

# Physical and Psychosocial Outcomes of a Weekend Retreat for People Living with Hypermobile Ehlers-Danlos Syndrome

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## Abstract

Patients living with hypermobile Ehlers-Danlos Syndrome (hEDS) often suffer from poor balance, kinesiophobia, social isolation, and sensory processing issues. While studies have examined medical and psychological interventions to help patients manage these symptoms, a knowledge gap exists regarding the role that weekend retreats can play in improving patients' symptom management, providing strategies for coping with physical challenges, and education on their diagnosis. We piloted programming for a three-night retreat in order to examine its impact on nine individuals living with hEDS in central Indiana. Programming included meals, lodging, group educational and recreational activities, individual preventive screening and education, and opportunities to socialize. Participants completed questionnaires at three different intervals: One at the beginning of the retreat, one immediately after it, and follow-up questionnaires at about five months out. After the retreat, participants scored better on most items relative to their pre-retreat scores. Although limited, our findings suggest that the retreat succeeded in improving symptom management and social networking among patients with this uncommon disease. Moreover, many of these positive effects were enduring and contributed to participants' long-term abilities to cope with the effects of living with hEDS.

**Keywords:** Ehlers-danlos syndromes; Wellbeing; Lifestyle; Retreat; Psychosocial; Coping and Adaptation; Social Networking; Relationships; Support.

overall quality of life [7-12]. As a multisystemic disorder, attending to all their clinical needs requires affected persons to spend significant time and energy attempting to coordinate care across numerous specialties and institutions something that can prove particularly challenging for a population whose members often suffer from fatigue and limited mobility in addition to the general difficulties of referral and access for patients with uncommon diseases [13-15].

Learning to live with the complications of hEDS is its own hurdle. Educational services such as EDS ECHO's community programming professional mental healthcare and support groups-both face-to-face and online-have proven important resources for this population [9-12,16-18]. These interventions can improve coping skills, decrease psychological distress, and increase patients' knowledge and sense of wellbeing.

However, retreats can intensify the benefits of traditional support groups and provide another potential modality of care for patients living with hEDS. Retreats can help educate patients and improve their sense of physical wellbeing and quality of life [19-22]. They can also uniquely reduce patients' sense of emotional and social isolation by providing them with a space to meet others with shared life experiences and foster a sense of community [20,23,24]. This can be particularly meaningful for individuals with uncommon diseases, who may never have had the opportunity to encounter another person with the same diagnosis face-to-face. This can also lower the strain of the health system by streamlining and facilitating group strategies and services with an overburdened specialized healthcare team [18].

Seeing the potential positive impact of this unique modality of supportive intervention, we convened a multidisciplinary team to design a three-night retreat for patients living with hEDS. Facilitators included nurse practitioner, physical therapist, physician, and social worker representatives, each of whom specialize in providing care for hEDS and other connective tissue disorders, as well as international leaders, clinicians, researchers and scientists who work in this domain. The retreat was held in central Indiana and included programming on multi-system

## Introduction

Hypermobile Ehlers-Danlos Syndrome (hEDS) is a hereditary disorder of the connective tissue. While patients with this condition are primarily affected by chronic pain, their lives are also impacted by poor balance and kinesiophobia [1-6].

Other symptoms arising from hEDS include social isolation, loneliness and sensory processing issues, which can lower patient's

management, clinician-associated, traumatization, gastrointestinal, dysfunction, ergonomics, pain neuroscience, healthcare system navigation, pelvic floor, strength training, and psychology [1]. Individual and group classes on hypermobile-friendly yoga, health screening, movement screening, and social networking were incorporated throughout the event. In addition to formal educational sessions, participants had numerous informal opportunities to network and share their stories with others. In this paper, we examine the impact of the retreat on our participants' balance, kinesiophobia, social isolation, sensory processing issues, and overall quality of life. We argue that our design may provide a prototype for retreats that can be replicated in the future and at other sites in order to meet the complex and comprehensive needs of this and similar patient populations.

