Effects of Patient-Provider Interactions on Diagnosis and Care for Women With Chronic Pelvic Pain: A Qualitative Study

Pamela Kays, PT, DPT, EdD, WCS

ABSTRACT

Background: Evidence indicates that women with chronic pelvic pain (CPP) frequently experience negative patient-provider interactions (PPIs) that contribute to diagnosis delays, comorbidity with other conditions, and psychological and socioenvironmental complications. However, specific components of PPIs and their effect on diagnosis and care for women with CPP are poorly understood.

Objectives: To determine the themes and patterns of PPIs affecting health care experiences for women with CPP.

Study Design: Phenomenological qualitative study using semistructured, in-depth interviews.

Methods: Thirteen women, aged 18 to 65 years, with CPP for a minimum of 6 months participated. Transcribed data from standardized, in-person interviews were analyzed with qualitative analysis software to manually code thematic nodes. For interpretive phenomenological analysis, an open and inductive approach with constant comparison was used.

Results: Emergent themes were consequences and effects of PPIs on health care. The described consequences of these interactions for women with CPP included increased emotional toll and decreased trust. The effects of these interactions on diagnosis and care included health care experiences related to information and resources provided, diagnosis, medical error (eg, misdiagnosis and inappropriate treatment), and plan (eg, treatment, management, and referral).

Conclusion: Results of the current analysis demonstrated certain components of PPIs adversely affected health care experiences for women with CPP by contributing to the emotional burden of living with CPP, interfering with communication and trust between patients and providers, and impeding proper diagnosis and treatment for these patients.

Key words: CPP, patient experience, patient-provider relationship, pelvic pain

INTRODUCTION

Research suggests chronic pelvic pain (CPP) affects about a quarter of women and results in almost a third of gynecological visits. Unfortunately, diagnosis and treatment of this condition is poorly understood. In the United States, a correct diagnosis for CPP conditions may be delayed by 10 or more years. Patient-provider interactions (PPIs) may be a contributing factor for this delay. Ideally, PPIs should contribute to quality health care and positive health outcomes but women with CPP frequently experience negative PPIs.

Studies have investigated patient perspectives of PPIs from women with CPP, but many were conducted 25 years ago. Since then, the benefits of patient-centered care and the influence of PPIs on patient experiences and health outcomes have been investigated for other conditions, such as chronic pain, gastrointestinal disorders, diabetes, and chronic obstructive pulmonary disease. Despite these additional studies, the overall literature in this area is sparse for all patient populations, and this lack of current literature specific to PPIs for women with CPP requires current investigations that include an updated understanding of patient-centered care and the influence of PPIs on patient experiences. However, because individual patients are complex and diverse, PPIs are complex and dynamic. This variety, coupled with the limitations of quantitative research, suggests a systems theory-based qualitative approach may be more appropriate when treating women with CPP.

Phenomenology was designed for experiential research and focuses on commonality of lived experiences from the first-person perspective. This qualitative approach is ideal for assessing an individual’s lived experiences, especially in relation to illness.
and medical experiences. Similarly, the systems theory and the Neuman systems model of health care are theoretical frameworks that focus on interactions and interconnected components of PPIs and, thus, can evaluate effects of diagnosis and care. These frameworks also include consideration of each individual’s circumstances and background to address internal and environmental stressors and achieve positive patient outcomes. As such, they are useful for qualitative studies because they are consistent with the concepts of patient-centered care and clinical empathy.

A recent publication reporting on PPIs from the perspectives of women with CPP indicated detrimental patterns are still common and persistent. Specifically, several health care provider (HCP) behaviors negatively shaped PPIs, such as faulting participants for CPP, labeling CPP as psychosomatic, dismissing participants, and normalizing the difficulties of women with CPP. Participants also emphasized that HCPs did not listen to, believe in, or take them seriously and that negative PPIs resulted when HCPs lacked compassion, honesty, and knowledge about pelvic pain conditions or made little effort to help. However, it was unclear how and to what extent these PPIs affected care of the individuals. Therefore, the purpose of the current analysis was to determine the themes and patterns of PPIs affecting health care experiences for women with CPP. Specifically, how PPIs affected diagnosis and care of this population was investigated.

