

A qualitative study exploring participants' feelings about an online pilates program designed for people with hypermobility disorders

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ABSTRACT

Background: and Purpose: Exercise is commonly recommended for management of the hypermobility disorders hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders (hEDS/HSD). However, a variety of barriers exist, including access to knowledgeable providers, fear of injury, pain and fatigue. The purpose of this study was to explore factors that influence people with hEDS/HSD using an online Pilates program designed for hEDS/HSD and their perceived outcomes of such a program.

Methods: This study used a qualitative grounded theory thematic analysis approach based on written survey comments from participants in an 8-week online Pilates program designed specifically for people with hypermobility disorders. Responses were analysed thematically for both facilitators and barriers to participation, and benefits and drawbacks as outcomes.

Results: The findings revealed four themes contributing to facilitators and barriers: Physical, Mind-Body, Instruction/Instructor, and Accessibility. Exercises designed for people with hypermobility, feelings of safety, knowledgeable instructor, and convenience were key facilitators. Unrelated illness, injury or pain, fear of injury, and difficulty accommodating a range of ability levels were key barriers. We found two themes for outcomes (benefits and drawbacks): Physical and Mind-Body. Key benefits included both physical and psychological improvements, while drawbacks included pain, fatigue, and feeling discouraged. Based on these findings, we propose elements of future online exercise programs to enhance engagement with this population.

Conclusions: This study describes how people with hypermobility disorders feel about an online Pilates program designed for hypermobility, and proposes how future online exercise programs might best serve this population.

1. Introduction

Hypermobility is defined as the ability to move one or multiple joints beyond what is considered a normal range. It is also a feature of connective tissue disorders like hypermobile Ehlers-Danlos Syndrome (hEDS) and Hypermobility Spectrum Disorders (HSD) (Nicholson et al.,

2022; Palmer et al., 2021; Russek et al., 2019; Simmonds, 2022). Signs and symptoms of hEDS/HSD are due to abnormal collagen in connective tissues. Although hypermobile joints are the most visible finding in hEDS/HSD, collagen is found throughout the body and symptoms may be multi-systemic: gastrointestinal, cardiovascular, neurological, neurodevelopmental, integumentary, and urogenital as well as

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³ Mrs. Di Bon is the creator and owner of The Zebra Club, and the exercise program studied is her intellectual property.

⁴ Dr. Nation was employed by The Zebra Club as a research associate during the analysis of this research.

musculoskeletal (Buryk-Iggers et al., 2022; Clark et al., 2023; Russek et al., 2019; Simmonds, 2022). Patients with hEDS may experience widespread pain, joint dislocations and subluxations, muscle weakness and gait abnormalities (Reychler et al., 2021), fatigue, and proprioception issues (Smith et al., 2013; Terry et al., 2015). The impact of hEDS/HSD on disability and function is varied, ranging from occasional discomfort to significant disability (Bovet et al., 2016; Scheper et al., 2016). Since current thinking is that hEDS and HSD are clinically similar in terms of symptoms, severity, and management, and the pre-2017 diagnoses of joint hypermobility syndrome could be either, we did not differentiate hEDS and HSD in this study (Aubry-Rozier et al., 2021; Copetti et al., 2019).

Conservative management of these conditions is supported in the literature. Research suggests that exercise can improve pain and physical functioning in patients with disability (Buryk-Iggers et al., 2022; Byrnes et al., 2018; Garreth Brittain et al., 2024) but to date, there are no formal exercise guidelines or consensus on the most effective exercise programs for patients with hypermobility (Buryk-Iggers et al., 2022; Garreth Brittain et al., 2024). Furthermore, research also shows that pain, fatigue, and fear of injury are common barriers to exercise (Simmonds et al., 2019), and it is not clear how the type or format of exercise impacts these barriers.

Pilates is a form of therapeutic exercise that has been demonstrated to improve pain, disability, and quality of life (Huang and Park, 2023). A recent meta-analysis found that Pilates significantly reduced pain and disability in people with chronic low back pain (Huang and Park, 2023). Pilates also improves posture, balance, and strength (Patti et al., 2024), and improves core muscle recruitment patterns and muscle strength (Franks et al., 2023). Pilates exercises are frequently used among people with hEDS/HSD, and patients have reported it to be among the most helpful types of exercises (Simmonds et al., 2019). For people with limited access to providers trained to instruct people with hEDS/HSD in exercise, an online program may enhance their ability to exercise safely; this was particularly true during the COVID-19 pandemic when people had limited access to exercise options. Recent research suggests that online Pilates programs may be feasible and beneficial for people with chronic conditions (Vetrovska et al., 2024).

From a somatic perspective, Pilates was originally developed to bring mind-body harmony through breath awareness and mental focus. The literature reports on quality-of-life improvements, enhanced quality of sleep, and the cultivation of mindfulness through the regular practice of Pilates (Zafeiroudi and C, 2022). Pilates has been described as a mind-body exercise that focuses on strength, stability, flexibility, muscle tone, posture and breathing (Alves et al., 2020; Lim and Hyun, 2021). Patients with hEDS/HSD have been found to experience anxiety, low self-confidence, hopelessness, and low self-efficacy (Lamari et al., 2021) and depression (Berghlund et al., 2015). Pilates could be beneficial in addressing both the physical and psychological needs of patients with hEDS/HSD and improving outcomes through mind-body integration. Pilates also emphasizes slow movement and body awareness, which may address the proprioceptive deficits observed in hEDS/HSD. Examining both the physical and mind-body aspects of a Pilates program for hypermobility could be beneficial in future patient exercise prescriptions and guidelines.

The qualitative data reported here were collected as part of a pragmatic clinical trial assessing the impact of an online Pilates program created specifically for people with hEDS/HSD. The current analysis sought to understand what factors influence the ability of people with hEDS/HSD to exercise using an online Pilates program designed for hEDS/HSD and the perceived outcomes of such exercise. This study addresses a gap in knowledge about the subjective experience of individuals with hypermobility using an online exercise program, particularly during the COVID-19 pandemic.

2. Method

2.1. Study design

These data were collected as part of a pragmatic trial evaluating the effectiveness of this online Pilates program for people with hEDS/HSD. At the end of the 8-week intervention, all participants were asked to describe how they felt about the exercise program, what aspects were challenging, and what aspects they enjoyed. Participant responses were written as part of SurveyMonkey™ data collection. Participants were also asked to identify specific challenges to doing the exercises; these data are reported as frequency responses. The study was approved by the Clarkson University Institutional Review Board.

