GYNECOLOGY

# Social media utilization, preferences, and patterns of behavior in patients with gynecologic pelvic pain

Check for updates

Carolyn C. Piszczek, MD, MCR; Christine E. Foley, MD; Sara Farag, MD; Megan Northup, MD; Patricia Overcarsh, MD, MPH; Jack Wiedrick, MS, MA; Amanda C. Yunker, DO, MSCR; Amanda M. Ecker, MD

**BACKGROUND:** Social media is increasingly becoming a health resource for people suffering from complex and debilitating health conditions. A comprehensive understanding of how and why social media and the Internet are used among patients with chronic gynecologic pain will allow for the intentional development and incorporation of web-based tools into patient care plans.

**OBJECTIVE:** This study aimed to determine whether gynecologic patients with pain are more likely to use social media and the Internet to understand and manage their condition than those without pain. The survey was designed to explore how gynecologic patients with and without pain use and interact with social media and other web-based health resources and the clinical, personal, and demographic factors influencing these behaviors.

**STUDY DESIGN:** Patients presenting with a new complaint to a gynecologist at 1 of 6 Fellowship in Minimally Invasive Gynecologic Surgery—affiliated hospital systems were screened, consented, and assigned to pain and no-pain groups. Participants were surveyed about social media and Internet use, symptoms, bother, physician selection, motivation, trust, and demographic information. Survey responses were compared using the Fisher exact tests, odds ratios, and risk ratios from standard tabular analysis, univariate or multivariate tests of means, and regression analyses, as appropriate.

**RESULTS:** Of 517 participants included in the study, 475 (92%) completed the survey, 328 (69.1%) with pain and 147 (30.9%) without pain. Study participants in the pain group reported more than double the odds of using social media than those without pain (37.8% vs 19.7%; odds ratio,

2.47; 95% confidence interval, 1.54—3.96) and triple the odds of using the Internet (88.4% vs 69.4%; odds ratio, 3.37; 95% confidence, 2.04—5.56) to understand or manage their condition. Participants with pain were more likely than those without pain to engage in social media at a higher level (3.5 vs 1.7 on a scale of 0 to 10; $P<.0001$), be motivated by interpersonal elements of online engagement (Hotelling's $T^2=37.3$; $P<.0001$), prefer an interactive component to their online health resource (35.6% vs 24.3%; risk ratio, 1.46; 95% confidence interval, 1.00—2.20; $P=.0433$), be influenced by others in their choice of a gynecologist (0.37 vs 0.32 on a scale of 0 to 1; $P=.009$), use social media as a coping tool (38.3% vs 17%; $P=.0001$), trust information found on social media (31.4% vs 16.7%; $P=.0033$), and trust other women with the same condition, informal health resources, and personal sources more and doctors and formal health resources less ($P=.0083$). Participants in both groups reported higher levels of social media engagement with higher levels of symptom bother (28% increase in engagement with every doubling of bother level ($P<.0001$).

**CONCLUSION:** Patients with gynecologic pain were more likely than those without pain to use social media and the Internet to understand and manage their condition. Patients with pain engaged in and trusted social media at a higher level, with engagement rising directly with bother level.

**Key words:** chronic pelvic pain, Internet use, online peer groups, online support groups, social networking, virtual community, web-based resources

## Introduction

The use of social media for health management is well described in the literature for chronic rheumatologic, orthopedic, and neurologic conditions.[1−12] Online support groups have been shown to improve a sense of community,[5,7] self-management,[5,6,10,12] patient empowerment,[8,9,13] and health literacy.[6,10]

Reproductive health-related concerns constitute 90% of social media health queries initiated by females[14]; however, the understanding of its use among gynecology patients is limited to those with pelvic floor dysfunction.[15,16] Online communities specific to chronic benign gynecologic pain conditions carry strong and committed memberships[17−19] and constitute a significant portion of these queries.[20] Understanding the motivations behind social media engagement is essential to enable the development and dissemination of web-based community tools targeted at improving patient-centered outcomes. A literature search of English-language journals using PubMed or Ovid and Embase resulted in no study evaluating social media use among patients with gynecologic pelvic pain.

The primary objective of this study was to compare the use rates of social media and Internet-based resources for benign gynecologic health purposes among patients with and without pelvic pain. The secondary objective was to determine how these patients interact with web-based health resources and characterize the motivations behind this behavior. We hypothesized that patients with pelvic pain would be more likely to use social media and the Internet for the management of their condition than patients without pelvic pain.

## Materials and Methods

We conducted a multicenter, cross-sectional, comparative survey study from February 2018 to June 2019. Participants were recruited from 6 hospitals affiliated with a Fellowship in Minimally

## AJOG at a Glance

### Why was this study conducted?
This study aimed to determine whether gynecologic patients with pelvic pain were more likely to use social media for the management of their condition than those without pain and how patients with pain use social media and other informal online health resources.

### Key findings
Compared with patients without pain, patients with pain were more likely to use social media and Internet resources to manage their gynecologic condition, use these virtual resources to a greater extent, be influenced by others in their choice of a gynecologist, engage in social media at a higher level, use social media as a coping tool, trust information found on social media, and trust health information from other people suffering from the same condition.

### What does this add to what is known?
This study provided an understanding of the prevalence and role of social media and Internet resources in the self-management of gynecologic pain conditions.

Invasive Gynecologic Surgery (FMIGS) program (Table 1). The study protocol was approved by the institutional review boards at each study site before participant enrollment. The Oregon Health & Science University served as the primary study site and data coordinating center. Each site was asked to recruit at least 30 participants.

Patients aged 18 to 89 years who identified as female in the electronic medical record and presented to an FMIGS-affiliated general or minimally invasive gynecology clinic with a new complaint were eligible for recruitment. The exclusion criteria included pregnancy, incarceration, or inability to independently complete the English-language screening questions and agreement for participation. Patients were recruited either by phone before their appointment or in-person at the time of their appointment. The fellow or attending gynecologist recruited the patient. If the patient stated they were open to completing a survey about social media and Internet use related to their gynecologic condition, they were directed to the REDCap link (or given the paper version) to review the study information sheet (Appendix), answer screening questions, and complete the informed consent. The REDCap link sequentially progressed with a built-in automatic stop if a patient failed the screening or declined to participate. The group-determining question followed, "Is your upcoming doctor's visit for pain or discomfort that you believe is related to your female organs?"; those answering "yes" were included in the pain (study) group; those answering "no" were included in the no-pain (control) group. The proportional group response rate (pain—to—no-pain participant recruitment ratio) was not fixed or controlled. The participants self-selected into which group they belonged. A group-specific survey opened after the participants responded to the group-determining question.

Surveyed information included demographics; symptom description, duration, and degree of bother; frequency and type of social media and Internet use; factors influencing physician selection; motivation for social media engagement; and trust in information sources (Table 2). No individually identifiable information was collected. Paper survey responses were manually entered into REDCap by the on-site investigator.

