Social and Informational needs of People with Pelvic Organ Prolapse

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Pelvic organ prolapse (POP) is a condition that many women experience postpartum and although it has significant implications on every aspect of their lives, many women are not adequately equipped to adjust to the condition. Human-computer interaction has examined how women use online health communities to find social support during their reproductive health experiences, however, there has yet been an investigation into more stigmatized health conditions with less shared knowledge, such as pelvic organ prolapse. This study aims to form a comprehensive outline of the informational needs and support types that their rehabilitation experiences necessitate. We qualitatively analyzed the 20 most popular Reddit posts from three relevant subreddit communities, r/PelvicOrganProlapse, r/PelvicFloor, and r/beyondthebump. In total including comments, we analyzed a total of 2,810 posts by 1,429 unique users. Our findings reveal a critical need for validation, empathetic communication, and tailored informational support within these communities. The insights from this study propose design interventions for OHCs that prioritize user needs and foster a more inclusive and supportive environment for women managing POP.

Keywords: Pelvic organ prolapse, Women's health, Online health communities, Human-centred computing, Health informatics

CCS Concepts: • **Human-centered computing → Empirical studies in HCI**.

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1 INTRODUCTION

Forty-one to fifty percent of women in the United States are estimated to be affected by pelvic organ prolapse (POP), significantly impacting their quality of life. In this condition, the pelvic floor, which supports pelvic organs, weakens, causing urinary and fecal incontinence, discomfort, and sexual difficulties [2, 22]. However, despite its prevalence, POP is a complex condition that many, including healthcare providers, do not understand well. The complexity arises because it involves multiple organs, various symptoms, and individual degrees of severity [8]. The lack of understanding leads to poor communication and dismissal from healthcare providers. Such dismissal can often result in misdiagnosis or delayed diagnosis, causing patients to suffer for extended periods without proper treatment [7, 10]. This promotes POP patients' feelings of being unheard and invalidated, forcing many to seek information independently online. Given the prevalence of POP and the systematic issues associated with its treatment, it is crucial to research this condition. This research will drive the development of improved understanding, communication, and treatment strategies for POP. Ultimately, these advancements will enhance the quality of life for those affected by the condition, underscoring the great importance of this work.

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The challenges associated with POP are multifaceted and interrelated. A notable absence of focused research on POP leads to a lack of comprehensive and effective solutions for individuals experiencing this condition. The insufficiency of adequate resources drives many women to resort to online forums and communities for information and support [7]. However, this self-directed search for information can easily expose patients to misinformation, leading to increased anxiety about their condition and well-being. The absence of reliable and easily accessible information presents a serious challenge in managing and understanding POP.

These challenges emphasize the research gap in the field of POP. Despite extensive research in online health communities (OHC) [24, 27, 31, 32], there is a noticeable lack of studies specifically addressing POP. The gap involves the lack of understanding of the specific needs, sources of information, and experiences of POP patients within OHCs. There are not sufficient insights into the informational needs of people who experience POP, the sources of information they turn to, or the experiences these patients go through. This gap in research limits the development of effective solutions tailored for POP patients and highlights the need for more targeted research in this area.

Given these challenges and the existing research gap, there is a substantial opportunity for Human-Computer Interaction (HCI) research to contribute significantly. HCI can contribute to creating digital tools and platforms that offer dependable information, encourage supportive communities, and aid in the self-management of POP. By addressing the unique challenges associated with the condition, research in HCI can significantly improve the lives of those impacted by POP, paving the way for improving understanding, communication, and POP care.

In this paper, we make an HCI contribution to the POP research gap by examining the digital information needs of individuals experiencing POP. Specifically, we answer two research questions:

- What are the digital information needs associated with Pelvic Organ Prolapse?
- How can technology be designed to support these digital information needs?

We adopted a qualitative research approach, focusing on Reddit discussions. We qualitatively analyzed the 20 most popular Reddit posts from three relevant subreddit communities, r/PelvicOrganProlapse, r/PelvicFloor, and r/beyondthebump. In total including comments, we analyzed a total of 2,810 posts by 1,429 unique users from June 2021 to April 2024. This study aims to explore women's interaction with technology and the benefits of technology in POP-related areas, including information sharing, accessing social support, and self-monitoring.

2 BACKGROUND

2.1 Pelvic Organ Prolapse (POP)

Pelvic Organ Prolapse (POP) is a condition in which the group of muscles and tissues that normally support the pelvic organs, called the pelvic floor, becomes weakened. The pelvic organs include the bladder, the uterus, and the rectum and POP significantly affects their function. This condition significantly affects a woman's quality of life often causing urinary and fecal incontinence, discomfort, and sexual difficulties [2]. Other symptoms most often correlated with POP include the appearance of a vaginal lump or bulge and pressure [14].

There is a need for further research on POP because of its prevalence. This condition affects 41-50% of women in the United States [5**?**], affecting their physical and mental well-being [8] and extending to their emotional and social well-being. POP can manifest in different forms including, Uterine prolapse(uterus), Rectocele(rectum), Cystocele(bladder), Enterocele(small intestine), Urethrocele(urethra), vaginal vault (Anterior or posterior) [5]. The condition consistently hinders women's abilities to engage in everyday physical activities, affecting their rest, sleep, and overall mood [8]. It also adversely impacts their sexual life and home life, influencing their roles as wives and mothers, as well as their perceived ability to parent effectively [26]. This physical and social cost causes psychological burden and emotional distress in patients [8, 21] one that is only worsened by the stigma associated with discussion POP[8]. A study demonstrates that as POP symptom severity worsens, patients have higher scores of psychological distress [14]. This further demonstrates how the POP negatively affects well-being and overall quality of life. The prevalence of this condition, particularly in women who are postpartum, menopausal, or post-hysterectomy [22]makes it a significant aspect of women's health to invest in understanding and improving.

2.2 Current Challenges with POP

There are three major challenges surrounding POP; a lack of education, poor communication of information, significant negative effects on quality of life, and an accumulation of financial burdens. Education on POP is critical in improving women's experiences with the condition. Although the condition is prevalent, there is a knowledge gap in patient knowledge and healthcare provider knowledge about the condition. There is a critical need for more educational material tailored for health professionals and consumers to enhance understanding and management of POP [7]. It is essential that healthcare providers are well educated on the symptoms and characteristics of the condition in order to make a timely diagnosis and direct patients to the right treatment care plan. It is equally important that consumers or patients are equipped with necessary information proactively and are confident in their ability to seek, and access credible information tailored to their care and management needs. Evidently, mutual effort and change are necessary for both physicians and patients.

