CONCEPTUALIZING AND MEASURING SYMPTOM INVALIDATION AS EXPERIENCED BY PATIENTS WITH ENDOMETRIOSIS

by

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ABSTRACT OF THE DISSERTATION

Conceptualizing and Measuring Symptom Invalidation as Experienced by Patients with Endometriosis

By ALLYSON BONTEMPO

Dissertation Director:
Lisa Mikesell

This dissertation is an explication and investigation into the phenomenon that I call symptom invalidation, which I define as communication that deems one’s symptoms or related experiences as not real or of value. The explication of symptom invalidation is facilitated by two important conceptual frameworks: invalidating environments (Linehan, 1993) and illness representations (Leventhal et al., 1997, 1980, 1984). Drawing on the experiences of patients with endometriosis, I explore what message features constitute invalidating communication, what the negative sequelae of invalidating communication are, whether invalidation communication can be reliably measured, and whether the association between invalidation and negative sequelae can be tested. There are four phases to this dissertation. For Phase I, I perform a systematic review of the literature that has reported on the negative sequelae of invalidation to detail the harmful consequences invalidating encounters may have for patients and identify why it is so important for coherence to be brought to the construct of invalidation. For Phase II, I then analyze open-text responses detailing the diagnostic stories of 1038 patients with endometriosis to elucidate what invalidating messages from clinicians look like. For Phase III, I administer...
and subsequently validate a self-report measure—the Perceived Symptom Invalidation Scale (PSIS)—constructed as part of an online survey. For Phase IV, I examine the relationship between the PSIS and the negative sequelae uncovered from Phase II as part of a secondary analysis of data.

For Phase I, I found that negative sequelae of invalidating encounters include negative patient affect, negative self-esteem, depression, and suicidal ideation; healthcare-related anxiety or trauma, loss of trust in clinicians or the broader healthcare system, frustration and anger toward clinicians or the broader healthcare system; symptom underreporting; and delays, breaks, or terminations in care. For Phase II, I found that patients experience invalidation in a variety of ways: it can be related to how clinicians identify the diagnosis and symptoms, how they communicate the cause of the patient’s symptoms, how they convey their understanding of the timeline of a patient’s illness, how they treat the consequences of the illness, and how they communicate their understanding of control over the symptoms. In addition to these forms of communication, patients also experience clinical decisions as invalidating, especially with respect to not investigating symptoms (e.g., not asking questions, not performing a physical examination, or not ordering appropriate testing). For Phase III, confirmatory factor analysis yielded a model with a good fit to the data. Convergent validity was confirmed via significant correlations with patient satisfaction, supportive clinician message quality, and cognitive/affective experiences of perceived betrayal. Finally, for Phase IV, I found that perceived invalidation is significantly correlated with all measures of negative sequelae—scared/terrified, less trusting of the medical system, angry, and cautious and reluctant about seeking further care.
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DEDICATION

To the invalidated, and those who have resisted
(and continue to resist) invalidation

To S.N.
Thank you for believing me and
validating my experiences when no one else would.
Stay curious and keep asking questions.
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CHAPTER ONE: INTRODUCTION

The first time I had any severe endometriosis symptoms, I was just shy of my 18th birthday and in the middle of my senior year of high school. I woke up one morning with severe abdominal pain, so much so that I could barely move. I was vomiting from the pain and was taken to the emergency room with possible appendicitis. After hours of tests, the ER doctor told me that I had “textbook anatomy” and that nothing was physically wrong with me. He mentioned to my parents that I “might be under too much stress” and suggested I see a psychiatrist.

In this excerpt, a patient describes symptoms that are not treated as “real” or of value when the clinician tells her that nothing is physically wrong with her, mentions that stress may be the cause of her problems, and suggests she see a psychiatrist. Despite having had a series of diagnostic testing in the emergency department, when the tests came back unremarkable, the clinician made a choice to believe the validity of the testing over the patient’s account of her own bodily experiences. Unfortunately, what is demonstrated in this excerpt is an all-too-common negative experience that many patients have had, and oftentimes invalidation occurs independently of whether or not diagnostic testing has been performed, when clinicians do not find it worthwhile to investigate patients’ symptoms.

This patient’s experience is like so many other patient stories I document in this dissertation: the patient’s symptoms and related experiences (e.g., beliefs, attitudes, and emotions related to the symptoms) are invalidated by clinicians or treated as not “real” or of value. One review examining the impact of disbelief and invalidation in chronic pain—though not specific to the patient-clinician interaction—demonstrates that invalidation causes experiences of stigma; isolation; and guilt, depression, and anger toward those who invalidate (Newton et al., 2013). Another review by Hintz (2022) examines higher-order concepts associated with chronic overlapping pain conditions.
(COPCs; Maixner et al., 2016) patients’ experiences of what she calls *disenfranchising talk* or talk that involves harming patients’ agency in communicating about COPCs. One of the author’s findings details a number of effects of disenfranchised talk which was found to negatively impact credibility and trust in self; access to care, support, and resources; and perception of the patient-clinician relationships. Hintz also described patients’ “responses to disenfranchised talk,” which involved submission and obedience, critique, and resistance: counter emplotment of facts and self-advocacy. These types of experiences are so prevalent and impactful that Burke (2019) terms this type of negative experience a “silent epidemic,” one that is “slowly eroding patient-physician relationships” (p. e1).

This “epidemic,” however, is not silent. Work detailing this phenomenon has been published since the late seventies (Dusenbery, 2018) and among dozens of different patient populations. It has appeared in various and expanding illness contexts including but not limited to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS; for a review, see Anderson et al., 2012), fibromyalgia (for a review, see Mengshoel et al., 2018), various autoimmune diseases (e.g., Gunning, 2022), chronic low back pain (e.g., Braeuninger-Weimer et al., 2019), the Ehlers-Danlos syndromes (e.g., Halverson et al., 2023), endometriosis (for a review, see Pettersson & Berterö, 2020), irritable bowel syndrome (e.g., Björkman et al., 2014), post treatment Lyme disease (e.g., Ali et al., 2014), systemic lupus erythematosus (lupus; e.g., Sloan, Naughton, et al., 2020), multiple sclerosis (MS; e.g., White et al., 2010), postural orthostatic tachycardic syndrome (POTS; e.g., Knoop & Dunwoody, 2022), vulvodynia (Hintz & Venetis, 2019) as well as other female genital pain syndromes (Bond, 2015), adult diagnoses of cystic fibrosis (e.g.,
Widerman, 2004), complex regional pain syndrome (e.g., Besa, 2015), primary ciliary dyskinesia (e.g., Whalley & McManus, 2006), encapsulating peritoneal sclerosis (Hurst et al., 2014), polymyalgia rheumatica (Twohig et al., 2015), and, perhaps most evidently, long coronavirus disease 2019 (long COVID-19; e.g., Ladds et al., 2020) and undiagnosed illness (often referred to as medically unexplained symptoms (MUS) or medically unexplained physical symptoms (MUPS) (Japp & Japp, 2005) (for a review, see Polakovská & Řiháček 2023). Such work has also been published more generally among children and adolescents in the context of pain (e.g., Wakefield et al., 2021), among cis-gender female military veterans of color (e.g., Mathur et al., 2020), and among the general adult population (e.g., Hildenbrand et al., 2022).

Additionally, the number of studies examining these experiences within specific illness contexts are on the rise. To illustrate, in Hintz’s (2022) meta-synthesis of disenfranchising talk experienced by patients with one or more of 10 COPCs, she found that from 1998-2000 to 2017-2020, there was nearly a 500% increase in studies on this topic in these illness contexts. One can only expect this increase to continue given the studies reporting on negative interactions patients with long COVID have recently described with clinicians (e.g., Buttery et al., 2021; Day, 2022; Ladds et al., 2020; Rushforth et al., 2021; Taylor et al. 2020), especially considering that roughly 40% of patients who get sick with COVID-19 go on to develop long COVID (Centers for Disease Control and Prevention (CDC), 2022c). That this type of negative experience is increasingly being documented and so many different patient populations have reported such invalidating experiences signals a greater need to home in on and interrogate the conceptualization of this important and continuously expanding communication
phenomenon. In this dissertation, symptom invalidation specifically by clinicians and as reported by patients with endometriosis is the context that will be examined.

Symptom invalidation, when perpetrated by clinicians, is the antithesis to patient-centered care, a healthcare ideal set forth by the Institute of Medicine in their landmark report, *Crossing the Quality Chasm: A New Health System for the Twenty-First Century* (Institute of Medicine, 2001), now over two decades ago. Indeed, clinicians’ understanding of their patient’s health beliefs, preferences, and values is a key tenet of patient-centered care (Epstein & Street, 2007; Epstein & Peters, 2009). However, symptom invalidation is in direct opposition to this key tenet. We, as scholars and advocates, owe it to patients to bear witness to, appreciate, and explicate their experiences of symptom invalidation, an agenda that serves as the overarching aim of this dissertation, with the intent of improving the patient experience.

**Goals of this Dissertation**

This dissertation has four main goals: First, I sought to establish the importance of invalidation by elucidating the negative sequelae invalidating experiences impose on patients as described in the literature (Phase I). After having established the importance and impact of invalidating experiences after reviewing the literature, I then sought to conduct original research to better conceptualize this phenomenon, especially given the findings of Phase I. Thus, I sought to explicate the concept of symptom invalidation as it takes place between patients and clinicians using patient narratives (Phase II). After having established what invalidation is, I then sought to operationalize this phenomenon. My aim was thus to validate a reliable self-report measure of symptom invalidation based on the findings from Phase II. Finally, to bring Phases I, II, and III together, I completed
a secondary analysis using the self-report measure of symptom invalidation from the open-ended responses from Phase II to predict whether the measure can predict items reflective of some of the negative sequelae discovered in the systematic review from Phase I. I achieve the aims of Phases II, III, and IV by examining the experiences of invalidation as experienced by patients with endometriosis because although it is roughly as common as diabetes, with a prevalence as high as 10% of cisgender females and the relative certainty with which it can be diagnosed, it still engenders a diagnostic delay of 8-12 years on average, with a significant literature base documenting this phenomenon. However, endometriosis is but one context in which symptom invalidation has been documented, and many other illnesses that are difficult to diagnose also report symptom invalidation between patient and clinician, demonstrating generalizability to other health contexts such as those listed above. It is during this multi-phase process of achieving these goals that we can bear witness to, appreciate, and persuade others of the significance of symptom invalidation in the clinical interaction.

**A Brief Overview of this Dissertation**

In Chapter 1, “Introduction,” I first present the phenomenon that will be interrogated throughout this dissertation—symptom invalidation. I then introduce the four phases that comprise this dissertation and provide an overview of this dissertation. Next, I discuss medical gaslighting, a term now commonly employed in the media and popular press, and its relationship to symptom invalidation. Lastly, I provide background on the paradigmatic case in which symptom invalidation will be explored in this dissertation—endometriosis.
In Chapter 2, “Conceptual Frameworks,” I first discuss the limitations of extant work on invalidation in healthcare, and subsequently explicate two conceptual frameworks that reconcile these limitations and help guide this dissertation—those of invalidating environments and illness representations. I also present the research questions and hypotheses for the four phases of this dissertation.