2.2. Participants

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 a medical diagnosis of hypermobile Ehlers-Danlos Syndrome or any of the pre-2017 diagnostic terms such as joint hypermobility syndrome. This was therefore a criterion sampling approach seeking participants with hEDS/HSD who were interested in doing Pilates; all comments were included from all participants who did Pilates at least once a week during the study. They had to be able to read and understand English and be willing to try to do Pilates exercises for 25 min 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 min. Because people with hEDS/HSD 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. Since this study was interested in the impact and challenges of doing Pilates, our primary analysis only included participants who reported doing Pilates at least once a week, on average, during the 8-week intervention period. In some cases, responses from individuals who responded to the 8-week survey but did not do the Pilates were compared to those who did the Pilates to explore the likelihood of response bias.

2.3. Intervention

The Pilates intervention included a 5-module video series ("Strengthen Your Hypermobility Core"™) where each video lasted 25 min, 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. Participants were asked to try to complete 3 Pilates modules per week, and to modify or omit activities that they did not feel they could do safely. 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. The Supplement includes more detail about the contents of the 5 Pilates modules.

2.4. Data collection

Data were collected through questionnaires on SurveyMonkey. Participants provided demographic information about age, gender, and

duration of symptoms/diagnosis as well as initial level of exercise and a checklist of common challenges to doing the exercises. These data are reported as frequencies. Participants were also asked the following narrative questions.

1. If you would like to comment on any of the challenges you had doing the exercises, please do so. If you had to stop doing the Pilates entirely, please briefly explain.
2. What did you enjoy or like most about the Pilates program?
3. How did the activities and exercises in the Pilates course affect you physically and/or psychologically?
4. If you had discomfort related to the Pilates, please briefly describe.

Except where noted otherwise, the current analysis only used responses from people who reported doing the Pilates at least once a week, on average, during the 8-week study interval.

2.5. Qualitative analysis

We performed a qualitative thematic analysis of survey responses using a grounded theory thematic analysis approach (Braun and Clarke, 2006, 2024). Each open-ended survey question was coded independently in NVivo™, and each narrative survey response became a meaning unit, with longer responses divided into multiple meaning units. Fig. 1 shows the qualitative analysis process. One author performed initial qualitative analysis, starting with line-by-line review, labeling of phrases, and manual coding allowed creation of meaning units using an inductive approach. This author then searched for and generated initial categories and themes among meaning units (Erlingsson and Brysiewicz, 2017). Together, three authors reviewed and refined coding, ensuring that all agreed on the coding. Since the three authors agreed on all coding decisions after discussion, no formal inter-rater reliability was done. After this, the author performing initial

analysis named and defined categories and themes to develop the thematic framework. This was an iterative process that continued until saturation occurred and no further revisions to the themes occurred.

2.5.1. Research team and reflexivity

LR implemented the study and collected data, assisted by CVZH, TJ, and AG. JDB, a certified Pilates instructor, created the series of online exercise modules for people with hypermobility. CN was asked to perform the qualitative analysis to minimize potential bias from LR or JDB. CN has used and personally benefited from the movement method presented in this research, which was helpful in providing insight into participant responses, but could potentially add bias. Bias was minimized by frequent checks with LR and JDB to ensure coding, categorization, and theme generation were transparent. Following completion of the thematic framework, coding files and thematic frameworks were sent to JS, an experienced qualitative researcher who is knowledgeable about Pilates for this population, to audit the qualitative methods, coding process and generation of themes.

2.6. Creation of the model

Once qualitative analysis was complete, LR, JDB and CN considered a variety of model structures to effectively represent the themes and subthemes. The model described below was selected as providing the best structure for the data and providing useful guidance for creating future exercise programs for this population.

3. Results

3.1. Participant demographics

Of the 672 people who agreed to participate in the Pilates research, 241 completed the 8-week survey, and 207 people who responded to the

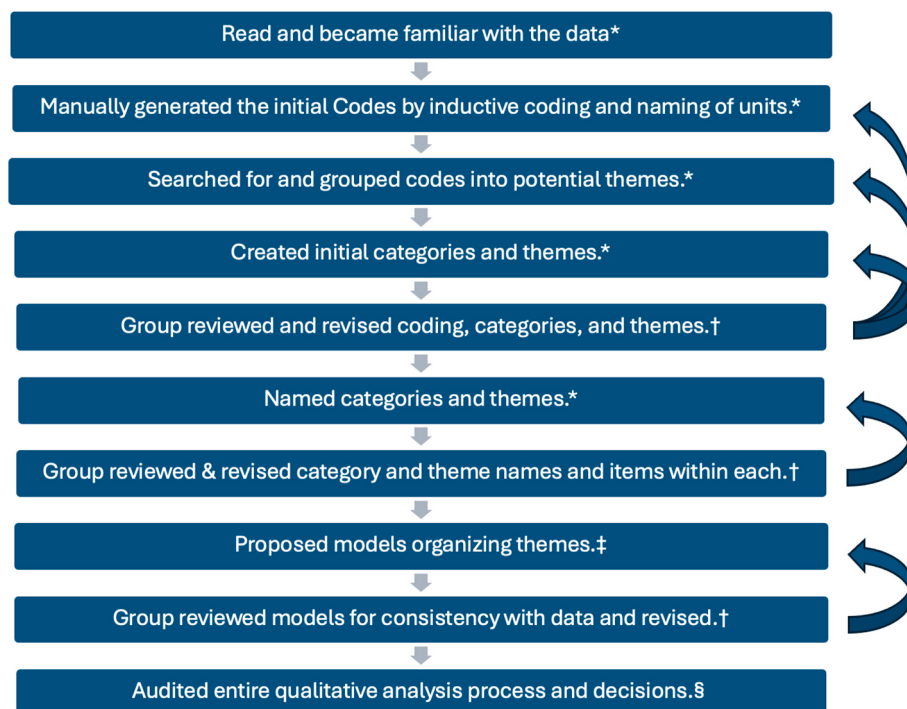


Fig. 1. Flow chart describing qualitative analysis process, using principles described by Braun and Clarke (2006). One researcher was primarily responsible for identifying codes, themes and categories. Three researchers met, reviewed and revised (feedback arrows) three times before everyone agreed about coding and grouping and no further changes were proposed.