In addition, there is a trend of poor communication of care options to women with POP on the part of healthcare providers. Care plans often do not consider women's concerns and preferences [2], leading to feelings of dismissal and frustration among POP patients

[10]; with some patients expressing that providers frequently present options subtly influenced by their bias and preferences [5]. Feelings of dismissal and a lack of support often force women to carry the burden of self-advocating or lead to many women seeking information on their own [10]. Many report feeling isolated and stressed as they desperately seek online resources and navigate misinformation while managing anxiety surrounding the condition [10]. The lack of support also leads to the avoidance of healthcare visits and the development of self-coping mechanisms when making treatment decisions [10]. This indicates a need for a way to address personalised informational needs within a supportive and welcoming environment; one that is conducive to inquiry and agency.

2.3 Human-Computer Interaction & Reproductive Health

Current HCI research explores the role of technology in women's health particularly in reproductive health. Studies highlight themes of social support in online health communities as well as the benefits and limitations of these communities in an attempt to better inform the design or process of a technological intervention. However, this research aims to closely examine the relationship between the social and informational needs of women experiencing pelvic organ prolapse. For post-partum depression, research assessed the role of stigma in support-seeking on online platforms [30] . Research in menopause explores the complexities of support influenced by emotional, social and cultural factors [25] , highlighting the need to reframe design intervention with a wellness perspective to account for biological and sociocultural contexts and structures [6]. Research on the impact of childbirth on online behaviours indicates that online community posts are not only sources of information and social support [13] but they are also instrumental in revealing outlier birth stories and validating underrepresented perspectives in the child birthing experience that are essential to informing the design of care plans [4] . The aforementioned research reveal nuances in the needs and wants of women in different health contexts relating to seeking validation and wellness support. However, there also exists an informational need that is not sufficiently explored; women not only seek validation but employ online health communities as a means to make sense of their experiences.

2.4 Online Health Communities & POP

Online Health Communities (OHCs) are digital groups in which members seek health support from one another [20, 28]. OHCs tend to focus on a specific health condition shared by community members [20], e.g., diabetes [33]. They can, however, focus on multiple conditions and/or broader health-related activities, e.g., parenting neurodivergent children [3] and personal health journalling [**?**]. These communities exist as both standalone sites and sub-forums within larger forums, e.g., Reddit subreddits [18] and Facebook groups [32].

HCI has studied OHCs across a variety of platforms and health conditions. This research emphasizes that OHCs allow members to interact with peers who share their health condition and receive informational, emotional, and social support [20, 23, 27, 28, 31]. Within these activities, OHCs function both as transition spaces and as bridges between experiental knowledge and medical expertise [20]. A limitation of the corpus, however, is its emphasis on well-understood health conditions. Young and Miller's work on vulvodynia [32], an enigmatic gynecological condition, emphasizes that most OHC research examines conditions which have well-known causes and treatments, and that OHCs for poorly understood health conditions remain understudied.

Our work builds on past HCI research by examining three OHCs for pelvic organ prolapse (POP), a prevalent health condition which is poorly understand and has been understudied in HCI. As we write above in Section 2.1, two key challenges within POP care are inadequate patient and provider education [7] and a lack of patient agency [2, 5, 10]. The HCI corpus suggests that OHCs, capable of providing informational support and meshing patient experiences and medical knowledge, could potentially address these challenges in POP care. But, because POP has been understudied in HCI, it remains unclear how technology could realize this potential and support people with POP through OHCs. In our work, we aim to elucidate the support needs of POP OHC members, and expand HCI's understanding of how support the management of this poorly understood health condition.

3 METHODS

This study involved a qualitative research approach to understand the experiences and perspectives of individuals discussing Pelvic Organ Prolapse (POP) on Reddit.

We approached the inquiry by examining data from social media platforms such as Reddit where users share opinions, testimonies, etc. Reddit was ultimately chosen as the primary data source due to its expansive user base and the diverse range of extensive discussions it hosts. Reddit is a web-based platform where users can initiate discussion threads under formed thematic communities and sub-communities known as 'subreddits'. The choice of Reddit was justified by its status as one of the largest online communities, offering a diverse dataset that includes a wide range of discussions on POP. Additionally, the platform's valuable compilation of first-hand accounts of experiences, coupled with a diverse demographic of users and its open accessibility, makes it a valuable source of qualitative data.

3.1 Data Collection

Data was extracted from the subreddits r/PelvicFloor (PF), r/beyondthebump (BTB), and r/PelvicOrganProlapse (POP). These were selected due to their large subscriber base and relevance to POP. They offer an abundance of user experiences and viewpoints on POP.

subreddit	total comments	unique users
r/beyondthebump	1905	1122
r/PelvicFloor	469	186
r/PelvicOrganProlapse	436	121

Table 1. Subreddit statistics from the 20 most commented on posts

The data collection period spanned from June 2021 to April 2024, using keywords such as “Pelvic organ prolapse”, “POP”, “Prolapse”, “Rectocele”, “Cystocele”, “Enterocele”, and “Urethocele”. These keywords served to filter through the data pool and isolate threads pertinent to POP, thereby ensuring only threads directly associated with POP were extracted. The necessity to gather nearly three years worth of data was driven by the aim to comprehend the most recent discussions concurrently across the three different subreddits. The choice of keywords was informed by medical terminology and prior research to guarantee the data’s relevance to POP. Terms such as “POP” and “prolapse” were included due to their direct relevance and common usage in the context of pelvic organ prolapse. The term “bulge” was incorporated based on its use in prior research [16]. The remaining terms were sourced from Cleveland Clinic’s page on POP; this is a globally recognized healthcare institution renowned for its comprehensive and reliable medical information [1]

The dataset consisted of comments and threads from the specified subreddits, filtering keywords indicative of POP. Posts indicating prolapse types not categorized as POP were filtered out. Prior to data collection, we obtained approval from Indiana University’s Institutional Review Board (IRB). We removed any personal identifiers from posts to maintain the anonymity of Reddit users.

The top 100 most commented-on posts from each subreddit were extracted and posts lacking body text or those deleted were automatically excluded from the analysis. Additionally, we manually excluded discussions of prolapse types not categorized under POP. The decision to focus on the top 20 most commented posts was based on the size of past corpora in data analysis (e.g., 1800-2000) [11, 15, 17, 19]. The intention is to capture a reasonable breadth of POP discussion across multiple thematic communities. This dictates including comment threads with sufficient responses and exchange of discussion while ensuring the data corpus is representative, digestible, and practical.

3.2 Data Analysis

The data analysis for this study was conducted in two stages. Initially, we employed an inductive qualitative coding approach. Our research team independently read the top 25 posts and comments from each subreddit and identified emergent themes. These themes were refined through team discussions until a consensus was reached on a set of codes that accurately represented the data. Incorporated within our codebook was Cutrona and Suhr’s support types framework which categorizes social support into five types: tangible/instrumental, emotional, informational, esteem/appraisal, and social network support [12]. Each post was coded for the presence of these support types, thereby allowing us to understand the nature of the support within the Reddit communities and offering insights into the specific needs and resources of individuals discussing POP.