In Chapter 3, “Methods,” I outline how symptom invalidation will be explicated throughout the course of this dissertation in a multi-phased manner. Phase I presents a systematic review of qualitative research to elucidate the negative sequelae of symptom invalidation. Phase II details the thematic analysis of patients’ written accounts of symptom invalidation from an online survey. Phase III details the administration and subsequent validation of a self-report measure constructed for the purpose of this dissertation—the Perceived Symptom Invalidation Scale (PSIS)—as part of an online survey. Phase IV examines the relationship between the PSIS and some of the negative sequelae uncovered from the systematic review from Phase II.

In Chapter 4, “Phase I: Elucidating the Negative Sequelae of Invalidating Experiences,” I provide the results of the first phase of this dissertation. In particular, I found that negative sequelae of invalidation include negative affect, negative self-esteem, depression, and suicidal ideation; healthcare-related anxiety or trauma; loss of trust in specific clinicians, clinicians generally, or the broader healthcare system; frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system; symptom underreporting; and delays, breaks, or terminations in care.

In Chapter 5, “Phase II: Explicating Symptom Invalidation,” I provide the results of the second phase of the dissertation. In particular, I found that patients experience
invalidation in a variety of ways: it can be related to how clinicians identify the diagnosis and symptoms, communicate the cause of the patient’s symptoms, convey their understanding of the timeline of a patient’s illness, treat the consequences of the illness, and communicate their understanding of control over the symptoms. In addition to these forms of communication, patients also experienced clinician actions (or lack thereof) as invalidating, especially with respect to not investigating symptoms (e.g., not asking questions, not performing a physical examination, not ordering appropriate testing).

In Chapter 6, “Phase III: Validating a Self-Report Measure to Assess Symptom Invalidation,” I describe the development of a self-report measure—the Perceived Symptom Invalidation Scale (PSIS)—to gauge perceptions of symptom invalidation among a sample of patients with endometriosis. Confirmatory factor analysis yielded a model with a good fit to the data. Convergent validity was confirmed via significant correlations with patient dissatisfaction with the healthcare interaction, supportive clinician message quality, and betrayal in the medical system.

In Chapter 7, “Phase IV: Examining the Negative Sequelae of Symptom Invalidation as a Secondary Analysis,” I present the results of the PSIS in examining its correlations with some of the negative sequelae of symptom invalidation uncovered from Phase II (Chapter 5). In particular, I found that perceived invalidation is significantly correlated with all measures of negative sequelae.

In Chapter 8, “Conclusion,” I provide an overview of the findings, highlight the conceptual and practical implications of this work, summarize the strengths and limitations of this dissertation, and point to future directions of this work.
**Introduction**

The novel coronavirus disease 2019 (COVID-19), the disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was declared by the World Health Organization (WHO) a pandemic on March 11, 2020 (WHO, 2020). Although first believed to present with only three symptoms—fever, cough, shortness of breath—as the pandemic ensued, other, non-respiratory symptoms were added to the list. The more comprehensive list of symptoms from the CDC includes fever or chills, cough, shortness of breath or difficulty breathing, fatigue, muscle or body aches, headache, new loss of taste or smell, sore throat, congestion or runny nose, nausea or vomiting, and diarrhea (CDC, 2020b). COVID-19 is an acute illness for those who survive it, and individuals generally remain infectious for 5-10 days (CDC, 2022a).

In the following year, however, it soon became apparent that a substantial number of patients were seemingly not recovering from COVID-19—they were continuing to experience COVID-19 symptoms and, to the world’s surprise, were even experiencing new symptoms, when the virus was no longer biologically active (Halpin et al., 2020). Some of the many symptoms of long COVID include fatigue, post-exertional malaise, fever, shortness of breath, cough, chest pain, increased heart rate, difficulty concentrating, headache, sleep problems, orthostatic hypotension, pins-and-needles feelings, change in smell or taste, diarrhea, stomach pain, joint or muscle pain, rash, and changes in menstrual cycles (CDC, 2022b), though we now know there are more than 200 symptoms—affecting at least 10 organ systems—associated with this post-infectious illness (Davis et al., 2023). It was not long after these long-term symptoms were identified that this illness experience was named by patients, themselves, as long COVID.
And then, on October 6, 2021, the WHO formally recognized long COVID as an illness, providing a clinical case definition of long COVID via consensus of a Delphi panel (WHO, 2021).

**Long COVID Shines Light on ‘Medical Gaslighting’**

What was soon learned from mainstream media and social media alike was that despite the naming of long COVID, from the very outset, patients with long COVID were experiencing interactions with clinicians during which their symptoms and they, themselves, were being “dismissed,” which many were referring to as acts of “gaslighting” by clinicians (hence, “medical gaslighting”). For example, on July 28, 2020, an article was published by NBC News about three individuals whose symptoms and related experiences were “gaslighted” and “dismissed” by clinicians (Chuck, 2020). Chuck (2020) defined “gaslighting” as “the psychological tactic of making a person second-guess whether something they know to be true is real” (para. 5). One individual, Alisa Court (35, female, Caucasian), experienced symptoms such as tingling in the calves, shortness of breath, achiness in the lungs, memory loss, migraine, chest tightness, and numbness in the legs. Her symptoms were “dismissed” and (mis)attributed to stress due to the economy and as “nothing more than acid reflux.” She reported being hesitant to seek further care and even doubted her own reality at times because of these negative experiences with clinicians. Such “gaslighting” or “dismissal” taught Court that she could not trust her own interpretations of reality. Court reported to NBC News, “‘Gaslighting’ is the word I’ve been using repeatedly. … I’m so ill and some people are telling me this is a figment of my imagination” (Chuck, 2020, para. 5). A second individual, Alisa Valdés (51, female, Hispanic) experienced symptoms such as burning in the digestive
tract, loss of appetite, and pain in the sternum and upper back. Her symptoms were misattributed to a “mental issue.” A third individual, Adrienne Crenshaw (38, female, black), experienced “extreme” hypertension, shooting pains around her heart, and tingling in her arms and legs. Her symptoms, too, were “dismissed” and (mis)attributed to psychological factors including anxiety, being prescribed anti-anxiety medication despite her insistence that her symptoms were not psychological in nature. Her symptoms were also misattributed to “grief” and “stress” when she would disclose to clinicians that her father died from the acute COVID-19 disease.

Roughly four months later, on November 22, 2020, Nitza Roches, a 43-year-old female was interviewed by Anderson Cooper on 60 Minutes and reported having symptoms of tremors, loss of balance, headache, dizziness, blurry vision, double vision, heavy limbs, memory problems, confusion, and brain fog. After receiving magnetic resonance imaging (MRI) and “a full blood workup” in the emergency department, her symptoms were attributed by the clinician to “anxiety attacks” and “nervousness” (Cooper, 2020). As Roches became upset during the interview, Cooper observed, “Even recounting that is emotional…to be told what you’re feeling is not real” (Cooper, 2020).

More and more stories began to be published in mainstream media on “medical gaslighting,” toward this patient population as patients with long COVID came forward with their stories of their interactions with clinicians and the healthcare system during which their symptoms were treated as not real or, even if so, not of value. A simple Google search of long COVID and medical gaslighting will reveal a plethora of stories on the healthcare experiences of these patients. Similarly, a simple search on social media on long COVID and medical gaslighting will reveal even more stories of the healthcare
experiences of these patients, especially when patients took to Twitter and other social media outlets using the hashtag #medicalgaslighting to share their new, enigmatic-like reality with the world.

The term “medical gaslighting” soon caught fire. For a phenomenon that has been occurring for many decades, only now are clinicians being called out with such magnitude. The evidence is in the statistics. In 2022, “gaslighting” was Merriam-Webster’s Word of the Year (Merriam-Webster, 2022); in particular, there was a 1740% increase in lookups for the word, with high interest in the word sustained throughout the year (Merriam-Webster, 2022).

‘Medical Gaslighting’ as a Common Healthcare Phenomenon

Since the emergence of long COVID and the broadcasting of the negative clinical interactions these patients experienced with clinicians, the phenomenon of “medical gaslighting” more generally has burgeoned in mainstream media. For example, The New York Times (Caron, 2022) published a piece on March 31, 2022, entitled “How to Spot ‘Medical Gaslighting’ and What to Do About It.” Caron (2022) highlights the signs of gaslighting for her audience, such as clinicians continually interrupting the patients, not allowing patients to elaborate, and not appearing as an engaged listener; clinicians minimizing or downplaying patients’ symptoms, for example, by questioning patients about whether they really have pain or related symptoms; clinicians refusing to discuss patients’ symptoms with them; clinicians not ordering key imaging or bloodwork to rule out or confirm a diagnosis; clinicians being rude, condescending or belittling; and clinicians’ blaming symptoms on mental illness but not actually screening for it nor providing patients with mental health referrals. After speaking with a few clinicians,
Caron (2022) came up with actions patients can take to combat “medical gaslighting,” including asking questions, bringing a support person, and patients focusing on their most pressing issue during an appointment, switching clinicians, reframing the conversation for the clinician, and looking to support groups.

As another example, on September 1, 2022, CNBC (Onque, 2022) published a piece entitled “How to Recognize ‘Medical Gaslighting’ and Better Advocate for Yourself at Your Next Doctor’s Appointment.” Onque (2022) highlights her interpretation of the signs of gaslighting for her audience. This includes if persistent symptoms are quickly attributed to weight, stress anxiety, or work overload. This also includes phrases such as “it’s all in your head,” “that’s normal for your age,” utterances of the phrase “I’m sure that’s not…” prior to diagnostic testing, and the graduation device “just” in statements such as “it’s just a little bit of swelling.” After speaking with Stacey Rosen, senior vice president for Northwell Health’s Katz Institute for Women’s Health, she, like Caron, came up with actions patients can take to combat “medical gaslighting,” such as taking notes before the doctor’s appointment, listing changes individuals may have noticed in their health, coming to the appointment prepared with a list of questions and concerns, jotting down notes during the appointment, and bringing a support person to the appointment to serve as an advocate (Onque, 2022).

**The Origin of the Term ‘Gaslighting’**

With this proliferation of discourse concerning the term “medical gaslighting,” it is necessary to take a step back and ask: “What is medical gaslighting?” or, more fundamentally, “What is gaslighting?” ‘Gaslighting,’ as a concept, dates back to the 1930s to *Gas Light*, a play by Patrick Hamilton, though it was later turned into a movie in
1944 starring Charles Boyer and Ingrid Bergman. The central premise of the story is that a man, Gregory Anton, plots to make his wife, Paula Alquist, believe she is going insane by dimming and brightening the gas-fueled lamp in the attic but insisting to her that the lamp is not in fact dimming and brightening. Over time, this leaves her to question her own judgment and, by proxy, her own sanity (Merriam-Webster, 2023). For this reason, the first definition of gaslighting in the Merriam-Webster dictionary is more historic (Merriam-Webster, 2023) and encompasses the following:

- psychological manipulation of a person usually over an extended period of time that causes the victim to question the validity of their own thoughts, perception of reality, or memories and typically leads to confusion, loss of confidence and self-esteem, uncertainty of one’s emotional or mental stability, and a dependency on the perpetrator

However, Merriam-Webster provides a more contemporary definition, which is “simpler” and “broader”: “the act or practice of grossly misleading someone especially for one’s own advantage” (Merriam-Webster, 2023).