### Sample size
We used a "best guess" baseline social media use rate estimate of 60% in the no-pain (control) group based on national health-related social media use rates extrapolated to study year,[21,22] with a planned interim refinement once 300 surveys were collected. To achieve 80% power at an alpha of 0.05 under the preliminary assumption that the pain to no-pain recruitment ratio would be 1:1, we estimated that 376 participants would be needed in each group to detect a 10 percentage point difference in the primary outcome. However, we recognized at the time that the actual baseline use rate and recruitment ratio would likely vary from 60% and 1:1, respectively; moreover, we incorporated a plan for using the observed use rate in the no-pain group and recruitment ratio to inform our refined sample size calculation. Note that the refined sample size was calculated with the researchers remaining blind to the outcome rate observed in the pain group but assumed that the recruitment ratio would continue as observed. The actual ratio at the time was 2.45:1, approximately the same as the final obtained ratio of 2.23:1, and the actual baseline use rate was 21%, similar to the final obtained rate of 19.7%. Recruitment continued until the refined sample size goal of 471 total participants was reached.

### Data analysis and statistics
Patient demographics were compared using standardized differences.[23] Primary and secondary outcomes were compared using the Fisher exact test. The raw survey responses were described using descriptive statistical analysis and augmented by the Fisher exact test or Mann-Whitney $U$ test, as appropriate. Indices for symptom bother, social media engagement, influenced level, and trust profile were calculated using factor analysis to construct composite variables and canonical correlation[24] and structural equation modeling to facilitate group comparisons. Intergroup comparisons for related blocks of survey questions were visually examined using radar plots, and the multivariate distances between group means were formally characterized using the Hotelling's $T^2$ tests.[25] Exploratory data analysis

(cluster analyses; linear, logistic, multi-nomial regression modeling) was used to determine whether additional covariate patterns existed that linked clinical profiles with social media usage profiles. All statistical analyses were performed using Stata (version 16; StataCorp LLC, College Station, TX).

## Results

From February 2018 to April 2019, 517 patients verbally agreed to participate in the survey study. A total of 516 were eligible, and 475 completed the survey. Those who consented but did not complete the survey were balanced between groups (P=.462). Overall, 328 patients were assigned to the pain group, and 147 patients were assigned to the no-pain group (Figure 1). 56 participants (11.8%) completed the paper surveys, and 419 participants (88.2%) completed the web-based surveys (in REDCap). Paper surveys entered manually underwent a reliability check where 2 people independently entered a randomly selected 12 of 56 surveys (21.4%) and input values were compared—a discrepancy proportion of 0.00545 was noted. All but 1 study site recruited at least 30 participants. Response variance was not explained by clinic origin or any clinic characteristic, including location, clinic environment (university vs community), or practice population by insurance type. The maximum variance explained by clinic origin was <3% for any survey outcome and approximately 0 for most outcomes; therefore, pooled analysis of all participants was performed. Percentages were calculated using the total number of participants completing the specific survey question.

Demographic information is shown in Table 1. Most survey participants were non-Hispanic (88.4%), White (79.0%), completed some college or beyond (71.8%), and lived in a household size of ≥2 (77.4%). A small minority of participants reported an annual household income below the federal poverty level by number of household inhabitants (7.9%). The mean age of the survey participants was 41 years (standard deviation, 13.3), with a range of 18 to 79

years. Baseline characteristics were similar between groups except for age, where the pain group was on average 4.7 years younger than the no-pain group (mean, 39.1 vs 43.8 years; Cohen d=0.36). We did not think that this age difference was large either clinically concerning gynecologic symptoms or sociologically in terms of preferences and comfort with technology, so we maintained that there is no appreciable confounding of the comparisons by age. To the best of our judgment, the groups were well matched.

The participants' presenting complaints, by study group, are shown in

Supplemental Figure 1, and a description of the location and timing of symptoms experienced by those in the pain group are shown in Supplemental Figure 2. Of note, 256 of 316 participants (81%) in the pain group and 63 of 138 participants (45%) in the no-pain group reported their presenting symptoms as chronic (present for ≥6 months).

Participants in the pain group were more likely than those in the no-pain group to use social media to understand or manage their gynecologic condition (37.8% vs 19.7; risk ratio [RR], 1.92; 95% confidence interval [CI],

### TABLE 1
### Demographics

| Characteristic | Pain n (%) or mean (SD) | No pain n (%) or mean (SD) | Cohen d |
|---|---|---|---|
| Race[a] | | | |
| Black | 36 (12) | 11 (8) | 0.12 |
| White | 233 (77) | 113 (84) | 0.17 |
| Asian | 12 (4) | 3 (2) | 0.10 |
| Hispanic | 33 (11) | 18 (13) | 0.07 |
| Amerindian or Alaskan | 1 (0.3) | 1 (1) | 0.06 |
| Pacific Islander | 0 (0) | 1 (1) | 0.12 |
| Multiracial | 21 (7) | 6 (4) | 0.11 |
| Age (y) | 39.1 (12.1) | 43.8 (15.3) | 0.36[b] |
| Education (y)[c] | 15.8 (3.0) | 16.0 (2.9) | 0.05 |
| Household size | 2.6 (1.5) | 2.5 (1.4) | −0.07 |
| Log (annual household income)[d] | 11.2 (1.0) | 11.3 (0.8) | 0.12 |
| Study site | | | |
| Cleveland Clinic Florida | 65 (19.8) | 21 (14.3) | |
| Legacy Health | 53 (16.2) | 54 (36.7) | |
| Oregon Health & Science University | 90 (27.4) | 23 (15.6) | |
| Scripps San Diego | 15 (4.6) | 6 (4.1) | |
| Vanderbilt | 65 (19.8) | 14 (9.5) | |
| University of Pittsburgh Medical Center | 38 (11.6) | 29 (19.7) | |
| Undefined[e] | 2 (0.6) | 0 (0) | |

Cohen d: differences with d<0.2 are considered evidence of adequate similarity between the groups.

SD, standard deviation.

[a] Race categories are not mutually exclusive and some participants declined to respond; percentages represent the fraction responding "yes" to the category among those who provided a response; [b] Statistically significant difference; [c] Among the participants, 10 = did not complete HS; 12 = HS diploma; 16 = college degree; 20 = postgraduate degree. The number is not the number of subjects in each education category but instead the meaning of "10", "12", "16" and "20" as a value on the scale; [d] Values reported in natural log units $x$; reported values obtained as $e^x$. Example: $e^{11.2} \approx 2.718^{11.2} \approx \$73,000$ annual income. Reported income showed an extreme skew, ranging from $0 to $40 M per year, but when log-transformed was approximately normal; [e] Patient selected a nonparticipating site as their clinic site.
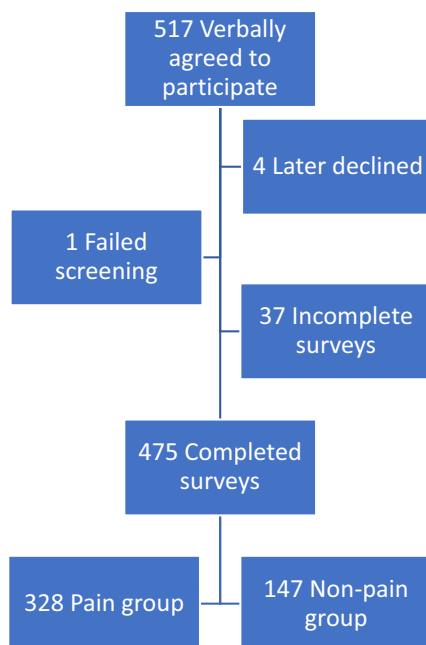
Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.