METHODS

Design
Using a phenomenological qualitative design, based on the systems theory and the Neuman systems model of health care as frameworks, previously collected data were further analyzed to determine the themes and patterns of PPIs affecting health care experiences for women with CPP. The interviews were conducted at a southwestern US health sciences university from September to October 2019.

Data Analysis
Data from the interviews were transcribed by a professional research transcription service. Transcriptions were compared with the audio recordings for accuracy and de-identified using generic place holders. Before analysis with NVivo software, participants were e-mailed the transcript to ensure their experiences were accurately represented.

Interpretative phenomenological analysis through an open and inductive approach with constant comparison was used for coding of data. Thematic nodes were reviewed for similarities and differences in relation to participants’ health care experiences, and visual maps and cluster analyses in NVivo were used to assess relationships and interactions among codes.

RESULTS

Thirteen participants, mean (SD) age 38 (12) years, completed the study. Participants reported 16 (11) years living with CPP and 12 (8) years between CPP onset and diagnosis. Participants were White (9, 69%) or Hispanic/Latina (4, 31%). Participants’ descriptions of health care experiences when seeking diagnosis and care for CPP highlighted emergent themes and illustrated their encounters with HCPs (Figure 1). All available data were analyzed, including participant descriptions of positive and negative PPIs, but specific consequences in response to negative PPIs were emphasized by participants and were predominant in the data. This emergent theme, consequences of PPIs for women with CPP, included the subthemes of emotional toll and trust. Participant descriptions also highlighted specific components of health care experiences directly influenced by PPIs. This other emergent theme, effects of PPIs on health care for women with CPP, included subthemes related to information and resources provided, diagnosis, medical error (eg, misdiagnosis and inappropriate treatment), and plan (eg, treatment, management, and referral).

Theme: Consequences of PPIs for Women With CPP
Participants described consequences of PPIs that not only influenced PPIs directly but also affected their experiences beyond PPIs (Figure 1). For instance, when HCP encounters lacked clinical empathy,
participants experienced increased emotional toll and decreased trust in HCPs.

**Emotional Toll**
The emotional toll of seeking diagnosis and treatment for CPP was mostly referenced in relation to negative experiences with HCPs. For one participant, it took 16 years before she was correctly diagnosed, which resulted in residual emotional effects. She described being “so afraid of going back to doctors that don’t believe me, even though now I have a diagnosis and I’ve got pictures. I’ve got all this proof. I still am afraid that I’m not going to be taken seriously.” The words angry, frustrated, anxiety, depression, afraid, crying, and emotional appeared frequently throughout the data. Descriptions about the emotional toll experienced by participants are presented in Table 1.

**Trust**
Multiple factors that shape PPIs for women with CPP interact to influence trust in HCPs. All participants expressed initially trusting HCPs, but diminished or lost trust was referenced frequently in response to negative PPIs. One participant explained, “I initially trusted that the doctors would be able to help me, but I lost trust for them time after time after time of being written off.” Other participants underscored similar experiences, stating, “It’s extremely frustrating. You lose hope, you lose any trust in a physician,” and “It takes me time to trust doctors, at this point.” These descriptions highlight the transformational effects negative PPIs can have beyond one PPI or one patient-provider relationship. Negative PPIs with one or a few HCPs affected participants’ trust in other HCPs. Additional descriptions related to loss of trust with HCPs are presented in Table 1.

**Theme: Effects of PPIs on Health Care for Women With CPP**
Participants described how PPIs affected their health care. Specifically, this theme of effects of PPIs on health care for women with CPP influenced experiences related to the subthemes of information and resources provided, diagnosis, medical error, and plan (Figure 1). As determined through coding similarity cluster analysis in NVivo, each of the 4 subthemes interacted with each other, illuminating the multifactorial nature of how PPIs affected health care for women with CPP (Figure 2).