The data analysis process was conducted using Dedoose which is a web-based application specifically designed for qualitative data analysis. This software aided the structuring and coding of the data and supported the identification of themes and patterns within the codebook. In compliance with the ethical guidelines of Indiana University’s IRB, all analyses were completed ensuring the anonymity of Reddit users.

	Descriptive	**Prescriptive**
Authoritative	**12% of the informational data.** "I had my hysterectomy specifically due to prolapse. My surgeon recommended taking my cervix and tubes during the surgery and I kept my ovaries" (POP, post #15).	**2% of the informational data.** "I'm a urology resident and do lots of prolapse surgery. You definitely should see a urogynecologist." (BTB, post #20).
Experiential	**61% of the informational data.** "I had a stage 2 bladder prolapse at 6w pp and then I did 5 weeks of PFPT with all of my homework and it's now more of a stage 1, I almost feel no symptoms." (BTB, post #3).	**14% of the informational data.** "See a urogynecologist, not a regular gynecologist... I'm generally a very patient person and really had a hard time with this, but I think the results are worth it." (POP, post #1)
Authoritative w/o Source	**9% of the informational data.** "There are so many different types of pess[a]ries for different prolapses. Maybe a second opinion?" (POP, post #20).	**6% of the informational data.** "Trying to fix organs that prolapsed using your natural tissue has a 40-50% success rate. The reason you have prolapse is because your tissue is weak...Robotic surgery is the way to go." (POP, post #13)

Table 2. Percentage of descriptive and prescriptive informational data, categorized by authoritative and experiential sources (there can be overlap between categories as some posts are in more than one category).

Our analysis approach was in-depth including both emergent themes from the most engaged posts and comments and a structured analysis based on Cutrona and Suhr's support types framework. This approach captured the involvement and complexity of the experiences and perspectives of individuals discussing POP on Reddit. The emergent themes provided insights into the individual experiences of POP patients while the structured analysis of support types offered an understanding of the types of support these individuals need. The combination resulted in an understanding of the experiences and perspectives discussed on Reddit, therefore giving us a broader understanding of the needs of POP patients. This approach to data analyses ensured the reliability and validity of the findings, contributing to the overall trustworthiness of the study.

4 FINDINGS

4.1 Informational Support Types

A total of 459 excerpts were identified as providing informational support to Online Health Communities (OHC) across three subreddits. To further analyze the informational support given to Reddit users, we categorized the excerpts based on two dimensions: the nature of the information (descriptive or prescriptive) and the source of information (authoritative or experiential).

Descriptive information describes what could be done or what could be the case, without prescribing specific actions. For example, one user provided insights into what could be useful to others: *"If it's any hope for you, pelvic floor therapy has been extremely helpful for me after surgery"* (POP, post #17). In contrast, prescriptive information provides explicit direction on what the users should do or what ought to be done, such as when another user stated: *"Get pelvic floor therapy!"* (BTB, post #13).

The source of information was categorized as either experiential, authoritative, or authoritative without a source. Experiential information is based on someone's personal experiences. Authoritative information is based on expert or scientific evidence from healthcare providers or reputable sources, not grounded in personal beliefs or experiences. Authoritative information without a source is similar but lacks citation of the source.

4.1.1 Experiential vs Authoritative.

Experiential information emerged as the most common support type, compromising about 77% of the data, where users shared their personal experiences. For instance, one user described her experience managing her POP symptoms: *"It took a year of doing yoga but I can do anything now. We do 2-5 mile hikes in the hills a few days a month and I have no problems."* (POP, post #19). Combined with descriptive support, this type of information was the most prevalent within the dataset, covering about 61% of all the informational data. Another user shared insights learned from her experience with POP: *"The tampon feeling is the worst and can be helped by relaxing the pelvic floor as much as possible, you are probably tensing it involuntarily as I was doing the same thing!"* (POP, post #3). This post illustrates how users shared personal experiences to provide insight and potential solutions to others. Table 2 further illustrates the distribution of descriptive and prescriptive informational data categorized by authoritative and experiential sources.

Authoritative information was less common, covering only about 14% of the informational data across the three subreddits. For example, this user shared what their healthcare providers communicated: *"I was told by multiple urogyn[ecologist]s and pfpts[pelvic floor physical therapists] that grade reversal is not the goal, symptom management is"* (POP, post #16). These types of support were most commonly combined with descriptive support (12%), where users shared expert evidence along with what could be done to help others with their POP. For instance, one user wrote: *"So you can have dysfunction and prolapse even if your muscles are too tight...So my therapist did internal work and recommended at home yoga poses: cat cow and child's pose."* (BTB, post #13). Additionally, about 14% of the data combined both experiential and authoritative information, providing comprehensive support. For example, one user stated:

> *"My urogyn went back and forth on whether to do a big giant repair (rectocele, cystocele, hysterectomy, sling, perineum repair) vs just rectocele. He was concerned I'd be back because I'd prolapse more with just a rectocele repair. I did the full repair. Issues are much improved."* (POP, post #2).

4.1.2 Prescriptive Support.

Prescriptive support combined with experiential information was the third most common support type covering about 14% of the informational data. This type of support often involved users sharing detailed regimens or specific actions that worked for them while providing explicit guidelines of what others should do. For example, this user shared a detailed regimen of a POP treatment that worked for them, *"Go on YouTube and look up pelvic floor stretches... I do 3sets of four different ones twice a day plus one set of three others...You need to hold the pose a minute or more."* (PF, post #1). Another user described how they managed their POP symptoms while telling others exactly what they should do:

> *"You should work with a pelvic floor PT, and consider pelvic floor yoga to help keep the muscles strong. I have stage 2 cystocele and am practically symptom-free now. It involves dedication to the right kinds of exercises a few days a week, but it was the answer for me that did not require surgery."* (POP, post #20)

These posts show how users share their personal experiences while providing explicit instructions.

4.1.3 Authoritative Information Without a Source.

Authoritative information without a source, combined with descriptive support, was seen in 9% of the data. For example, this user stated a fact (without citing the source) while giving information about what the case could be for others: *"Many people have a rectocele, but it only becomes a concern if it's symptomatic, particularly during bowel movements."* (POP, post #6). Prescriptive support combined with authoritative information without a source appeared in 6% of the data, such as when one user stated a fact and provided explicit instructions: *"Surgery is covered under most insurances. Call and find out."* (BTB, post #3). Additionally, about 4% of all the informational data combined authoritative information without a source with experiential information. For instance, one user described her personal experience while sharing expert advice:

> *"My understanding is that pregnancy generally takes a toll on the pelvic floor and can cause or worsen prolapse by itself, but I know for sure that mine (and the severity of my prolapse) was caused by the pushing stage of my vaginal birth. So if I did end up going for a second kid I might elect for a C section for my own mental health, even though most bad prolapses are caused by first time births."* (BTB, post #3).