## FIGURE 1
## CONSORT flow diagram



CONSORT, Consolidated Standards of Reporting Trials.

Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.

1.27−2.98; P=.0009). Patients with pain were more likely to use the Internet to understand or manage their gynecologic condition (88.4% vs 69.4%; RR, 1.27; 95% CI, 1.01−1.61; P=.0329). The pain group spent more time per week using social media (mean, 1.26 vs 0.44 hours; P=.0001) and the Internet (mean, 1.70 vs 0.93 hours; P<.0001). Moreover, they reported a significantly higher frequency of social media use (odds ratio [OR], 2.72; 95% CI, 1.75−4.23) and Internet use (OR, 2.84; 95% CI, 1.93−4.16) (Table 3).

The participants' level of bother from their presenting gynecologic symptom was assessed both with a single measurement on a visual scale from 0 to 100 and a composite index on a scale of 0 to 1 that consisted of 3 components: days per month of bother, amount of bother by visual scale, and the fraction of the respondent's life affected by bother. The index formula is shown in Table 3. Participants in the pain group reported bother from their presenting symptom for a longer period (mean, 5.71 vs 2.53 years; P<.0001), more frequently

(mean, 15.33 vs 6.56 days per month; P<.0001), and to a more severe degree as measured by both the visual scale (mean bother level [0−100], 74.53 vs 43.65; P<.0001) and composite index (median bother index [0−1], 0.30 vs 0.04; P<.0001) than the no-pain group (Table 3).

Patients in the pain group reached out to more sources of information (mean, 3.1 vs 2.5; P=.0005) and used all resources at a higher rate than those in the no-pain group (Hotelling's $T^2$=24.4; P=.0006) (Table 4; Figure 2). Participants in the pain group similarly used more mediums of information (mean, 2.2 vs 1.8; P=.0069) and used all mediums at a higher rate (Hotelling's $T^2$=16.5; P=.0134). Participants in both groups ranked their preferred sources and mediums of information similarly, with specialists and in-person as the most preferred and clinics or hospitals and podcasts as the least preferred (Table 4).

Participants in the pain group saw a mean of 2.92 physicians for the specific presenting complaint (interquartile range [IQR], 1−4; range, 0−15) compared with 1.80 (IQR, 1−2; range, 0−8) in the no-pain group (P<.0001). Based on the response to survey question 14, we designed an "influence level" index to describe the degree to which a participant was externally influenced in choosing their gynecologist vs making the choice independently. Index formulas are shown in Table 4. Patients with pain scored consistently higher on the index (0.37 vs 0.32 on a scale of 0 to 1; P=.009).

Participants in both pain and no-pain groups most frequently reported seeking medical knowledge as their motivation for going online (82.3% [pain] and 75.5% [no pain]); moreover, physician reviews (59.5% and 54.4%) and learning about other individuals' experiences (60.7% and 37.4%) were selected at high rates. Participants in the pain group were more likely to be motivated by interpersonal elements of online engagement (Hotelling's $T^2$=37.3; P<.0001) and preferred an interactive component to online health resources (35.6% vs 24.3%; RR, 1.46; 95% CI, 1.00−2.20;

P=.0433). Participants with pain reported a greater degree of social media interaction than participants without pain (Hotelling's $T^2$=32.1; P<.0001). Social media engagement level was measured with a 10-point index derived from the respondent's social media use time and positive responses to questions measuring aspects of social media involvement. Participants in the pain group engaged in social media at a higher level (3.5 vs 1.7; z=5.80; P<.0001). Respondents in both groups engaged in social media to a level commensurate to their bother, as measured by engagement and bother indexes (Figure 3); engagement increased by 28% with every doubling of bother (P<.0001). The pain group demonstrated consistently larger probabilities of engagement at all levels of bother, with an average 15 percentage point increase in the probability of engagement at any level of bother (P=.0006). Moreover, participants in the pain group reported higher use of social media as a coping tool (38.3% vs 17.0%; RR, 2.25; 95% CI, 1.45−3.65; P=.0001).

In addition, trust in social media was higher in the pain group than in the no-pain group, both as a binary response (question 22, "Do you trust the information you find on social media") (31.4% vs 16.7%; RR, 1.89; 95% CI, 1.20−3.08; P=.0033) and when measured on a scale with other nonsocial media sources of information (question 23) (Hotelling's $T^2$=17.9; P=.0083). Trust profiles from survey question 23 responses were constructed into informative composites using factor analysis via a representative structural equation model (Table 4). They were grouped into a "trust doctors" factor from the adjusted summative responses of trust in doctors and hospitals or clinics; a "trust others" factor from the adjusted summative responses of trust in health media, women with the same condition, and friends or family; and a "trust anyone" factor as a simple average of the other 2 factors. Participants in the pain and no-pain study groups did not differ in their total level of trust ("trust anyone" difference, −0.4; P=.9203); however, they had opposite profiles in

---

**TABLE 2**
**Survey questions (pain group version)**

1. Do you use SOCIAL MEDIA to learn about or manage the gynecologic condition you are seeing the doctor for?
   ○ Yes
   ○ No

2. Do you use the INTERNET to learn about or manage the gynecologic condition you are seeing the doctor for?
   ○ Yes
   ○ No

3. How many HOURS PER WEEK do you spend on SOCIAL MEDIA (in relation to your gynecologic pain condition)?
   _____

4. How many HOURS PER WEEK do you spend on the INTERNET (in relation to your gynecologic pain condition)?
   _____

5. How frequently do you use SOCIAL MEDIA (in relation to your gynecologic pain condition)?
   ○ Monthly
   ○ Weekly
   ○ A few times a week
   ○ Daily
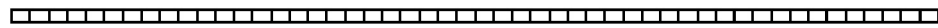   ○ Other (please specify): _____

6. How frequently do you go ONLINE (in relation to your gynecologic pain condition)?
   ○ Monthly
   ○ Weekly
   ○ A few times a week
   ○ Daily
   ○ Other (please specify): _____

7. Has your pain/discomfort been bothering you for 6 months or longer?
   ○ Yes
   ○ No

8. For how many YEARS has your gynecologic symptom or condition bothered you?
   _____

   (May use decimals for portions of a year – example: 9 months is 0.75)

9. How many DAYS PER MONTH does your gynecologic symptom or condition bother you?
   _____

10. How much does your gynecologic symptom or condition bother you? CLICK ON SLIDER TO ENTER RESPONSE (you must click slider to register a response, even if you are not moving it)