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Participant Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional toll</strong></td>
<td>I left [patient-provider encounters] with lower self-esteem and began doubting my own perceptions and my own instincts. I started approaching those appointments just with a lot of anxiety. So anxious, that you have an anxiety attack, like I used to, just knowing that the doctor’s appointment is coming up, or going to the doctor’s appointment. You feel uncomfortable; you feel anxious going to see them. That’s not how you should feel. There’s nothing visibly wrong with me, and the doctors will not listen to me, so why bother? I spent a lot of time very angry about that. That left me in 2 more months of pain, and 2 more months of pain, and 2 more months of pain, and that led to years of pain, and years of me frustrated. I was completely crushed that a doctor would … not look at me as a person, because in reality I was going to her for her help. I needed help at that point. Finally seeing because all the years that I did suffer, and go through all of that from the doctors, causing emotional pain. For the 14 to 16 years of being told that it was all in my head and being written off, I felt cheated. … it’s almost like I lost a big chunk of my life, and I am never going to get it back. … I just feel like I lost such a huge chunk of my life, and all I can do is accept it.</td>
</tr>
<tr>
<td><strong>Loss of trust</strong></td>
<td>To me, doctors knew it all. I mean, that was it. If the doctor said it, that was the truth, and so that, I think, burst my bubble of trust in, or blind trust I should say, in the medical community. Over time I lost confidence in them, or trust that they could help me. I initially trusted that the doctors would be able to help me, but I lost trust for them time after time after time of being written off. It was too little too late. I don’t trust him and will never see him and will not recommend him to anybody. I initially had trust in them, but then I just—it was lost over time, whether they would refer me out to another doctor, or they would simply dismiss me and say, “There’s nothing we can do,” or they just weren’t sure what was going on. You lose a lot of trust in physicians. At this point, I was really disenchanted with my OB, and I’m like, “Okay, he’s not going to help me, so I’m going to help myself.” It takes me time to trust doctors at this point. It started out as a 100% trust because I was a 16-year-old, and I was like, “Okay, he has to know. He’s a doctor.” Then as time went on, it just nosedived into the negative numbers. It’s extremely frustrating. You lose hope, you lose any trust in any physician. I think I stopped looking after the age of 18, because I had just given up on doctors and didn’t really that they were going to listen to me. I didn’t trust her…. After that last visit with her, I was like, “I’m done.” There was none [no trust].</td>
</tr>
</tbody>
</table>
Figure 2. Interconnected themes and related subthemes of the current analysis and the overall study for health care provider behaviors and traits influencing patient-provider interactions for women with chronic pelvic pain subthemes of the current analysis are highlighted. The subtheme of conditioning into silence was not referenced enough to establish substantial connections with any other subthemes. The figure was constructed through coding similarity cluster analysis using NVivo software.

Information and Resources
The subtheme of information and resources provided by HCPs was frequently referenced by participants. Mostly associated with negative PPIs, participants indicated they were often provided with little to no information or resources to better understand and manage their condition. One participant reported, “I was never given any kind of printout or handout or any kind of referral for care.” Conversely, when participants described the less frequently reported positive PPIs, they indicated an increased exchange of information and resources from HCPs. Another participant described her positive experience with a provider regarding information: “She acknowledged my belief but then gave me information and facts. Once she informed me, I was able to make a decision; I felt empowered to make a decision.” All participants considered a diagnosis the most important information they could be provided. Additional descriptions regarding information and resources provided, or not provided, by HCPs are presented in Table 2.

