and it is unclear whether they are clinically significant. Still, 88% of Pilates participants would recommend the program to others and there were no known significant adverse effects. Refinements to the exercise routines and implementation could improve outcomes by allowing users to select from a menu of modules those that are most appropriate for their fitness levels and specific joint or health issues. Since data collection for this study, this online Pilates program for people with hypermobility has been modified to address some of these issues and it would be worthwhile to assess the revised program. Online exercises designed for people with symptomatic hypermobility could provide a cost-effective approach to life-long exercise for this population.

Data Sharing Statement

Data sharing is available on reasonable request from the corresponding author, in line with ethical approvals.

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Disclosure

Mrs. Di Bon is the creator and owner of The Zebra Club, and the exercise program studied is her intellectual property. Mrs. Di Bon was involved in implementation of the intervention, but not in data collection or analysis.

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