

# Patient-Provider Interactions and Influence on Healthcare for Women with Chronic Pelvic Pain

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# Background

- Chronic pelvic pain (CPP) affects up to 25% of women<sup>1</sup> and accounts for 10-33% of gynecological visits.<sup>2,3</sup>
- Diagnosis and treatment are poorly understood,<sup>1,3-6</sup> and diagnosis is delayed by more than 10 years on average in the U.S.<sup>6,7</sup>
  - Reasons for these delays are not well understood.<sup>6</sup>

# Background

- Previous studies found healthcare provider (HCP) attitudes towards patients with CPP influenced results of treatment and could contribute to lack of clinical resolution.<sup>8-12</sup>
- Patient-provider interactions (PPIs) play a crucial role in quality healthcare and positive health outcomes<sup>5,10,12-21</sup> but can be frustrating and strained, associated with negative perceptions, and emotionally burdensome to patients and providers, particularly related to chronic pain conditions.<sup>2,6-10,13,14,22-24</sup>

# Background

- Empathy is an important component of patient-centered care and successful PPIs, particularly for individuals with chronic pain conditions. <sup>2,10,11,13-17,19,25-28</sup>
- Clinical empathy requires the provider to:
  - 1) Understand the patient's situation, perspective, and feelings
  - 2) Communicate that understanding and confirm its accuracy with the patient
  - 3) Act on that understanding for the benefit of the patient<sup>25</sup>

# Purpose

The purpose of the current study was to investigate the lived experiences of patient-provider interactions from the perspective of women with chronic pelvic pain.

# Guiding Questions

- How do women with CPP describe their healthcare experiences when seeking diagnosis and treatment/management options for pelvic pain conditions?
- How do women with CPP describe the level of empathy from providers involved in their healthcare experiences regarding difficulties in coping and living with CPP?
- How do PPIs affect diagnosis and care for women with CPP?

# Methods

- This study was conducted through a phenomenological qualitative design using semi-structured, in-depth, individual face-to-face interviews
- A topic guide was created to provide structure to interviews and was refined through instrument audit by 2 experienced qualitative researchers and a pilot interview
- One researcher conducted all interviews for consistency, took notes during audio-recorded interviews, and facilitated member checking for participants to confirm the accuracy of their interview data

# Participants

- Voluntary participants were recruited through women's health and pelvic health physical therapy Facebook pages and by referral from local pelvic physical therapists.
- Non-probability, purposive sampling was used to select participants based on study goals.<sup>29</sup>



# Participants

## Inclusion Criteria

- Adult females aged 18-65 years
- CPP for a minimum of 6 months (per the definition of CPP)<sup>1,3,4</sup>
- Had sought medical consultation or care for CPP
- Able to travel to interview location

## Exclusion Criteria

- Pain did not meet the definition of CPP
- Pelvic pain specific to menstruation, intercourse, pregnancy, or malignancy

# Data Analysis

- Interview data was transcribed from audio recordings, and transcriptions were compared with audio recordings by the researcher for accuracy
- Each transcript was emailed to the appropriate participant for member checking to confirm their experiences were accurately represented
- Files were imported into NVivo qualitative data analysis software.<sup>30</sup>

# Data Analysis

- Data were coded using interpretative phenomenological analysis through open, inductive approach with constant comparison.
  - This method was chosen because it has been widely used in qualitative research investigating illness experience.<sup>31</sup>
- Data coded into thematic nodes were reviewed for similarities and differences in participants' experiences, particularly in reference to PPIs and HCP empathy.
- Data from all 13 interviews were analyzed, but thematic saturation was reached after analysis of data from participant 11.
  - Determined when no new themes emerged during analysis of 3 consecutive transcripts.

# RESULTS

# Participants

**Table 1.** Demographic Characteristics of Study Participants (N=13)

Demographic Variable	No. (%) or Mean (SD)
Race and ethnicity	
White	9 (69)
Hispanic/Latino	4 (31)
Age <sup>a</sup> , y	38 (12)
	23-63
Years living with CPP	16 (11)
Years between CPP onset and diagnosis <sup>b</sup>	12 (8)

<sup>a</sup>Age is reported as mean (SD) and range.