    Not at all Moderately Greatly

    ▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯▯

11. To whom do you go for information related to your gynecologic pain or discomfort? CHECK ALL THAT APPLY
    ○ Your family doctor (primary care doctor)
    ○ Specialist doctor (gynecologist)
    ○ Clinic/hospital/medical organization
    ○ Health magazines or informational websites
    ○ Women with the same condition (through patient communities or social media)
    ○ Friends, family
    ○ Other (please specify): _____

12. Where do you prefer to find this information? CHECK ALL THAT APPLY
    ○ In person
    ○ Website in written form
    ○ Website in video form
    ○ Books/magazines
    ○ App
    ○ Podcast
    ○ Other (please specify): _____

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*     *(continued)*

**TABLE 2**
**Survey questions (pain group version)** *(continued)*

13. How many physicians have you seen specifically for your gynecologic pain?

_____

14. What made you choose the gynecologist you are seeing today? CHECK ALL THAT APPLY
   - ○ Recommendation of another physician or healthcare provider
   - ○ Recommendation of friend or family member
   - ○ Recommendation on social media website or app
   - ○ Selected from in-network providers
   - ○ I get all my care at this facility
   - ○ Other (please specify): _____

15. Why do you go online (in relation to your gynecologic pain condition)? CHECK ALL THAT APPLY
   - ○ Community and/or social support
   - ○ Share my experience or story
   - ○ Learn about other people's experiences
   - ○ Physician reviews and/or recommendations
   - ○ Medical knowledge
   - ○ Other (please specify): _____

16. Which of the following ONLINE resources do you access for health information (related to your gynecologic pain condition)? CHECK ALL THAT APPLY
   - ○ I do not get health information online
   - ○ Social media (example: Facebook, blogs, patient online communities, YouTube, Yelp)
   - ○ Informational media (examples: Health magazines, WebMD, Google, podcasts)
   - ○ Physician, clinic, hospital, or medical society websites
   - ○ Other (please specify): _____

17. Do you prefer your source of information to have a way for people to interact (peer/patient support groups, forum to provide comments, read comments from others, personal messaging, etc)?
   - ○ Yes
   - ○ No
   - ○ Don't care either way

18. When engaging in social media (related to your gynecologic pain condition), what is your involvement? CHECK ALL THAT APPLY
   - ○ Read about other people's experiences
   - ○ Comment on other people's experiences
   - ○ Write about my own experience
   - ○ I don't engage in social media related to my female pain condition
   - ○ Other (please specify): _____

19. Which types of SOCIAL MEDIA do you use (in relation to your gynecologic pain condition)? CHECK ALL THAT APPLY
   - ○ None
   - ○ Social networks (examples: Facebook, Instagram, Twitter)
   - ○ Video share (example: YouTube)
   - ○ Consumer-created content (example: Wikipedia)
   - ○ Physician/hospital rating sites (examples: Yelp, Healthgrades)
   - ○ Health apps (example: calorie counter, pain diary, bladder diary)
   - ○ Blogs
   - ○ Patient communities (example: HysterSisters)
   - ○ Other (please specify): _____

20. Have you written online about your experience with a physician or clinic/hospital?
   - ○ Yes
   - ○ No

21. Does information you find on SOCIAL MEDIA affect the way you MANAGE OR COPE WITH your gynecologic pain condition?
   - ○ Yes
   - ○ No

22. Do you TRUST information you find on SOCIAL MEDIA (in relation to your gynecologic pain condition)?
   - ○ Yes
   - ○ No

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*                    *(continued)*

---

**TABLE 2**
**Survey questions (pain group version)** *(continued)*

23. How much do you trust health information (related to your gynecologic pain condition) from:
CLICK ON SLIDER TO ENTER RESPONSE (you must click slider to register a response, even if you are not moving it)

| | | Not at all | Moderately | Completely |
|---|---|---|---|---|
| a. | Your family doctor (or primary care doctor) | | | |
| b. | A specialist doctor (gynecologist) | | | |
| c. | A hospital, clinic, or official medical organization | | | |
| d. | Health magazines or informational health websites | | | |
| e. | Other people suffering from the same condition[a] | | | |
| f. | Friends and family | | | |

The no-pain group survey questions were worded the same except that "pain" and "pain or discomfort" were omitted and "pain or discomfort" replaced with "symptom or condition."

Slider scale (0—100), where 0 = "not at all," 50 = "moderately," 100 = "greatly or completely."

[a] Whom you do not know personally but found through a support group or social media.

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*

---

terms of how they allocated that trust, with the pain group participants trusting doctors and official medical sources to a lesser degree and other women with the same condition, informal health media, and personal sources to a greater degree.

## Comment
### Principal findings
Here, patients presenting to the gynecologist with the primary complaint of pelvic pain were more likely to use social media and Internet-based resources related to their gynecologic complaint than patients presenting for no-pain conditions. Our study found that (1) most gynecologic patients used online resources to learn about or manage their condition, (2) participants with greater degrees of symptom bother engaged in online resources to a greater extent regardless of the study group, (3) those with pain use social media to a higher degree per level of bother than those without pain, and (4) those with pain trusted social media, valued social media, and used it as a coping tool more than those without pain. Participants, regardless of the study group or bother level, use online health resources from traditional sources at similar rates; those with higher levels of bother and those in the pain group used laymen and peer resources and engaged in interpersonal

components of these resources. Overall, these findings showed that most patients incorporate online resources, and a large minority incorporate social media in the management of their gynecologic conditions and that those with pelvic pain do so to a greater extent. This supported our hypothesis.

### Results
Our study findings suggested that bother level and pain independently influence online resource usage and that patients experiencing significant bother and/or pain value connectedness through the virtual community as an important part of their comprehensive healthcare. Similar to our findings, rheumatologic and orthopedic studies have demonstrated a direct relationship between persistent pain and social media use with a commensurate decline in trust in the formal medical system.[4,26,27] Bright et al[4] and Hadert et al[27] linked the failure of formal treatment to relieve chronic knee and joint pain, respectively, to online community engagement and a decrease in provider trust. Maintaining the patient-physician relationship is essential to optimizing health outcomes[28]; however, Americans doubt professional opinion when in conflict with social media content.[29]

The therapeutic effect of the online community for the management of

gynecologic pain needs to be studied and measured. Noncomparative studies involving patients with fibromyalgia, arthritis, and knee conditions reported a therapeutic benefit to condition-specific social networking sites, discussion forums, and blogs.[3,4,30] A survey involving 231 patients with nongynecologic chronic pain found that those engaged in social media for chronic disease management had improved psychological, social, and cognitive health.[3] A study of noncancer patients with chronic pain showed decreased anxiety and opioid misuse among participants randomized to a peer-led online community intervention focused on behavioral change.[30]

### Clinical implications
Our study suggests that higher social media use and engagement stems from medical needs unmet by the formal healthcare system. Cultivating a patient care environment in which both social media and formal care can exist together might achieve better patient outcomes.

