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Using Digital Ethnography To Understand The Experience Of Women Suffering from Pelvic Organ Prolapse

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Abstract

Objective: To characterize the decision-making process and illness experience of women experiencing pelvic organ prolapse (POP) using large-scale social media analysis.

Methods: Digital ethnographic analysis of online posts identified through data mining was performed. Grounded theory methodology was applied to two hundred posts via traditional hand coding. To supplement our qualitative approach, we applied a Latent Dirichlet Allocation (LDA) probabilistic topic modeling process to review the entire dataset of identified posts to ensure thematic saturation.

Results: 3,451 posts by 2,088 unique users from 117 websites worldwide were identified via social media data mining. We found that the anonymity of online forums allowed for information and support exchange among women with POP. Our analysis revealed that the exchange of online information aids in the decision-making process and, in some instances, appears to be the primary source of information. There was confusion about the anatomical and surgical complexities of prolapse. Our study also identified misconceptions, perceived risk factors, prevention methods, and management recommendations that were discussed online.

Conclusion: This large-scale online community-based analysis demonstrated the utility of social media to better understand women's experience with POP. Thematic findings highlighted essential concerns and challenges involved in the surgical decision-making process and the understating of the anatomical complexity of sector defects, specifically to cystocele, rectocele, etc.

Keywords

qualitative research; grounded theory; pelvic organ prolapse

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Disclosures:

Dr. Jennifer T. Anger is an expert witness for Boston Scientific and advisory board member for Axonics.

Introduction

Pelvic organ prolapse is defined as the descent of one or more of the anterior wall, posterior wall, or apex of the vagina.¹ The surgical management of POP has an estimated annual cost of over 1.4 billion dollars, and by eighty years of age, 13% of women will have surgery.^{2,3} POP remains associated with fear, shame, and embarrassment.⁴⁻⁸ Due to embarrassment and lack of anonymity, genitourinary conditions such as prolapse pose obstacles for many patients to openly discuss their concerns.

A nationwide study in the United States analyzed the extent to which internet resources are used for medical information.⁹ The study found that 40% of women search for diagnoses online compared to 30% of men. Over half of adult users search for health information, and over a quarter of internet users read other individuals' posts about health issues.⁹ The ubiquitous use of social media and internet forums to search and share medical information anonymously, has provided researchers with a rich resource of publicly available data which can be used to discover new insights into patient experiences. Using social media and online forums to gain an understanding of women's experiences with POP is an unexplored area that has the potential to inform interventions, patient counseling, and patient-centered care. The American Urogynecology Society Prolapse Consensus Conference recently identified large-scale, community-based research as an area for further investigation.¹⁰ Our objective was to describe the experiences of women affected by POP with a mixed methods approach using digital ethnography. Whereas ethnography is defined as a fieldwork method to comprehend social and cultural norms, digital ethnography adapts traditional ethnographic principles of immersing one's self in the respective population of study to online networks.¹¹

Methods

Online Posts Selection

This study was determined exempt from IRB review. We collaborated with a data mining company (Treato ®) that used a proprietary Boolean Logic algorithm to conduct social media data mining by collecting and analyzing patient content on websites.¹⁶ Their database of patient content includes posts from e-forums, blogs, and websites. In collaboration with the PLUS Consortium, a multi-site study of risk factors and protective factors for lower urinary tract symptoms (LUTS) among women, and Treato ®, we selected search terms related to POP and its treatment to identify online posts (Table 1).¹² We performed two methods of analysis, a qualitative hand-coding approach, and a combined quantitative and qualitative approach.

Qualitative Grounded Theory Coding Process

To reach thematic saturation, the identified posts were randomized, and, based on our prior work, two hundred posts were selected after excluding those that contained non-English language content or were advertisements.^{13,14} Thematic codes of the two hundred posts were created using Grounded Theory qualitative methods.¹⁵ Briefly, Grounded Theory, as described by Kathy Charmaz, is a hypothesis-generating iterative process that involves line-by-line coding to develop categories which are grouped together to form common

themes. From these themes arise emergent concepts.¹⁶ Two investigators from our team independently coded the posts based on the subject matter content. After reviewing the codes for consistency, the data were merged by all authors.