Most of the informational support on Reddit came from the personal experiences of individuals dealing with or who have dealt with POP. Experiential and descriptive support were the most prevalent types, suggesting users prefer sharing what could be done or what helped them rather than prescribing specific actions.

4.2 Patient-Doctor Dynamics

We further identified 44 excerpts in which Reddit users expressed feeling ignored or being overlooked. These excerpts, coded "Not being heard", describe an instance in which patients feel that a healthcare professional isn't listening to, acknowledging, understanding, and/or caring about their concerns, thoughts, and/or experiences.

4.2.1 ***To Be Heard*** . In this research, we examine the communication dynamics between patients and doctors reported by Reddit users to understand what it means to "not be heard" and assess its relevance to patient's outcomes and experiences. We classified the "Not being heard" code into four main subthemes, (1) "Not believed or validated by HCP", (2) "Believed but undesired treatment", (3)"Emotional invalidation" and (4) "Not aligned". The first describes when patients feel like their concerns aren't being heard or validated. The second describes when patients feel believed but the treatment recommended by their health care provider (HCP) is undesired by patients. The third describes examples in which a patient's experience is actively invalidated and the patient is being told how to feel. In these instances, the HCP often has a rigid understanding of what the patient should be feeling based on medical knowledge. The fourth subtheme details cases where the care given or recommended to a patient is not aligned with their experience or their concerns aren't well addressed.

4.2.2 ***Not Believed or Validated*** . The code encapsulates themes of patients feeling like their concerns aren't being heard or validated. It often details dismissive language or impatience from the HCP. In some instances, patients were not believed until their situation escalated or their condition became worse. Reddit posters used phrases and language such as, "*no one believes me*" (BTB 1), "*dismissed by docs*" (POP 13), "*no one listened to me*" (POP 17), or "*He... denied every experience I was having*" (PF 9). A particularly compelling excerpt from a patient expresses the extent to which dismissiveness affected their ability to seek necessary support and learn about care options:

> "*I'm currently in physiotherapy and it's helped but I don't think the organs will ever go back. I've had irregular periods my entire life and I never wanted kids, so I always considered hysterectomy even before prolapse.* ***So many doctors are horrible and impatient. When I first asked my urogyno about the surgery, her first reaction was to laugh. I have no idea why that would be funny***." (POP 11)

In this example, the healthcare provider's (HCP) response is unprofessional and nearly patronising. The patient's reaction suggests that this offset the dynamic of the conversation, leaving them feeling confused about "*why that would be funny*". Because the patient is invalidated by the HCP's response, it crippled any chance of the patient inquiring further about their care options, getting informational support, and making an informed decision about their treatment.

> "*I know how hard it is to find a urogynocologist, especially the wait and* ***it's even worse when THEY act like it's no big deal. I went through the same sort of issue with my urogynocologist.*** *I went around mine by getting an appointment with her nurse and told her I wanted a pessary and she said just call the office to make a pessary appointment so I did . Odd process in that office. Then I asked for muscle relaxers. Surprisingly she said yes without a problem.* ***When I asked for valium suppositories for levator ani she said no. I ended up twice in the ER where they called her. After that she prescribed the valium.*** *Don't give up, INSIST.*" (POP 13)

In the second example, the patient expresses frustration over having their experiences belittled when the healthcare provider "*acts like it's no big deal.*" The patient also describes requesting Valium, being denied, and only receiving the prescription after their condition significantly worsened, requiring two emergency room visits. This illustrates that not being heard or believed is a significant barrier to receiving adequate care and support needs. Additionally, themes of self advocacy begin to emerge as emphasised by the patient's advice to " *Don't give up, INSIST.*"

4.2.3 ***Believed but Undesired Treatment*** . This theme describes when patients feel that their concerns are acknowledged by healthcare providers, but the recommended treatment is not what the patient prefers or expects. In these cases, Reddit users, and patients, would sometimes request a specific treatment implying that they have some knowledge of their treatment options whether based on personal research or different HCPs. The following examples illustrate the trends in their experiences

> "*I also asked my* ***urogynecologist for a referral for PFT. I thought that would be the next step but she was just going to prescribe me the pessary*** *and then I would end up getting surgery eventually is [sic] things worsened.*" (PF 15)

In the first example, the patient sought a referral for pelvic floor therapy (PFT), believing it to be the next appropriate step in their treatment. However, the urogynecologist instead suggested a pessary. This highlights a disconnect between the patient's expectations and the treatment plan offered by the healthcare provider.

> "*For the past few weeks I've had to push on my taint to poop.* ***Asked my OB (last week) what's up, he said do keegles. Right, not like I don't do them everyday, but okay doc.***" (BTB 10)

In the second example, the patient discusses difficulty with bowel movements and mentions needing to physically push on their perineum to defecate. When they brought this up with their OB, the response was to simply "do Kegels," a recommendation the patient found insufficient since they were already performing these exercises regularly. This response reflects the patient's dissatisfaction with the treatment advice, as it doesn't address the specific concerns they raised.

Both of these examples underscore how even when patients are believed, the treatment offered can still leave them feeling dissatisfied, potentially leading to frustration and a lack of trust in their care. It also potentially highlights a need for greater attention to shared decision-making in healthcare, with an integration of the patients preferences and the HCP's expertise.

4.2.4 ***Emotional Invalidation*** . The subtheme of "Emotional Invalidation" highlights instances in which a patient's experience is actively invalidated and the patient is being told how they should or should not be feeling. This subtheme emerged as the most frequent, accounting for 50% of experiences categorized under "Not being heard." In these cases, healthcare providers (HCPs) often exhibit a rigid understanding of what patients should feel based on their medical knowledge, disregarding the patients' actual experiences. For example, one patient reported their urogynocologist dismissing their concerns about a rectocele, saying "*she rolled her eyes*", stating that if the condition recurred after treatment, she wouldn't address it again (POP 2). The HCP's response not only invalidates the patient's experience, but it also limits their trust in the effectiveness of future treatment or care.