### Research implications
Our study described social media and Internet use among patients with pelvic pain and brought forth factors influencing its use. To move from this objective awareness to improved patient

### TABLE 3
### Social media use, Internet use, and symptom bother

| Variable | Pain | No pain | OR (95% CI) P value |
|---|---|---|---|
| Use social media | | | |
| Yes | 124 (37.8) | 29 (19.7) | 2.47 (1.54−3.96) |
| No | 204 (62.2) | 118 (80.3) | P=.0001 |
| Use the Internet | | | |
| Yes | 290 (88.4) | 102 (69.4) | 3.37 (2.04−5.56) |
| No | 38 (11.6) | 45 (30.6) | P<.0001 |
| Time per week (h) | | | |
| Social media | 1.26 (3.39) | 0.44 (1.40) | P=.0001 |
| Internet | 1.7 (2.75) | 0.93 (2.15) | P<.0001 |
| Frequency of social media use | | | |
| Daily | 16 (5.2) | 1 (0.8) | 2.72 (1.75−4.23) |
| A few times per week | 25 (8.1) | 5 (3.9) | P<.0001 |
| Weekly | 33 (10.7) | 7 (5.4) | |
| Monthly | 76 (24.8) | 21 (16.3) | |
| Less than monthly | 157 (51.1) | 95 (73.6) | |
| Frequency of Internet use | | | |
| Daily | 27 (8.7) | 5 (3.7) | 2.84 (1.93−4.16) |
| A few times per week | 39 (12.5) | 7 (5.2) | P<.0001 |
| Weekly | 60 (19.2) | 13 (9.6) | |
| Monthly | 101 (32.4) | 41 (30.4) | |
| Less than monthly | 85 (27.2) | 69 (51.1) | |
| Chronic symptoms | 256/316 (81.0) | 63/138 (45.7) | P<.0001 |
| Years of symptom bother | | | |
| Mean (SD) | 5.71 (7.05) | 2.53 (4.88) | P<.0001 |
| Median (25th, 75th, 90th percentile) | 3 (0.75, 8.00, 15.00) | 0 (0.00, 3.00, 9.00) | |
| Days per month of bother | | | |
| Mean (SD) | 15.33 (10.46) | 6.56 (9.58) | P<.0001 |
| Median (25th, 75th, 90th percentile) | 15 (5, 25, 30) | 2 (0, 10, 30) | |
| Bother level (0−100) | | | |
| Mean (SD) | 74.53 (22.44) | 43.65 (35.33) | P<.0001 |
| Median (25th, 75th, 90th percentile) | 78 (61, 94, 100) | 50 (2, 74, 96) | |
| Bother index (0−1)[a] | | | |
| Mean (SD) | 0.37 (0.28) | 0.16 (0.24) | P<.0001 |
| Median (25th, 75th, 90th percentile) | 0.30 (0.12, 0.59, 0.82) | 0.04 (0.00, 0.23, 0.55) | |

Data are presented as number (percentage), number/total number (percentage), or mean (SD), unless otherwise indicated. Chronic is defined as ≥6 month duration.

Bother index $= \dfrac{days\ per\ month}{30} \times$ (amount of bother on 0 to 100 percentage scale) $\times \left(1 - \dfrac{1}{\{\%\ of\ life\ affected\}}\right)$ % of life affected $= \dfrac{years\ of\ bother + 1\ if > 6\ months}{age}$.

CI, confidence interval; OR, odds ratio; SD, standard deviation.

[a] Each of the 3 components was subjected to a minor continuity correction to keep the values strictly >0 and <1.

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*

**TABLE 4**
**Social media preferences, trust, motivation, and engagement**

| Variable | Pain n (%) | No pain n (%) | Comparison statistic | P value |
|---|---|---|---|---|
| **Source of health information** | | | | |
| Specialists | 304 (92.7) | 128 (87.1) | | |
| Primary care physician | 172 (52.4) | 66 (44.9) | | |
| Friends/family | 174 (53.0) | 69 (46.9) | | |
| Health media | 146 (44.5) | 47 (32.0) | Hotelling's $T^2$=24.4 (df=6) | .0006 |
| Other women | 128 (39.0) | 34 (23.1) | | |
| Clinics or hospitals | 91 (27.7) | 24 (16.3) | | |
| Other | 20 (6.1) | 8 (5.4) | | |
| Mean response count | 3.1 (1.4) | 2.5 (1.3) | Mean difference=0.6 | .0005 |
| **Preferred medium of information** | | | | |
| In person | 298 (90.9) | 126 (85.7) | | |
| Website in written form | 236 (72.0) | 92 (62.6) | | |
| Website in video form | 75 (22.9) | 18 (12.2) | | |
| Books or magazines | 62 (18.9) | 21 (14.3) | Hotelling's $T^2$=16.5 (df=6) | .0134 |
| App | 40 (12.2) | 9 (6.1) | | |
| Podcast | 22 (6.7) | 5 (3.4) | | |
| Other | 8 (2.4) | 5 (3.4) | | |
| Mean response count | 2.2 (1.1) | 1.8 (0.9) | Mean difference=0.4 | .0069 |
| Influenced level (0—1)[a] | 0.37 | 0.32 | Cohen's d=0.25 | .0090 |
| **Motivation to go online** | | | | |
| Community or social support | 78 (23.8) | 16 (10.1) | | |
| Share my experience | 46 (14.0) | 2 (1.4) | | |
| Learn about others' experiences | 199 (60.7) | 55 (37.4) | Hotelling's $T^2$=37.3 (df=5) | <.0001 |
| Physician reviews | 195 (59.5) | 80 (54.4) | | |
| Medical knowledge | 270 (82.3) | 111 (75.5) | | |
| Prefer interactive online media | 115 (35.6) | 35 (24.3) | RR=1.46 (95% CI, 1.00—2.20) | .0433 |
| **Involvement in social media** | | | | |
| Read about others' experiences | 184 (56.1) | 50 (34.0) | | |
| Comment on others' experiences | 43 (13.1) | 3 (2.0) | | |
| Write about my experiences | 46 (14.0) | 2 (1.4) | Hotelling's $T^2$=32.1 (df=3) | <.0001 |
| I do not engage | 139 (42.4) | 95 (64.6) | | |
| Engagement level (0—10)[b] | 3.5 (3.2) | 1.7 (2.2) | Mean difference=1.8 | <.0001 |
| Use of social media to cope | 123 (38.3) | 24 (17.0) | RR=2.25 (95% CI, 1.45—3.65) | .0001 |
| Trust social media | 100 (31.4) | 24 (16.7) | RR=1.89 (95% CI, 1.20—3.08) | .0033 |
| **Trust level mean (0 to 100)** | | | | |
| Primary care doctor | 68.6 | 75.3 | | |
| Specialist doctor | 87.6 | 91.1 | | |
| Hospital or clinic | 71.8 | 74.0 | Hotelling's $T^2$=17.9 (df=6) | .0083 |
| Health media | 52.2 | 49.7 | | |
| Other women suffering | 56.9 | 49.8 | | |
| Friends or family | 56.7 | 57.8 | | |

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*                    *(continued)*

## TABLE 4
### Social media preferences, trust, motivation, and engagement (continued)

| Variable | Pain n (%) | No pain n (%) | Comparison statistic | Pvalue |
|---|---|---|---|---|
| Trust doctors[c] | 73.5 | 79.7 | z=−1.89 | .0588 |
| Trust others[c] | 58.5 | 51.9 | z=1.75 | .0801 |
| Trust anyone[c] | 66.1 | 66.5 | z=−0.10 | .9203 |

*CI*, confidence interval; *RR*, risk ratio; *SD*, standard deviation.