Diagnosis
Another frequently referenced subtheme was diagnosis. Participants stressed the importance of finding an explanation or cause for their CPP. One participant described her experience before her diagnosis: “Until we got to that diagnosis and until we got to that understanding of what it even was, we couldn’t treat it. If it’s not spoken about or said, you can’t do anything about it.” Another participant also expressed the importance of diagnosis and the implication
<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Positive Descriptions</th>
<th>Negative Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and resources</td>
<td>He gave me the names of several online support groups and websites ... and places where I could do legitimate research. He answers any questions I have and tries to go into as much detail with why we’re doing what we’re doing. (She) drew pictures, she sat down ... she goes, “I want to draw you a picture of what’s going on in your pelvis.” Yeah, she does listen, but she’s also teaching me so much. That OB/GYN welcomed questions and studies. He would print some out for me and share them with me, ... So it felt very much a sharing of knowledge. He didn’t take offense when I questioned his rationale behind why we would try this versus that.</td>
<td>Unfortunately, I wasn’t very informed when we left, even after asking questions. I never felt very informed. (The provider) gave me a pamphlet and told me nothing. With my previous doctors, I got nothing. I would leave there with just the statements of, “We’ll see you again in 2 months. We’ll see you again in a month and see how it’s doing.” No resources. No information to look up. No. No one explained really anything to me. I had to basically find out everything for myself.</td>
</tr>
<tr>
<td>Diagnosis&lt;sup&gt;a&lt;/sup&gt;</td>
<td>It was like coming out of a depression [participant becomes visibly emotional]. It was just a huge difference. Finally having a name to it and saying, “Okay, this is what’s causing it. This is real. This could be treated.” Just the validation in that moment still, to this day, is literally one of the happiest moments of my life. Even though it’s a really weird thing to say that you’re happy about getting that diagnosis. Just relief of knowing that it wasn’t in my head, that there was something there that was causing all of this pain.</td>
<td>Maybe it’s because I didn’t have a medical diagnosis, and so she was like, “Well, get out. What can I do to get you out?” It’s hopeless. This is never going to go away. If they tell me that it’s not there, how can I even address this? How can I even fix this? I’d gone to a doctor and I was having pain and I asked, “could it be certain things?” I mean could it be extreme things like cancer? When you’re in that type of pain, you’re thinking the worst because it definitely knocks you off your feet. You’re thinking it’s the worst thing [without a diagnosis].</td>
</tr>
<tr>
<td>Interactions of diagnosis with overall study subthemes&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Fourteen years into having this pain, my (new) urologist finally saw me, not just my chart. They said, “This person is in pain,” and they asked me questions, invited me to talk about my pain instead of telling me it was all in my head. My urologists showed me compassion. It took a few extra minutes out of their day to talk about these issues with me, but it led to me getting my life back.</td>
<td>I really thought that a lot of the MDs are super knowledgeable, and OBs, and if they would have done research or asked questions, they could have maybe gotten me a referral to a specialist if they would have reached out. I think if they would have put forth a little bit more effort, I probably would have had answers a lot sooner, but I just felt like they didn’t know, and so they just didn’t really care, unfortunately.</td>
</tr>
</tbody>
</table>

Abbreviations: MD, physician; OB/GYN, obstetrician/gynecologist.
<sup>a</sup>Positive descriptions correspond to having a diagnosis, and negative correspond to no diagnosis.
<sup>b</sup>Overall study subthemes of health care provider behaviors and traits<sup>c</sup> were interconnected with the current study’s diagnosis subtheme.

that, without it, her CPP was considered to be all in her head: “Look! It’s not something fake. It’s not something I’m doing to myself. It’s something real. It’s a condition that is this and needs this type of treatment.” Clearly, women with CPP place considerable importance on a correct diagnosis to understand the cause of their pain and take steps toward treatment and management of their condition. Lack of diagnosis, or an explanation for CPP, was frequently associated with negative PPIs. Having a diagnosis, however, was associated with more positive PPIs and decreased emotional toll. Additional descriptions related to diagnosis are presented in Table 2.

Descriptions related to this subtheme also elucidated interactions between diagnosis and previously reported subthemes of HCP behaviors and HCP traits.<sup>34</sup> According to participants, HCP behaviors and traits contributed to negative PPIs that delayed diagnosis. One participant stated, “Here’s someone [a patient] that had a legitimate problem. Because of their [the provider] ignorance, or their pride, their unwillingness to dig deeper or whatever, I went undiagnosed for so many years.” Additional descriptions highlighting the connection between PPIs and diagnosis are presented in Table 2.