*Author performing primary data management.

†Three authors performing analysis.

‡Fourth author performing audit.

survey and did the Pilates at least once a week. Therefore, 34 of the 241 respondents did not do Pilates at least once a week and were not used in the qualitative analysis. This gave an overall compliance rate of 30 % for people who both did the Pilates and completed the 8-week data collection survey. Demographic data for the 207 participants described in the qualitative analysis are shown in Table 1. Most (97.5 %) participants were female, average age was 39.2 years, years diagnosed 4.3 years, duration of symptoms 25.2 years. About half (47.7 %) of the participants reported doing less than 15 min of exercise prior to starting the Pilates, and about half (50.7 %) reported doing more than 15 min.

3.2. Quantitative analysis of challenges to doing pilates

Common challenges that interfered with doing the Pilates are shown in F 2, with ‘personal issues,’ ‘symptoms other than pain or fatigue,’ ‘fatigue,’ and ‘not enough time’ reported by more than 30 % of respondents. Since these data were for people who did Pilates at least once a week and might not reflect challenges of people who did not do the Pilates, we also looked at reasons for people who did not do Pilates at least once a week; they identified the same four reasons as most common. Pain due to the exercises was reported by 18.7 % of participants, with most saying that they modified or omitted exercises to avoid this. People who chose to withdraw from the study (not included in primary analysis) were asked to share reasons; 62 people formally withdrew and 24 of those provided reasons. Most cited unrelated health issues (8/24), time limitations (5/24), and that they were either already doing Pilates or the exercises were not sufficiently challenging (6/24).

3.3. Results of qualitative analysis

Four main themes emerged from the data: Physical, Mind-Body, Instruction, and Accessibility. Themes and subthemes are shown in Tables 2 and 3. We also categorized comments as factors influencing participants’ ability to do the exercises (facilitators and barriers, Table 2), and outcomes of doing the exercises (benefits and drawbacks, Table 2).

3.3.1. Factors impacting ability to do pilates: facilitators and barriers

3.3.1.1. Theme 1: physical. All four themes included comments related to factors facilitating or barriers to doing the Pilates exercises. ‘Physical’ facilitators included the fact that the ‘Exercises designed for hEDS felt safe and appropriate,’ they were ‘Gentle and slowly progressed,’ and ‘Simple, well thought out and combined’. Many comments demonstrated the importance of these being exercises selected or modified specifically for people with hypermobility.

- ‘It is designed and already modified for EDS. I love that she showed what we CAN (and are likely to do) and then showed what we SHOULD do. I definitely would have done what she showed us not to do otherwise! It was

Table 1
Participant demographics.

	Number	Average ± STD	Minimum	Maximum
Age (years)	201	39.2 ± 9.9	19	65
Years Diagnosed	201	4.3 ± 5.3	0	44
Years of Symptoms	201	25.2 ± 12.7	1	60
Gender:				
* Female				196 (97.5 %)
* Male				2 (1 %)
* Other or no response				3 (1.5 %)
Initial level of exercise most days:				(total, 198)
* None				33 (16.4 %)
* <15 min				63 (31.3 %)
*15–30 min				64 (31.8 %)
>30 min				38 (18.9 %)

Table 2
Themes and sub-themes, separated into barriers and facilitators.

Theme	Facilitators	Barriers
Physical	· Exercises designed for hEDS felt safe and appropriate · Gentle and slowly progressed · Exercises simple, well thought out and combined	· Illness or unrelated injuries · Fatigue
Mind-Body	· Self-efficacy · Relaxation was rewarding · Felt safe	· Fear of injury · Stress unrelated to the Pilates
Instruction/ Instructor	· Instruction clear and simple · Instructor knowledgeable about hypermobility · Attention to ‘watchpoints’ and common problems	· Repetition of basics
Accessibility	· Convenience of doing at home · Adjustable to different needs · Manageable length of each lesson	· Time management challenges · Mismatch with capability · Technology challenges

Table 3
Themes and sub-themes, separated into benefits and drawbacks.

Theme	Benefits	Drawbacks
Physical	· Felt better overall · Strengthening · Improved alignment and stability	· Increased pain · Increased fatigue
Mind- Body	· Self-efficacy · Relaxation and calm · Improved body awareness	· Discouraged by limited ability to do the exercises

- so nice to see someone like me, who could show me how to move like we are supposed to, so it was SO easy to understand what I have been doing wrong and how to fix it. This will really help me with my yoga too! I like that it makes me feel like it is ok to go easy and slow, but still be effective, unlike my other programs that don’t understand the toll exercise has on someone with POTS and EDS, and think pushing is motivating! Lol’ - Female, 46
- ‘Being ‘normal’ in the ‘class’ rather than being the one person where the instructor is saying ‘now, you shouldn’t do this bit ...’ was lovely. Not feeling worried whether the instructor had remembered that I was in the room and had limitations - as I did at a physical class. Not feeling I was disrupting other people’s experience as tutor made adjustments!’ - Female, 35
 - ‘It was so amazing to have a program tailored for people like me. The exercises were meaningful and useful.’ - Female, 29
 - ‘Felt very manageable and it was nice that it was specifically aimed at hypermobile bodies so I felt safe doing it unlike in normal exercise classes where the instructor seems to be unaware of hypermobility’ - Female, 22

Participants also appreciated the fact that the exercises were gentle and progressed slowly.

- ‘It was nice and gentle, definitely an option for me when I have a low level of condition’ - Female, 41
- ‘I very much appreciated that parts of this program are gentle enough to do regardless of my current level of symptoms’ - Female, 34
- ‘The slow build up of exercises. Too often I start exercise regimes and need to stop too soon. Here I became aware of doing little and learning about my body and its movements’ - Female, 56
- ‘The slower pace helped me to not injure myself. I was surprised at how much isolated movements worked just as well as multiple, quick reps/sets’ - Female, 37

People also commented that they liked that the exercises were ‘Simple, well thought out and combined.’

- ‘The exercises, how thought out and well designed they were to hit all the muscle groups and compliment [sic] each other for every module.’ - Female, 32
- ‘I really enjoyed the combination of relaxation techniques with exercises. In 25 min I could get both type of exercises.’ - Female, 34

Physical barriers included ‘Illness or unrelated injuries’ and ‘Fatigue.’ The most common of these being unrelated illness and unrelated pain and injuries.