Topic Modeling Analysis

The entire data set of posts was processed by a quantitative Latent Dirichlet Allocation (LDA) probabilistic topic model to examine themes within the collection of posts in an unattended manner.^{17,18} LDA allowed us to explore themes in the text based on the contextual co-occurrence of words, and it provided topics as data points to be reviewed for thematic analysis.. For example, the word "bank" can mean something related to finance when it is used with words like "money" or it can mean something else when used with words like "river" and "stream." The topic output can be thought of as a "word cloud," with a distribution of words ordered from most to least prevalent. A topic is as a multinomial distribution over all of the words in the collection. Think of a topic as a di, but with a number of sides equal to all the unique words in the collection. Each face of the "topic di" has a different weight (i.e., the di is not "fair"). For a topic, most of the weight is on a few faces, which is why we only look at the top 10-20 words in a topic. In LDA, each word is assigned to a topic. Thus, you can compute how much of a topic is in a post by dividing the number of words assigned to a topic by the total number of words in the post. A topic's prevalence in a collection is the number of words in the collection assigned to the topic divided by the total number of words. The topics were sorted from most to least prevalent and were manually reviewed to assign qualitative themes based on the "word cloud" content by the research team, which was composed of experts in POP, health services research, computer science, and qualitative analysis. We cross-referenced the posts that contributed to the specific topics to confirm proper thematic interpretation.

Combining conventional qualitative methods, limited by manual review, with LDA, allowed for review of all the identified online posts, therefore ensuring that we reached thematic saturation by capturing the wide range of content.

Results

Between January 6, 2016 and December 5, 2018 there were 3,451 posts by 2,088 unique users from 117 websites worldwide (Appendix 1). Table 2 shows example topics with their respective prevalence in the collection of posts and their assigned themes. Thematic saturation was reached using both the LDA model and grounded theory with similar findings. We combined the results from both methods of analysis into six themes with subthemes related to the experience of women with POP. Table 3 shows illustrative quotes, that, although limited in number, capture the language used by patients to convey their experiences.

Access to care was a theme that included subthemes about interacting with the health system, searching for Female Pelvic Medicine and Reconstructive Surgery (FPMRS) fellowship-trained surgeons, and experiencing revisional surgeries for prolapse recurrence after surgeries by non-fellowship trained surgeons. Both negative and positive interactions with primary care and specialty physicians led women to seek supplemental information

online. Others detailed the difficulty accessing FPMRS surgeons due to location, timeliness of referrals, surgery scheduling availability, and insurance coverage. Additionally, women expressed frustration with what they perceived to be inadequate initial evaluations of POP. Others questioned which diagnostics should be used to diagnose and stage prolapse accurately.

Online engagement was another identified theme. Based on the word content, it is apparent that women sought peer support before ever seeking care, after receiving care, but before having surgery, and after surgery in the early post-operative period. Information seeking and sharing of lay knowledge were significant factors in helping women self-diagnose, self-manage, and fill gaps in anatomical understanding. Online users mentioned symptoms not yet discussed with a medical professional such as “bulge,” “lump, ball,” “pulling sensation,” “urinary retention pain,” and “burning.” Many women also queried their peers about the risk of their bulge being a cancerous mass. Online forums allowed for an exchange of information between patients to help understand specific sector defects (cystocele, rectocele, enterocele). Women sought to understand which symptoms (pain, urinary straining, and constipation) were specific to which respective prolapse defect. Posts about the post-surgical management of prolapse revealed concerns about pain management (i.e., using frozen pads), urinary leakage, dyspareunia, and suture-related soreness. Overall, patients expressed gratitude for the online peer support and for having a space to discuss their concerns.

The quality-of-life effects of POP was another prominent theme. Subthemes included sexual dysfunction and the adverse impact of prolapse on intimate relationships due to embarrassment, anxiety, and pain. Other feelings expressed included shame, depression, and suicidality. Women also expressed the impact of POP on their ability to comfortably work. Occupations that required prolonged standing or sitting often exacerbated prolapse symptoms.

POP prevention and risk factors was another identified theme with a focus on understanding the etiology of POP and modifiable factors known among online users. There was an overall consensus that prolapse is a normal part of aging along the lifespan of women, especially multiparous women. Patients commented about the lack of proper counseling regarding the association between prolapse and vaginal deliveries and infant birth weight. Women also believed that prolapse was due to frequent penetrative vaginal intercourse. Additionally, users advocated adopting a “well-women posture” (techniques from www.wholewoman.com) for the treatment and prevention of POP. There were also recommendations to avoid running, cycling, and weightlifting.