The following examples are particularly compelling:

> " *She[doctor] says "it does not hurt " then what is this pain I'm feeling constantly all day long and worse when I'm on my period and on my feet ? ... None of these doctors have any clue how it feels cause none of them deal with it themselves.* **These doctors are truly worthless if they're not gonna do their jobs and actually listen and take our pain seriously**. **It's so hard to have hope when there are doctors like this thinking they know everyone's body and pain**. I really hope they get they're shit together for the sake of woman's healthcare , I pray they're better resources to come " (POP 17)

In this example, the patient is clearly frustrated by the dismissive attitude of the doctor especially considering the debilitating nature of their pain. They question the doctor's active denial of their pain. They then emphasise that the doctor, while very experienced and knowledgeable, cannot adequately empathise and fails to understand the severity of their condition because the HCP does not have personal experience of the pain. They express dwindling trust in the HCP as a resource for future care.

> "*This happened to me too for 16 months after my son.* ***I kept telling my GYNO (3 of them actually) that I had a uterine prolapse and bladder prolapse and they kept saying "it's a uti" "it's just vaginal dryness" "it's not a prolapse"*** *and now I'm 27, had to have a hysterectomy and 5 other procedures to correct a triple prolapse and a vaginal vault prolapse.* ***It was devastating but truthfully the lead up where no one listened to me was worse***." (POP 17)

In the second example, after struggling with multiple gynecologists who dismisses her symptoms as minor issues or misdiagnosed them as unrelated conditions, the patient's condition worsened severely. This ongoing invalidation eventually led to severe health consequences, requiring extensive surgical intervention through the hysterectomy. The patient reflected that the lack of recognition of her genuine concerns was more distressing than the subsequent medical procedures. This not only highlights the serious dangers of active invalidation but also the lasting impression on the patient's psyche and ability to seek care support in the future.

> "*When* ***a doctor tells me I shouldn't feel pain*** *I ask him how it would feel if I stapled his dick to his leg. Fuck those people.* ***When a doctor says you shouldn't feel bad, get in their pathetic face and make them feel as shitty as you do***. *They're bad at their jobs and bad human beings, and should be mocked, ridiculed and talked down to because of it. I hope you feel better soon.*" (PF 2)

In the last example, this patient expressed intense frustration with doctors who told them they shouldn't be in pain. They detail their anger, irritation and consequent hostility when confronted with such. Their extreme language and lamentation highlights how the dismissive attitude of the HCP can exacerbate patient suffering and betray patient trust in the healthcare system in general.

These examples highlight the detrimental impact of emotional invalidation on patient experiences. When patients' feelings and experiences are disregarded, it not only affects their immediate care but also their overall trust in healthcare professionals. Such invalidation potentially reveals a critical gap in empathetic and effective communication within patient care.

4.2.5 ***Not Aligned***

. The subtheme "Not Aligned" details cases where the care given or recommended to a patient is not aligned with their experience or their concerns aren't well addressed. This misalignment between patient needs and the care provided can leave patients feeling unsupported and frustrated. For instance, a Reddit user reported that after asking for estrogen treatment, the HCP denied them based on their age and normal blood work results. They stated, "*I walked out of that appointment in tears because I waited MONTHS for it and ended up leaving with more questions than answers.*"(POP 13). Despite their clear need and their long wait, the HCP refusing to address their concern resulted in the patient leaving with distress and unanswered questions. This misalignment between the patient's needs and the care they received highlights the importance of considering the patient experience, symptoms and voiced desires when giving treatment decisions. The following excerpts feature instances that emphasise the risks of unaligned treatment.

> " *I felt pain but* ***they kept telling me it was normal*** *and when they were checking inside (5 seconds max) they said it all looked ok.* ***When told I had still to splint well after the surgery she shrugged and sent me to the Gastro doctor that sent me to MRI that found out I still have the prolapses.*** " (POP 11)

In this example, the HCP's impatience when they assess the patient, in addition to their inattentiveness to the patient's persistent symptoms combined with their dismissive comments left the patient unsupported and the patient's needs unaddressed. Because of the negligence of the initial doctor, the patient is forced to endure the prolapse longer until the subsequent gastroenterologist visit. The unresolved prolapse demonstrates the lack of alignment between the patient's experience and the care initially provided; exemplifying the patient not being heard or listened to.

> "*This was exactly how I felt when I walked in to my urologists office and it was all 60/70yr olds and I was the only 20 yr old. Long story short* ***they told me it was all in my head and that if anything it was decent and not a prolapse, 4 months later and I'm getting a pessary because it got much worse from them not taking me seriously.*** *" (POP 14)*

In this example, the patient reports feeling dismissed by their urologist as they minimised the severity of their symptoms and suggested to the patient that it was "all in their head". Because the patient's concerns were not taken seriously, their diagnosis was delayed, causing their condition to worsen significantly. This highlights the dangers of dismissiveness as it can lead to a deterioration in the patient's condition. Further, it demonstrates the importance of taking patient concerns seriously regardless of age as it appears the patient's age contributed to the lack of seriousness on the doctor's part.

Overall, evidence suggests that dismissiveness and misalignment in patient-doctor dynamics are particularly concerning in women's health. When healthcare providers fail to align their care with the patient's experiences, concerns and preferences, it can lead to inadequate treatment, increased frustration and potentially worse health outcomes. This misalignment reveals a need for more active listening when formulating patient care plans.

5 DISCUSSION

Previous research has highlighted users' value on personal experiences and general information when seeking health-related information in Online Health Communities (OHCs) [9, 29]. Building on this foundation, we dove into the specific ways in which POP is discussed and managed on Reddit. By categorizing the informational support types based on the nature of support (descriptive or prescriptive) and source of information (experiential or authoritative), we gained a more comprehensive understanding of the informational needs in OHCs. This is particularly relevant for individuals dealing with POP.

5.1 Informational Support Types

5.1.1 ***Descriptive vs. Prescriptive Information.*** Descriptive information, which indicates what could be done/could be the case without prescribing specific actions, was found to be 50% more prevalent than prescriptive information. This suggests that users in OHCs prefer sharing insights and possibilities rather than giving direct advice to others. The prevalence of this support type emphasizes the community's focus on sharing experiences and knowledge that can be adapted to individual situations. Specifically, users often share lifestyle changes, treatments, or doctors they have tried, thus allowing others to consider these various options and decide what might work best for them. This offers a supportive environment where patients can learn from other's experiences without feeling pressured to follow specific instructions.

In contrast, prescriptive information, which provides explicit direction to users, was less common but still substantial. This kind of support is essential for patients looking for concrete advice and step-by-step instructions to manage their POP. Prescriptive information suggests users are willing to tell others exactly what will help them based on their strategies. Users often tell others the specific detailed regimens, particular workouts, or steps they took to relieve their symptoms and share with the forum exactly what actions to take. People who may feel overwhelmed by the plethora of options available and are looking for clear, actionable directions may find this type of information particularly valuable. By prescribing specific actions, users can provide a sense of clarity and confidence to those seeking this type of help.