- ‘Was sick for the majority of the last 5 weeks or so and stuck in bed.’ - Female, 48
- ‘I had a flare up of bladder infection which made me extremely tired and flu like’ - Female, 26
- ‘Residual pain from a car accident last fall in my neck and shoulder.’ - Female, 36

Sometimes it was not clear whether increased pain was the result of the Pilates exercises or unrelated, simply a result of living with hypermobility.

- ‘I struggled with some of the exercises - finding a couple of them caused pain.’ - Female, 33
- ‘I had a flare up of back pain which meant I had missed some planned sessions.’ - Female, 39

Fatigue was a common problem limiting ability to engage in exercise.

- ‘I have ME and MUST stay within my ‘energy envelope’, that is pace myself very carefully. If I had another big energy expenditure during the week, such as being around family or attending an out of town medical appointment, I usually only managed two sessions that week.’ - Female, 38
- ‘I had a huge increase in fatigue. This correlates with starting the Pilates. For the first three weeks I did three weekly sessions, but the fifth week onwards I did no sessions. This could also be exacerbated by the winter, seasonal changes etc.’ - Female, 35
- ‘My overall energy decreased throughout the 8 weeks, this is the same issue I have had previously when trying to stick to an exercise regime, even if only doing a couple of times a week and omitting exercises if needed.’ - Female, 37

The other physical challenges included flares unrelated to Pilates and other comorbid conditions like POTS and craniocervical instability (CCI).

- ‘I cannot do standing exercises due to my POTS symptoms.’ - Female, 29
- ‘There was 1 week where the vertigo cause by my Chiari and CCI was bad that prevented me from working out.’ - Female, 29
- ‘I did have a flare up at one point and found it very difficult to do any type of exercise without exacerbating the pain for about a week.’ - Female, 32

3.3.1.2. Theme 2: mind-body. The theme Mind-body reflects the bidirectional interaction between how people think or feel emotionally, and physical state or activity. Facilitator sub-themes within Mind-body included: ‘Self-efficacy,’ ‘Relaxation was motivating,’ and ‘Felt safe.’ Self-efficacy, the belief that proactive behaviors can impact outcome, was included in Mind-Body because it can be driven by emotion, and it can impact psychological state such as affect (Martinez-Calderon et al., 2024).

Comments related to ‘Self-efficacy’ included.

- ‘It has made consistent movement more feasible for me, which is nice considering how much I miss regular strength training’ - Female, 38
- ‘I liked being able to take 25 min to focus on myself only.’ - Female, 28
- ‘Sense of accomplishment with completing the modules. Dedicated time to spend on my own health.’ - Female, 54
- ‘The progress I’ve felt. The power of having something even minimally active that I can do in the face of this blasted syndrome.’ - Female, 42

Many comments described how ‘Relaxation was motivating’.

- ‘I liked it, it was kinda like meditation. Especially during warm up and closing the sessions. After some sessions, I slipped immediately on relax mode as soon as Jeannie started speaking.’ - Female, 38
- ‘I made me feel more energetic and relaxed’ - Female, 37

Another sub-theme was that they ‘Felt safe’ doing the exercises.

- ‘I felt safe doing the exercises.’ - Female, 38
- ‘That it was designed for E-D and I felt more confident that I could do it safely without injury or pain.’ - Female, 37
- ‘The course had a psychological impact as well. I was able to feel safe and seen on a level I have never experienced before when starting a new exercise program.’ - Female, 31

Few people reported barriers related to Mind-body; those noted included ‘Fear of injury’ and ‘Stress unrelated to Pilates’.

- ‘Worried about hurting my back, big anxiety flare which stopped me from exercising’ - Female, age not disclosed
- ‘Had to stop entirely due to flare caused by activating these weak core muscles, then was scared to try again without first consulting GP & PT & changing medication first. Almost ready to begin program again, can’t wait, because it really will help-it’s an incredible program that works, my body just wasn’t ready yet.’ - Female, 42

Stressors unrelated to doing the exercises included generalized anxiety and stressful life events.

- ‘I didn’t complete much Pilates in the final two weeks due to a severe flare in my symptoms (not related to this course but personal stress and anxiety).’ - Female, 41
- ‘I had to leave my home due to the bushfires in Australia and have been in a campervan and hotels and travelling around which has made it harder to do the exercises as often as I would have liked.’ - Female, 57

3.3.1.3. Theme 3: instruction. The theme Instruction included the sub-themes of ‘Instructor knowledgeable about hypermobility,’ ‘Clear instructions,’ and ‘Attention to “watchpoints”’ (common errors). Many pointed to the fact that the instructor was hypermobile herself and very knowledgeable about hypermobility.

- ‘The program being demonstrated by someone who has and understands the challenges of moving with hypermobility.’ - Female, 54
- ‘The fact that Jeannie could demonstrate the pitfalls of a hypermobile body so clearly helped get it right.’ - Female, 47

Comments about the clarity of instructions included.

- ‘The instructions are so clear and simple yet so detailed and on point.’ - Female, 35
- ‘Clear instruction and focus on form’ - Female, 27

Another sub-theme was attention to watchpoints or specific areas that hypermobility people may find challenging.

- *'The watchpoints were very useful - especially as I was usually doing exactly those things wrong!'* - Female, 33
- *'I love that Jeannie points out the watchpoints for hypermobile people, which no other exercise programme does. Most make us hyperextend and go too far in range of movement which isn't helpful for us, but this one didn't do that.'* - Female, 44

The primary barrier related to Instruction related to the nature of a fixed exercise program: 'Repetition of basics.' For example, a few people commented that watching the same basic instruction decreased their motivation to do the modules.

- *'I find it extremely hard to motivate myself to do anything that involves watching a how to each time. I think there should be a quick recap list of exercises covered.'* - Female, 27

While most comments about instructional language were positive, one participant mentioned feeling triggered by language about body awareness, perhaps about the belly expanding during breathing. While this was only one report, we felt this was important enough to acknowledge, as other people who found the body/core awareness focus triggering might have stopped doing the exercises entirely. With only one participant noting this, it did not justify being a sub-theme but was important to acknowledge.