Non-surgical management of POP as a definitive treatment and as a strategy to decrease the progression to more severe stages of prolapse was another overarching theme. Pessaries and intra-vaginal topical estrogen were two subthemes. Patients shared both positive and negative experiences associated with pessary use, such as difficulty with intra-vaginal placement and success with donut versus cubed-shaped pessaries. There were also concerns about the effectiveness of pelvic floor physical therapy. Another subtheme centered on self-management strategies prior to seeking medical care. For example, one strategy recommend was compression shorts to soothe pain associated with a cystocele. They also advised

avoiding strenuous high-impact physical activity, using warm water per rectum, and taking stool softeners to relieve rectocele discomfort.

Surgical decision-making was another important theme. Pre-operatively, women expressed concerns regarding the best practices to repair isolated sector defects and combined sector defects. Based on keyword content, it was evident that some women had consulted an FPMRS-trained surgeon, but valued the perspectives presented on forums. However, there were consistent recommendations on posts that women should seek consultation with a pelvic floor specialist. Users questioned the effect of uterine preservation on surgical management outcomes. Surgical outcomes with or without mesh and recovery duration with surgical repair of concomitant sector defects were also concerns. Post-operatively, comments focused on the prevention of prolapse recurrence with lifetime weight restrictions and avoidance of high impact physical activity. Both positive and negative perceptions related to mesh use and surgical experiences were discussed.

Emergent Concepts

From the six identified themes arose three emergent concepts. First, the anonymous nature of social media provides women with the liberty to address their needs regarding POP. Second, the complexities in the diagnosis and management of POP create challenges for women navigating the healthcare system. Third, online forums serve as sources of information that aid women in understanding the anatomical considerations of sector defects and surgical management options for POP. In addition to providing a “second opinion” for women who have already seen a physician, online forums are often used as a resource for women who have not yet seen a provider.

Discussion

We described the experiences of women affected by POP using digital ethnography, a technique that has been successfully applied in the study of SUI, Ankylosing Spondylitis, and Ulcerative Colitis by analyzing the online posts of individuals.^{13,14,18} This mixed-methods study of online posts likely demonstrates the most pressing concerns of women sampled from a broader population given that there is a high prevalence of internet use among the middle-aged to elderly and 40% of women older than 65 years old have reported relying on social media use for pelvic floor disorders.^{19,20} Based on the word content of the posts, our analysis included both treatment naïve women and women in the peri-operative stages. We identified specific barriers to accessing FPMRS care, the quality-of-life burden associated with POP, and the role of forums in facilitating online engagement and helping women navigate the complexities of their symptom experience and medical care pathways. Additionally, we found that social media allows women to anonymously share their prior experiences, knowledge about risk factors, and prevention strategies that facilitate a plethora of second opinions to complement surgical decision making. A multicenter survey identified that 53% of respondents used social media sites to further learn about pelvic floor disorders and 63% of self-referred women to a FPMRS physician stated using social networking websites to comprehend their symptoms.²⁰ Furthermore, despite YouTube being a widely used website, over 50% of POP videos showcase content with poor understandability.²¹

However, there remains a lack of analysis regarding the influence and utility of social media on patient understanding, decision making, and general patient attitudes concerning POP.

Similar to our findings, prior focus groups have also identified fear, embarrassment, concerns about malignancy risks, and a tendency among women to minimize their symptoms.^{4-6,22} Additionally, unlike other qualitative studies, we found misconceptions about risk factors that are not evidence-based such as posturing maneuvers to prevent POP, frequency of sexual intercourse, and high-impact physical exercise. A focus group study of women recruited from specialty clinics found that treatment understanding, even without complete diagnosis comprehension, was essential to reduce fear associated with POP.²² In contrast, the current study showed that diagnostic and management complexities are barriers for women navigating different healthcare systems. Unlike prior focus group studies, online users complained about delays in care due to many factors, including providers' dismissal of patient symptoms, a delay in referrals to specialists, and a lack of regional availability of specialists in FMPRS. A prior study by Wieslander et al. corroborates the challenges with the referral process for POP management and lack of patient comprehension about different surgical approaches for sector defects.²² Sung et al. identified a conceptual framework to improve patient-reported outcome measures for women seeking treatment for POP with domains pertaining to vaginal bulge symptoms, physical, social, and mental health.²⁷ Our study complements the conceptual framework presented by Sung et al. by proposing additional thematic dimensions necessary for the development of outcome measures and decision-making aids. We hypothesize that some women may not be receiving necessary counseling and education from physicians, or perhaps that additional reassurance from peers is essential for POP decision-making. Future efforts should focus on facilitating peer interactions regarding outcome treatment expectations, networking groups, and urogynecologic society sponsored forums of frequently asked questions.