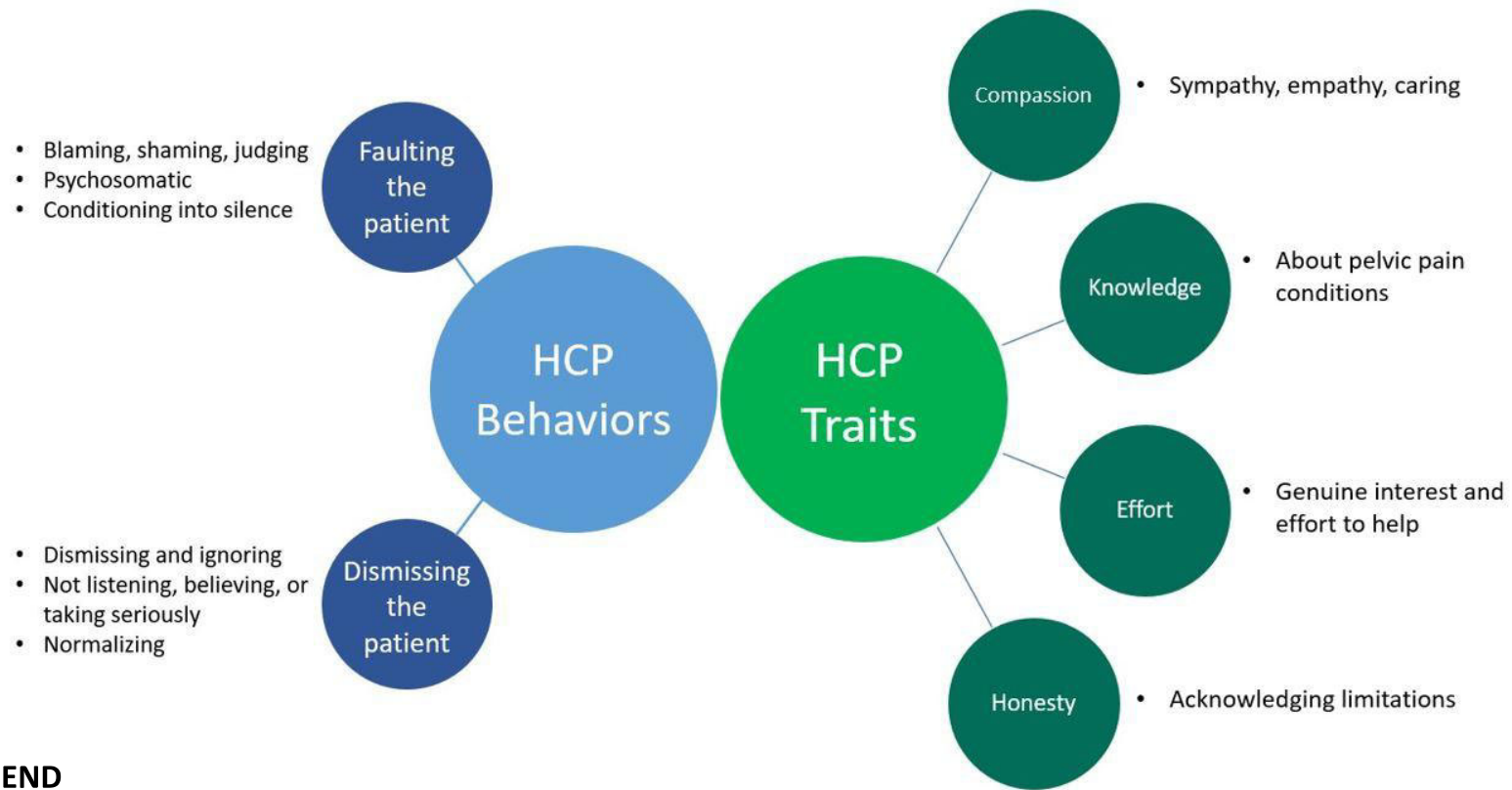
<sup>b</sup>Two participants were still seeking a diagnosis; therefore, the mean time between onset and diagnosis was based on data from 11 participants.