- *'Some of the focus on your core stuff in the beginning was eating disorder triggering for me and it was hard to get past that to do the other exercises'* - Female, 31

3.3.1.4. Theme 4: accessibility. The facilitators for this theme included subthemes of 'Convenience of doing at home,' 'Adjustable to different needs,' and 'Manageable length of each lesson.'

The flexibility afforded by a home-based program made it accessible for those with energy-limiting conditions. It may be relevant that some people participated in the research during the COVID-19 epidemic when it was difficult or impossible to get out of the home.

- *'Also, that I could do the program at home. I would not be able to go to a class or Dr at a certain scheduled time to complete these tasks.'* - Female, 40
- *'I liked being able to do the class at home, because leaving the house drains my energy.'* - Female, 54

People commented that the module length of 25–30 min worked well for them.

- *'I liked the fact that I could achieve quite a lot in 30 min and I could do some of the exercises during the day.'* - Female, 56
- *'They weren't too long which was nice.'* - Female, 38

Many participants appreciated the fact that the instructor suggested a variety of modifications, allowing them to adjust exercises to their ability or modify for their situation.

- *'There was enough variation in the exercises to keep me mentally interested. And the instructions were easy to understand and modify to fit my abilities at any given time.'* - Female, 31
- *'I liked how the exercises could be differentiated and options explained.'* - Female, 27
- *'... the range of difficulty given and modifications explained'* - Female, 38

main Accessibility barrier was 'Time management challenges,' followed by 'Mismatch with capability' and 'Technology challenges.' The primary accessibility barrier appeared to be time, with 30 % of

respondents noting 'not enough time, or trouble scheduling time' and 37 % of respondents reporting that 'personal issues' interfered (Fig. 2). Some people also reported challenges using the technology (web-based modules).

- *'Time management is an issue for me. I can't schedule my weeks or days, could use help.'* - Female, 35
- *'I found it hard at times to remember where the programme was on the web and this meant a barrier to just doing it'* - Female, 51

'Mismatch with capability' included reports of exercises being too difficult or too easy and being unable to do certain exercises due to specific limitations such as inability to stand, sit or put weight on extended wrists.

- *'Wrist issues (still got them), from weight bearing on wrists.'* - Female, 27
- *'Waaaaaay too intense balance/stability requirements for hypermobile joints. Need recumbent options, much slower progression, movements that improve joint stability rather than require it as a prerequisite for balance.'* - Female, 43
- *'I can do the first session without pain, but the other sessions are too much for me. I need to reduce reps, or do sessions half at a time to be successful.'* - Female, 39
- *'My challenge was doing the exercises when they were not challenging enough.'* - Female, 49
- *'I would have really liked more exercise. I guess it wasn't hard enough for me to put an hour of my time into each week.'* - Female, 35

3.3.2. Outcomes of doing pilates: benefits and drawbacks

3.3.2.1. Theme 1: physical. Many comments described Physical benefits and drawbacks of doing the exercises. Physical benefits had three sub-themes: 'Felt better overall,' 'Strengthening,' and 'Improved alignment and stability.' 'Felt better overall' encompassed a range of physical benefits from less pain *'I have less pain in my neck and shoulders'* to a generally feeling better after completing a class. Representative quotes include.

- *'I always felt better, physically and psychologically after I did them. And I felt good about making positive impacts on my long term health and ability level.'* - Female, 36
- *'I think I was better prepared for my body to carry a pregnancy!'* - Female, 44
- *'The sessions I did definitely helped. Physically I felt better, and psychologically it helped also.'* - Female, 49

'Strengthening' included statements related to feeling stronger.

- *'Physically I increased strength considerably. I struggled to complete one rep of many of the exercises at the beginning. I can now do 10 reps on both sides of all the exercises. The strength I have gained has allowed me to increase my walking ability.'* - Female, 31
- *'They really helped build muscles I didn't know existed with no extra pain in joints.'* - Female, 25

'Improved alignment and stability' included statements about feeling like they had better control of body alignment and stability.

- *'The exercises had the positive impact of helping with body awareness and helped me to pay better attention to posture and joint location.'* - Female, 42
- *'I got stronger and more stable.'* - Female, 29

The primary drawbacks in the Physical theme included 'Increased pain' and 'Increased fatigue.' Sometimes pre-existing pain interfered

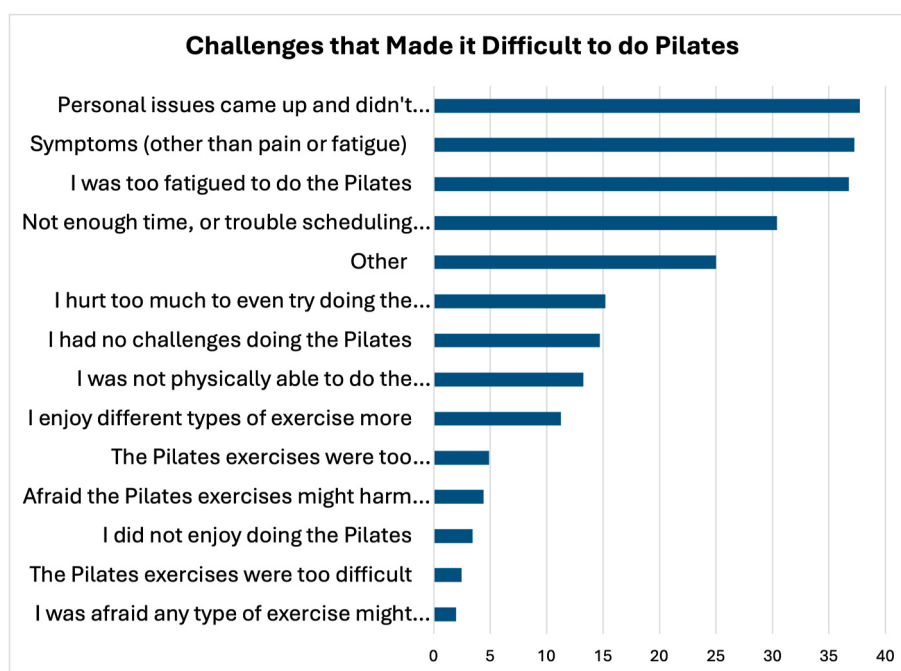


Fig. 2. Reported challenges that made it difficult to do the Pilates exercises. The 207 participants reported here completed Pilates exercises an average of once a week for 8 weeks. Analysis of 34 participants who completed the survey but did not do the 8 weeks of Pilates revealed the same primary challenges.

with doing the exercises (discussed below with ‘barriers’) and sometimes the exercises exacerbated pain. Participants often described modifying or avoiding certain moves that caused pain.