The definition of ‘medical gaslighting’ is similar across many mainstream media sources, defining medical gaslighting as an individual having their symptoms dismissed by a clinician. For example, Caron (2022) of the New York Times defines medical gaslighting as “the experience of having one’s concerns dismissed by a medical provider” (para. 4). Chuck (2022) of NBC defines medical gaslighting as “the psychological tactic of making a person second-guess whether something they know to be true is real” (para. 5). Psychology Today defines it as occurring when “physicians or other medical providers … blame a patient’s symptoms on psychological factors” (Stollznow, 2022,
Healthline defines medical gaslighting as “the repeated denial of someone’s reality in an attempt to invalidate or dismiss them” (Rosario, 2019, para. 21). WebMD defines it as “when the doctor dismisses your concerns (Swift Yasgur, n.d., para. 8). Health.com defines it as occurring “when healthcare professionals dismiss symptoms you report to them or don’t take you seriously” (Booth, 2023, para. 8). Prevention.com defines it as occurring “when a health care professional dismisses a patient’s concerns or symptoms and wrongly blames their illness or symptoms on psychological factors” (Solis-Moreira, 2022, para. 3).

Across the aforementioned definitions of medical gaslighting, there is frequent usage of the word “dismiss.” The definition of dismiss relevant to this context is “to reject serious consideration of (something or someone)” (Merriam-Webster, n.d.). However, some of the definitions of medical gaslighting also highlight an element of reality or validity that is not captured by this notion of dismissal. For example, Chuck (2022, para. 5) of NBC defines medical gaslighting as “the psychological tactic of making a person second-guess whether something they know to be true is real” (Chuck, 2022, para. 5). That is, notions of reality are conjured up in discussion of what is medical gaslighting. This dismissal of the reality of the symptoms resonates with the concept of invalidation, which is defined as “to make invalid,” with invalid being defined as “being without foundation or force in fact, truth, or law.” Accordingly, to have one’s symptoms dismissed is to have them not attended to; to have one’s symptoms invalidated is to have them considered not real.

Throughout this dissertation, I will refer to this phenomenon as symptom invalidation. I have chosen the term “invalidation” owing to this element of reality that is
often questioned or doubted in instances of medical gaslighting that is not inherent in the term “dismiss.”

With all this growing attention, there lacks a concerted, scholarly effort to think about this concept carefully. There are many questions left unanswered, such as “What is invalidation?” “What is the harm associated with invalidation” “Can invalidation be measured?” and “Can we measure the harm associated with invalidation?” Answering these questions will help establish the nuance embedded in this concept but which, for now, remains unknown. Answering these questions is the goal of this dissertation.

**Paradigmatic Case: Endometriosis**

To investigate symptom invalidation in this dissertation, I draw upon the case of endometriosis. Endometriosis is broadly defined as the presence of tissue (epithelium and/or stroma) similar to the lining of the uterus (i.e., the endometrium) in ectopic location (i.e., beyond the endometrial surface) (International Endometriosis Working Group, 2021) (see Figure 1). This tissue is most commonly located within the pelvis, encompassing the fallopian tubes, ovaries, and local perineum (also called pelvic endometriosis; Jubanyik et al., 1997), but can also be found on the gastrointestinal tract, urinary tract, pulmonary system, among other locations (also called extrapelvic endometriosis; Jubanyik et al., 1997). Extrapelvic endometriosis accounts for roughly 12% of cases of endometriosis (Nezhat & Hincapie, 2021).
Endometriosis generates a systemic inflammatory reaction (Giudice, 2010), and results in bleeding, scarring, adhesions, and nodules (Shafir et al., 2018; Tabibian et al., 2017) (see Figure 2 and Figure 3) that may distort patients’ internal anatomy (Kennedy et al., 2005). As such, pain is the most common symptom of endometriosis. Such pain often includes chronic pelvic pain, dysmenorrhea (i.e., pain with periods) and dyspareunia (i.e., pain with sexual intercourse) (Eskenazi & Warner, 1997). Fatigue is also a common, global symptom of endometriosis (Ramin-Wright et al., 2018). Other symptoms experienced by patients are often contingent on the location of their endometriosis in cases of extrapelvic endometriosis. For example, endometriosis that is located on the bowel can present symptoms such as diarrhea, constipation, bloating, deep dyspareunia (i.e., pain with intercourse), and dyschezia (i.e., painful bowel movements), and even bowel obstruction in advanced stages (Nezhat et al., 2018). Endometriosis that is located on the bladder or ureters can present symptoms such as painful voiding, incontinence (i.e., loss of bladder control), bladder spasm, hematuria (i.e., blood in urine), and even ureteral obstruction and resulting kidney dysfunction, damage, and/or loss in advanced
stages (Nezhat et al., 1996). Endometriosis that is located on the diaphragm and/or thorax (i.e., the chest) can present symptoms such as shoulder pain, chest pain, right upper quadrant pain, cough, or shortness of breath (Nezhat et al., 1998; Nezhat & Hincapie, 2021). In advanced stages, it can present with hemothorax (i.e., bleeding around the lungs), pneumothorax (i.e., collapsed lung), hemoptysis (i.e., coughing up blood) as well as pericarditis (i.e., swelling and irritation of the tissue surrounding the heart) (Nezhat et al., 1998; Nezhat & Hincapie, 2021). Infertility is often present with endometriosis, as well. It has been estimated that 35-50% percent of patients who experience pelvic pain and/or fertility issues suffer from endometriosis (Eskenazi, & Warner, 1997).

**Figure 2** Red Flame-Like Superficial Endometriosis on the Peritoneum
Figure 3 The Cul-de-Sac with Blood from a Ruptured Hemorrhagic Cyst

Endometriosis is not uncommon, even though it is incorrectly perceived as rare by clinicians (Van der Zanden et al. 2020) and many clinicians are unaware of its true prevalence (Van der Zanden et al. 2020; Zale et al., 2020). Endometriosis is diagnosed in roughly 10% of cis-gender females of reproductive age (Shafrir et al., 2018), which equals roughly 190 million cis-gender females worldwide (Zondervan et al., 2020). That is, it has a prevalence that is roughly that of Type II diabetes in the United States (CDC, 2020a).

Endometriosis leads to significant social and economic disability, constituting a large proportion of gynecologic practice and generating significant direct and indirect medical costs. In 2011, the best estimate was $12,419 per patient per year, with one third of direct medical costs comprising outpatient and emergency department visits, laboratory testing, imaging studies, prescriptions, and management of pain, and with two-thirds of indirect cost of lost productivity (Rogers et al., 2013). Furthermore, a critical narrative review of the psychosocial impact of endometriosis revealed that patients commonly face difficulties with diagnostic delay and uncertainty, health-related quality
of life, intimate relationships, family planning, education and work, emotional wellbeing, and medical and self-management (Culley et al., 2013).

Despite endometriosis affecting up to 10% of cisgender females and the rather definitive nature of diagnosis (i.e., surgical visualization with confirmed histology of biopsied tissue; Simoens et al., 2007), it has an average diagnostic delay ranging from 8-12 years (Kiesel & Sourouni, 2019), with one U.S. study finding that 75.2% of patients reported having had their endometriosis initially misdiagnosed as another physical and/or mental health condition (Bontempo & Mikesell, 2020). Accordingly, a disease with such a profound diagnostic delay and misdiagnosis rate can be accompanied by greater diagnostic uncertainty among clinicians. This delay also creates a longer window in which invalidating encounters can take place, should clinicians become frustrated and dismiss patients’ symptoms when they are uncertain of the cause (see Schiff et al., 2018).

Clinicians’ use of inappropriate, nondiscriminatory diagnostic testing for pelvic pain is one factor that reportedly contributes to this significant diagnostic delay (Ballard et al., 2006). Consequently, when negative test results inevitably arise, clinicians may be faced with even greater diagnostic uncertainty. Clinicians may subsequently struggle with how to reconcile this discrepancy and may subsequently defer to trusting medical testing over the word of the patient. As suggested earlier, one potential method clinicians may engage in for managing their subsequent communication with patients may be to dismiss patients’ symptoms. Patient-clinician tension resulting from such dismissal and invalidation has already been vastly documented in qualitative studies among patients with endometriosis and has also been captured in four meta-syntheses (see Culley et al., 2013; Dancet et al., 2014, Pettersson & Berterö, 2020, Young et al., 2015).
CHAPTER TWO: CONCEPTUAL FRAMEWORKS

Current Conceptualization of Invalidation in Healthcare

Over 10 years ago, Kool et al. (2009) recognized the absence of a term to describe what they referred to as “a lack of understanding” from others, while they also acknowledged there is no “single good term to capture all of the components of this phenomenon” (p. 1650). They characterized this lack of understanding as “a constellation of features that includes nonacceptance by others, misunderstanding, disbelief, rejection, stigmatization, and suspicion that the problem is exaggerated or psychological” (p. 1650). As such, they undertook a multi-phase approach to elucidate what this “lack of understanding” was. Kool et al. first conducted interviews with patients with fibromyalgia. Next, the authors engaged a Q-sort technique again with patients with fibromyalgia. Lastly, a hierarchical cluster analysis was performed, from which a dendrogram of the clusters was created (see Figure 4).

**Figure 4** Higher- and Lower-Order Clusters of Invalidation from Kool et al. (2009)
It is from these clusters that Kool et al. (2009) defined the term “invalidation,” which they refer to as a lack of understanding. Specifically, they defined invalidation as “…the perception of cognitive, affective, and behavioral responses of others that are perceived as denying, lecturing, overprotecting, not supporting and not acknowledging with respect to the condition of the patient” (Kool et al., 2009, 2010; p. 1990). Their definition of invalidation comprises the five higher-order clusters derived from their hierarchical cluster analysis. Because two of the five clusters were framed positively (“supporting” and “acknowledging”), they report that for their definition of invalidation, they reframe the clusters to represent the opposite of those two clusters (i.e., “not supporting” and “not acknowledging”).

Semantically, invalidation means “to weaken or destroy the cogency of,” with invalid (adjective) defined as “being without foundation or force in fact, truth, or law” and as “logically inconsequent” (Merriam-Webster, n.d.). As such, at the core of invalidation is the process by which something is treated as not being grounded in fact, truth, or law—as not being grounded in reality. That which is in question is not deemed legitimate or real. Kool et al.’s (2009) definition of their term invalidation thus warrants reconsideration. There are two main concerns. First, the definition provided is too expansive in that it spans five distinct higher-order clusters, each with its own definition: denying, lecturing, overprotecting, not supporting, and not acknowledging. As such, a definition of invalidation is not actually provided. Second, only two of the five higher-order clusters (denying, not acknowledging) resemble current notions of invalidation, calling into question the boundary conditions of invalidation according to Kool et al. (2009), which possibly extend into the realm of social support.
It is imperative that these two constructs—invalidation and negative social support—are not conflated. Recurrent discussions of the social support literature call into question what construct Kool et al. are ultimately intending. Indeed, more work needs to be done in defining and conceptualizing invalidation as a construct. Furthermore, scholars should proceed with caution when consulting Kool et al.’s construct of invalidation and while using their Illness Invalidation Inventory (Kool et al., 2010), the construct validity of which is consequently called into question. For example, is the Illness Invalidation Inventory (Kool et al., 2010) one that measures invalidation or one that measures negative social support? More clarity is needed on this issue.