[a] Influenced level was determined using canonical correlation applied to survey question 14 to create an index of responses on a scale of 0 to 1: *influenced level* = 4· {*social media*} + 2·{*word of mouth*} + 1·{*referral*} − 2·{*in network*} − 1·{*always go here*}, anchored at 0 and scaled by the maximum value (to create a scale of 0 to 1). Physician referral, word of mouth, and social media recommendations in the "influenced" set; personal ("selected from in-network providers") and default selection ("I get all my care at this facility") reasons in the "noninfluenced" set;
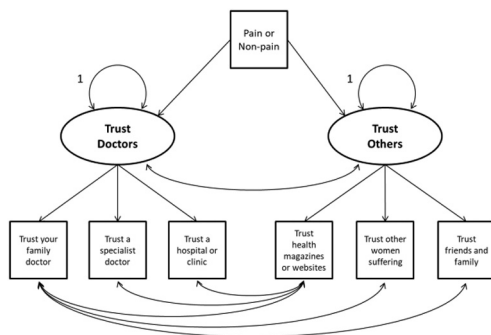


[b] Engagement level was derived through factor analysis into a composite index of responses on a scale of 0 to 10: hours per year on social media log-transformed (to reduce skew) and standardized to create an index of time, a value of 0 indicating a typical amount of time spent, and positive or negative values indicating more or less than typical, counted in SD units. Those with a time index of >0 received 1 point each for a positive response to questions 1, 2, 16, and 19. For all time index values, we gave 1 point each for a positive response to questions 17, 18, and 20; [c] The trust profile model assigned indicators to either the "trust doctors" or "trust others" factor, allowing certain residual covariances among the indicators and a residual covariance (ie, variance not explained by pain status) among the latent factors, whose respective variances are standardized to 1. Factor scores for each of the 2 latent factors were calculated using predicted values from this model, centered at the no-pain group mean of the corresponding indicators, and finally scaled to have a common variance typical of the indicator variance.

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*

care, clinical effectiveness studies measuring and comparing patient outcomes are needed. Such research will inform patient-centered online resource development and dissemination efforts. Given the wide accessibility of online platforms and the relationship of increased symptom bother to increased online resource use demonstrated in our study, these tools would inherently reach the patients that needed them most and enhance the return on investment.

### Strengths and limitations
Our study included participants from geographically diverse locations in both academic and community clinics. The survey systematically asked questions in multiple ways to increase the reliability of observed response differences between study groups. Moreover, the survey had a high response rate. All participants were required to answer the primary outcome questions. The remaining questions received response rates from approximately 80% to 100%.

Recruitment bias is a significant limitation of our study. Patients willing to complete a web-based survey may be more likely to engage in social media and the Internet. We attempted to minimize this bias by offering paper surveys; however, only 56 study participants (11.8%) used this option.

The population of patients presenting to an FMIGS-affiliated clinic for care limited the generalizability of our study findings because of referral patterns and the complexity of gynecologic pathology within these practices. In addition, our study participants were largely non-Hispanic, college-educated, White females—a population that might have easier access to technology and greater fluency with an online platform than the general population. Lastly, although the survey was thoroughly reviewed for content, clarity, reading level, and ease of use, it was not formally validated.

### Conclusions
Our study found that gynecologic patients with pain use social media more than those without pain, and many perceived a significant health benefit. The therapeutic effect of social media has been demonstrated in nongynecologic patient populations with chronic pain. Its effect on patient-centered outcomes in chronic pelvic pain needs to be
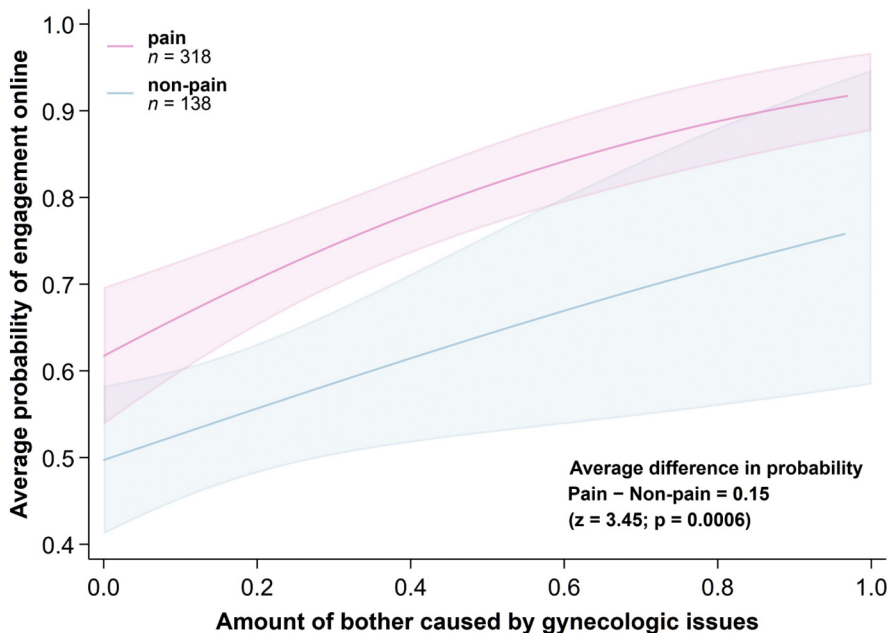
**FIGURE 2**
**Sources of health information**

**Do you turn to ___ for information about your condition?** (% 'yes')
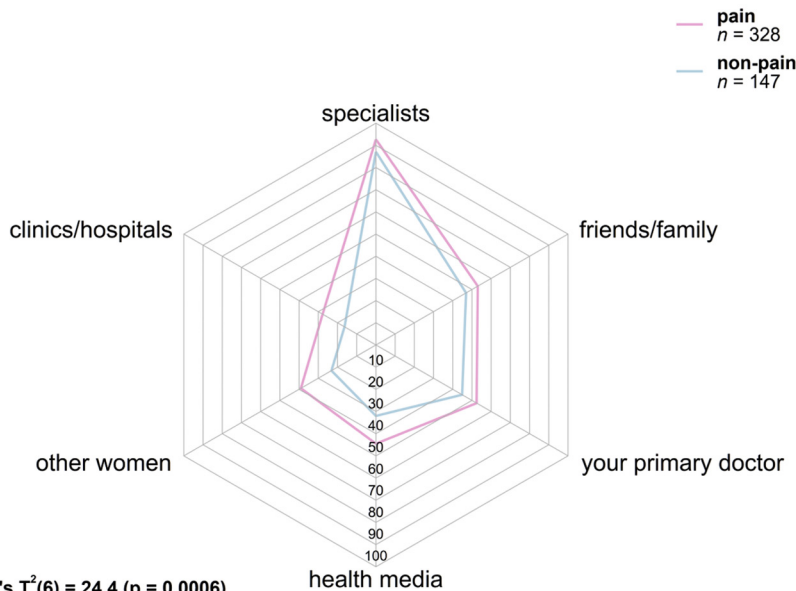
**Hotelling's $T^2$(6) = 24.4 (p = 0.0006)**

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*



**FIGURE 3**
**Degree of bother and probability of online engagement**

Average difference in probability
Pain − Non-pain = 0.15
(z = 3.45; p = 0.0006)

The X-axis was measured using the bother index. The Y-axis was measured using the engagement index. The *asterisk* indicates a 28% average increase in the engagement level with every doubling of the bother level (z=5.83; *P*<.0001). The *double asterisks* indicate the average difference in the probability of the engagement at any level of bother (0.15; z=3.45; *P*=.0006).