Abbreviation: CPP, chronic pelvic pain.

# Themes: HCP Behaviors and Traits

- Through the descriptions of participants' healthcare experiences, certain **HCP behaviors and traits** were emphasized that directly described empathy or interactions with provider empathy in relation to PPIs and positive versus negative healthcare experiences.

# Themes: HCP Behaviors and Traits



## FIGURE LEGEND

**Figure 1.** Healthcare Provider (HCP) Behaviors and Traits Influencing Patient-Provider Interactions for Women with Chronic Pelvic Pain by Subtheme

# Theme: HCP Behaviors

"It turned back on me. That I either did something to deserve it, or that I was making it up."

## Blaming, shaming, judging

"I almost felt like I'm being judged when I'm there for my pelvic [pain], like I brought it on or something."

"I approached those encounters with a lot more anxiety and almost with shame."

## Dismissing

"I was 'written-off'. I didn't fit into their box of what they see and treat all the time, so they didn't want to deal with me."

"I don't think they believed I actually had the pain I was in."

## Not listening, believing, or taking seriously

"They don't take me seriously when I'm there for pelvic [pain]."

"They kind of assume what's going on, instead of actually listening to the patient."



# Theme: HCP Behaviors

"I started to believe them. After so many times of being told that it was all in my head, I started to doubt myself—doubt my own intuitions."

"Oh, absolutely. I had several doctors say that to me— 'It's all in your head.'"

"Basically, you know that there's a problem, and it's really upsetting you, but every time you try and bring it up, you're told, 'Oh, that's not important,' 'Oh, you're imagining things,' 'Oh, it's not real.' Most of what I experienced was just being pressured into silence."

**Psychosomatic**

**Conditioning into silence**

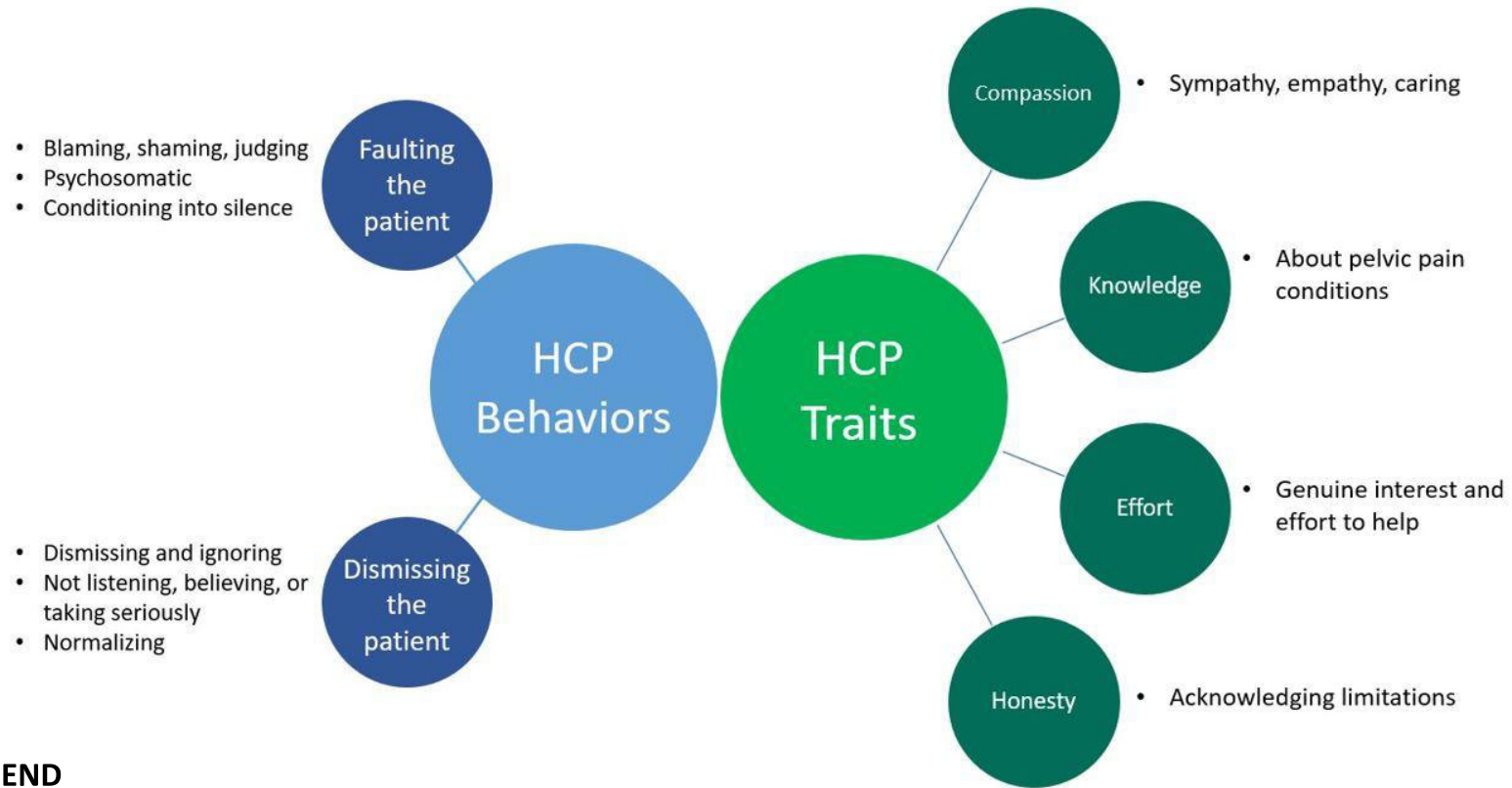
"All women have this. Why are you making such a big deal out of it?"