## Materials and Methods

A three-night retreat was designed to be piloted with patients living with hEDS in central Indiana. The retreat was scheduled for mid-April 2023 and held at Bradford Woods in Martinsville, Indiana. Bradford Woods is Indiana University's 2,500-acre outdoor programming center, located about 45 minutes southwest of Indianapolis. The retreat consisted of educational programming, recreational activities, and events for socializing. Meals and lodging were also provided. All of this was offered at no cost to the participants. The event was funded by the Indiana University (IU) Health Center for Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD), with support from the Ehlers-Danlos Society, IU Health Foundation, and Forefront Community Therapy.

Quantitative data were obtained from five standardized instruments completed before the retreat ("pre-retreat questionnaires"), immediately after the retreat ("post-retreat questionnaires"), and about five months following the retreat ("follow-up questionnaires"). Additionally, summative data were collected from a "satisfaction questionnaire" that was circulated three months after the retreat. The post-retreat questionnaires were sent electronically to participants and could be returned either by email or through their patient portals.

## Participants

Candidates for the retreat all had a confirmed diagnosis of hEDS based on the robust 2017 diagnostic criteria and had been seen at IU Health's EDS and HSD Clinic [25]. Inclusion criteria involved their self-identification as female or nonbinary, being between the ages of 21 and 40, and living in Marion or one of the surrounding counties in Indiana. Candidates were required to have a self-reported Karnofsky performance status between 60 and 100 indicating that they needed no more than occasional assistance in performing activities of daily living, as nursing resources were not available at the retreat [26]. Patients who are pregnant and patients who are not comfortable communicating in English were also excluded for practical reasons. Ultimately, nine women participated. Reasons candidates declined participation included being away for college, childcare concerns, and pet-care concerns.

All participants provided written consent prior to initiating the weekend intensive. All participants received a study information sheet approved by the IU Institutional Review Board (Protocol#19137) and agreed to have their responses used for this study. While everyone successfully completed the pre- and post-retreat questionnaires, two failed to complete the follow-up questionnaire and were no longer able to be reached by phone or email.

## Intervention

The program was conceptualized and organized by a physical therapist, a medical geneticist, and a nurse practitioner, each of whom specializes in the care of patients with hEDS. The retreat agenda included adaptive yoga and breathing sessions, pelvic floor physical therapy, educational presentations on clinician-associated traumatization, patient advocacy, pain and biofeedback, managing common complaints including gastrointestinal, ergonomic, self-management techniques, proprioception and interoception, a group mental health workshop, as well as zip-lining and opportunities for informal socializing [1]. Participants had one-on-one sessions with a medical geneticist physical therapist, pelvic floor physical therapist, and a social worker. They could opt-in for a one-on-one session with a gastroenterologist. All facilitators, practitioners, and lecturers volunteered their time and agreed not to be compensated financially for their labor.

All physical activities were preceded by instructions from the facilitator and followed by a debriefing session. Social networking was encouraged among participants through shared rooms, communal meals, and group classes moderated by the retreat facilitators.

## Evaluation tools

The Berg Balance Test ("Balance") is a 14-item scale assessing balance and fall risk status [27]. Looking at various positions, this assessment pulls in visuomotor and vestibular impact along with strength, proprioception, and mobility. Scores range from 0 to 56, with lower numbers indicating a greater difficulty of accomplishing tasks. Measurement and assessment of the standardized tool were assessed by a physical therapist facilitator at the event. The Tampa Scale for kinesiophobia ("Kinesiophobia") is a 17-item questionnaire that measures patients' often debilitating subjective experience of excessive pain-related fear of movement and reinjury [28]. Its psychometric properties have been examined extensively and found to have good internal consistency and substantial reliability though some have questioned its content validity [29-31]. Nonetheless, it remains one of the most widely used questionnaires for measuring kinesiophobia. The revised UCLA (University of California, Los Angeles) Loneliness Scale ("Loneliness") is a 20-item questionnaire dealing with issues related to loneliness and social connectedness [32]. In this tool, the construct of loneliness is distinguished from related constructs such as depression, absence of affiliative motivation, and reduced social risk-taking. Higher scores indicate higher degrees of loneliness. Documented internal consistency and both concurrent and discriminant validity of the scale are high.

Adolescent/Adult Sensory Profile (“Sensory”) is a 60-item questionnaire that evaluates the sensory processing of everyday events by patients between the ages of 11 and 65. It is based on a theory that integrates neurological and behavioral responses to sensory stimuli [33,34]. It divides items into six domains: Taste/smell, movement, visual, touch, and auditory processing, as well as activity level, and it identifies four sensory processing patterns or “quadrants” low registration, sensation seeking, sensory sensitivity, and sensation avoiding. Its reliability and validity have been demonstrated [35].

