

Oregon Health & Science University
School of Medicine

Scholarly Projects Final Report

Title *(Must match poster title; include key words in the title to improve electronic search capabilities.)*

Health-related quality of life outcomes in patients with Ehlers-Danlos Syndrome and treated vs. untreated pelvic organ prolapse

Student Investigator's Name

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Project Course *(Indicate whether the project was conducted in the Scholarly Projects Curriculum; Physician Scientist Experience; Combined Degree Program [MD/MPH, MD/PhD]; or other course.)*

Scholarly Projects Curriculum

Co-Investigators *(Names, departments; institution if not OHSU)*

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Concentration Lead's Name

Dr. Alex Foster

Project/Research Question

Which healthcare related quality of life realms are impacted by patients who have both pelvic organ prolapse and Ehler's Danlos Syndrome?

Type of Project *(Best description of your project; e.g., research study, quality improvement project, engineering project, etc.)*

Research study – Cross-sectional survey

Key words *(4-10 words describing key aspects of your project)*

Pelvic organ prolapse, Ehlers-Danlos Syndrome, psychosocial impacts, pelvic floor disorders

Meeting Presentations

If your project was presented at a meeting besides the OHSU Capstone, please provide the meeting(s) name, location, date, and presentation format below (poster vs. podium presentation or other).

N/A

Publications *(Abstract, article, other)*

If your project was published, please provide reference(s) below in JAMA style.

N/A

Submission to Archive

Final reports will be archived in a central library to benefit other students and colleagues. Describe any restrictions below (e.g., hold until publication of article on a specific date).

N/A

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Next Steps

What are possible next steps that would build upon the results of this project? Could any data or tools resulting from the project have the potential to be used to answer new research questions by future medical students?

As the study elucidated issues with sexual satisfaction in respondents of this study, it could lead to a future study focusing on this topic in a similar patient population.

Please follow the link below and complete the archival process for your Project in addition to submitting your final report.

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Student's Signature/Date *(Electronic signatures on this form are acceptable.)*

This report describes work that I conducted in the Scholarly Projects Curriculum or alternative academic program at the OHSU School of Medicine. By typing my signature below, I attest to its authenticity and originality and agree to submit it to the Archive.

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Report

Introduction (*≥250 words*)

Little research has examined the health-related quality of life of patients with concurrent Ehlers-Danlos Syndrome (EDS) and pelvic organ prolapse (POP). Pelvic organ prolapse is a broad term that encompasses a variety of pelvic floor disorders including uterine prolapse, cystocele, rectocele, and enterocele [1]. POP is a common condition with a variable prevalence dependent on the method of POP evaluation. For those who are assigned female at birth (AFAB), POP prevalence of 41-50% can be seen on physical examinations, though these rates reflect that many people with POP are asymptomatic [2]. When assessing symptomatic POP, prevalence is shown to be 3-6% [2]. The complex and multifactorial pathology of POP is associated with risk factors such as parity, vaginal delivery, age, and BMI [3].

Decreased quality of life and psychological implications have been associated with POP. Though the impact varies between patients due to the wide range of symptoms and clinical presentations, POP has been linked to sexual dysfunction, urinary and/or fecal incontinence, and decreased physical quality of life [4,5]. Findings of psychological impacts of POP include worse self-perceived body image, as well as patient reported feelings of guilt, shame, and a feeling of being “broken” [4,5]. As many of these factors (i.e. depression, social stigma, etc.) can be affected by how patients are treated and managed within the healthcare system and whether they receive accessible care, these findings highlight the importance of improved awareness, research, and access to healthcare specialists.