- ‘Occasionally the exercises would flare up my left shoulder blade region or left SI joint issues. I learned to modify those exercises and to skip session 4 entirely.’ - Female, 38
- ‘Twisting did cause pain that lasted several days, so I skipped those exercises.’ - Female, 43

Some people reported pain in specific regions while others reported widespread increase in pain.

- ‘I have struggled with my right knee. It hurt when I straightened up from the bent knees while standing against the wall. I didn’t do that exercise again and it is improving.’ - Female, 56
- ‘It felt good to be doing exercise but then sometimes further down the line I had setbacks with pain’ - Female, 31
- ‘An unhealthy decrease in sleep due to increased pain. Also, increase in pain and hypermobility in extremities and neck.’ - Female, 34
- ‘My hip got aggravated and I had trouble walking and sleeping from that. My right shoulder pain increased a lot. My ribs on my left side went out of alignment and caused a lot of pain.’ - Female, 39

3.3.2.2. Theme 2: mind-body. ‘Mind-body’ included the sub themes of ‘Self-efficacy,’ ‘Relaxation and calm,’ and ‘Improved body awareness.’ ‘Self-efficacy’ encompassed benefits to mental health, hope, confidence, and generally feeling good.

- ‘I felt very anxious initially because I was so unstable. Overall I think my confidence has increased.’ - Female, 42
- ‘Psychologically they gave me hope as there isn’t much exercise out there that you can do and not injure yourself due to over hEDS [sic].’ -Female, 33
- ‘I felt empowered exercising’ - Female, 48
- ‘I always felt better, physically and psychologically after I did them. And I felt good about making positive impacts on my long term health and ability level.’ - Female, 36

Another sub-theme was ‘Relaxation and calm.’ This was often mentioned in the context of the breathing exercises incorporated into the program, for example, ‘Breathing helps me to relax’ (Female, 36) and ‘I felt a sense of calm and well-being particularly with the breathing exercises. (Female, 39)’

- ‘It was a relaxing time for myself.’ - Female, 51
- ‘I also liked the feeling of calm both during and after each session.’ - Female, 41
- ‘It calmed me down’ - Female, 30
- ‘They were quite calming and helped me to relax in the evening.’ - Female, 32

Participants commonly identified ‘Improved body awareness’ as a benefit. This included proprioception, posture, knowing what joint ranges were safe, as well as an overall newfound awareness of movement patterns.

- ‘I felt more aware of how I was moving and breathing in my day to day life’ - Female, 33
- ‘Improved proprioception in other daily exercises.’ - Female, 65
- ‘I think it was a true wake-up call regarding my body using the wrong muzzles [sic]. I think of myself as a physically strong person, but I had a real challenge to use the right muzzels [sic] to do the exercises.’ - Female, 32
- ‘The exercises had the positive impact of helping with body awareness and helped me to pay better attention to posture and joint location.’ - Female, 42
- ‘Learning about my body and about using slow controlled movement and reducing range and releasing tension.’ - Female, 45

The Mind-body theme included two sub-themes that were drawbacks. The most common was ‘Discouraged by limited ability,’ where a number of participants reported negative feelings associated with being unable to complete the program. The other Mind-body drawback related to one person reporting that she was triggered by thinking about her core, as noted above; again, since this was only one comment, it was not identified as a sub-theme.

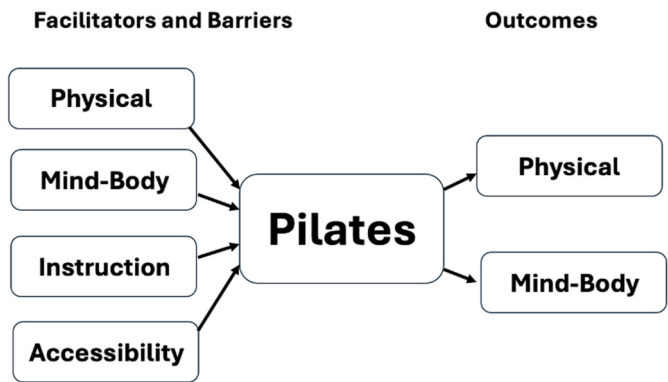


Fig. 3. Model of themes related to doing the Pilates program designed for people with hypermobility. Facilitators and barriers are shown on the left as impacting whether people do the Pilates. Outcomes are shown to the right as consequences of doing the Pilates. See Tables 2 and 3 for subthemes, and text for thick description.

- ‘Initially felt good and was happy I could do some exercises, really looked forward to them etc. Then as my fatigue increased it got more and more difficult and I felt sad I wasn’t able to do them.’ - Female, 37
- ‘Frustrated that I couldn’t complete the program as I had hoped.’ - Female, 38

3.4. Model describing attitudes towards the pilates program

Fig. 3 presents the model showing the proposed relationship among the themes identified. Facilitators and Barriers included issues that impact the willingness of participants to engage in the Pilates program. This included both factors associated with participants, such as pain, fatigue, or fear, as well as factors associated with the implementation of the online program, including aspects of instruction and accessibility. Outcomes reflected the perceived results of participation, which include both physical and mind-body components.

4. Discussion

4.1. Overall findings

This study explored participant perceptions of an online Pilates

program designed specifically for people with hEDS/HSD. Exercise has been identified as the keystone to managing hypermobility (Byrnes et al., 2018; Garreth Brittain et al., 2024), but there are not enough movement specialists (physiotherapists, Pilates instructors, physical trainers, etc.) with expertise in managing hypermobility issues (Bennett et al., 2019). As in previous research (Simmonds et al., 2019), we found that pain, fatigue, and fear were significant obstacles for doing regular exercise. However, we found that symptoms other than pain or fatigue and lack of time were also challenges. These results suggest that healthcare providers should also try to address these other symptoms and not focus only on pain (Alves et al., 2020, 2024; Buryk-Iggers et al., 2022; Byrnes et al., 2018; Cruz-Diaz et al., 2018).