The Short-Form 36 (“SF-36”) is a 36-item questionnaire developed to evaluate health-related quality of life. This self-report tool focuses on the domains of physical functioning, energy, emotional wellbeing, social functioning, pain, general health, and role limitations due to physical or emotional problems. Questions are scored from 0 (low) to 100 (high) with the maximum score of 3600 signifying optimal overall health. The SF-36 has been validated in numerous populations and languages [36,37]. The satisfaction questionnaire consisted of 13 items assessing participants’ overall impression of the retreat and places for improvement. Questions included Likert prompts such as “Overall, how satisfied were you with the variety of presentations given?” and “do you feel that the downtime built into the weekend was sufficient?” Many Questions, However,

allowed for free-text responses, such as “Are there any other ways, not addressed above, that you feel the retreat could be improved?”.

### Data analysis

Descriptive statistics were used to analyze data from the questionnaires. Because this was a pilot study and the number of participants was low, multivariate statistical analysis was not warranted.

## Results

### Demographics

Ten individuals living with hEDS were invited to participate in the retreat. One woman ultimately was unable to participate due to ongoing medical issues unrelated to the retreat. Of the nine who completed the retreat, all identified as female. The majority identified as white. The mean age was 33 (range 26-46). The majority were employed at least part time and were married. On average, they traveled 35 miles to the retreat center (range: 27-64 miles). The mean Karnofsky performance status was 68 (range: 60-80). On average, they had been diagnosed 2.7 years prior to the retreat (range: Approximately one month to five years). For more information, see **Table 1**.

**Table 1:** Demographic information about each of our retreat participants, suggesting the diversity of potential experiences captured in this study.

<b>Gender</b>	Female	9 (100%)
<b>Age</b>	Average	33 years
	Range	26-46 years
<b>Race/Ethnicity</b>	Non-hispanic white	7 (78%)
	Hispanic white	1 (11%)
	More than one	1 (11%)
<b>Education</b>	Some college	2 (22%)
	Bachelor’s degree	3 (33%)
	Graduate degree	4 (44%)
<b>Marital status</b>	Single	2 (22%)
	Married	6 (67%)
	Divorced	1 (11%)
<b>Employment status</b>	Employed at least part-time	6 (67%)
	Unemployed	3 (33%)
<b>Distance traveled</b>	Average	35 miles
	Range	27-64 miles
<b>Karnofsky score</b>	Average	68
	Range	60-80
<b>Time since diagnosis</b>	Average	2.7 years
	Range	Approximately 1 month-5 years

## Questionnaires

All participants completed the pre-retreat and post-retreat Balance, Loneliness, Sensory, and SF-36 questionnaires. One participant failed to complete the Kinesiophobia questionnaire. Unlike the pre-retreat and post-retreat questionnaires, follow-up

questionnaires were completed outside of the context of Bradford Woods. They were returned four to six months after the retreat (average: 147 days). As was mentioned above, two participants were unable to be recontacted and never returned this questionnaire. Their scores are broken down in **Table 2**.

**Table 2:** Participants' responses to our questionnaires, demonstrating the impact of the retreat at three time points.

Time		Pre-retreat average (SD)	Post-retreat average (SD)	Follow-up average (SD)
	Berg Balance Test	54 (2)	56 (1)	N/A
	Tampa Scale of Kinesiophobia	39 (6)	31 (5)	31 (7)
	Revised UCLA Loneliness Scale	44 (11)	42 (9)	46 (15)
Adolescent/ Adult Sensory Profile	Taste/smell processing	20 (8)	20 (8)	19 (8)
	Movement processing	24 (9)	23 (8)	23 (9)
	Visual processing	29 (11)	28 (10)	26 (11)
	Touch processing	36 (14)	35 (13)	34 (14)
	Activity level	28 (11)	29 (11)	26 (11)
	Auditory processing	31 (13)	31 (12)	30 (13)
	Low registration	44 (10)	42 (9)	42 (5)
	Sensation seeking	49 (5)	49 (5)	46 (5)
	Sensory sensitivity	47 (9)	46 (6)	48 (5)
	Sensation avoiding	48 (9)	47 (8)	45 (7)
SF-36	Physical functioning	49 (34)	57 (28)	63 (32)
	Role limitations due to physical health	14 (18)	14 (23)	18 (30)
	Role limitations due to emotional problems	44 (26)	26 (32)	38 (25)
	Energy/fatigue	28 (17)	35 (16)	31 (21)
	Emotional wellbeing	36 (24)	48 (23)	41 (22)
	Social functioning	54 (18)	58 (12)	52 (18)
	Pain	36 (13)	44 (15)	47 (17)
	General health	31 (19)	38 (19)	43 (17)