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*

studied. In the meantime, physicians caring for this patient population may find that social media provides a modern, pandemic-proof, opportunity to partner with their patients and promote collaborative care. ∎

**References**

**1.** Atkinson NL, Saperstein SL, Pleis J. Using the internet for health-related activities: findings from a national probability sample. J Med Internet Res 2009;11:e4.
**2.** Curry E, Li X, Nguyen J, Matzkin E. Prevalence of internet and social media usage in orthopedic surgery. Orthop Rev (Pavia) 2014;6:5483.
**3.** Merolli M, Gray K, Martin-Sanchez F, Lopez-Campos G. Patient-reported outcomes and therapeutic affordances of social media: findings from a global online survey of people with chronic pain. J Med Internet Res 2015;17:e20.
**4.** Bright P, Hambly K, Tamakloe S. What is the profile of individuals joining the KNEEguru online health community? A cross-sectional mixed-methods study. J Med Internet Res 2016;18:e84.
**5.** Ammerlaan J, van Os-Medendorp H, Scholtus L, et al. Feasibility of an online and a face-to-face version of a self-management program for young adults with a rheumatic disease: experiences of young adults and peer leaders. Pediatr Rheumatol Online J 2014;12:10.
**6.** Camerini L, Camerini AL, Schulz PJ. Do participation and personalization matter? A model-driven evaluation of an Internet-based patient education intervention for fibromyalgia patients. Patient Educ Couns 2013;92:229–34.
**7.** Shigaki CL, Smarr KL, Gong Y, et al. Social interactions in an online self-management program for rheumatoid arthritis. Chronic Illn 2008;4:239–46.
**8.** van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER, van de Laar MA. Self-reported differences in empowerment between lurkers and posters in online patient support groups. J Med Internet Res 2008;10:e18.
**9.** van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. Qual Health Res 2008;18:405–17.
**10.** Willis E. The making of expert patients: the role of online health communities in arthritis self-management. J Health Psychol 2014;19:1613–25.
**11.** Willis E. Patients' self-efficacy within online health communities: facilitating chronic disease self-management behaviors through peer education. Health Commun 2016;31:299–307.

**12.** Willis E, Royne MB. Online health communities and chronic disease self-management. Health Commun 2017;32:269–78.

**13.** van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER, van de Laar MA. Participation in online patient support groups endorses patients' empowerment. Patient Educ Couns 2009;74:61–9.

**14.** Sadah SA, Shahbazi M, Wiley MT, Hristidis V. Demographic-based content analysis of web-based health-related social media. J Med Internet Res 2016;18:e148.

**15.** Mazloomdoost D, Kanter G, Chan RC, et al. Social networking and Internet use among pelvic floor patients: a multicenter survey. Am J Obstet Gynecol 2016;215:654.e1–10.

**16.** Alas A, Sajadi KP, Goldman HB, Anger JT. The rapidly increasing usefulness of social media in urogynecology. Female Pelvic Med Reconstr Surg 2013;19:210–3.

**17.** Nancy's Nook. Charting a path to better endometriosis care. 2021. Available at: nancysnookendo.com. Accessed May 15, 2021.

**18.** Pelvic Pain Support Network. Providing support, information and advocacy for those with pelvic pain. 2021. Available at: pelvicpain.org.uk. Accessed May 15, 2021.

**19.** HysterSisters. Woman to woman hysterectomy support. 2021. Available at: https://www.hystersisters.com/?__cf_chl_captcha_tk__=xLRzOBZyTByG0Ve99BhPob7pm37KRkmpKinlfJkHL8U-1636524906-0-gaNycGzNBz0. Accessed May 15, 2021.

**20.** Bunde M, Suls J, Martin R, Barnett K. Hystersisters online: social support and social comparison among hysterectomy patients on the internet. Ann Behav Med 2006;31:271–8.

**21.** Hackworth BA, Kunz MB. Health care and social media: building relationships via social networks. Acad Health Care Manag J 2011;7:1–14.

**22.** Perrin A. Social media usage: 2005-2015. 2015. Available at: https://www.pewresearch.org/internet/2015/10/08/social-networking-usage-2005-2015/. Accessed May 21, 2017.

**23.** Austin PC. Balance diagnostics for comparing the distribution of baseline covariates between treatment groups in propensity-score matched samples. Stat Med 2009;28:3083–107.

**24.** Hotelling H. Relations between two sets of variates. Biometrika 1936;28:321–77.

**25.** Hotelling H. The generalization of Student's ratio. Ann Math Stat 1931;2:297–334.

**26.** Maclachlan LR, Mills K, Lawford BJ, et al. Design, delivery, maintenance, and outcomes of peer-to-peer online support groups for people with chronic musculoskeletal disorders: systematic review. J Med Internet Res 2020;22:e15822.

**27.** Hadert A, Rodham K. The invisible reality of arthritis: a qualitative analysis of an online message board. Musculoskeletal Care 2008;6:181–96.

**28.** Birkhäuer J, Gaab J, Kossowsky J, et al. Trust in the health care professional and health outcome: a meta-analysis. PLoS One 2017;12:e0170988.

**29.** Kane GC, Fichman RG, Gallaugher J, Glaser J. Community Relations 2.0. Harv Bus Rev 2009;87:45–50.

**30.** Young SD, Lee SJ, Perez H, Gill N, Gelberg L, Heinzerling K. Social media as an emerging tool for reducing prescription opioid misuse risk factors. Heliyon 2020;6:e03471.

## Author and article information

From the Division of Advanced Gynecology, Legacy Medical Group, Portland, OR (Dr Piszczek); Department of Obstetrics, Gynecology, and Reproductive Sciences, University of Pittsburgh School of Medicine, Pittsburgh, PA (Dr Foley); Division of Minimally Invasive Gynecologic Surgery, Department of Gynecology and Women's Health, Cleveland Clinic Florida, Weston, FL (Dr Farag); Department of Obstetrics and Gynecology, Scripps Clinic Medical Group, San Diego, CA (Dr Northup); Division of Minimally Invasive Gynecologic Surgery, Department of Obstetrics and Gynecology, Vanderbilt University Medical Center, Nashville, TN (Drs Overcarsh and Yunker); Biostatistics and Design Program, OHSU-PSU School of Public Health, Oregon Health & Science University, Portland, OR (Mr Wiedrick); and Department of Obstetrics and Gynecology, Oregon Health & Science University, Portland, OR (Dr Ecker).