**Medical Error**

Another subtheme, which complicated the process of diagnosis, was medical error. Most participants referenced this subtheme through misdiagnosis, miscategorization, or inappropriate treatment. Some participants indicated new or different symptoms were often inaccurately attributed to existing diagnoses instead of the HCP specifically investigating pelvic pain symptoms to rule out other conditions. For example, one participant described her experience of
this process as, “Here’s some medication. Take this for nausea. It’s tied to your stomach. Have this to calm yourself down, calm the body down,” and they never actually acknowledge or recognize the actual pelvic pain.” Another participant described her difficulties with misdiagnosis and inappropriate medical treatments:

The first one that started was the interstitial cystitis, which started as, “Oh, it might be a UTI [urinary tract infection].” Of course, that leads into the chronic UTIs for the doctors. Going to the doctor saying it’s UTI, treating me with antibiotics. Looking back at all of my records, it was never confirmed that it was a UTI. They did for years treat me as just chronic UTIs with multiple antibiotic rounds, even putting me on antibiotics for 3 months at a time. It was extremely frustrating. The fact that they put my body through all of this, and I was putting a lot of trust in them. Things that they knew better, and they never confirmed it.

Additional participant descriptions related to medical error are presented in Table 3.

Plan
The final subtheme was related to plan, specifically treatment, management options, plan of care, and referral. Plan was the most frequently referenced subtheme of the effects of PPIs on health care among participants. Participants regularly described negative PPIs during which HCPs did not suggest or discuss a plan with the patient. Consequently, participants indicated that they felt stuck and sometimes hopeless without some action step, plan, or direction for finding relief from their pelvic pain. One participant stated, “If it’s not something that they can do themselves, then refer out, but don’t just stop patient care.” Participants communicated that even disappointing information, such as unfavorable or inconclusive test results, was more easily processed and accepted if discussion of the next steps was included. A participant described this sentiment as follows: “Even if it’s more of a negative appointment, there’s a lot more positivity to leaving the office with more hope of, ‘Okay, well, now I know where we’re going.’” Without a plan, participants felt ambiguity or stalled in their journey to manage CPP. Additional descriptions related to plan are presented in Table 3.

DISCUSSION
The current analysis investigated the themes and patterns of PPIs affecting health care experiences for women with CPP. Results suggested certain components of PPIs had negative consequences and effects on health care, and participants emphasized negative PPIs more often than positive PPIs. Specifically, participants reported increased emotional toll, decreased trust, and a perception of incomplete health care related to lack of information and resources provided, lack of diagnosis, medical error, and lack of plans for management of CPP. As a result, these health care experiences contributed to the emotional burden of living with CPP, interfered with communication and trust between the participant and providers, and impeded proper diagnosis and treatment. Although the long-term effects of these patterns in PPIs are poorly understood, the consequences and effects on health care, as described by participants in the study, highlight potential barriers that exist for women with CPP. These results were similar to findings in other patient populations,\textsuperscript{12,16,17,25} but the overall literature related to patient-centered care and the influence of PPIs on patient experiences and health outcomes is sparse, making comparisons difficult. The current analysis was part of a larger study,\textsuperscript{34} and Figure 2 illustrates the interconnectedness of the themes and related subthemes of the current analysis with the overall study. This interconnectedness among various aspects of PPIs highlights the importance of provider empathy for achieving positive outcomes for women with CPP.

Several themes from the current analysis are consistent with previous research describing negative effects of lack of empathy, such as increasing the patient’s emotional burden and delaying diagnosis and care.\textsuperscript{6,7,21–23} Similar to descriptions from previous studies investigating CPP,\textsuperscript{6,7,19,22,24,28,30–39} participants in the study described negative PPIs as contributing to, if not the source of, the emotional toll. This emotional toll affected their quality of life, relationships, sense of self, and outlook on HCPs and the health care process. These findings are supported by the study of McGowan et al,\textsuperscript{22} which also found women with CPP disengaged from the health care process. The persistence of similar findings across decades of research for women with CPP\textsuperscript{6,7,19,22,24,28,30–39} suggests that evidence is not being translated into health care practice for treatment of these individuals. Until we integrate the best available evidence into health care practice for these patients, they will continue to experience negative consequences of PPIs and have poor outcomes.