**Note:** One participant did not complete the Tampa Scale of Kinesiophobia. Two participants did not complete the follow-up questionnaire.

The average balance score improved from 54 to 56 immediately following the retreat. Two individuals scored perfectly before the event, causing a ceiling effect and attenuating the scale's ability to assess mean improvement. Every other individual had improvements in their scores. The average kinesiophobia score dropped 8 points, from 39 to 31, after the retreat and maintained this lower level at the four-to six-month follow-up. This represents an overall sustained decrease in the experiences of kinesiophobia after the retreat.

The average loneliness score dropped by two points immediately after the retreat, demonstrating an initial decrease in loneliness. Only three individuals reported an increased level

of loneliness, and these numbers were only small (1-3 points). However, the average score increased to 46 on the follow-up questionnaire—a five percent increase over the average pre-retreat score and a nine percent increase over the average post-retreat score. Four participants reported an increased sense of loneliness over their post-retreat score, and two of these were substantially worse (9 and 20 points higher). There were no noteworthy changes in average sensory scores, either on the post-retreat or follow-up surveys, relative to the pre-retreat survey. Notably, average scores were considered “more than most people” for ages 18-64 in all quadrants except “sensation seeking,” in which all average scores for all three time points fell within the “similar to most people” range.

The overall average SF-36 score increased after the retreat. Averages increased in many of the individual domains as well. Specifically, increases were seen in average physical functioning, energy and fatigue, emotional wellbeing, social functioning, pain, and general health. At the four-to six-month follow-up, increases were still seen in each of these domains over pre-retreat scores except in emotional wellbeing and social functioning. The satisfaction questionnaire revealed strongly positive experiences. Seven of the nine participants (78%) said they were extremely satisfied with their weekend retreat experience, and the remaining two (22%) said they were somewhat satisfied. When asked whether they would recommend the retreat to a friend, the mean score out of 10 was 9.63. One respondent stated that she “really loved the experience and wants to help grow the community.” All participants (100%) felt that the number of attendees was “just right,” and one respondent noted that this size allowed for “an individualized experience that could refine and tailor the discussion to align with my concerns.” All participants (100%) said they were extremely satisfied with the variety of presentations over the weekend. The most highly valued were “overall management theme” and “Physical Therapy (PT) management and movement for the individual living with EDS,” followed by “medical trauma,” and then “pain/biofeedback” and “ergonomic insight for the individual with EDS.” Facilitators were praised for being “warmer, less restricted, and more human and down to earth” than healthcare providers whom participants had encountered outside of the retreat.

Many participants mentioned community-building as a major positive outcome of the retreat. One respondent noted that she was “able to connect with other people in person with hEDS for the first time.” Others mentioned the value of having all this educational programming and care in a single setting. One respondent noted that it “would have taken months to incur these resources through various appointments outside of the retreat setting.” The satisfaction questionnaire also revealed ways in which participants believed the programming could have been improved. They noted a primary interest in additional presentations on sleep disorders, neurodiversity and other mental health issues, neurology, and workplace accommodations and occupational therapy. Participants were split evenly between those who felt there was sufficient versus insufficient scheduled downtime during the retreat. While a third were satisfied with the food options over the weekend, another third were neither satisfied nor dissatisfied and two were somewhat dissatisfied. In particular, participants mentioned challenges of food intolerances and allergies, and a desire for more fresh produce. The primary other suggestions for improvement included more planned recreational activities and more group-building activities.

## Discussion

A three-night retreat has been developed as a strategy to provide supportive programming for patients living with hEDS. All participants reported that they were at least somewhat satisfied with their experience, with 78% stating that they were extremely satisfied, and they were very likely to recommend such a retreat to friends. Practically, they believed the number of

participants (nine) was “just right,” and noted that this size allowed for individualized attention, learning, and care.