**Minimizing/  
Normalizing  
CPP as  
woman  
problems**

"I had been trained to stop talking about my pain; otherwise, I would be referred to a psychologist."

"What I ended up doing is just not talking about it to anybody and bottling it up."

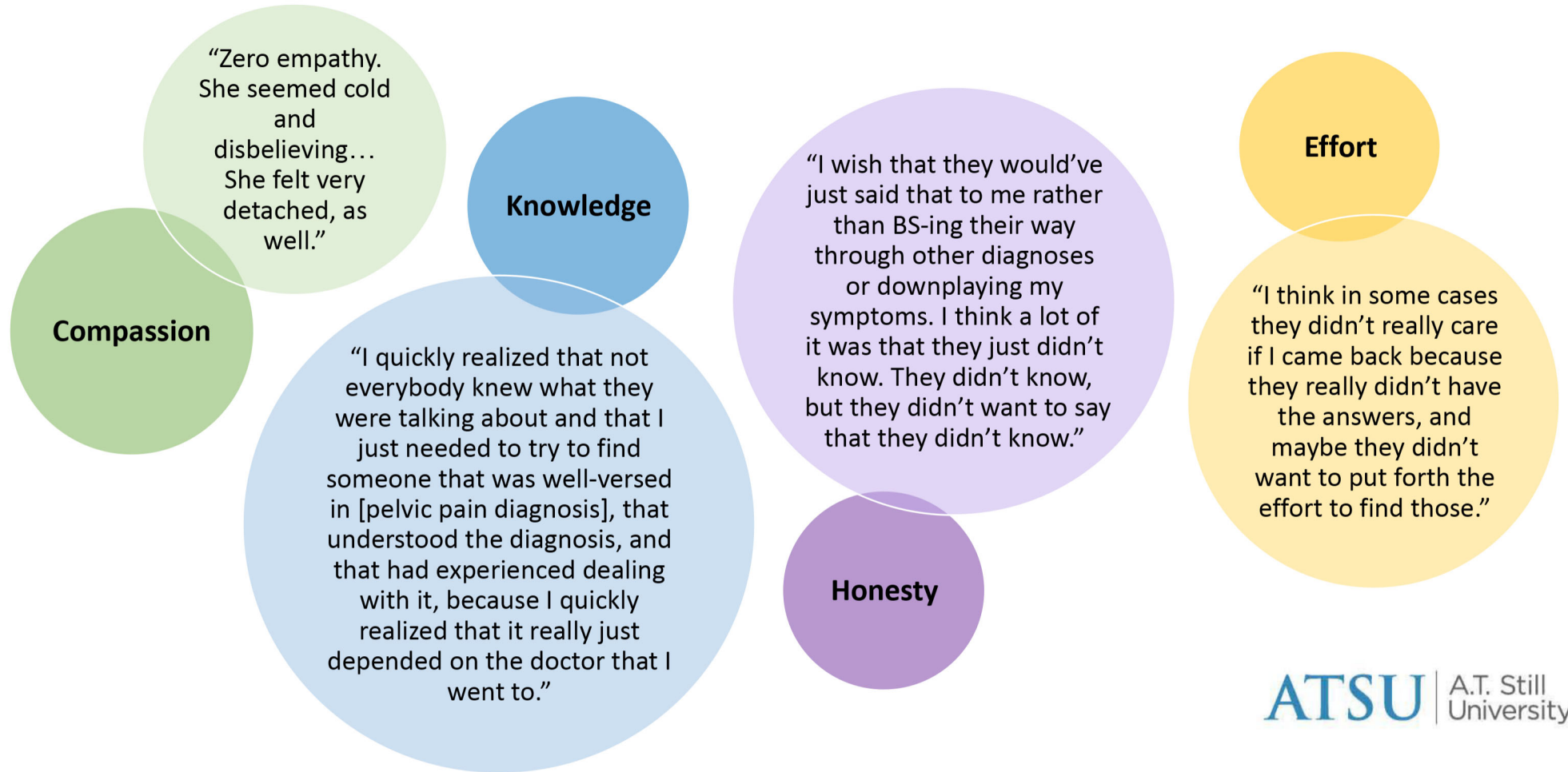