4.2. Implications of the model and recommendations

Analysis revealed that comments included both factors impacting participants’ ability to do the Pilates, and outcomes of the Pilates. Therefore, a two-phase model, as shown in Fig. 3, was adopted as best fitting the data. All four themes contributed to barriers and facilitators, whereas outcomes included only the themes Physical and Mind-body. Table 4 shows implications and recommendations identified for development of future exercise programs for people with hEDS/HSD.

4.2.1. Implications and recommendations related to the physical theme

The Physical theme indicated that an exercise program for this population needs to be hypermobility-specific, and should also address fatigue and pain, which were frequent challenges. Some participants reported that the program was too difficult, while others reported that it was too easy. Therefore, exercises need to be offered at multiple difficulty levels. People reported a variety of challenges such as being unable to stand due to POTS, unable to get into quadruped due to wrist problems or cervical instability. A program should provide multiple options so people can select modules that are appropriate for them and change modules when they have a flare. Since pain and fatigue were common barriers to doing exercise, a program should include very gentle and easy exercises, and preferably exercises or activities that can help decrease pain and fatigue.

Although 18.7 % of people reported increased pain due to the exercises, only 5 % reported that they were unable to do at least some of the exercises due to discomfort. (Fig. 2). However, the sample is likely biased because we only included people who completed 8 weeks of the Pilates program. To explore this further, we looked at responses from

Table 4
Implications for design of online exercise programs.

Theme	Implication	Recommendation
Physical	● Appropriately modified Pilates exercises can be appropriate for people with HSD ● Exercises should be appropriate for people with HSD, addressing a variety of limitations, such as inability to get on hands and knees, stand, stabilize the neck, lift the arm, etc. ● Fatigue and unrelated symptoms were often more limiting than pain	● Pilates program should be specific for people with HSD ● Provide a variety of modules so people can select modules that are appropriate for their specific limitations and fitness level, ranging from very, very gentle to more vigorous. ● Have modules suitable for the most limited individuals. ● Provide modules that can be done even when fatigued, in pain or other experiencing symptoms. ● Provide content for pain management through Pilates. ● Have a range of modules graded by difficulty; help people select modules they can do successfully. ● Emphasize relaxation and breathing. ● Include body awareness at all levels ●Continue to offer on-line in an easy-to-use format. ●Provide a range of module lengths to accommodate different fitness levels and time availability. ●Provide a range of modules that accommodate special needs, such as POTS, fatigue, cervical instability
Mind-Body	● It is important that participants be able to successfully do a set of exercises without flaring. ● Relaxation and breathing were important benefits. ● People valued improved body awareness.	● Instructor should be knowledgeable about HSD ● Clear instruction with “watchpoints” ● Instructor should create a safe and encouraging environment ● Have separate modules for ‘basic concepts’ and for doing the exercises. ● Be cautious about triggering language.
Accessibility	● On-line format was convenient, but some people found the technology complicated ● Some people liked ~25 min while others found that was too much	
Instruction/ Instructor	● Clear instruction with “watchpoints” was important ● It was important that the instructor had HSD specific knowledge	

people who did not do 8 weeks of Pilates; the percentage reporting increased discomfort attributed to the exercises actually decreased from 18.7 % (of 207 people who did Pilates) to 18.3 % (of 241 people who did not do Pilates), suggesting that sample bias might not actually alter the frequency of discomfort doing the exercises. Furthermore, twice as many participants reported time management as a limiting factor compared to the difficulty or discomfort doing the exercises (Fig. 2).

4.2.2. Implications and recommendations related to the mind-body theme

The Mind-Body theme showed that exercises enhanced relaxation and breathing, body awareness, and feeling empowered from being able to do the exercises. Relaxation and breathing have long been identified as valuable components of the Pilates training (Fleming and Herring, 2018; Huang and Park, 2023; Yang et al., 2021). To enhance the sense of accomplishment, a program should have modules that even the most disabled person could do successfully to avoid becoming discouraged (Anar, 2016; Chhabra et al., 2018; Lara-Palomo et al., 2022; Teepe et al., 2022; Weise et al., 2022). Knowing that the program contained hEDS/HSD-specific exercises enhanced the sense of safety.

Since body awareness (proprioception and interoception) are both compromised in people with hEDS/HSD (Sharp et al., 2021), exercises that enhance body awareness are likely to be helpful (Carroll, 2023; Franks et al., 2023; Patti et al., 2024). Careful wording is also important to avoid triggering body image problems; one author [JDB] has noted this sensitivity to wording and vulnerability to triggering with other clients and feels instructors and clinicians should be attentive to this.

Some people simply did not enjoy doing Pilates, preferred other types of exercise, or simply became bored with a single type of exercise for 8 weeks. Since exercise is a lifelong self-care strategy for people with hEDS/HSD, programs should provide a variety of exercise types, including some non-Pilates options to appeal to the most people (Yalfani et al., 2020).

4.2.3. Implications and recommendations related to the accessibility theme

Accessibility of the online program was clearly beneficial, especially for people who did not have hEDS/HSD specialists close to their homes and during the COVID lock-down when online exercises provided a valuable way for people to remain active (Didyk et al., 2022). The technology needs to be convenient and easy to use. Time constraints were a major barrier, so future exercise programs should have modules spanning a range of durations, allowing people to do only 5 or 10 min if shorter times are more convenient (Anar, 2016; Quentin et al., 2021; Weise et al., 2022).

Content should range a wide span of ability levels, as some people found the current standardized approach too easy, while others found it too difficult. Many people noted that they modified certain exercises to accommodate specific limitations. Content should therefore provide options for people with specific limitations, such as the inability to bear weight through extended wrists, the inability to stand, and cervical instability. Clear instructions for modifying any exercise makes them more accessible to more people. Perhaps exercise modules could list potential accessibility barriers in written descriptions and search filters so people can avoid modules with activities inappropriate for them. Having options also helps people continue to exercise when having a flare (Chhabra et al., 2018).