Previous research has shown that patients with Ehlers-Danlos exhibit higher rates of POP compared to the general population [6,7]. Due to the abnormal structure of connective tissue in these patients, POP can present in the absence of well-established risk factors such as parity, and often at a younger age [8,9]. Ehlers-Danlos Syndrome has an incidence of 1:5000 and is divided into multiple subtypes, with hypermobility type (hEDS) comprising the largest group [10]. Additionally, “Pelvic floor, rectal, and/or uterine prolapse in children, men, or nulliparous women without a history of morbid obesity or other known predisposing medical conditions” remains a minor criterion for clinical diagnosis of hEDS [11]. Though pelvic organ prolapse (POP) affects many people, qualitative research detailing the impact on quality of life is limited, even more so amongst the EDS patient population. As both POP and EDS are complex conditions with multisystem presentations, these patients face extensive challenges being diagnosed and treated for their conditions.

EDS shares aspects with POP in the sense that both conditions primarily affect those who are AFAB and can lead to a high psychosocial burden on patients. EDS has been shown to correlate with a high rate of psychiatric diagnoses and decreased health-related quality of life [12,13]. Areas of impacted quality of life include professional limitations, impact on social and personal relationships, and experiencing frequent pain [14]. This study seeks to examine health-related quality of life outcomes in patients with both EDS and POP. Given limited literature addressing this patient population, these findings may provide preliminary insight into patient experiences and inform future research.

Methods (*≥250 words*)

An anonymous cross-sectional survey was designed to evaluate health-related quality of life (HR-QOL) outcomes among individuals self-identifying as having both EDS and POP. Inclusion criteria included age 18 and older, assigned female at birth (AFAB), residence in the United States, existing diagnosis of EDS by a qualified provider, and self-reported POP based either on prior treatment or a positive response to a

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screening item adapted from the Pelvic Organ Prolapse Distress Inventory-6 (POPDI-6). Recruitment occurred through self-selection in online patient communities for EDS or POP patients. The survey was developed, administered, and stored using REDCap.

The survey included demographic and clinical information on EDS and POP. Symptom burden of POP was assessed utilizing the Pelvic Organ Prolapse Distress Inventory-6 (POPDI-6) [15]. HR-QOL outcomes were measured by validated PROMIS® short-forms which evaluated anxiety, depression, management of social interactions, management of daily activities, management of symptoms, sexual satisfaction, satisfaction of social roles, and isolation [16-20]. Additional survey items were created by the research team to assess patient satisfaction with provider knowledge and clinical information provided about EDS and POP. Branching logic was implemented to tailor question flow based on participant responses. This study was reviewed and approved by the Institutional Review Board, and all participants were provided electronic informed consent.

Statistical Analysis

Descriptive statistics were used to summarize demographic characteristics, clinical features, and patient responses to questions surrounding care improvement. PROMIS® measures were reported as standardized T-scores (mean = 50, SD = 10) using REDCap autoscoring. Inferential statistical testing was not performed due to the small sample size. Analyses was conducted using available participant responses, without imputation of missing responses.

Results (≥500 words)

Demographics

A total of 26 participants accessed the survey, of whom 11 were excluded for not meeting inclusion criteria. Fifteen completed surveys were included in final analysis. The median age of participants was 39 years (range 21-60). Most participants identified as Caucasian (14/15, 93.3%), with one participant leaving race undisclosed. The most common parity was two children (7/15, 46.7%). A summary of demographic characteristics is included in Appendix A.

Clinical EDS Information

Most participants reported hypermobile EDS (13/15, 86.7%), followed by classical EDS (1/15, 6.7%), and unknown subtype (1/15, 6.7%). All participants reported knowing the age at which they were diagnosed with EDS, with a median age of 39 years (range 21-60 years). All participants were aware that EDS can be associated with pelvic organ prolapse. A summary of clinical EDS characteristics is included in Appendix A.

Clinical POP Information

Clinical POP characteristics are summarized in Table 1. Most participants (14/15, 93.3%) had received treatment for POP at some period. Of those receiving treatment, half (7/14, 50%) had received surgical treatment, and (12/14, 85.7%) had received non-surgical treatment such as a pessary or pelvic floor physical therapy. Of those who had undergone POP surgery (n = 7), two participants (28.6%) reported the use of mesh, while five (71.4%) reported no mesh. All but one participant had knowledge of their age at the time of POP symptom onset, of which the median age was 30 years (range 14-59 years). The majority of participants (9/15, 60%) indicated that EDS played a role in their decision to have, or not have, a particular POP treatment modality.