# Themes: HCP Behaviors and Traits



## FIGURE LEGEND

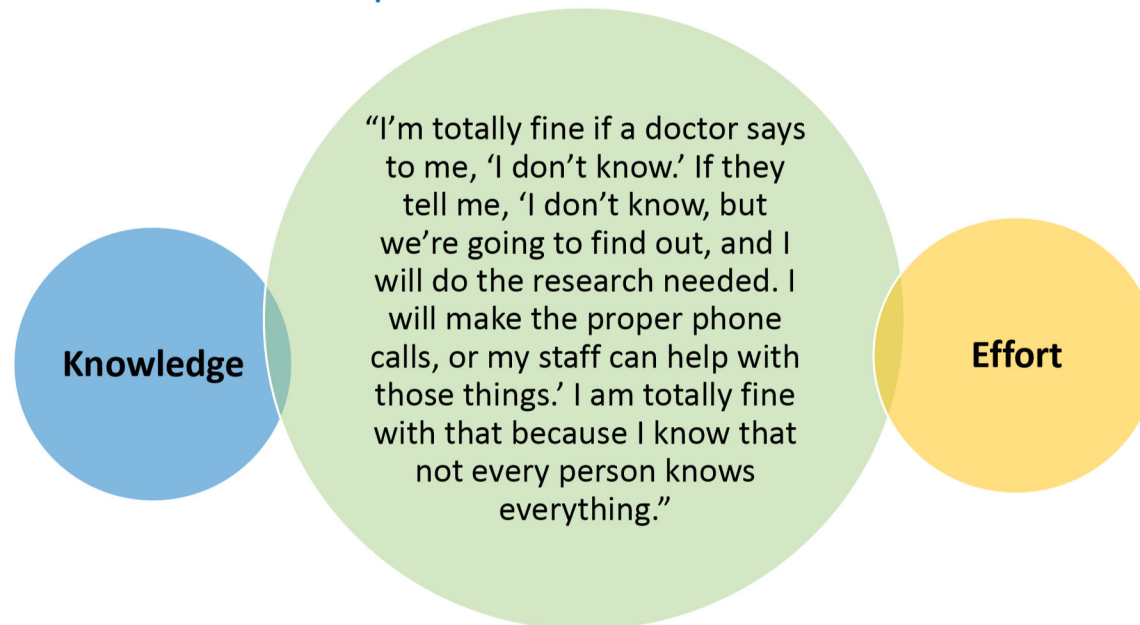
**Figure 1.** Healthcare Provider (HCP) Behaviors and Traits Influencing Patient-Provider Interactions for Women with Chronic Pelvic Pain by Subtheme