Guiding Conceptual Frameworks

To reconcile the problems outlined above, I draw from two frameworks that, together, better situate invalidation as a construct reflecting the questioning or outright rejection of the legitimacy of “realness” of a patient’s symptoms. What follows is an explication of two frameworks guiding the naming, defining, and elucidation of the phenomenon of symptom invalidation. The first framework, that of invalidating environments (Linehan, 1993), comprises unique characteristics, consequences, and coping responses, which serve to guide the understanding of the process of symptom invalidation. In other words, it helps draw the boundaries of what constitutes “invalidation” and “invalidating messages” and what does not. These are factors that are missing from prior work. The second framework, that of illness representations (Leventhal et al., 1997; 1980; 1984), serves to guide the understanding of the features of what is being invalidated. In other words, it helps draw the boundaries of what health features constitute “symptoms” when invalidation is occurring. These boundaries of what
can be invalidated is also missing from prior work. Together, these two frameworks—validating environments and illness representations—help situate symptom invalidation as a phenomenon with clear conceptual boundaries regarding both the process and the features encompassing symptom invalidation.

**Framework #1: Invalidating Environments**

Invalidating environments is a construct borne out of the field of clinical psychology. It is a biosocial framework used to understand the development of the psychiatric disorder *borderline personality disorder*. The main proposal according to this framework is that individuals with borderline personality disorder are emotionally vulnerable and lack emotion modulation skills, and that these complexities are embedded in biological predispositions, which are aggravated by specific environmental experiences—particularly, invalidating environments (Linehan, 1993). *Invalidating environments* are environments “in which communication of private experiences is met by erratic, inappropriate, and extreme responses” (Linehan, 1993, p. 49). Invalidating environments throughout childhood are believed to facilitate the development of emotional dysregulation, which is characterized by emotional vulnerability (high sensitivity to emotional stimuli, emotional intensity, and slow return to emotional baseline) and by a deficit in emotional modulation. Emotional dysregulation ultimately, over time, develops into borderline personality disorder (Linehan, 1993), a personality disorder marked by “a pattern of instability in interpersonal relationships, self-image, and affects, and marked impulsivity” (American Psychiatric Association, 2013, p. 645).

Nevertheless, invalidating environments, or invalidation, is a phenomenon that is fundamentally communicative in nature—it is intended as a biosocial framework, as
Linehan states. Linehan (1993) further elaborates on the nature of invalidating environments:

… the expression of private experiences…is often punished, and/or trivialized. The experience of painful emotions, as well as the factors that to the emotional person seem causally related to the emotional distress, are disregarded. The individual’s interpretations of [their] own behavior, including the experience of the intents and motivations associated with behavior, are dismissed. (p. 49)

Although the work on invalidating environments in relationship to borderline personality disorder speaks to the environment some parents create for their children by failing to acknowledge or outright rejecting their emotional experiences, such environments can be created in any setting, including healthcare. In healthcare, invalidating environments can similarly speak to the environment clinicians create for some patients by failing to acknowledge or outright rejecting their somatic experiences.

Characteristics of Invalidating Environments

Linehan states that there are two primary characteristics of invalidating environments. First, invalidating environments tell the individual they are wrong in their description and analysis of their own lived experiences and, second, they attribute an individual’s experiences to socially unacceptable personality traits. These two characteristics are expanded upon below.

Characteristic #1: They tell the individual they are wrong in their description and analysis of their own experiences. The first characteristic of invalidating environments is that they tell the person they are wrong in their description and analysis of their own experiences, that they are wrong specifically about their beliefs about what is causing their emotions, beliefs, and actions (Linehan, 1993).
Characteristic #2: They attribute a patient’s experiences to socially unacceptable personality traits. The second characteristic of an invalidating environment is that it attributes a person’s experiences to socially unacceptable personality traits (Linehan, 1993). In particular, Linehan (1993) details:

Negative emotional expressions may be attributed to traits such as overreactivity, oversensitivity, paranoia, a distorted view of events, or failure to adopt a positive attitude. Behaviors that have unintended negative or painful consequences for others may be attributed to hostile or manipulative motives. Failure, or any deviation from socially defined success, is labeled as resulting from lack of motivation, lack of discipline, not trying hard enough, or the like. … In any case, the individual’s private experiences and emotional expressions are not viewed as valid responses to events. (p. 50)

This second characteristic entails three crucial points, which can all be similarly applied to healthcare. First, this characteristic highlights that patients’ beliefs that something is wrong with them—though incorrect—are attributed to traits such as overreactivity, oversensitivity, paranoia, a distorted view of events, or failure to adopt a positive attitude. This is seen when clinicians reportedly tell patients that they are exaggerating their symptoms. Åsbring and Närvänen (2002) describe this when they state that clinicians “seemed to believe that the women’s problems were concocted, nonexistent, or exaggerated. This led to the women’s feeling accused, resulting in the adoption of a defensive position” (p. 153). Not only are patients deemed wrong in their description and analysis of their own experiences, but they are deemed as essentially imagining, making up, or exaggerating their symptoms, which clearly speaks to Characteristic #2.

This type of communication that invokes negative personality traits of patients is also seen when clinicians reportedly tell patients that they are being dramatic, as described in the following excerpt:
When I first started getting my period as a teenager it was extremely painful and I had very heavy bleeding. The doctor said that I was being overly dramatic and that the cramps couldn’t possibly be that bad. (Bontempo, 2019)

Patients may also be viewed as “paranoid,” “neurotic,” “hysterical,” or “mad” (Krebs & Schoenbauer, 2019), which are other examples of having one’s communication of their somatic experiences attributed to socially unacceptable personality traits. For example, it is presumed that because patients are hysterical, they are “misattributing” their symptoms to physical pathology. For example, Denny (2004b) discusses how diagnosis is a liberating experience for patients with endometriosis, particularly because it vindicates patients from the labels given to them by clinicians prior to the eventual diagnosis: “When women did finally get a diagnosis, the initial reaction was usually one of relief, followed by a sense of vindication. They were not mad or hypochondriacs, labels that a number had had ascribed to them” (p. 41). In addition to relief and vindication, patients also report experiencing validation (e.g., Bennett et al., 2021).

Other misattributions included other mental health problems such as anxiety and depression (e.g., Krebs & Schoenbauer, 2019; Markovic et al., 2008; Peters et al., 1998; Sloan, Naughton, et al., 2020; Sloan et al., 2021; Stewart & Sullivan, 1982), which were presumed to distort patients’ view of events. For instance, one patient with endometriosis stated, “[The clinician] [t]old me that I must have anxiety that causes me to be more sensitive to pain” (Bontempo, 2019). Another patient with endometriosis quoted her clinician, saying, “‘There’s a good app you [can] download to manage anxiety.’ This is the age-old ‘it’s all in your head’ dressed up in progressive and modern terminology” (Bontempo, 2019). Another patient with endometriosis stated, “My first OBGYN…told
me most of my pain was mental and I needed to adjust my way of thinking to better manage my symptoms” (Bontempo, 2019). Lastly, another patient with endometriosis stated:

I complained of cyclical pain and particularly fatigue on many occasions. I explained that the pain was interfering with my life. I was referred to a psychiatrist and put on antidepressants and told that I had depressive illness and therefore my periods seemed worse to me than they really were. (Bontempo, 2019)

In the first excerpt, the patient reports that anxiety is treated as the cause and is responsible for distorting this patient’s view of events—making the patient “more sensitive to pain.” In the second excerpt, depression is treated as the cause, similarly responsible for distorting this patient’s view of events—in this case, making menstrual periods “seem” worse to the patient than they actually were. In the last excerpt, a vague reference to the pain being “mental” is treated as the cause—again working to distort patients’ view of events. It is the prescription of the “treatment” for the patient to adjust her way of thinking “to better manage [her] symptoms.”

Second, this characteristic also highlights that patients’ behavior of showing up to a medical appointment may be attributed to hostile or manipulative motives. One motive is that patients are attention-seeking, or what is better known clinically as having histrionic personality traits (American Psychological Association, 2013), such as described in the excerpt from Sloan, Naughton, et al. (2020, p. 6) regarding patients with lupus: “You’re diagnosed as attention seeking and therefore everything you say is written off as fairy stories or exaggerated.” Not only is this patient’s description of her experience written off as “wrong” (i.e., invalidation characteristic #1) displayed in the choice of words “written off,” but her “experiences” (or lack thereof) are attributed to
socially unacceptable personality traits when the patient frames the clinician’s understanding of their experience as “fairy stories” and “exaggerated” (i.e., invalidation characteristic #2).

Another motive that has been discussed is pain medication-seeking. As an example, one patient reported that she was treated as though she was drug-seeking:

As I got to be 17/18 years old, I became a “pill” seeker and was treated horrendously by multiple doctors. All because I would plead for any kind of relief they could give me so I wouldn’t lose another job because I can barely get out of bed. (Bontempo, 2019)

A third motive that has been discussed is faking symptoms so that patients can avoid going to school and/or work. For example: “I have had multiple doctors tell me and my mom that my pain wasn’t real and I “just didn’t want to go to school.”

Last, this characteristic additionally highlights that failure to respond or deviation from the typical response to treatment—whatever that may be—is attributed to a lack of motivation, lack of discipline, or not trying hard enough. Given that the causes attributed to patients’ problems are often internal causes—or causes residing within and largely under the control of patients—it is not surprising that such attributions are reflections of patients’ character.

To sum up Characteristic #2, one patient from Gunning’s (2022, p. 2017) work elaborates:

I would say the overall message that I have gotten from medical professionals, from family, from society, is ‘this is your fault…’ ‘It’s because you’re eating too much.’ ‘It’s because you’re too lazy.’ ‘It’s because you’re doing bad in school and you just want an excuse.’ ‘It’s because you have let yourself go.’ At the base of every comment, it is my fault.

It can be seen that the entire character of the patient is called into question when symptom invalidation occurs and when clinicians make misattributions of causes for
patients’ symptoms, just as is postulated in the second characteristic of invalidating environments as initially stated by Linehan et al. (1993).

**Consequences of Invalidating Environments**

**Consequence #1: They fail to teach the individual to label private experiences.** The first consequence of an invalidating environment according to Linehan (1993) is that it fails to teach the individual to label private experiences in a manner normative in their larger social community for the same or similar experiences. Linehan (1993) details:

First, by failing to validate emotional expression, an invalidating environment does not teach the [individual] to label private experiences, including emotions, in a manner normative in [their] larger social community for the same or similar experiences. Nor is the [individual] taught to modulate emotional arousal. Because the problems of the emotionally vulnerable [individual] are not recognized, little effort goes into attempts to solve the problems. The [individual] is told to control [their] emotions, rather than being taught exactly how to do that. It is a bit like telling [an individual] with no legs to walk without providing artificial legs for [them] to walk on. The nonacceptance or oversimplification of the original problems precludes the type of attention, support, and diligent training such an individual needs. Thus, the [individual] does not learn to adequately label or control emotional reactions. (p. 51)

In the context of symptom invalidation, when clinicians do not validate patients’ reported bodily experiences, they are consequently not teaching patients how to label or interpret these bodily experiences and symptoms. Such invalidation may even confuse patients, and patients often report feeling like they are crazy and that they can no longer rely on or trust their own judgment. To demonstrate, a patient with endometriosis interviewed in Zale et al. (2020) reported: “I felt crazy. I felt crazy for the longest time. And then when I finally did get my diagnosis, my mind was finally at ease. And it confirmed that I wasn’t crazy and there was really something wrong with me.” This patient demonstrates that with the self-doubt and self-inference she felt “crazy” when she could not reconcile
repeated negative test results with her perceived abnormal bodily experiences. However, it is not until she receives a diagnosis of endometriosis that she reclaims her ability to rely on her interpretations of her bodily experiences and ultimately experience long sought-for validation.

