



## **DYSpareunia and Vulvodynia in Women with Ehlers-Danlos Syndrome: An Online Survey**

J. Glayzer<sup>1</sup>, M. Suarez<sup>1</sup>, M. Meinel<sup>1</sup>, W.H. Kobak<sup>2</sup>, J.M. Schlaeger<sup>1</sup>

<sup>1</sup>Department of Human Development Nursing Science, University of Illinois at Chicago, Chicago, USA,

<sup>2</sup>Obstetrics and Gynecology, University of Illinois Health, Chicago, USA.

### **INTRODUCTION**

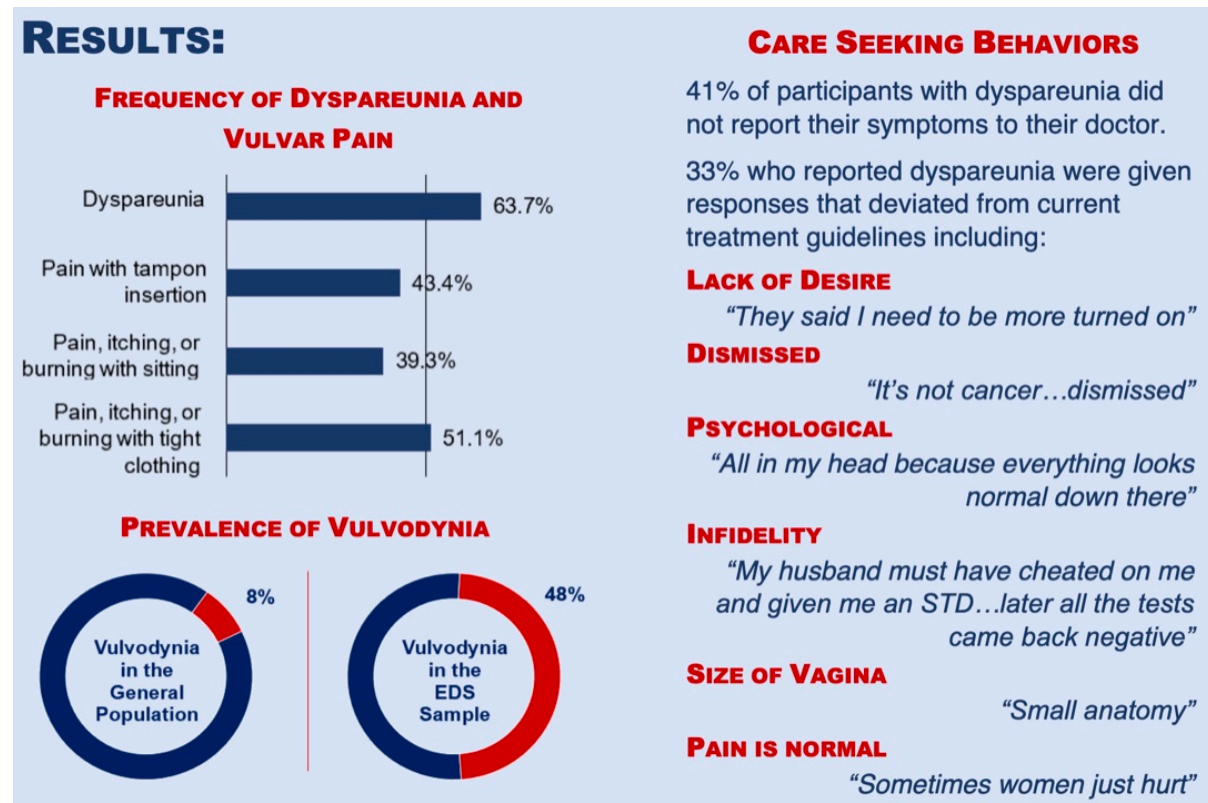
Vulvodynia is debilitating vulvar pain accompanied by dyspareunia (pain with sexual intercourse) that affects 8% of women in the USA.<sup>1</sup> Vulvodynia has no known cause or consistently effective treatment. Women with Ehlers-Danlos syndrome (EDS) may have a higher rate of vulvodynia based on a study that reported 77% of participants with EDS had dyspareunia<sup>2</sup> compared to 20% in the general population.<sup>3</sup> This study aims to examine the rate of dyspareunia; vulvodynia; and, gynecological conditions associated with dyspareunia in women with EDS. The multidimensional conceptualization of pain framework was used to develop this social media survey.

### **METHODS**

Women over the age of 18 years and diagnosed with EDS were recruited and completed a survey through a link on Facebook EDS support groups and Twitter. A descriptive analysis of self-reported medical history and symptoms revealed associations between dyspareunia and gynecological conditions. Participants were asked about 4 symptoms found to be valid, reliable, sensitive, and specific, used to diagnose vulvodynia in lieu of a pelvic exam.<sup>1</sup> The 4 symptoms included: 1) dyspareunia; 2) vaginal pain with tampon insertion; 3) vulvar pain and or burning and itching with sitting; and 4) vulvar pain and or burning and itching from tight clothing in contact with the vulva. A participant screened positive for vulvodynia by reporting dyspareunia and at least one of the other 3 symptoms.

### **RESULTS**

Women (N=1178) were 38.1±11.5 years old, primarily White (n=1093, 94.6%), and resided in 29 countries with the majority in the USA (n=923, 78.4%). 736 (63.7%) reported dyspareunia; 497 (43.4%) reported vaginal pain with tampon insertion; 450 (39.3%) reported vulvar pain and or burning and itching with sitting; and, 584 (51.1%) reported vulvar pain and/or burning and itching from tight clothing in contact with the vulva. 575 (48.8%) of the total sample screened positive for vulvodynia. Women who reported dyspareunia also reported ovarian cysts, fibroids, or scar tissue in the pelvis or vagina, 545 (47.9%); endometriosis, 291 (25.4%); and lacerations from childbirth or surgery, 210 (19.3%).



## CONCLUSION

There was a high number of self-reported vulvodynia symptoms indicative of a vulvodynia diagnosis in lieu of a pelvic exam in our global sample of women with EDS. This suggests that women with EDS may have a higher rate of vulvodynia (6 times as high) compared to the rate of vulvodynia in American women who do not have EDS (8%).<sup>1</sup> This substantiates the need to focus future research efforts on characterizing vulvodynia in women with EDS. Also, EDS patients should be screened for the presence of vulvodynia which will impact their ability to be diagnosed and treated.

## REFERENCES

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## DECLARATIONS OF INTEREST

None