# Theme: HCP Traits



# Theme: HCP Traits

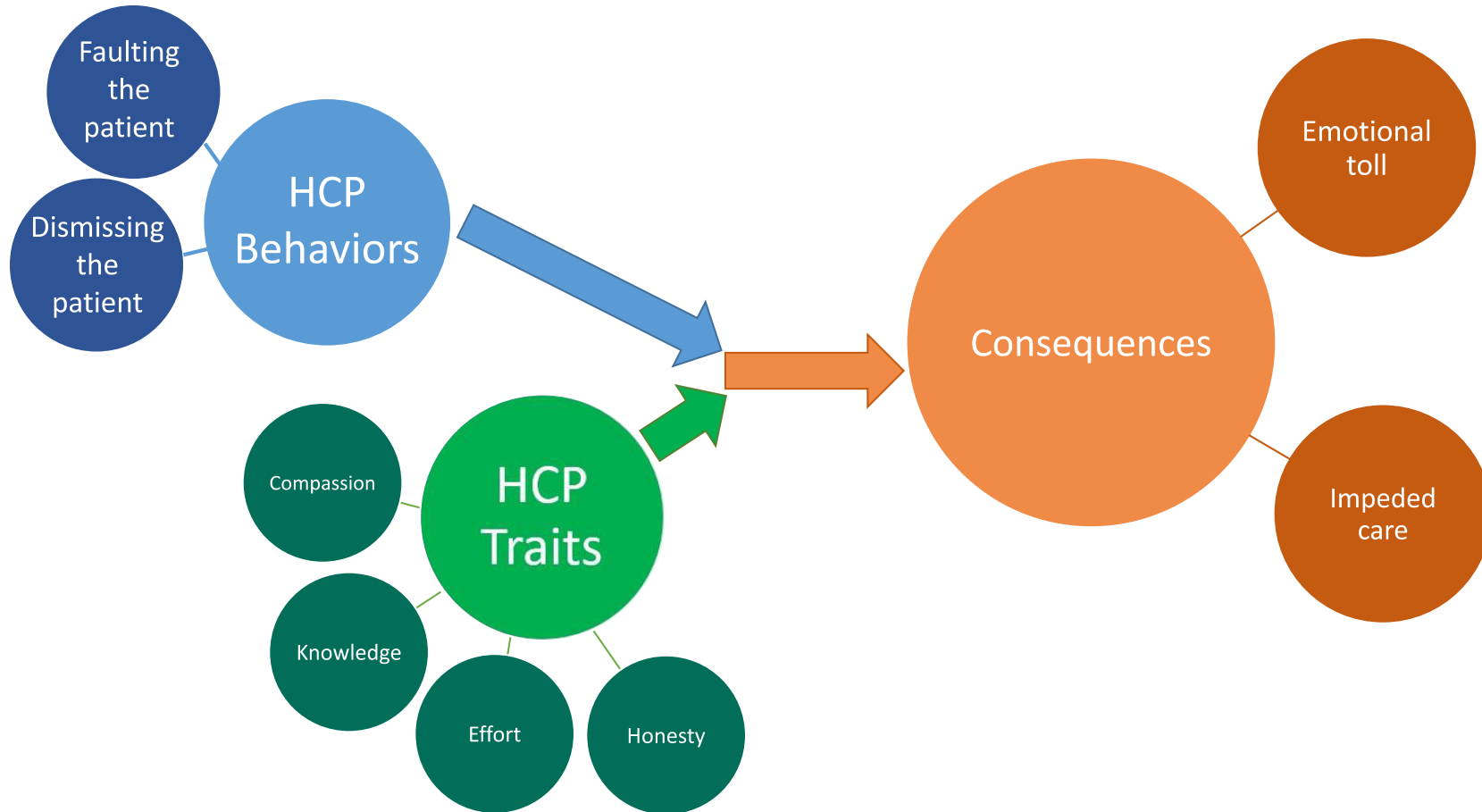
- An interaction became evident between the subthemes of **HCP knowledge** and **HCP effort** to help:
  - Participants were less concerned about a HCP's lack of knowledge if the provider demonstrated an effort to help



# Themes: HCP Behaviors and Traits

“One hundred percent, I was treated like it was, one—a women’s issue and therefore not important, and two—must be something that I had caused. I fully believe that the fact that I am a woman meant that a lot of my pain was dismissed. That makes me so angry!”