The balance between descriptive and prescriptive information reflects the various needs of OHC members. While some individuals like to explore various options and customize them to fit their unique situation, others look for specific steps to implement into their lives. By understanding this balance, healthcare professionals and OHC moderators can better tailor their support to meet the diverse preferences of POP patients. Encouraging a mix of both natures of support can help to ensure that all users find support that resonates with them. This will ultimately enhance the overall effectiveness of the OHC.

5.1.2 ***The Value of Experiential Information.*** The high prevalence, and most common support type, of experiential information covered almost 80% of the data. This emphasizes the high-value POP patients place on personal experiences in OHCs. Users frequently offered insights and potential solutions based on what worked for them providing real-world examples and relatable stories. This preference suggests that individuals often seek and value peer support in online communities. Peer support provides a sense of shared empathy and understanding for one another which can be comforting for individuals dealing with a condition like POP. The preference for descriptive support further emphasizes the desire for shared understanding and empathy. Combining experiential and descriptive support promotes an environment where patients can consider various posts and options and make choices based on a variety of experiences.

5.1.3 ***Limitations of Authoritative Information.*** Authoritative information, based on scientific or expert evidence, was less common in the data covering only about 14%. The nature of OHCs, where users are more likely to share personal experiences than to cite authoritative sources, suggests the cause of this decreased prevalence. Although it is less common, authoritative information is essential for providing evidence-based advice and enhancing the credibility of information shared online. However, assuring the validity of authoritative information shared online presents challenges.

One limitation is that authoritative information on POP is often hard to access, as many times there is a lack of complete information or it resides in scientific publications [7, 10]. Additionally, past research has shown that people in these forums don't all have the scientific literacy to read and understand current specialized medical journals [10]. Users may also question the reliability of authoritative sources especially if users do not have access to the cited experts or the original source of information. Another limitation is the potential for discrepancies in the information shared by patients. When patients share information based on memory, there is a risk that they may not accurately remember what their doctors told them, and important details may be excluded or misinterpreted resulting in incomplete or incorrect information within the OHC. Similarly, the reliability of information from YouTube or other websites that are shared is not always guaranteed. Users often do not have the expertise to verify the credibility of these sources which can lead to the spread of inaccurate information. This suggests the need for mechanisms to verify and promote trustworthy information within OHCs.

5.1.4 ***The Importance of Peer Support.*** We found that while authoritative information is important, users are more likely to engage with and trust information that comes from individuals who have faced similar journeys. POP patients have more confidence in managing their condition when a sense of community and understanding is fostered. However, it is important to note that the experiential success stories and positive experiences are often embedded in the comments while the initial posts predominantly feature negative experiences. This means that users who only look at the initial posts likely have increased stress or anxiety about the condition if they are only seeing negative stories and only those who dive deeper into discussions find balanced perspectives and encouraging stories. Additionally, in OHCs, users often share their initial experiences, questions, or concerns in posts, but they do not return to the forum to update their posts with progress updates or new information. As a result, other OHC members may not have a complete picture of the outcome or effectiveness of the support given.

5.1.5 ***OHC Design Opportunities.*** Based on our analysis surrounding POP in OHCs has led us to several HCI design opportunities aimed at improving user experience and support.

To enhance the informational support for OHC members, it is beneficial to allow users to purposefully explore both prescriptive and descriptive information. We propose a system with two interfaces that enable users to choose between these types of information. This system can include tabs that divide posts into "Descriptive Insights" and "Prescriptive Advice," making it easier for users to find their preferred information type. This method can cater to users who seek a variety of different options along with those who want clear, actionable steps. By understanding and adapting the balance between descriptive and prescriptive information, healthcare professionals and HCI designers can more effectively customize support to meet the varied preferences of POP patients.

Given the high value that POP patients place on personal experiences, we suggest developing a feature that categorizes experiential posts based on particular themes or outcomes. For example, grouping stories by pessary usage, surgery outcomes, lifestyle changes, physical therapy, etc. This can be implemented through tagging or user-generated labels where users can assign keywords or categories to their posts and comments. These tags can be used to filter and search for posts on similar topics making it easier for users to find relevant personal experiences that relate to their own situations. Additionally, adding a rating system to experiential posts where users can vote on which stories they found the most helpful or relatable can help make the most valued experiences most visible to users. This OHC design aims to provide an environment where patients can look for specific themes or consider various posts/themes and make decisions based on a range of experiences.

To improve the clarity and reliability of information within OHCs, it is essential to distinguish between authoritative and non-authoritative information along with knowing the credibility of the information. We propose implementing a verification system for this support type within OHCs. Working in collaboration with healthcare professionals who can review and approve posts containing scientific or expert evidence is one way to accomplish this. Verified posts can be marked with badges or labels to indicate their credibility. Establishing the credibility of authoritative information can enhance the available information and decrease the potential for discrepancies in the forums. Furthermore, providing summaries of scientific papers in plain terms can help close the knowledge gap for users with different levels of scientific literacy. This is beneficial in allowing more patients to understand scientific/expert information shared in OHCs. By taking these measures, there is a guarantee of accurate and consistent information across the community.

To enhance peer support within OHCs, we propose encouraging more initial posts that give support much like "Ask Me Anything" (AMA) style posts. AMA posts are a type of post where users invite others to ask them questions about their experiences or expertise. Users could be encouraged to write initial posts on OHCs sharing their own coping strategies, success stories, or other encouraging information. These posts would be more prominent and easier to find than comments buried within other threads. For example, a user who has used a pessary might create a post titled: "I have been using a pessary that has been helping my POP symptoms for six weeks. AMA". In this post, they could share detailed information about how the pessary is working for them. Other users could then ask questions and engage in a focused discussion about pessaries. By encouraging more visible and focused support posts, the community is provided with a richer and more supportive environment that leverages the collective knowledge and experiences of users. This makes it easier for users to find the help they need and see a more balanced perspective throughout the OHC.

Additionally, we propose implementing features that encourage users to update their posts. Users who have shared postings on the site can receive automated reminders to provide updates on their progress or outcomes. For instance, a few weeks after posting about attempting a new treatment for POP, a user may get a reminder asking if they would like to share how the treatment has been working for them. Furthermore, to facilitate the addition of new content, each user's post could include a visible "Update Post" button to make it easy to add new information/updates. This button can be prominently displayed to urge users to keep their posts current. Posts that have been updated can be labeled as "Updated" or highlighted to increase their visibility to other users. This can encourage users to check back on posts they are following to see the most recent updates. By encouraging users to update their posts, others who may be following similar journeys can observe the full progression and outcomes of various treatments. It also promotes a sense of ongoing support and involvement, as users can continue to share their experiences and learn from one another over time.