**Consequence #2: They fail to teach the individual to form realistic goals or expectations.** “Second, by oversimplifying the ease of solving life’s problems, the environment does not teach the [individual] to tolerate distress or to form realistic goals or expectations” (Linehan, 1993, p. 51). In the context of symptom invalidation, patients may be robbed of the opportunity to understand and appreciate the healthcare ideal of patient-centered care, and instead may believe that their invalidating healthcare environments are the healthcare norm. For instance, enacting patient-centered communication includes tuning in to and incorporating the patient’s perspective (i.e., their individual beliefs, desires, and needs), understanding the patient’s biopsychosocial context (i.e., factors in their psychological and social lives that contribute to and detract from their functioning and quality of life), establishing agreement and common ground regarding diagnosis and treatment, and allowing patients (and family members) to be active participants in their care to the extent they wish (e.g., shared decision-making (Epstein et al., 2005; Street, 2017). These communicative behaviors, if enacted, are linked to more positive health outcomes (see Street et al., 2009). Accordingly, patients who experience symptom invalidation, especially repeatedly, may perhaps come to believe symptom invalidation—again, the antithesis to patient-centered communication—is the healthcare norm and ideal. This can be problematic, as it is important for patients to
be aware of not only their legal but their moral rights and to receive safe and high-quality healthcare.

**Consequence #3. Extreme displays and/or problems are often necessary to provoke a helpful environmental response.**

Third, within an invalidating environment, extreme emotional displays and/or extreme problems are often necessary to provoke a helpful environmental response. Thus, the social contingencies favor the development of extreme emotional reactions. (Linehan, 1993, p. 51)

Although not much of the literature on symptom invalidation goes into such detail, some data suggest that patients may escalate their typical requests for help to more extreme communicative behavior, such as “begging” clinicians for help. An example of this is demonstrated in the following patient quote of a patient with endometriosis:

I am a grad student at [university]. When accessing the campus health center for extreme period pain, the BCN said 'try motrin and come back in a month' after I had explicitly said I had taken 20 aspirin in a 24 hour period with no relief. She refused to give me a referral to an obgyn until I begged in front of the waiting room. (Bontempo, 2019)

Not only does this patient report begging the clinician, but she reports she does so in front of a waiting room of people rather than in the privacy of an appointment room, illustrating somewhat extreme measures to be heard. Other types of behavior reported by patients include bringing others with them to their appointments because previously, they had not received the help they needed from the clinician. These others typically include the patient’s mother or male partner. Bringing one’s mother may be more common in illness contexts that have a younger age of onset, such as endometriosis, which can begin at menarche. One patient reported: “My mom also continually had to come to my appointments with me to advocate and force tests and referrals to be done” (Bontempo, 2019). Bringing one’s male partner may be more common for female patients, especially
if they perceive gender bias to be contributing to the symptom invalidation or, more
generally, the failure to take action for patients’ symptoms. It may also take place if they
feel like they need the social/emotional support of a loved one to have the courage to
advocate for themselves. For example, one patient reported:

I was referred to a gynaecologist in order to get a diagnostic [laparoscopic] surgery. His student in training (doctor) states that he agreed, it sounded like endo. When the doctor came in he said it probably wasn’t, and refused to listen to me. He refused to do a [laparoscopy], gave me a prescription for visanne and left. The next time I went back I took my boyfriend who literally just sat there, but was enough for me to push the doctor to do a diagnostic [laparoscopy]. (Bontempo, 2019)

Overall, this preliminary data suggest that patients strategically escalate their typical
requests for help to more extreme behavior, such as “begging” clinicians for help and
bringing others such as mothers and male partners to these medical encounters who may
be perceived as more authoritative figures.

Consequence #4. They fail to teach the patient when to trust their own
emotional and cognitive responses as reflections of valid interpretations of
individual and situational events.

Finally, such an environment fails to teach the [individual] when to trust her
own emotional and cognitive responses as reflections of valid interpretations
of individual and situational events. Instead, the invalidating environment
teaches the [individual] to actively invalidate her own experiences and to
search her social environment for cues about how to think, feel, and act. A
person’s ability to trust herself, at least minimally, is crucial; she at least has
to trust her decision not to trust herself. (p. 51)

Much of the extant work on symptom invalidation details experiences that mirror this
consequence. The above discussion on the negative sequelae of negative affect and poor
self-esteem is also pertinent. These sequelae relate back to the discussion on patients’
accounting for the visit, or “doctorability” (Heritage & Robinson, 2006). These
interactions in which symptom invalidation occurs seemingly result in patient self-doubt—particularly, the inability for patients to trust themselves concerning the genuineness of their bodily experiences as well as their interpretation of these bodily experiences (e.g., Ballard et al., 2006; Denny, 2004b). For example, a patient with endometriosis, as reported in Ballard et al. (2006, p. 1298), stated:

You know, I was thinking, I was in a very stressful job - was my job something to do with it? Am I psychologically making myself have this pain? I’ve just got to the point where I just don’t understand it at all!! I did think to myself, am I making this sort of thing happen? I mean that’s how I felt eventually. I started thinking am I doing this on purpose so that I haven’t got to go to work?

Here, the patient appears to be unable to reconcile the “normal” status of her symptoms as communicated by clinicians with her own interpretations of her lived personal bodily experiences. As a result, she appears to suppress the latter and tries to make sense of this discrepancy by questioning her own lived experiences.

**Coping Responses to Invalidating Environments.**

In general, invalidating environments are said to be aversive to the experiencing individual and, as such, are believed to be associated with three coping responses (Linehan, 1993), which are described below. Individuals who experience invalidation typically either “leave the invalidating environment, attempt to change their behavior so that it meets the expectations of their environment, or try to prove themselves valid and thereby to reduce the environment’s invalidation” (p. 52).

Leaving the invalidating environment is relevant given the negative sequelae discussed above, most evidently patients delaying, taking breaks from, or terminating seeking care during and even after their search for a diagnosis (e.g., Åsbring & Närvänen, 2002; Berglund et al., 2010; Grundström et al., 2020; Sloan, Naughton, et al., 2020).
Patients appear emotionally taxed from these often-repeated encounters, and thus it appears that one such coping mechanism for patients is to literally leave the invalidating environment. Importantly, what constitutes the invalidating environment can vary, which can be seen in patients’ differential responses to these invalidating encounters. Particularly, patients may choose to “leave” or not return to the specific clinician with whom they had said interaction; or, at more of an extreme, patients may choose to “leave,” not return to, or take a break from the healthcare system more generally. As an example, Rhodes et al. (1999) noted in their sample of patients with chronic low back pain: “The majority of patients in our study who described negative experiences of [diagnostic] testing turned away from medicine to some extent, expressing anger or resignation about its failure to help them” (p. 1196). It can be seen here, unsurprisingly, that patients can have multiple goals in the healthcare setting (Kerr et al., 2021; Scott et al., 2020); although their ultimate goal is to achieve a diagnosis so that their symptoms can be managed and quality of life improved, they are also faced with the perhaps ancillary goal of managing their mental health, particularly as a result of these negative encounters. Patients have indeed reported having to turn away from the healthcare system (see Chapter 4).

Attempting to change one’s behavior so that it meets the expectations of the environment is also relevant, for example, patients not disclosing health-related information to clinicians (e.g., Berglund et al., 2010; Peters et al., 1998; Sloan, Naughton, et al., 2020; Wakefield et al., 2021). If patients have learned that clinicians will invalidate what they report to them concerning their symptoms, not providing health-related information to clinicians that they can dispute or invalidate may seem like an attractive
option for preventing such invalidation. Put simply, clinicians cannot dispute or invalidate information if they are not aware of it. This can lead to patients denying their bodily experiences—at least outwardly to the clinician—in the medical encounter. For example, Rhodes et al. (1999), in their discussion of patients with chronic back pain, noted: “The patient…faces a choice between disavowing pain…or turning away from medicine (p. 1196). Patients have in fact reported choosing to not disclose all health information to clinicians (see Chapter 4).

Trying to prove oneself valid and thus reducing the environment’s invalidation, can arguably be seen in (typically forced) patient self-advocacy. Such self-advocacy does not resemble a role in a larger cooperative relationship with the clinician but a one-sided effort in which only the patient appears to be the active agent in the patient’s care. For example, in Ladds’ et al. (2020) interview study of UK patients with long COVID, the authors noted that some of their patients “felt a responsibility…to persuade clinicians that their symptoms were real, undertake their own research…and construct their own care pathway…” (p. 8). However, this work to prove oneself valid has been described as a “burden” for patients that is often physically, cognitively, and emotionally exhausting. Patients in fact report having to take control of the clinical interaction in order to make progress on identifying a cause for their symptoms. For example, one patient from Mikesell and Bontempo (2022) stated, “95% of doctors know FUCK ALL about endometriosis. I had to do all of my own research and fight my way to a doctor who knew what they were doing.”
Framework #2: Illness Representations

Equally fundamental for understanding the concept of symptom invalidation is a consideration of the specific features of clinician messages that are perceived as invalidating. In elucidating the specific features of clinician messages reported by patients that can lead to perceptions of invalidation, I will draw from the conceptual framework of illness representations (Leventhal et al., 1980, 1984, 1997).

The origin of illness representations was originally borne out of the work on the revised drive reduction theory (Dollard & Miller, 1950) that was undertaken by Leventhal and colleagues. Although a discussion of the revised reduction theory is beyond the scope of this chapter, the central premise is that health behaviors and attitudes are bolstered when the rehearsal and enactment of a recommended response decrease fear by removing the individuals’ feelings of vulnerability to the threat. However, the work of Leventhal and colleagues showed distinct effects of fear that did not align with the drive reduction model. In particular, all of the effects that fear had on behavior had dissolved as the memory of the health-based threat message diminished with time (Leventhal et al., 1997). However, there were two major features of the model that emerged from the data, which formed the basis of Leventhal’s (1970) parallel process model (see Figure 5).
The first major feature was that there was a parallel (i.e., independent) processing of 1) the cognitive representation of danger (e.g., the illness threat) and 2) the processing of fear. These were two separate processes (Leventhal et al., 1997). The second major feature was that there was a division of the representation of the illness threat from the actions for performing the health coping procedures. In their studies, the main attribute of this behavioral finding was that health-related behaviors were sustained far beyond the effect of fear (Leventhal et al., 1997). In their studies, individuals subjected to low or high fear-based messages reported efforts to reduce smoking and/or received their tetanus shot for several weeks post communication. (Leventhal et al., 1997). However, these behaviors only persisted if the fear-based messages were complemented by a message describing a clear behavioral plan.