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Table 1. POP Treatment and Symptom History

Variable	Category	n	%	Summary
POP treatment history				
	Received any treatment	14	93.3	
	Surgical treatment	7	50	
	Non-surgical treatment	12	85.7	
	Surgery with mesh	2	28.6	
	Surgery without mesh	5	71.4	
				Median 30 (14–59)
Age at POP symptom onset				
EDS influenced POP treatment decision	Yes		9	60
	No		5	33.3
	I'm not sure		1	6.7

Pelvic Organ Prolapse Distress Inventory (POPDI-6)

Raw POPDI-6 scores were converted to a 0-100 scale and are summarized in Table 2. Symptom burden had a mean score of 54.7 ± 20.5 (median 62.5, range-25.0-91.7). Based on predefined severity categories, five participants (5/15, 33.3%) had mild symptom burden and ten (10/15, 66.7%) has moderate to severe symptom burden.

Table 2. Pelvic Organ Prolapse Distress Inventory-6 (POPDI-6) Scores

Measure	n	Mean \pm SD	Median (range)	Symptom severity category
POPDI-6 (0–100 scale)	15	54.7 ± 20.5	62.5 (25.0–91.7)	Mild: 5/15 (33.3%) Moderate to severe: 10/15 (66.7%)

Symptom severity categories were defined based on the 0-100 POPDI-6 scale (0-33 = mild, 34-66 = moderate, 67-100 = severe).

Care Improvement

Most (13/15, 86.7%) participants reported having seen a provider specializing in POP. Satisfaction with the information given to them by their provider regarding POP was reported as very or extremely satisfied by 53.3% of participants. Satisfaction with provider’s knowledge of EDS was variable, with 26.7% very or extremely satisfied, and 46.7% not at all or somewhat satisfied. Satisfaction with information about EDS was similarly mixed with 33.3% not at all satisfied, and 26.7% extremely satisfied.

HR-QOL PROMIS® Measures

Fifteen participants completed the PROMIS® short-form measures, with associated data shown in Table 3.

Table 3. PROMIS® HR-QOL Measures

Domain	n	Mean \pm SD	Median (Range)	PROMIS® Interpretation
Anxiety	15	56.55 ± 6.97	58.0 (40.3–65.5)	Mild
Depression	15	51.97 ± 8.71	52.0 (41.0–69.5)	Within normal limits

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Self-efficacy: Managing Social Interactions	44.73 ± 15 5.61	43.7 (37.4–58.2)	Mild impairment
Self-efficacy: Managing Daily Activities	45.27 ± 15 7.28	43.3 (35.2–59.2)	Descriptive only
Self-efficacy: Managing Symptoms	42.69 ± 15 7.24	45.6 (32.1–55.7)	Descriptive only
Sexual Satisfaction	45.34 ± 11 9.88	46.8 (32.5–65.3)	Descriptive only
Satisfaction in Social Roles	46.86 ± 14 11.60	47.05 (27.9–63.8)	Within normal limits
Social Isolation	53.07 ± 14 8.13	51.65 (40.7–69.7)	Mild

PROMIS® adult cut-point guidance was applied to the domains of anxiety, depression, self-efficacy in managing social interactions, satisfaction in social roles, and social isolation. Domains without published cut-points including self-efficacy in managing daily activities, self-efficacy in managing symptoms, and sexual satisfaction, are reported descriptively.

Sexual Activity Screening

Eleven participants (11/15, 73.3%) reported being currently sexually active. Among the four that reported they were not sexually active, three (3/4, 75%) indicated that POP and/or EDS were the primary reason for their inactivity.