# Theme: Consequences of Negative PPIs



# Theme: Consequences of PPIs

- Negative patient-provider interactions increased the **emotional toll** of living with CPP and **impeded effective care**.
- Participants described that their care was impeded in the following ways:
  - Lack of information and resources
  - Lack of diagnosis
  - Medical error
  - Lack of a management plan

# Theme: Consequences of PPIs

"I'm 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."

"For 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."

**Emotional toll**

"Finally seeing because all the years that I did suffer and go through all of that from the doctors, causing emotional pain."

"I was completely crushed that a doctor would... not look at me as a person, because in reality I was going to her for help. I needed help at that point."

Information and resources: "I got nothing. I would leave there with just statements of, 'We'll see you again in two months. We'll see you again in a month and see how it's doing.'"

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."

**Impeded care**

Medical error: "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... even putting me on antibiotics for three months at a time. It was extremely frustrating. The fact that they put my body through all of this."

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."



# Implications

- Negative PPIs resulted when HCPs demonstrated a pattern of behaviors and traits:
  - **Faulting the patient** for CPP (blaming, shaming, judging)
  - **Labeling CPP as psychosomatic**, or “all in your head”
  - **Not listening to, believing, or taking seriously** the patient’s reports of CPP
  - **Dismissing** the patient’s concerns and experience of CPP
  - **Normalizing** the difficulties and experience of CPP
- Negative PPIs resulted when HCPs **lacked compassion, knowledge, honesty, and effort** to help during patient encounters with women with CPP.

# Implications

- Negative PPIs contributed to detrimental consequences:
  - Patients became conditioned into silence and reluctant to discuss their CPP
  - The healthcare process was impeded
  - The patients' emotional toll of living with CPP increased
    - CPP conditions are associated with increased comorbidity of physical/medical conditions, as well as increased psychological and socio-environmental complications. <sup>1,5-10,15,23,34-36</sup>
- Negative PPIs persist and are common for women with CPP, despite decades of research on patient-centered care, clinical empathy, and the influence of PPIs on patients' healthcare experiences and health outcomes.

# Implications

- Positive PPIs resulted when HCPs:
  - Listened to, believed, and took seriously patients' reports of CPP
  - Demonstrated compassion, knowledge, honesty, and effort to help patients
  - Did not fault patients for CPP
  - Did not dismiss patients' reports or experiences of CPP
  - Did not normalize or minimize CPP as a typical "woman problem"
  - Did not label CPP as psychosomatic
- Positive PPIs fostered a feeling of validation for patients' experiences of CPP

# Implications

- The interaction discovered between **HCP knowledge** and **HCP effort** to help appears to be lacking in the literature, therefore this finding may be unique to the current study.
- **HCP effort** to help represents the third component of clinical empathy: acting on empathetic understanding in a way that benefits the patient.<sup>25</sup>
- **HCP effort** may be a major aspect of empathetic and patient-centered care needed to achieve beneficial PPIs and positive outcomes, particularly for women with CPP.

# Limitations

- Study population limited to participants who were able to travel to a specified location in a metropolitan area in the Southwest to participate in face-to-face interviews
- Although the sample size of 13 was considered adequate for phenomenological study and saturation was reached after 11 interviews, the exact point of saturation is debatable.<sup>32,33</sup>
- Only 2 race and ethnicity categories were represented in the study
  - Those categories represent the general population of the local geographic area
  - Results may not be generalizable to other geographic areas
- All participants conveyed healthcare experiences across multiple clinics and providers
  - Some participants described healthcare experiences that spanned multiple states
  - Such data was not formally collected or analyzed

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