Findings from our study reveal that the pilot retreat allowed participants to increase their education related to their diagnosis, develop and test new strategies for managing their symptoms, and improve their social connections within the hEDS community. In particular, the retreat provided participants with the tools to decrease their kinesiophobia and sustain improvement in perceived physical functioning, energy, and general health over several months. Balance scores also improved markedly after the event. Considering the lack of any specific balance or strength training at the event, these improvements are notable and strongly support the impacts of education, confidence, and feelings of environmental safety. All participants reported being extremely satisfied with the variety of presentations, highlighting in particular the utility of education related to managing their symptoms and clinician-associated traumatization [1]. They also praised the utility of having such a wide array of programming in a single setting.

Previous studies have found that the weekend retreat format is a successful modality by which to foster a sense of community and belonging among participants in addition to building self-esteem and mental health education [38,39]. We found similar success, at least initially. Loneliness scores dropped immediately after the retreat weekend, but they actually increased on the follow-up questionnaire. The reason for the dip in this specific metric is unknown, but free-text responses from the satisfaction questionnaire suggest that patients nonetheless felt a strong and novel sense of community belonging post-retreat.

Implementing retreats with programming similar to the one documented here may address critical needs of patients with hEDS and similar conditions by providing a more holistic, “one-stop” approach to care, education, and networking. In free-text responses, participants noted that obtaining the same resources outside of the retreat format would have been challenging and time consuming. Moreover, while the retreat took place over a single weekend, its effects were long lasting. Four to six months afterward, participants still reported improvements in kinesiophobia, physical functioning, energy and fatigue, pain, and general health over their pre-retreat scores. This suggests that even a relatively time-limited intervention may provide patients with significant benefits. We also note that, given the high demand for specialized providers along with their overall scarcity, an onsite retreat could help to streamline and decrease the burden on these clinicians.

In large part, the retreat appears to have succeeded in its goal of providing care for the whole person. However, we did identify certain shortcomings to our program design. Several metrics suggest that socioemotional health was not improved in a sustainable manner. Initial improvements in emotional wellbeing and social functioning (assessed by the SF-36) were not maintained at follow-up. Similarly, a few participants’ loneliness scores rose after the retreat had ended. We believe that creating a virtual space for participants to continue to interact, such as a Discord server or Facebook group, could help to maintain improvements after the retreat, and additional group-building

activities could be incorporated into the retreat programming. Moreover, though satisfied with the variety of presentations, participants nonetheless desired further topics to be covered, especially regarding mental health issues. Finally, some participants noted that more attention in menu planning should be paid to food intolerances, which may be particularly common among patients with hEDS [40,41].

## Conclusion

Findings from our pilot retreat for patients living with hEDS demonstrate that this programming format is an effective and impactful intervention to improve understanding and management of many symptoms. It provided participants with unique access to a combination of interventions and community that people typically cannot access so intensively and in a single place and time. We anticipate that the recommended conclusions by our pilot would help others to implement and optimize future retreat programming for this and similar populations. We believe that this retreat format may additionally have the potential for positive impact for an even larger population, including patients living with other connective tissue disorders as well as chronic pain and the debilitating effects of long COVID.

## Limitations

These findings suggest that our retreat design could provide a successful prototype for retreats to be replicated in the future and at other sites. However, the generalizability of our data is limited in certain ways that should be noted. First, this report is only meant to be preliminary and is based on a small number of participants. Additionally, the demographics of our population were narrow, and the effects of gender, age, and physical functioning should be considered in future work on this topic. Individuals attending our retreat were primarily married and employed at least part-time. Their Karnofsky scores suggested that on average, they required only occasional assistance with personal needs. Each of these factors implies that they may have significant supports and capacities that enabled their participation. Future work should consider how to assist participation of individuals without access to such resources.

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## Conflict of Interest Statement

Dr. Francomano is Chair of the Medical and Scientific Board for the Ehlers-Danlos Society (uncompensated) and Director of the IU Health Center for EDS and HSD.

## Ethical Statement

The Indiana University Institutional Review Board approved this study (Protocol#19137). All participants gave their informed consent.

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