4.2.4. Implications and recommendations related to the instruction theme

The instructor and instruction style were clearly important. People should know that the instructor understands their specific needs, communicates clearly, and is reassuring and supportive. Knowing that the exercises were designed for people with hEDS/HSD and taught by someone with thorough knowledge and understanding of common challenges for hypermobile people helped people feel safer while exercising (McNeill et al., 2018; Moreno-Ligero et al., 2023). Participants identified ‘watchpoints’, or common errors, as important to help them identify errors in their movement. Participants suggested that basic

principles be addressed in separate modules so that they could progress to doing the exercises rather than hearing basic instructions each time. Separate ‘principles of movement’ modules would therefore be helpful. The instructor’s calm and reassuring manner, frequently identified as a benefit, is consistent with recommendations in the literature (Simmonds et al., 2019). Lastly, the instructor should be sensitive to triggering language, as noted above.

4.2.5. Comparisons with qualitative research related to exercise programs

The themes and sub-themes identified in the current study are consistent with prior research. A study of exercise beliefs in people with hEDS/HSD found that pain, fatigue, and fear were the primary barriers to exercise, which is consistent with our findings. That study found themes related to trust in the provider’s knowledge and condition-related experience and sense of safety were positive beliefs that also echoes current findings (Simmonds et al., 2019). A study of remote exercise coaching for oncology patients identified themes of self-efficacy, physical activity habits, accountability, physical complaints, and facilities. Participants in that study valued the convenience of remote coaching and gained confidence and self-efficacy through the increased independence compared to exercising in a clinic (Weemaes et al., 2023). Another study of exercise behavior in people with chronic health conditions identified several similar barriers: pain, fatigue, breathlessness, lack of motivation, financial issues, accessibility, and decreased social support (Jäger et al., 2022). The current study did not attempt to create a community to provide online social support, but that would likely be a valuable addition to future online exercise programs.

4.3. Strengths and limitations of the current study

4.3.1. Strengths

The key strength of the current study is hearing participants’ descriptions of factors affecting their ability to exercise using the online Pilates program. This study was a component of a larger, pragmatic clinical trial that measured and assessed functional changes in response to the exercises, and the quantitative branch of this study will better determine whether the exercises were effective in improving function and quality of life. By focusing on the narrative comments provided by participants, we were able to gain insight into how they felt about doing the Pilates exercises. The four themes show that the physical aspect of exercise is only one component. Also, the current study explored factors other than pain and fatigue that may limit a person’s participation in regular exercise. Education about pacing and time management may enhance exercise engagement. Other strengths of the current study include the fact that it was multinational, had a fairly large sample size, the robustness of our thematic analysis, and the thick description that allows readers to hear the words participants used. Also, to our knowledge, this is the only study of an online Pilates program, which is particularly important for individuals who do not have access to hEDS/HSD Pilates instructors, or who cannot easily leave their homes due to factors such as COVID-19.

4.3.2. Limitations

There were several limitations to the current study. First is the high dropout rate, which could bias results toward people who want to do Pilates exercises. We attempted to keep people engaged with weekly email contact, but it appeared that some of those emails might have been blocked by spam filters. More human contact might have helped keep people engaged, especially after a flare. A smaller study could have allowed us to maintain better contact with all participants. Because the study initially enrolled 672 people in the quantitative portion, we sent group follow-up emails (email addresses blinded); it was not practical to follow up with each person to encourage participation.

Although the videos already included suggested variations that are commonly required by people with hEDS/HSD, some individuals had issues that required further modification or elimination of exercises for

their own safety or fitness level. The instructor was available to answer individual questions and suggest modifications when participants contacted us. To our knowledge, the potential modifications included things such as: omitting all standing exercises for people with dysautonomia or balance issues that prevented any standing, decreasing range of motion or eliminating shoulder or hip movement for individuals with specific injuries to shoulders or hips. While the presence of modifications limits our ability to identify specific exercises that people should do, it reflects the real-world situation where people need to modify any set exercise program. Future online exercise programs should perhaps include explicit options that allow people to customize their exercises.

Although the initial study looking at the impact of doing Pilates had hoped participants would do Pilates 3 times a week, this qualitative study included people who had done Pilates at least once a week. This decision was made because we wanted to learn what factors interfered with participants' ability to do Pilates 3x/week. We viewed responses from people who did not do the Pilates at all, in case they had different reasons for being completely unable to participate; however, those responses were similar to the responses considered in the current report.

Clearly, all participants volunteered to do Pilates, so results can only be generalized to others who are interested in Pilates. Therefore, the results might not generalize to other forms of exercise. Also, most participants were female, further limiting generalizability to factors that might impact men engaging in a similar program. Because data were collected via written questionnaires, we did not have the opportunity to ask follow-up questions or to do member-checking or data triangulation as a strategy to ensure credibility (Korstjens and Moser, 2018). Also, the questions asked participants to focus on the benefits and challenges of doing Pilates, which might have limited the scope of responses.

Some bias is inevitable in qualitative research because the researchers are interacting with the data through the interpretative process. We attempted to minimize this through strategies to improve reflexivity, such as reflecting on our biases and having a person other than the instructor or the lead researcher lead the qualitative analysis. The research team periodically reflected on their potential assumptions or biases to minimize impact on conclusions. For example, the team carefully considered every reported Drawback to make sure they were reflected honestly in the conclusions (Korstjens and Moser, 2018).

4.4. Clinical relevance

- People with hEDS/HSD found an online exercise program designed for hypermobility helpful for improving both physical and psychological wellness. Online exercise may be a valuable modality to help people with chronic conditions remain active.
- Themes identified included four 'Facilitators and Barriers': Physical, Mind-body, Accessibility, and Instruction. Recognizing Facilitators and Barriers can inform future exercise programs for this population, and possibly other groups with chronic conditions.
- Outcomes of this Pilates program included Physical and Mind-body themes, with both 'Benefits and Drawbacks.' Reported benefits include improved body awareness, self-efficacy, and relaxation, as well as strength and stability.

CRedit authorship contribution statement

Leslie N. Russek: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Jeannie Di Bon:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Jane Simmonds:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis, Conceptualization. **Catherine S. Nation:** Writing – review & editing, Writing – original draft, Validation, Methodology, Formal analysis.

Cheyenne Vivlamore Zion Higgins: Writing – review & editing, Investigation, Data curation. **Tiffany Jandrew:** Writing – review & editing, Investigation, Data curation.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Jeannie Di Bon reports a relationship with The Zebra Club that includes: equity or stocks. Catherine S Nation reports a relationship with The Zebra Club that includes: employment. Leslie N Russek serves as an unpaid scientific consultant to The Zebra Club. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jbmt.2025.03.002>.

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