As in the overall study,\textsuperscript{34} consequences of PPIs in the current analysis also had a subtheme related to trust. Neumann et al\textsuperscript{13} described human understanding and feeling understood as building blocks of trust within the patient-provider relationship. In their systematic review and meta-analysis on the influence of patient-provider relationships on health care outcomes across various chronic health conditions, including fibromyalgia, osteoarthritis, diabetes,
Table 3. Descriptions From Study Participants About the Effects of Patient-Provider Interactions on Health Care of Women With Chronic Pelvic Pain by Medical Error and Plan Subthemes

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Participant Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical error</td>
<td>The first one that started was the interstitial cystitis, which started as, “Oh, it might be a UTI.” Of course, that leads into the chronic UTIs for the doctors... treating me with antibiotics. Looking back at all of my records, it was never confirmed that it was a UTI. They did for years treat me as just chronic UTI with multiple antibiotic rounds, even putting me on antibiotics for 3 months at a time. It was extremely frustrating. The fact that they put my body through all of this, and I was putting a lot of trust in them. Things that they knew better, and they never confirmed it. I even had to stop seeing doctors for a while as far as the urology, because I went through so many... that continued to say, “Oh it's just chronic UTI.” All of those years but one sample were all negative for culture, but every single one of those doctors treated me with antibiotics. “Oh, you probably just have a yeast infection.” I'm like, “I haven't had a yeast infection for 11 years. This is the same pain I've had for a decade.” She's like, “No, it's a yeast infection.” I took those steps on my own. I'm not hypervigilant with my healthcare since 2016 when it became very obvious of how my care was mismanaged for years. I knew there was something more to my issue than IC, ... There's more to it, and nobody wants to admit there's more to it. ... I have sat there the entire time and tried very hard to explain to him in every way I possibly can that there is more going on. There is more, I have had this for 6 years. Do not tell me it is just a flare-up. There is more. ... They have me categorized, and that's all I am, is an IC patient. Once you go there, there's no other help at all. My OB was like, &quot;It's definitely not something I can fix. It can't be any sort of pelvic floor disorder whatsoever. You obviously have a GI problem.&quot; However, I have to say that people get confused when you throw out endometriosis, and I think a lot of providers automatically use that as, maybe it's not a crutch, but that's the word I'll use. That's the crutch they use for why you have pelvic pain. Instead of, &quot;Let's talk about your right-sided pelvic pain that seems to be made worse by pushing on your coccygeus muscle,&quot; they will say, &quot;Let's talk about your endometriosis pain.&quot; That often gets merged together, &quot;Well, it's all endometriosis.&quot; No, it's not. It's 2 different pains. Somebody will say something like, &quot;Well, that's just your endo [endometriosis].&quot; Well, I had a laparoscopy and I didn't have any signs of endometriosis, so how is that my endo? Endometriosis is a good fallback and a good explanation for what might be going on when it's not the key issue or key problem.</td>
</tr>
</tbody>
</table>

| Plan              | That's what you need, is that next step, because usually they just drop the ball, and then you're starting all over again. My OB/GYN just ended the conversation and didn't schedule a follow-up, didn't talk to me, didn't run any tests, just made me feel like I was crazy, shut me down, and sent me home. Being able to go to pelvic floor physical therapy—that was different because it was like there was a plan, and there is actually something you do for this, which I had no idea it even existed until seeing this specialist. I am in crippling pain, crying in the bed, and they tell me there's nothing they can do and send me home. No pain management. Nothing. I'm glad that there was a plan. For the first time in my life going through this, there was a plan. Even if it's more of a negative appointment, there's a lot more positivity to leaving the office with more hope of, "Okay, well, now I know where we're going." Disharmoning. Just so many different emotions of why can't we do something? Why isn't there something that can be done? My expectation was probably that I was going to get some sort of treatment plan. Not as much that it was cured, but some sort of relief, I guess. I think that when I have a plan I feel more hopeful. Even if it wasn't going to cure it, we could do something about it, whether it be knowing on those days that (I) need to rest more... or we need to do heat and ice, or we need to send you to pelvic floor therapy, or let's try this medication. Give me an avenue, give me something I can go to. |