As Leventhal et al. (1997) stated:

The [behavioral] plan [in the studies] generated a procedure that converted a belief about a threat into action, but it did not motivate performance. What was unclear, however, was the nature of the motivating belief. It was clearly not the fear, as all of the post communication effects of fear had faded within a day or two (Leventhal & Niles, 1965). Something else, therefore, had changed. We called this something the cognitive representation of the disease threat.
It was here when the concept of illness representations was born. Inherent in the naming of this phenomenon was the assumption that an individual’s beliefs are necessary components in psychological theories of illness (Leventhal et al., 1997).

From this corpus of work, it became clear that something—an “active ingredient”—was missing from this research group’s studies specifically explaining the motivating beliefs behind performing health protective behaviors, or coping procedures. *Coping procedures* are “ways of expressing distress, of calling for assistance and of manipulating the social environment” (Leventhal et al., 1997, p. 29). What was found to be missing was the *cognitive representation* of the disease threat—or *illness representations* (Leventhal et al.)—which influences coping procedures, which, in turn, influences one’s appraisal of a given coping procedure, the selection of new coping procedures, change in one’s illness representation, and/or change in the eliciting health-related stimuli (Leventhal et al.). Illness representations, which are more or less individuals’ theories of illness (Leventhal et al.), serve as the motivating factors for or beliefs underlying the performance of coping procedures (Leventhal et al.) in health-related scenarios.

*Features of Illness Representations*

Leventhal and colleagues (Leventhal et al., 1980, 1984, 2003; Penrod, 1980) and Lau and Hartman (1983) initially conceptualized five domains of illness representation in the 1980s: illness label, cause, timeline, consequences, and control (Lau & Hartman, 1983; Leventhal et al., 1980, 1984, 2003; Penrod, 1980). *Identity* is understood as both (a) the name (i.e., *label*) for an individual’s somatic experiences (i.e., the diagnosis or diagnostic label) as well as (b) the somatic experiences (i.e., *symptoms*) or conditions that
individuals perceive as corresponding to the given illness label. This distinction—that the symptoms in question must be perceived by the individual as related to the given illness label—is reflective of the symmetry rule, which stipulates that labels and symptoms are inextricably linked and as such, somatic experiences create a pressure for labeling what those experiences represent. Additionally, labels create a pressure for identifying somatic experiences associated with that label (Leventhal et al., 1997). As such, when individuals are given a diagnosis, they will search for related symptoms and when individuals experience symptoms, they will search for a diagnosis for those symptoms. For example, an individual who experiences intense menstrual cramping, chronic pelvic pain, and pain with intercourse (i.e., symptoms) will search for a diagnosis—or label—for those symptoms (i.e., endometriosis). Similarly, given the same context, an individual who receives a diagnosis—or label—of endometriosis upon discovery of their infertility, will search for symptoms reflective of that diagnosis.

*Cause* is the factors or determinants to which the identity label is and/or the symptoms are attributed. They are often separated into internal or external determinants (Lau & Hartman, 1983). Internal determinants reflect factors that are within a person’s control or responsibility, whereas external determinants reflect factors that are outside a person’s control or responsibility. Examples of *internal* causes are not taking care of oneself, poor sleep hygiene, stress, and substance abuse, whereas examples of *external* causes are contagious diseases, chronic illnesses, food poisoning, unavoidable accidents, and poor weather (Lau & Hartman, 1983). *Timeline* is beliefs about the expected and/or experienced age of onset, duration, and decline of symptoms/label (i.e., the illness identity). The expected and/or experienced duration of symptoms/label comes in three
forms: symptoms/illness experienced as acute, episodic/cyclical, and chronic. Acute courses have a sudden onset but tend to be short-lived, such as the coronavirus disease 2019 (COVID-19). Episodic/cyclical courses are experienced as having recurrent episodes or exacerbations of illness, an example being seasonal allergies. Chronic courses have a long-lasting or never-ending course, for example, Type I diabetes. Consequences is the expected and/or experienced negative physical, cognitive, and social impact on an individual’s overall functional capacity. They are beliefs about the symptoms’ impact on life functions, including expected physical, cognitive, and social disruption. Lastly, control is (a) whether and/or (b) to what degree one or more of the symptoms and/or overall label (i.e., identity) is perceived by an individual as preventable, controllable/manageable, or curable.

It should be noted that the self-report measures that have been developed since the inception of illness representations do not precisely align with Leventhal and colleagues’ initial five constructs. The original model of the self-report measure of illness representations—the Illness Perception Questionnaire (IPQ; Weinman et al., 1996)—did include five subscales to assess identity, cause, timeline, consequences, and control. However, subsequent versions of the measure have varied. For example, the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) added items to assess “emotional representations” and “illness coherence.” Emotional representations, as stated by the authors, are part of the original conceptualization of illness representations. In particular, the original model proposes that as a response to health threats, individuals develop parallel (i.e., independent) cognitive and emotional representations, which, consequently, present opportunities for problem- and emotion-focused coping
procedures, respectively (Leventhal et al., 2001; Moss-Morris et al., 2002), hence their addition of emotional representations to the IPQ-R. Furthermore, according to the authors, illness coherence refers to “a type of meta-cognition reflecting the way in which the patient evaluates the coherence or usefulness of his or her illness representation” (p. 2). The most recent version of the measure, the Brief IPQ, is now a 9-item measure rather than an 80-item measure (the IPQ-R), though it does not add any new hypothesized domains to illness representations.

**Common-Sense Rules Define the “Fit” between Representations and Coping**

**Procedures**

**Time frame rule.** Every procedure has an associated outcome expectation and a time frame (Leventhal et al., 1997). For example, ibuprofen is expected to relieve muscle pain within 20-30 minutes. Because of this expectation, we can gauge that an individual has a specific belief about ibuprofen (that it relieves muscle pain within 20-30 minutes). Similarly, vitamins are expected to generate an increased sense of well-being within days to weeks and an antacid is expected to relieve heartburn within several seconds. Because of these expectations, we can also gauge that an individual has a specific belief about vitamins and antacids (Leventhal et al., 1997). Similarly, because there is an expectation about how long something will take to work (e.g., vitamin, antacid), this expectation represents a belief likely held by the patient—or the representations (in this case, timeline) of their coping procedures. To note, the same five domains that comprise illness representations also represent coping procedures (Leventhal et al., 1997).

**Direct contact rule.** The direct-contact rule assumes direct contact of the therapy with the pathogenic agent (Leventhal et al., 1997). The more direct one’s procedure is
with the pathogenic agent, the more powerful the procedure is expected to be and thus
more control one is expected to have over the health threat. Examples of the direct
contact rule are that an acidic stomach is relieved by consuming antacids, a cut is treated
by applying an antiseptic agent, and illness-related fatigue is relieved by rest (Leventhal
et al., 1997).

**Dose-dependent rule.** In discussing control as a domain, it is worth noting the
dose-dependent rule for this control domain, which stipulates that “the more severe or
intractable the symptom the greater the dose or strength of the treatment required”
(Leventhal et al., 1997, p. 30). Furthermore, the unavailability of these medications
without an expert’s prescription—positioning clinicians as gatekeepers—perpetuates the
belief in their “special power” (Leventhal et al., 1997). Thus, the harder it is to obtain a
prescription for a medication, the more “special power” it is expected to have. That it
cannot be obtained without a clinician reaffirms the clinician’s power in the patient-
clinician dyad.

**Similarity/Dissimilarity in Illness Representations**

**Among partners and family.** Roughly a decade after the work on illness
representations, work began that examined the similarity/dissimilarity (or
convergence/divergence) of illness representations held by two different individuals.
Indeed, patients can hold different views about their health and the nature of their health
conditions than do their spouses (Heijmans et al., 1999) and family members (Clipp &
George, 1992; Hachett et al., 1997; Peyrot et al., 1988). Relevant to the context of
symptom invalidation is when patients’ illness representation diverges from that of
others’ illness representations of patients’ illness. In these situations, this divergence
represents a dissimilarity in illness representations. Heijmans et al. stated that dissimilarity seen in illness representations can vary in one of two directions. Others can minimize the seriousness of the patient’s illness by minimizing the symptoms and consequences of the illness, termed illness minimization (Cohen Silver et al., 1990; Wortman & Lehman, 1985). Or, others can exaggerate the seriousness of the patient’s illness, termed illness maximization (Coyne et al., 1988; Thompson & Pitts, 1992).

Generally, when patients minimize their illness, others will engage in compensatory behavior and instead maximize the patient’s illness. In contrast, when patients maximize their illness, others will engage in compensatory behavior and instead minimize the patient’s illness (Heijmans et al., 1999).

It is generally when illness minimization occurs by others that patients are given the impression that they are “not being taken seriously” (Heijmans et al., 1999, p. 464). In fact, diverging views of an illness can comprise a great source of stress (Leventhal et al., 1985) and lead to “confrontation” (Leventhal et al., 1980). Furthermore, it seems that illness minimization can be more harmful to a patient’s adjustment to illness than illness maximization, though the actual amount of harm is contingent on the nature of the illness and the particular illness representation domain (Heijmans et al., 1999). What is particularly noteworthy is that in Heijmans et al. (1999), among those with myalgic encephalomyelitis (ME/CFS), spouses’ maximization of consequences and minimization of the role of environmental and psychological factors facilitated emotion-focused coping procedures among patients. In other words, if spouses acknowledged the burden of ME/CFS and acknowledged a biological (i.e., external determinants) rather than
environmental or psychological cause (i.e., internal determinants) for ME/CFS, patients reported engaging in more emotion-focused coping procedures, a sign of positive coping.

ME/CFS is an important condition to examine owing to the contested nature of the illness and the lack of legitimacy it receives from clinicians and the larger healthcare system. Contested illnesses are those that are “medically suspect because they are not associated with any known physical abnormality” (Conrad & Barker, 2010, p. 70). It is not uncommon for patients with ME/CFS to consequently be told that their illness is psychological, especially a depressive illness (Pilkington et al., 2020). Indeed, one of the themes from a meta-ethnography by Pilkington et al. (2020) was psychologisation. In particular, they wrote:

People with CFS/ME do not want their illness to be viewed as predominantly psychological at the exclusion of physical symptoms. They want their physical symptoms treated, and psychological symptoms e.g. depression to be regarded and treated as a consequence of their CFS/ME. Acknowledging the physicality of illness can enable the exploration of mind-body interaction safely.

This conclusion drawn by Pilkington et al. (2020) aligns with the aforementioned findings of Heijman’s (1999) study.

Dissimilar illness representations also take a toll on the relationship. Research has demonstrated that a divergence of illness representations between patients and spouses is correlated with lower relationship satisfaction (Heijmans et al., 1999). This is especially so when patients and spouses diverge on biological causes for patients’ illness in ME/CFS. Heijmans et al. (1999) interpreted these findings as patients being more satisfied with their relationship with their spouse when their spouse “acknowledged” their own personal views of their illness. As such, when satisfaction with their relationship was low, patients tended to report feeling “misunderstood” by their spouse (Heijmans et al.,
Similarity in scores closely reflects the validation of patients’ experiences and dissimilarity in scores closely reflects the invalidation of patients’ experiences.