Although our study provides population-level data that may include women who have not sought a professional consultation, there are limitations. Our study does not provide demographic information and probably does not capture the perspective of women satisfied with their care, as we speculate, they may have less motivation to post. The omission of non-English content may limit the external validity of these findings. Our number of identified posts and generalizability could have been limited by the collection of websites accessed by Treato®, our search terms, and the data mining Boolean algorithm that required mentions of symptoms and treatments. Additionally, we are unable to accurately draw temporal associations concerning surgery dates and visits with healthcare professionals. Furthermore, the extent of our analyses relies on online users' continuing to post after their initial concern with updates. Finally, the quality of all websites from which the posts were identified from is unknown.

Conclusion

Applying digital ethnography with grounded theory and LDA topic shed light on the most critical concerns for women with POP considering treatment. Women primarily used online forums for information support to help them self-manage and understand the complexity of prolapse. With the growing number of adult internet users searching for health information

online, it is imperative that we use this information to improve patient-centered care and innovate how we engage and provide resources to patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Search and exclusion terms used in the Treato® algorithm.

Condition terms	Treatment terms	Exclusion terms
Pelvic organ prolapse, Vaginal Prolapse, Vaginal vault prolapse, Uterine prolapse, Cystocele, Enterocele	<u>Surgical</u> : Cystocele repair, Enterocele repair, Uterosacral ligament suspension, Sacrocolpopexy (sacral colpopexy), Sacrospinous fixation, Vaginal bulge expansion, Perineal repair, Vaginal tightening, Mesh <u>Non-surgical</u> : Vaginal tightening, Vaginal rejuvenation, Pessary, Physical therapy <u>Signs and symptoms</u> : Pelvic prolapse, Cystocele, Rectocele, Vaginal bulge, Uterine prolapse, Enterocele	<u>Excluded words</u> : Dog, Cat, Baby, Babies, Child, Pet, Infant, Kid, Men <u>Posts by</u> : companies, advertisements, doctors, urologists, offices, physical therapists, nurses

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Table 2.

Example “word cloud” topics with their respective prevalence and assigned theme

Topics	Prevalence %	Themes
Rectocele, help, many, questions, thanks, ladies, experience, looking, surgery, advice, great, cystocele, hi, forum, site, hello, experiences, question, suggestions, possible, advance, info.	9.6	Information seeking and giving, online peer support
prolapse, birth, pelvic, post-partum, vaginal, delivery, pregnancy, uterine, months, pregnant, giving, time, told, rectocele, partum, worse, ob, damage, postpartum.	9.3	Etiology of prolapse, childbirth trauma
Vagina, feel, falling, prolapse, inside, bulge, cervix, opening, bit, unnormal, know, feels, noticed, tissue, coming, concerned, looks, bulge, lump, maybe.	9.1	Self-diagnosis, uncertainty of etiology, symptom sharing
Stitches, post rectocele, surgery feel, pressure, swelling, repair, today, normal, cystocele, feels, taking, internal, pressure, pain perineum, hi, sore, yesterday, meds, dr, swollen, discomfort.	8.6	Post-operative recovery, symptom sharing
Pelvic, exercises, help, muscles, physio, prolapse, cystocele, health, issue, exercise, strengthen, pt, weak, won't, support, women's, symptoms, working, sure, avoid, running.	6.0	Non-surgical management (physical therapy)

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Table 3.

Combined grounded theory and LDA themes with illustrative patient quotes from online posts.