Abbreviations: IC, interstitial cystitis; OB/GYN, obstetrician/gynecologist; UTI, urinary tract infection.

and obesity, Kelley et al.\(^{40}\) reported the interconnectedness of genuineness/honesty, empathy, and trust. In the current analysis, negative and unhelpful PPIs decreased participants’ trust in HCPs. Participants indicated that they initially trusted HCPs when they first sought diagnosis and treatment for CPP, but their trust was decreased or lost because of negative PPIs and lack of empathy from providers. Trust is an important aspect of patient-provider relationships because patients with chronic illnesses must be able to rely on the judgment and recommendations of the HCP.\(^{9}\) Without trust, the patient is less likely to follow recommendations of the HCP.

One subtheme related to the effect of PPIs on diagnosis and care for women with CPP was information and resources provided by HCPs. Almost all participants indicated they were not provided with sufficient information or resources to better understand and manage their condition, which contributed to negative PPIs and decreased self-efficacy for disease management. However, when HCPs supplied information and resources about CPP, participants were more likely to feel heard, believed, and taken seriously, which resulted in more positive PPIs. Little evidence exists in the literature about the importance of education and resources for women with CPP. However,
similarities have been reported between experiences of women with CPP and women with gastrointestinal conditions. For example, Drossman and Ruddy indicated patient education for gastrointestinal conditions that included interactive learning through dialogue between the provider and the patient improved understanding, shared decision-making, treatment adherence, and patient motivation. Future studies could investigate the patient education aspect of PPIs for women with CPP to improve practice and optimize patient outcomes.

Almost all participants stressed the importance of having a diagnosis for their CPP, similar to previous studies involving individuals with chronic pain. With a diagnosis, participants felt their CPP could finally be addressed through appropriate and directed treatments. However, participants indicated they could have arrived at diagnosis and treatment sooner if only HCPs had listened to them or taken them seriously. Such expressions of clinical empathy could have decreased their duration of living with CPP and the associated emotional toll. These findings exemplify a systems approach to care and stress the connection between empathetic components of patient-provider relationships and diagnosis and care for women with CPP.

Medical error in the form of misdiagnosis, mis-treatment, or inappropriate treatment for the actual diagnosis was frequently described by participants. A study by Fox and Chesa also highlighted this connection between medical mismanagement and PPIs for women with chronic illness. In the current analysis, participants attributed medical misdiagnosis in part to HCPs not believing their reported symptoms and concerns. These descriptions align with reported experiences of women with gastrointestinal conditions. Moreover, women with chronic pain are commonly misdiagnosed with mental health conditions without proper evidence, increasing emotional burden and other consequences. However, by listening to better understand the patient’s illness experience, HCPs can facilitate determination of proper diagnosis and, consequently, treatment. Again, these findings underscore the connection between clinical empathy within PPIs and diagnosis and care for women with CPP.

Almost all participants also indicated that without a plan to move forward they felt stuck, disheartened, and hopeless about obtaining relief from CPP, which contributed to the previous subtheme of emotional toll as a consequence of negative health care experiences for these patients. Once they had a plan, participants were more hopeful, or at least felt more productive, about getting closer to answers. Participants also spoke negatively of HCPs who “dropped the ball” in contrast to those who “kept the ball rolling.” Fong-Ha et al. reported similar findings in their review of patient-provider communication across the health care spectrum. Drossman and Ruddy found that “patients do not want to be abandoned in their pain” and that commitment to and investment in the patient’s well-being are demonstrated by an HCP’s attentiveness to ongoing care. Taken together, these findings underscore the importance of communicating “what comes next” to patients to foster more positive and productive PPIs rather than providing more ambiguous suggestions or no suggestions at all.