Through these design opportunities, OHCs can create a more supportive and engaging environment where individuals can find the encouragement and informational support they need while promoting a sense of community and understanding.

5.2 Examining the Support Deficit

Further, we aim to understand the root cause of Reddit users (patients) seek informational and social support outside of their healthcare providers. Related works reveal that women's experience of receiving care for POP consists of a general sense of discontent, discomfort, feeling ignored, and lacking education on their condition [2]. Additionally, studies on birth stories also highlight a persistent distrust in women's reports of their pain and their experiences [4]. To better understand the factors driving patients to seek help on Reddit, we examined their reported experiences with healthcare providers prior to engaging with the platform.

Qualitative analysis can quickly become complex because of challenges such as ambiguity of context, missing information and the subjective interpretation of tone in patient testimonies. We attempt to strike the balance of letting analysis be a self-evident process while acknowledging the inherent subjectivity and nuance of interpretation. By employing the Braun and Clarke qualitative analysis model and iterative methods, we identified a key factor: the experience of being heard as a foundational trigger for seeking external support. When patients feel unheard, they are more likely to turn to online communities to fill the gaps left by their healthcare providers. Understanding what occurs in the hospital consultation room is crucial for identifying the informational deficits that drive patients to seek "missing pieces" [4] elsewhere.

5.2.1 ***Patient Validation in Healthcare Outcomes .*** The importance of being heard in the patient-doctor relationship emerged as a critical factor in dictating patient satisfaction and outcomes. We learned that for many patients, being heard means more than just having their symptoms acknowledged; it encompasses having their concerns validated, feeling respected regardless of their age or perceived knowledge of their condition, and receiving a diagnosis that reflects their unique experiences rather than preconceived notions. Additionally, patients often desire treatment plans that align well with the concerns they voice and they appreciate when healthcare providers consider their suggestions and preferences during decision-making. The outcomes of treatment heavily influence whether patients feel heard, as ineffective treatments—regardless of whether they were desired—often leave patients feeling frustrated and disregarded. This issue is consistent across different types of healthcare providers, including general practitioners, OB-GYNs, and urologists, with no significant differences in the quality of responses or recommendations. However, in a few cases, patients experienced validation and more active responses when visiting an urgent care or emergency room. This is particularly interesting considering the typically fast-paced environment of these facilities and their services. However, the data reveals that patients often resort to these visits only after their conditions have significantly worsened because they were not addressed by the HCP.

5.2.2 ***The Power of Being Heard.*** Being believed can be the difference between a complete resolution and a life-threatening evolution of a condition. Through the analysis of the comments, we learned that when patients perceive that they are not believed or validated, it not only causes frustration but also hinders a patient's ability to make informed decisions and consequently affects the quality of care they do receive. When not believed, patients become less likely to share further details about their experiences or inquire further about their options. With many explicitly seeking patience and empathy, it suggests that they want to be believed and humanised in the consultation process. This demonstrates that they seek no only a diagnosis of their symptoms (informational support) but also acknowledgement or faith of their reported distress (emotional support) from their healthcare providers. Unfortunately, patients who are not believed or validated are often forced to endure suffering until a drastic change in their conditions, at which point a drastic care option is necessary. It is around this stage that patients begin seeking support outside of hospital rooms.

On the other hand, findings show that in cases when patients feel their concerns are acknowledged, if they do not have perceived influence on the prescribed treatment, or if the treatment is not one they expressly desired the misalignment between their expectations and the treatment offered can result in frustration. Perceived influence refers to whether or not patients feel like there is an explicit connection between the experience they described and the function of the treatment that the HCP recommends. The dissonance of it can be equally as harmful because it causes patient dissatisfaction, harms patient trust, and in some cases delays adequate care if the initial care plan is not well customised. It suggests patients prefer customised care plan as it gives them some form of agency in their treatment.

To put it simply in analogy, in the first instance, both parties are not on the same page, leading them to different conclusions; while in this second instance, they are on the same page but not in the same paragraph leading to different interpretations. When patients feel heard, it fosters trust, satisfaction, and a sense of partnership in their care. Conversely, when this essential element is missing, it can lead to frustration, distrust, and a search for support outside the traditional healthcare system, such as through online communities. These findings emphasise the need for healthcare providers to integrate patient preferences with medical expertise, promoting a more collaborative approach to care. Abhyankar voices this best stating "person-centred care legitimises and values people's lived experiences and embodied knowledge and offers it a genuine voice(space) during the clinical encounter [2]."

5.2.3 ***Empathetic Communication.***

Communication, both verbal and nonverbal, is a shared responsibility between the patient and the healthcare provider. There is a critical breakdown in communication when information transfers from the doctor to the patient, often exacerbated by the technical knowledge differential between them. Antoniak et al. [4] briefly highlight how this knowledge gap negatively affects power dynamics, as doctors are less likely to simplify information and more likely to be dismissive. This was a consistent challenge across all examples of "not being heard". Patients do not want to be judged based on their age or their knowledge of their condition; rather, they expect doctors to process, apply, and communicate information in a way that is clear and easy to understand, without being condescending. Some users reported their interactions with HCP stating " *her first reaction was to laugh*" or "*she rolled her eyes*".

Another notable trend was that unfortunately, patients suggested that many doctors either lack the fundamental understanding or are not cognisant of the fact that while they (HCP) may have encountered multiple patients with a particular condition, it is often the first time a particular patient is experiencing it, making it a "big deal" (POP 13) for them. It significantly impacts their quality of life. Doctors must balance validating the patient's pain with providing assurance that they can overcome it. The many cases of emotional invalidation, where doctors dictate how patients should or should not feel and actively dismiss their experiences, can exacerbate patient suffering and erode trust in the healthcare system. Empathy and emotional support play a critical role in patient care as active invalidation can deepen patient distress and eventually lead to a breakdown in the patient-provider relationship.

Self-advocacy An emerging theme observed in this study is the increasing trend of patients resorting to self-advocacy as a means of coping with inadequate care and communication from healthcare providers. This theme is deeply intertwined with the four primary issues identified: being "Not Believed or Validated," receiving "Believed but Undesired Treatment," experiencing "Emotional Invalidation," and encountering care that is "Not Aligned" with their needs. Patients reported feeling compelled to fight for their treatment, often after their initial concerns were dismissed or minimised. For example, one patient recounted, "*I will definitely make another appointment and fight for something because I shouldn't have to suffer*" (POP 13), highlighting the desperation and determination to obtain appropriate care. While self-advocacy can empower patients to take control of their health, it also reflects a significant shortcoming in the healthcare system. The need for patients to advocate strongly for themselves suggests that the system is failing to provide the support and validation they require. Moreover, self-advocacy as a coping mechanism is not a sustainable solution; it places undue stress on patients who may already be in a vulnerable state. This finding emphasises the necessity for healthcare providers to actively listen, validate patient experiences, and incorporate their preferences into care decisions, thereby reducing the need for patients to take on this burden themselves persistently.