Themes	Example Quotes
<p>Access to Care</p> <ul style="list-style-type: none"> Healthcare system navigation Specialty care access Physician interaction Diagnostic evaluation of POP 	<p>“Do not have rectocele surgery unless you’ve been diagnosed via defecography or dynamic MRI of the pelvis AND AND AND your symptoms are making you miserable.”</p> <p>“You can very well gain many more nuisances from the surgery as well as real detrimental health issues”.</p> <p>“I need a second opinion about how to proceed from here. Looking for great southern California urogynecologist for second opinion regarding repair and safe exercise.”</p> <p>“I think if I were in your position, I’d want to get a second urogynecologist opinion, but I know it can be hard to find depending where you live.”</p>
<p>Online Engagement</p> <ul style="list-style-type: none"> Information seeking & sharing Peer support Symptom sharing & validation 	<p>“I haven’t had prolapse surgery yet, but maybe soon so I was interested in your post and others going through this scary process.”</p> <p>“My main and really only symptom is incomplete evacuation which makes me incredibly uncomfortable and miserable.”</p> <p>“I’ve loved browsing the forums and realizing I’m most definitely not alone.”</p> <p>“I read squats can hurt the prolapse repairs. I am so down that I can’t seem to do anything...it is so depressing when normally you are active, isn’t it? Will I never be able to exercise the same way to avoid prolapse??”</p>
<p>Quality of Life</p> <ul style="list-style-type: none"> Sexual dysfunction Emotional burden Effect on occupation 	<p>“I am ashamed that my V isn’t a closed and airless space between the cystocele and uterine prolapse...it’s an open hole of shame.”</p> <p>“I am so down that I can’t even seem to do anything. It is so depressing when normally you can be more active without this thing coming out the vagina, isn’t it?”</p> <p>“It’s so gross and embarrassing to even type out and I don’t even want to talk to a doctor in person about this big ball coming out my vagina.”</p> <p>“Sacralcolpopexy, bladder sling and surgery... I don’t even know where to start... I have so many questions. Happy to get this all fixed, but I’m overwhelmed.”</p>
<p>Prevention & Risk Factors</p> <ul style="list-style-type: none"> Aging Pregnancy & vaginal delivery Posturing Avoiding high impact activities 	<p>“Being informed of the risks of birth procedures is important. No one told me of the risks of uterine prolapse. I now wish I my natural births had C sections.”</p> <p>“I have adopted the Well woman posture...the posture has been great help. I see the benefits of posture and proper breathing...I hope it will help my tissues.”</p> <p>“My posterior prolapse has happened due to there being some weakness from birth 6 years ago, but I put on weight and overdid it at gym, and something just went so now I have this bulge.”</p>
<p>Non-surgical Treatments</p> <ul style="list-style-type: none"> Progression of POP Pessary use Intra-vaginal estrogen Physical therapy Self-management 	<p>“I have a question regarding pelvic floor exercises...Which video should I purchase? I prefer to buy one that I can stream online.”</p> <p>“Will these PT exercises even help to make this bulge disappear?”</p> <p>“The only option for relief is surgery (which I DO NOT WANT!).”</p> <p>“Rectocele prolapse can be fixed by strengthening your wall”; “a pelvic floor physiotherapist can often help you to strengthen the muscles to compensate for your lax connective tissues until they heal.”</p> <p>“Estrogen cream scares me a bit because of the increased cancer risk (mostly breast)...Has anyone used estrogen cream and not had nasty side effects?... I am prepared to try the estrogen cream if it does work to halt or reverse the prolapse a bit.”</p>
<p>Surgical Decision Making</p> <ul style="list-style-type: none"> Peer Advice Peri-operative concerns Long term outcomes POP recurrence Choice of operation(s) Mesh perceptions 	<p>“I had a total hysterectomy due to uterine prolapse. Also, a bladder sling at the same time. It’s been 15 years since surgery and I still say it’s the best decision I’ve made.”</p> <p>“I have the choice of having the A and P repair with or without a hysterectomy. I am torn.”</p> <p>“I had a cystocele and rectocele 5 weeks ago with a mesh insertion. I have ended up with urinary retention and my bladder would try to expel the catheter.”</p> <p>“I haven’t had surgery yet but maybe soon so was interested in your post and others going through this. Especially with mesh, it seems that most also have sturdy long-term results.”</p> <p>“The vaginal mesh is safe like the hernia surgery type.”</p> <p>“I would ask here to find a reputable urogynecologist who is experienced mesh repairs and has a good record.”</p>