**Among clinicians.** More recently, work has begun to examine the similarity/dissimilarity (or convergence/divergence) of illness representations held by patients and their clinicians, owing in part to the development of a new self-report questionnaire to assess clinicians’ illness representations of their patients (Arat et al., 2016). The work that has stemmed from this questionnaire has largely focused on rheumatic diseases such as lupus and systemic sclerosis (Arat, Lenaerts, et al., 2017, Arat, Moons, et al., 2017; Elera-Fitzcarrald et al., 2020; Kirren et al., 2023) and multiple sclerosis (De Nigris Vasconcellos et al., 2021). When an individual has a consultation with a clinician, they enter a patient-clinician relationship, where the patient is exposed to the clinicians’ knowledge, beliefs, and expectations (Leventhal et al., 1984), which presumably constitutes clinicians’ own illness representation for the patient. When this happens, Leventhal et al. (1980) note that there can be “a confrontation between [patients’] private, implicit theories of illness... and the practitioner’s medical model” (p. 18). When such a confrontation occurs, patients may feel that one or more domains of their illness representation is being invalidated by clinicians’ medical model, which presumably constitutes clinicians’ own illness representation. This is especially likely given that when there is dissimilarity between patients’ beliefs and those of others, such patients tend to deny input from social figures if it is inconsistent with their own personal experiences (Leventhal et al., 1984). It can be seen how invalidating environments and illness representations bleed together to cultivate what I term *symptom invalidation*, or
communication that deems one’s symptoms or related experiences as not “real” or of value.

Although it has not yet been studied — considering the work is still in its infancy — there is reason to believe that dissimilar illness representations will also take a toll on the patient-clinician relationship as it does between patients and their spouses (Heijmans et al., 1999). The findings that tensions arise when a biological cause does not emerge as a causal determinant for patients’ illness — especially if symptoms are psychologized (Pilkington et al., 2020) — likely hold true for patients with various illnesses. Internal causes, such as those that are psychological and not biological, have been documented in extensive work outside the illness representations sphere. Relational constructs such as satisfaction and trust in the clinician may be compromised under these conditions.

The Present Dissertation

The goal of this dissertation is multi-faceted: (a) to elucidate the negative sequelae symptom invalidation imposes on patients (Phase I), (b) to explicate the concept of symptom invalidation as it takes place between patients and clinicians (Phase II), (c) to validate a reliable self-report measure of symptom invalidation based on the findings of (b) (Phase III), and finally (d) to document the negative consequences of symptom invalidation using this self-report measure from (c) (Phase IV). What follows is a brief discussion of each of these four phases of the dissertation. See Figure 6 for a list of all research questions and hypotheses.

Phase I: Elucidating the Negative Sequelae of Invalidating Experiences
Although there is no shortage of literature on clinicians’ reported invalidation of patients’ symptoms, there is far less empirical work regarding the negative sequelae of this invalidation for patients. Little effort has gone into elucidating the negative sequelae of invalidation, and there are no systematic reviews to date of which the author is aware that aggregates a list of these sequelae. Doing so can shed light on quality and safety issues that may arise as a result of invalidation in healthcare settings. The goal of this phase is to provide a systematic review of the extant qualitative literature that documents patient-reported invalidation of their symptoms by clinicians. Accordingly, a systematic review will be performed rather than a qualitative synthesis or meta-synthesis as it is the more appropriate qualitative method given the goal of this review (i.e., aggregate results), rather than synthesize for the purposes of developing a conceptual model, theory, or new interpretation (France et al., 2014). For work that aims to summarize or aggregate findings from individual primary qualitative studies to answer particular questions, a systematic review is more appropriate (France et al., 2014; Popay et al., 2006).

The illness contexts that will specifically be examined in this review are those for which diagnosis is generally difficult, prolonged, and/or uncertain, as they are expected to yield more articles on the topic of invalidation owing to increased opportunities for communication. The illness contexts that will be explored include Ehlers Danlos syndrome (EDS) (including hypermobility spectrum disorders), endometriosis, irritable bowel syndrome (IBS), long coronavirus disease (long COVID), systemic lupus erythematosus (lupus), undiagnosed illness (also referred to as medically unexplained symptoms; Japp & Japp, 2005), and postural orthostatic tachycardia syndrome (POTS). Using these illnesses as the contexts for this review, the research question guiding this review is as follows:
**RQ1:** What are the negative sequelae of invalidation among patients with difficult to diagnose conditions?

**Phase II: Explicating Symptom Invalidation**

Phase II utilizes a cross-sectional mixed-methods online survey to elucidate the topical features of clinicians’ invalidating messages as reported by patients with endometriosis. The aim is to elucidate the specific features of clinicians’ messages as reported retrospectively by patients that can lead to cognitive/affective experiences of invalidation. Although a number of studies have detailed experiences akin to what I am defining as invalidation in its findings, a clear understanding of what does and does not constitute ‘invalidation’ is lacking. Establishing clear boundaries around this construct is essential in developing a strong and rigorous corpus of work that is also replicable. For this reason, I draw on the literature of invalidating environments to focus the process of invalidation and I draw on the literature of illness representations to establish a comprehensive understanding of the features that can be invalidated during this process.

As such, the following two research questions are advanced:

**RQ2:** How well do the five established illness representation features (a) identity, (b) cause, (c) timeline, (d) consequences, and (e) control map onto patients’ reported experiences of invalidation?

**RQ3:** What additional features in addition to the five established features of illness representations do patients describe that are reflective of symptom invalidation?

**Phase III: Validating a Self-Report Measure to Assess Symptom Invalidation**

Phase III utilizes a longitudinal mixed-methods online survey to develop and validate a reliable self-report measure to assess symptom invalidation and its effects
among patients with endometriosis. Such a measure will allow for the quantitative and systematic assessment of symptom invalidation across illness contexts for future study. Diverse language has been used in describing the dismissal of patients’ symptoms (see Bontempo, 2022b) and so it is unclear whether these variations refer to one larger latent construct of invalidation or if there is more nuance that is being captured in these differences. For instance, across the literature symptoms have been described as ‘dismissed’ (e.g., Ali et al., 2014; Braeuninger-Weimer et al., 2019; Denny et al., 2009; Zale et al., 2020), ‘passed off’ (Denny et al., 2009), are ‘not taken seriously’ (Cox, Ski, et al., 2003; Denny, 2004b; Markovic et al., 2008), ‘invalidated’ (Besa, 2015), ‘rejected’ (Markovic et al., 2008), and ‘challenged’ (Cooper & Gilbert, 2017; Price & Walker, 2014). It is these items that comprise the items of the PSIS. Because at least three items will be required to load onto a factor for each factor to be considered stable (Costello & Osborne, 2005), more than three items were selected should one or more items fail to load onto a factor or demonstrate cross-loading and have to be discarded. The following research questions guiding this phase are as follows:

*RQ4: Does the PSIS demonstrate sound internal consistency?*

*RQ5: Does the PSIS demonstrate sound convergent validity?*

**Phase IV: Testing the Negative Sequelae of Symptom Invalidation**

Results from the systematic review of qualitative literature from Phase I demonstrate that invalidation can lead to negative affect, negative self-esteem, depression, and suicidal ideation; healthcare-related anxiety and trauma; distrust in specific clinicians, clinicians generally, or the broader healthcare system; frustration and anger toward clinicians or the broader healthcare system; decisions to not disclose health-
related information to specific clinicians or clinicians generally; and delays, breaks, or terminations in care. However, these observations stem from qualitative work and have not yet been statistically tested and validated using quantitative methodology. As such, this phase of the dissertation provides a secondary analysis using items from the cognitive/affective reactions subscale of the Institutional Betrayal in the Medical System scale (Tamaian & Klest, 2018) to examine the relationship between symptom invalidation and cognitive/affective reactions that resemble the negative sequelae identified from Phase I. The cognitive/affective reactions subscale contains the following items as a result of the invalidating interaction: ‘scared/terrified’, ‘less trusting of the medical system’, ‘angry’, and ‘cautious about seeking care’ and ‘reluctant to seek further medical care’ (with the last two combined). These are the items that will be used to assess healthcare-related anxiety and trauma, loss of trust in clinicians, frustration and anger toward clinicians and the healthcare system, and delays, breaks, or terminations in care, respectively. The following hypotheses are thus advanced:

**H1:** Perceived symptom invalidation will be positively correlated with feeling scared/terrified as a result of the invalidating interaction.

**H2:** Perceived symptom invalidation will be positively correlated with loss of trust in clinicians as a result of the invalidating interaction.

**H3:** Perceived symptom invalidation will be positively correlated with feeling angry as a result of the invalidating interaction.

**H4:** Perceived symptom invalidation will be positively correlated with caution and reluctance to seek further medical care as a result of the invalidating interaction.
Figure 6: Dissertation Research Questions and Hypotheses by Dissertation Phase

**Phase I**

- **RQ1**: What are the negative sequelae of invalidation among patients with endometriosis?

**Phase II**

- **RQ2**: How well do the five established illness representation features (a) identity, (b) cause, (c) timeline, (d) consequences, and (e) control map onto patients’ reported experiences of invalidation?
- **RQ3**: What additional features in addition to the five established features of illness representations do patients describe that are reflective of symptom invalidation?

**Phase III**

- **RQ4**: Does the PSIS demonstrate sound internal consistency?
- **RQ5**: Does the PSIS demonstrate sound convergent validity?

**Phase IV**

- **H1**: Perceived symptom invalidation will be positively correlated with feeling scared/terrified as a result of the invalidating interaction.
- **H2**: Perceived symptom invalidation will be positively correlated with loss of trust in clinicians as a result of the invalidating interaction.
- **H3**: Perceived symptom invalidation will be positively correlated with feeling angry as a result of the invalidating interaction.
- **H4**: Perceived symptom invalidation will be positively correlated with caution and reluctance to seek further medical care as a result of the invalidating interaction.
CHAPTER THREE: METHODS

This study comprised four phases, as introduced previously. Phase I involved a secondary analysis of extant literature on the negative sequelae of invalidation. Phases II, III, and IV involved analysis of different survey data from the same individual study and the following sections describe the method for Phase I followed by the study from which Phases II, III, and IV were drawn.