Corresponding author: Carolyn C. Piszczek, MD, MCR. carolynfortune@gmail.com

# Social media use in women with gynecologic pain: a multicenter patient survey

## Purpose

Many women use the internet, and specifically social media, as a healthcare resource. Social media includes technology that allows you to connect with other individuals. This includes things like Facebook, Yelp, blogs, and on-line patient communities and support groups.

You are invited to be part of this research study because you are a patient in the gynecology clinic with a new complaint. You may or may not experience pain related to your female pelvic organs. The purpose of this study is to better understand how women with and without pelvic pain use the internet and social media to learn about and manage their condition.

## Procedures

You will be asked to complete an anonymous survey about your preferences for gathering information about your gynecologic condition, with an emphasis on your internet and social media use. You will also be asked how your gynecologic symptoms affect your life. You will first be asked a series of questions to determine eligibility. If you qualify, the survey will start and should take 10-15 minutes to complete. This is a one-time survey. You can stop the screening or survey at any point without penalty. In efforts to maintain confidentiality, your name and other identifying information will not be collected or attached to your screening or survey responses.

If you have any questions, concerns, or complaints regarding this study now or in the future, or you think you may have been injured or harmed by the study, please email studyinvestigators@ohsu.edu.

## Risks

There is a very small risk of breach of confidentiality. In addition, the survey asks questions about the way your gynecologic condition affects your life. To some, this information is private; being asked these questions can seem intrusive. We do not expect the psychological effects of this survey to be severe or long-lasting.

## Benefits

You may or may not benefit from this study. By completing the survey, you are helping us learn how to benefit patients similar to you in the future.

## Confidentiality

In this study, we are not collecting any identifiable information about you. Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.
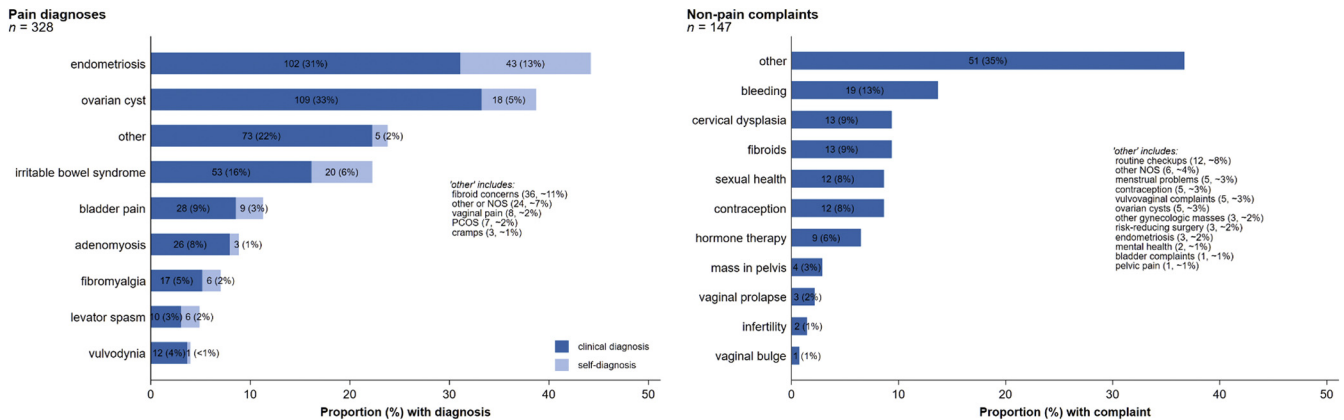
## Participation

This research is being overseen by the Institutional Review Board ("IRB"). You may talk to the IRB at (503) 494-7887 or irb@ohsu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject and research-related injuries.
- You want to get more information or provide input about this research.

You may also submit a report to the OHSU Integrity Hotline online at https://secure.ethicspoint.com/domain/media/en/gui/18915/index.html or by calling toll-free (877) 733-8313 (anonymous and available 24 hours a day, 7 days a week).

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

## SUPPLEMENTAL FIGURE 1
### Patient-reported diagnoses



NOS means that the participant selected "other" as the response but did not fill in any text after the "please specify" prompt. In the pain group survey, more than 1 diagnosis could be selected; in the no-pain group survey, only 1 diagnosis could be selected. A total of 8 respondents in the no-pain group skipped this question.

NOS, not otherwise specified.

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*

## SUPPLEMENTAL FIGURE 2
### Location and timing of pain
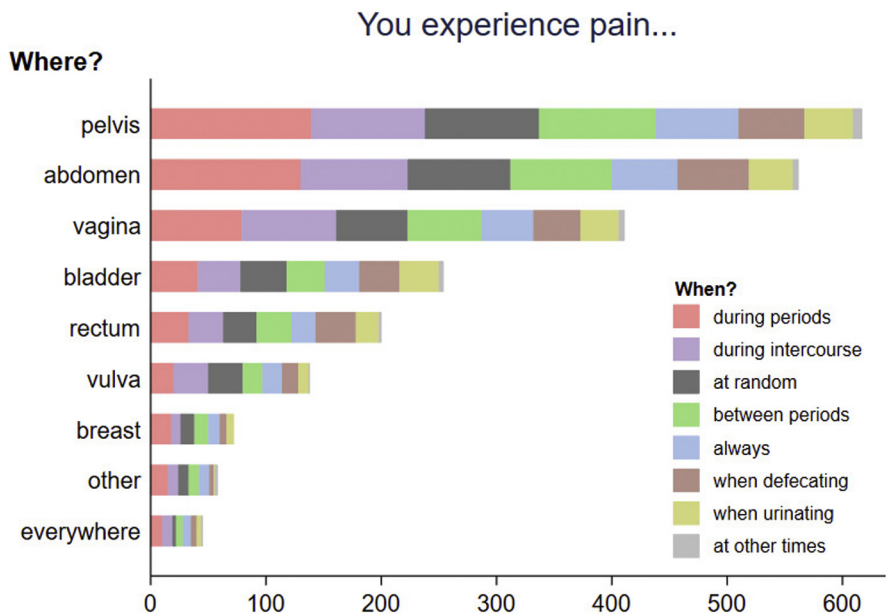


More than 1 location could be selected. Pelvic (65.9%), abdominal (59.8%), vaginal (40.2%), bladder (22.9%), rectal (16.5%), vulvar (16.5%), breast (8.5%), and everywhere (3.7%). More than 1 time relationship could be selected. Menstrual (56.1%), during intercourse (42.7%), random (42.4%), intermenstrual (36.3%), always (25.6%), with defecation (21.3%), and with urination (14.9%).

*Piszczek et al. Social media use in patients with gynecologic pelvic pain. Am J Obstet Gynecol 2022.*