There are multiple components that shape PPIs and the resulting consequences and effects of those interactions on health care for women with CPP. Howe et al. identified warmth and competence as the central components of PPIs to optimize patient outcomes. Although the interpersonal skills, or warmth, of health care delivery (communication, empathy, and integrity) may seem less crucial than technical skills, or competence (foundational knowledge, technical ability), poor interpersonal skills can interfere with optimal care, as illustrated in the current analysis. A particularly salient statement from one participant was: “I got great results with the person who was empathetic, and I got horrible results from the person who wasn’t.” This participant had experienced both types of PPIs, and her health care experiences expressed by this statement highlight the interconnected themes and subthemes of the current analysis. Moreover, this statement underscores the substantial benefits available to women with CPP when providers embrace clinical empathy and a systems theory approach to achieve high-quality patient-centered care. Ultimately, results of the current analysis highlight potential barriers in the health care process that exist for women with CPP and illustrate how negative health care encounters affect their emotional well-being and care outcomes. The results also reveal how little we know about the lived experiences of women with CPP and how much additional research is necessary to improve diagnosis and care for this patient population.

Limitations of the current analysis and the measures taken to minimize researcher bias are the same as those reported in the overall study. One important limitation is that only 2 race and ethnicity categories were represented (White and Hispanic/Latina). Those categories represent the general population where the study was conducted, so results may not be generalizable to other areas. Furthermore, only English-speaking participants receiving care in the United States were included in the study so that the researcher could communicate with participants, but this also limits generalizability of results to other populations in the United States and in other countries. Some
described health care experiences occurred in multiple states, and all experiences occurred across multiple clinics, health care disciplines, and types of providers (eg, physicians, physician assistants, nurse practitioners, physical therapists, and nurses). However, such data were not collected or analyzed. The literature review found no studies investigating pelvic physical therapists, specifically, and PPIs for women with CPP, and there is sparse literature regarding PPIs from the patient’s perspective by health care discipline. Voluntary response bias is an inherent limitation of self-reported information, and researcher bias is also a concern with qualitative research. However, the author tried to be transparent about data collection, analysis, and presentation. Peer debriefings were also used to offset researcher bias.

The results of the current analysis may be useful to inform HCPs and HCP educators about the consequences and effects of PPIs, particularly negative PPIs, for women with CPP. Awareness of the components that contribute to negative PPIs and the effects and consequences of negative PPIs in this population, as reported in the current analysis, are vital for taking active steps toward progress. However, additional research should include more diverse populations and geographic regions to increase generalizability. Future studies investigating PPIs from the patient's perspective by health care discipline may also highlight areas for improvement in HCP education. Based on salient themes from the current analysis and the overall study, additional studies could also explore effective educational techniques to promote positive PPIs. Furthermore, the resulting themes from the current analysis may be useful for developing quantitative assessment tools that support the qualitative data. Through improved research and education for HCPs, best practices can be advanced to maximize diagnosis, treatment, and outcomes. Ultimately, the goal of such studies would be alleviation of the physical and emotional suffering of women with CPP through better quality health care.

CONCLUSIONS

Overall, findings of the current analysis identified consequences of PPIs for women with CPP and their effects on health care. Negative PPIs affected trust in HCPs and diagnosis and care. Lack of empathy during PPIs increased emotional burden and delayed diagnosis and treatment. These findings highlight the consequences and effects of negative PPIs for women with CPP and suggest areas for improvement. Because clinical empathy facilitates positive PPIs, it can circumvent negative components that adversely affect health care experiences, diagnosis, and care of these patients. Ultimately, increased HCP awareness and use of clinical empathy to foster positive PPIs may decrease the emotional burden of living with CPP, cultivate communication and trust between patients and providers, and improve health care outcomes for women with CPP.

Acknowledgments

The author gratefully thanks the study participants for sharing their experiences, as well as Lori Bordenave, PT, DPT, PhD, Candace Ayars, PhD, and Deborah Goggins, MA, ELS, for additional research and editing support.

REFERENCES

Erratum

The Effect of Imposed Pelvic Inclination Angle on Pelvic Floor Muscle Activity—A Pilot Study Using Ultrasound Imaging, Digital Inclinometry and Surface Electromyography: Erratum

In the January/April 2012 issue of the journal, an erratum on page 61 omitted an author's name from a poster. The citation in the erratum should have included L. Dunning, as listed below:


REFERENCES


DOI: 10.1097/JWH.0000000000000263