Discussion (≥500 words)

This exploratory study aimed to gather information on health-related quality of life among individuals with POP and EDS. Despite a small sample size limiting generalizability, several descriptive trends emerged which may provide insight into issues affecting this patient population as well as guide future research initiatives.

With a median age of 30 years at time of POP onset, patients with Ehlers-Danlos Syndrome reported a relatively early age of onset compared to the general population at 70-79 years [21]. This finding is in line with previous literature citing earlier ages, generally implicating connective tissue dysfunction as the main contributing factor [8,9]. The average age at time of EDS diagnosis was 39 years, indicating that many participants began experiencing POP symptoms prior to when they were diagnosed with EDS. For young individuals who may or may not have other health issues, it is understandable why POP symptoms at a young age could contribute to psychological symptoms such as anxiety and depression which are further explored below.

Across assessed PROMIS® measures, the mean T-scores generally fell within one standard deviation of population norms, suggesting that overall health-related quality of life outcomes were not markedly different from reference norms. However, several patterns were observed which can be discussed as general trends. Within the mental health domains, anxiety scores were slightly elevated while depression scores were within the average to mild range. Though within one standard deviation, these trends can be viewed as targets when considering efforts to improve patient care. Within the self-efficacy domains, multiple areas showed trends below the population mean but within one standard deviation, including managing symptoms, daily activities, and social interactions. Though again not statistically significant, a general trend toward lower self-efficacy may indicate subtle challenges in these patients which could be a focus of future research investigation.

Another area of interest which emerged from this study was sexual health. Sexual satisfaction scores varied between respondents though tended to fall below the population mean. Three out of four participants who

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were not sexually active identified EDS and/or POP as the main cause of inactivity. Though conclusions cannot be drawn from such a small subgroup, these responses suggest that burden of sexual dysfunction (i.e low libido, physical discomfort from POP, anxiety/depression, negative body image), may contribute to decreased health-related quality of life and highlights an area which warrants further investigation.

This study has several limitations, most notably a small homogenous sample size which limits both statistical analysis and generalizability. Second, recruitment took place through self-selection in online patient communities. While this broadened accessibility in a rare patient population, it also introduced selection bias into the study group. In addition, patients with more severe or debilitating symptoms are more likely to join patient support communities, potentially skewing results related to symptom severity. Lastly, diagnoses and medical histories were self-reported and unable to be verified.

Despite these limitations, this study contributed preliminary descriptive data on HR-QOL outcomes as well as elucidated areas of future research and care improvement within an understudied patient population. Future research with larger and more diverse cohorts will be necessary to further characterize HR-QOL outcomes and expand on our findings related to sexual dysfunction.

Conclusions (2-3 summary sentences)

This exploratory study provides preliminary insight into HR-QOL outcomes in patients with Ehlers-Danlos Syndrome and pelvic organ prolapse. While most HR-QOL measures fell within normal ranges, trends in symptom burden (anxiety, depression, self-efficacy) and sexual health suggest areas that warrant further investigation in a larger cohort.

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Appendix A

Variable	Category	n	%	Summary
				Median 39 (21–60)
Age (years)	25–34		2	13.3
	35–44		8	53.3
	45–54		2	13.3
	55–64		3	20
Race	Caucasian		14	93.3
	Prefer not to answer		1	6.7
Marital status	In a relationship		2	13.3
	Married		10	66.7
	Divorced		3	20
Number of children delivered	Median 2 (0–4+)			
	0		1	6.7
	1		1	6.7
	2		7	46.7
	3		4	26.7
	4+		2	13.3

Only categories with non-zero responses are shown in the table.

Variable	Category	n	%	Summary
EDS subtype	Hypermobile (hEDS)		13	86.6
	Classical EDS		1	6.7
	I'm not sure		1	6.7
	All other subtypes		0	0
Age at EDS diagnosis	Median 39 (21–60)			
Aware EDS associated with POP	Yes		15	100

All EDS subtypes were included in the survey; only categories with non-zero responses are shown for clarity.