Echo Chambers and Support Dynamics in Online Health Communities A limitation of this study is the inherent tendency for topic threads or subreddits to quickly fill with responses echoing the sentiments of the initial post. It can lead to a reinforcement of particular viewpoints or experiences without a balanced representation of diverse perspectives. In these online spaces, individuals who have similar experiences or frustrations are more likely to engage, as a result, the discourse within these communities may sometimes become skewed, emphasising negative or extreme experiences over more moderate or varied ones.

The Role of HCI and the Implications for Women's Health

As HCI continues to evolve, it presents significant opportunities to address the gaps in patient care experienced by women, particularly in the context of Pelvic Organ Prolapse (POP). Given the findings that many women turn to Online Health Communities (OHCs) because their voices are dismissed or inadequately addressed by healthcare providers, future HCI interventions should focus on creating spaces where these individuals feel genuinely heard, validated, and supported. This can be achieved by designing OHCs that prioritise empathetic communication, foster peer support, and provide easy access to reliable, representative information. The following features are simply ideas we generated from findings, and they require future research if considered for implementation.

One feature to consider adding is topic banners for posts and comments. As users draft their posts, they have the option to add words that help readers understand the highlights of their post, ex. "reassurance", "advice", "Consultation", "stage 2", "PT". The feature could also provide suggestions of themes that are frequent in the subreddit. When the post is made, it would have the themes highlighted as banners under the paragraph. Essentially the goal is to help people know what themes they can expect to read about and figure out how relevant it is to them or the stage they are in before proceeding to read. It make is a more productive user journey for people seeking information. Adding the theme banners on the top of a post makes it easier for users to distinguish the support types they can expect in a post; ex, experiential vs informational as we learned that when users seek to fill the support deficit, such as with OHCs, they seek clearly communicated information unlike that they receive from HCPs.

Another recurring theme observed is the need for validation among users. This could be addressed by enabling the creation of polls within Reddit posts. Users often seek reassurance by asking if others share their experiences or symptoms. While responses in the comments can provide some support, quantifying these responses through polls could offer a more tangible sense of validation. For example, a poll asking, "How many people also feel this way?" with simple "yes" or "no" options could generate a percentage of agreement among respondents. Knowing that 80% of community members share their experiences could help the poster feel validated, seen, heard, and less isolated—a sentiment that emerged frequently in our findings.

We've established that echo chambers can be an inherent product of an online health community, however, it is possible to make them productive and useful. Adding a "themes" slider gradient that organises posts into categories for users seeking nuanced information; a colour gradient from green to red with categories such as positive experiences, mixed experiences and bad experiences. This helps to address the issue of echo chambers and gives the option to present a more balanced representation of experiences, good and bad. It could ultimately, help newer members of the community feel less hopeless and more informed and equally help users with high bounce rates who have no intention of contributing.

Healthcare Providers should also consider practicing active listening and recall methods such as summarising patient concerns with phrases like "So what I'm hearing is…,"; this can ensure patients feel understood and valued. Additionally, validating language that centres the patient and contextualises their pain in the broader scope of their lives can foster a deeper sense of empathy and trust. Another initiative could consist of a communication framework that empowers patients to confidently vocalise their experience. Examples could be in form of pain maps, or models to communicate the impact of a specific care plan; these frameworks could assist in bridging any gaps in understanding, and potentially improve health outcomes. Feedback is also an essential factor for improving patient-doctor dynamics. Providing an anonymous feedback system can give doctors useful insights from patients that can help doctors be better listeners and communicators. This could be equally effective if medical training included extracted excerpts of patient experiences from OHCs as case studies. Integrating excerpts in the form of skits or interactive modules could make them more engaging and elucidating for doctors.

6 LIMITATIONS

The study's limitations include findings that are only representative of individuals who have access to the internet and are using Reddit. This excludes a portion of the population who does not have internet access or those who do not actively use this platform. Additionally, due to the anonymous nature of Reddit, we cannot determine the demographics of the users. This limitation makes it difficult to classify the representation of different countries, races, nationalities, and ethnicities within the study. Another limitation is we cannot confidently deduce the thoughts and opinions of individuals who visit the subreddit forums but do not contribute in the form of comments or initial posts. This silent majority have different experiences and perspectives that are not captured in this study resulting in the overrepresentation of certain viewpoints and experiences while others are underrepresented or absent. The final limitation is the data was collected from only three subreddits (r/PelvicFloor, r/beyondthebump, and r/PelvicOrganProlapse). Although these provide valuable insights into the support needs of individuals discussing POP, this is not representative of all OHCs discussing POP and potentially limits the findings. In the future, a larger study with a more diverse range of online platforms and languages will capture a wider range of experiences and perspectives related to POP.

7 CONCLUSION

Our study has highlighted critical gaps in the care of women experiencing Pelvic Organ Prolapse (POP), specifically how healthcare providers often fail to validate, believe, or align with their patients' experiences, leading to significant consequences in emotional and physical health. The emergence of self-advocacy as a coping mechanism underscores patients' deep-rooted challenges in their interactions with healthcare professionals, pointing to a systemic need for better communication and more patient-centered care. Additionally, the findings reveal how online health communities (OHCs) serve as vital spaces for women to seek the support and validation they often lack in clinical settings.

We have also explored what women seek in OHCs and examined the quality of information valued versus what is available; specifically, we know that women predominantly value experiential, descriptive information that offers flexibility and personalization, emphasizing the importance of peer support and shared empathy.

Given these insights, HCI offers promising opportunities to bridge these gaps. Designing OHCs that prioritize empathetic communication, validation, and clear, reliable information can help empower women, ensuring they feel heard and supported. Techniques such as active listening, validation, and personalized communication frameworks are essential interventions that can reshape the healthcare experience for women.

Looking forward, future research should explore whether the trends identified in this study are consistent across different OHCs and platforms, broadening the scope to understand how various communities address the needs of their users.

Further research should also investigate how technological intervention can improve the credibility and reliability of information shared in OHC. The information circulating on these platforms must be trustworthy if we aim to achieve more positive health outcomes.

As research continues to explore the unique challenges faced by women in healthcare, HCI must advocate for a more inclusive and responsive design approach that not only addresses the technical aspects of care but also honors the lived experiences and emotional needs of women navigating conditions such as pelvic organ prolapse.

8 ACKNOWLEDGEMENTS

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