Phase I

A systematic review was performed to amalgamate a sample of qualitative studies about patients’ negative experiences communicating with clinicians about their symptoms in the context of Ehlers Danlos syndrome, endometriosis, IBS, long COVID, lupus, undiagnosed illness, and POTS. Particularly, an aggregative or ‘integrative’ approach was used (Dixon-Woods et al., 2007; Popay et al., 2006), for which results are summarized from individual original qualitative studies to answer specific research questions, also called a “meta-summary” (France et al., 2014). Without a commonly accepted self-report measure of symptom invalidation, there are no existing quantitative studies. Qualitative research is thus the focus of this review. Qualitative studies also typically provide some raw data (i.e., exemplar quotes) that can be examined firsthand along with how authors are framing participant quotes. It has been advised that thematic analysis is more appropriate when synthesizing a large number of studies than is a meta-ethnography (Campbell et al., 2011; Noyes & Lewin, 2011; as cited in France et al., 2014, p. 3). As such, the PRISMA guidelines were adhered to as much as possible for this type of qualitative review (Moher et al., 2009), the reporting of which largely follows these guidelines.
Eligibility Criteria

Inclusion Criteria

Studies were included in this systematic review if they reported on invalidating interactions patients had with clinicians. As mentioned earlier, I define symptom invalidation as the process by which a patient’s symptoms and related experiences are deemed not “real” or of value. As such, if the legitimacy of the patient’s symptoms is questioned or are disregarded by clinicians, then the article fulfilled this criterion. Words that were particularly helpful in signaling whether invalidation was taking place in the articles were those identified by Bontempo (2022a). Studies were also included if they were reported from the perspective of the patient, were among the illness contexts investigated in this review (i.e., EDS, endometriosis, IBS, long COVID, lupus, undiagnosed illness, POTS), reported on negative sequelae of invalidation, were journal articles, used qualitative methods, were peer-reviewed, were published, and were written in the English language. There were no age limits on participants nor were any date restrictions enforced.

Exclusion Criteria

Studies were excluded if they did not report invalidating interactions patients had with clinicians from the perspective of the patient (e.g., were clinicians, partners, parents), were not among the illness contexts investigated in this review (e.g., was not in the context of EDS, endometriosis, IBS, long COVID, lupus, undiagnosed illness, POTS), did not report on any negative sequelae of invalidation, were not journal articles (e.g., were books, book reviews, review articles, study protocols), used only quantitative methods, were not peer-reviewed, were not published (e.g., were on preprint servers), and
were not in the English language. For undiagnosed illness, syndromes with their own name but may be considered “MUS” by some were not included with the undiagnosed illness articles (e.g., fibromyalgia, vulvodynia, Gulf War illness) since they constitute their own illness. For IBS, articles were not included if they referred to a functional gastrointestinal disorder or related functional illness. Commentaries, letters to the editor, and opinion pieces were also excluded, being that they did not present empirical findings.

**Information Sources and Search Strategy**

A systematic search was carried out in March 2023. Three electronic databases (Scopus, PsycINFO, PubMed) were individually searched by the author for relevant citations using the keywords adapted from Shallcross et al.’s (2018) and Hintz’s (2022) meta-syntheses for each of the seven illness contexts. Each illness was searched along with the Boolean operators “interview*,” “qualitative stud*,” and “ experience.” Thus, 21 total searches were conducted. The scope of the review was also narrowed via search terms for qualitative studies (vs. quantitative studies). If studies were mixed method, the qualitative portion of the study was used, if relevant.

**Study Selection Process**

The journal articles that were identified from the search strategy were screened for eligibility by examining the titles and abstracts of these studies. For each of the three databases, ineligible journal articles were removed as well as duplicate journal articles. Once these journal articles had been removed from each of the three database searches, titles and abstracts were screened by the author utilizing the inclusion and exclusion criteria listed above. For the abstracts meeting the inclusion criteria, the full texts of these articles were then read in full to identify sequelae in the results. Articles that did not
report any negative sequelae were excluded from the analysis. This same study selection process occurred for the journal articles identified via manual review of reference lists and the “cited by” feature of Google Scholar. Figures 7, 8, 9, 10, 11, 12, and 13 show a detailed guide of the search terms and search strategy for each of the seven illnesses within each of the three databases.
Figure 7 PRISMA Flow Diagram for EDS Articles

Scopus
- Identification
  - Records retrieved (n=35)
  - Records excluded (n=6)
    - Not an article (n=6)
- Screening
  - Records retrieved and screened for eligibility via title and abstract (n=29)
    - Records excluded (n=22)
      - Not about invalidating patient healthcare experiences (n=13)
      - Not about EDS (n=6)
      - Not patients as subjects (n=2)
      - Not original research (n=1)
- Included
  - Records retrieved and screened via full manuscript review (n=7)
    - Records excluded (n=2)
      - Not about invalidating patient healthcare experiences (n=2)
      - No sequences identified (n=1)
  - 4 records

PsycINFO
- Identification
  - Records retrieved (n=8)
  - Records excluded (n=0)
- Screening
  - Records retrieved and screened for eligibility via title and abstract (n=8)
    - Records excluded (n=0)
      - Not about invalidating patient healthcare experiences (n=5)
- Included
  - Records retrieved and screened via full manuscript review (n=3)
    - Records excluded (n=0)
      - Not about invalidating patient healthcare experiences (n=2)
  - 1 new record

PubMed
- Identification
  - Records retrieved (n=0)
- Screening
  - Records retrieved and screened for eligibility via title and abstract (n=0)
    - Records excluded (n=0)
- Included
  - Records retrieved and screened via full manuscript review (n=0)
    - Records excluded (n=0)
  - 0 new records
  - Records added via manual search of references and published reviews/syntheses (n=2)
- 7 total studies
Figure 8 PRISMA Flow Diagram for Endometriosis Articles
Figure 9 PRISMA Flow Diagram for IBS Articles
Figure 10 PRISMA Flow Diagram for Long COVID Articles
Figure 11 PRISMA Flow Diagram for Lupus Articles
Figure 12 PRISMA Flow Diagram for Undiagnosed Illness Articles
Figure 13 PRISMA Flow Diagram for POTS Articles

Scopus
- Records retrieved (n=4)
  - Records excluded (n=1)
    - Not an article (n=1)
  - Records retrieved and screened for eligibility via title and abstract (n=3)
    - Records excluded (n=1)
      - Not about postural orthostatic tachycardia syndrome (n=1)
  - Records retrieved and screened via full manuscript review (n=2)
    - Records excluded (n=1)
      - No sequence identified (n=1)
  - 1 record

PsycINFO
- Records retrieved (n=6)
  - Records excluded (n=0)
- Records retrieved and screened for eligibility via title and abstract (n=6)
  - Records excluded (n=6)
    - Not about postural orthostatic tachycardia syndrome (n=5)
    - Not about invalidating patient healthcare experiences (n=1)
  - Records retrieved and screened via full manuscript review (n=0)
    - Records excluded (n=0)
  - 0 new records

PubMed
- Records retrieved (n=0)
  - Records excluded (n=0)
- Records retrieved and screened for eligibility via title and abstract (n=0)
  - Records excluded (n=0)
- Records retrieved and screened via full manuscript review (n=0)
  - Records excluded (n=0)
  - 0 new records
- Records added via manual search of references and published reviews/syntheses (n=0)
- 1 total study
Data Extraction Process

A data extraction spreadsheet was created in Microsoft Excel to collect journal characteristics, including journal title, year of publication, country of analysis, study aim, data collection method, and type of data analysis used.

To identify sequelae, a data extraction spreadsheet was created in Microsoft Word that was applied to each paper in the data extraction process. Articles that fulfilled the inclusion criteria were thoroughly examined and information from each included article was collated in the data extraction spreadsheet. Information that was included was the first author’s last name, year of publication, illness context (i.e., EDS, endometriosis, IBS, long COVID, lupus, undiagnosed illness, and POTS), and the sequelae as they emerged from the data. Eventually, a final list of sequelae was compiled and applied to the data extraction spreadsheet. This spreadsheet was iteratively revised during the data analysis process, which is described under “Synthesis of Results.”

Quality Assessment

There is no widely accepted quality assessment tool with which to evaluate the quality of qualitative papers (Young et al., 2015). It is challenging to adopt “standard” quality assessment criteria to qualitative research, the purpose of which is to unveil complexity, diversity, and change, rather than pursuing replicability and generalizability, which is standard for quantitative research (Liamputong, 2009; Young et al., 2015). The current review used the seven quality assessment criteria utilized by Young et al. (2015), which stemmed from a variety of different sources including Fossey et al. (2002), Critical Appraisal Skills Programme (2010), Popay et al. (1998), and Greenhalgh and Taylor (1997). Using these criteria, the papers identified for potential exclusion were re-
reviewed by the author and a final decision was made. Criterion 1 asks whether the article makes the research objective(s) clear. Criterion 2 asks if there is evidence that a qualitative approach is justified by the research question(s). Criterion 3 asks if the selection of participants was appropriate, adequate, and clearly articulated. Criterion 4 asks if the method for data collection is appropriate. Criterion 5 asks if the data analysis procedure was sufficient and transparent. Criterion 6 asks whether the interpretation of the results parallel the perspective of those it claims to represent. Finally, Criterion 7 asks if the relationship between the researcher and participants has been considered. One POTS study did not meet the quality assessment criteria and was deemed too poor for inclusion in the systematic review. Specifically, Stiles et al. (2018) did not meet any of the criteria except for Criterion 1 and Criterion 7. Stiles et al. (2018) provided nearly no data on methodology (Criterion 2, Criterion 3, Criterion 4, Criterion 5), nor provided a discussion of the findings (Criterion 6). This study was thus excluded. All other studies were retained for analysis.

**Synthesis of Results**

There currently exist various methods for synthesizing the results of qualitative research; however, few of these have been assessed (Dixon-Woods et al., 2005). Owing to its facilitation of organized, structured summary of themes (Young et al., 2015), thematic analysis (Braun & Clarke, 2006) was used while examining the included studies for negative sequelae of invalidation. Given that there were two a priori research questions prior to reviewing the articles, a deductive, or “theoretical” thematic analytic approach, was undertaken following the six steps of thematic analysis laid out by Braun and Clarke (2006). Furthermore, the analysis took a semantic approach to generating
themes, for which themes are identified within the explicit or surface meanings
(“semantic content”) of the data (Braun & Clarke, 2006), given that the research question
guiding this review is very explicit and the data can be extracted more easily from the
surface content of the articles.

Using Braun and Clarke’s (2006) approach, the analysis process began with
repeated reading to ensure immersion in the data. Articles were read carefully, and notes
were taken of patterns of sequelae as reported in the articles. An initial list of sequelae
was constructed from this process. The identified sequelae were then systematically
assessed and reorganized, facilitated by a matrix table that listed all the articles on the y-
axis and all the sequelae on the x-axis. All the sequelae that were listed in the matrix table
were evaluated against the data and examined to see whether each sequela represented a
stand-alone sequela or whether it should be combined with one or more other sequelae,
separated into two or more distinct sequelae, or removed. The articles were then re-
reviewed to capture sequelae that may have evolved during the process and were
therefore missed initially. The sequelae were then named, defined, and then refined as
needed. Finally, the results were assembled using data extracts from the articles as
illustrative examples of the sequelae.
Phases II, III, and IV

Examining the literature exploring invalidation and its negative consequences demonstrated how important this construct can be for defining patient experiences. Having established the relevance of this construct, I set out to more precisely conceptually define and operationalize symptom invalidation to help unify the work being done across disparate fields and contexts.

Procedure

Data collection took place between March and June 2019. Patients were recruited from an advertisement that was posted by both national (i.e., Endometriosis Research Center, Endo What?) and international (i.e., Endometriosis Association of Ireland and Trinidad and Tobago Endometriosis Association) endometriosis non-profit organizations to their open social media sites. The Center for Endometriosis Care, a healthcare center composed of endometriosis specialists, also posted the advertisement to its open social media site. The advertisement was also able to be shared on such open social media sites by other individuals and organizations.

Individuals who accessed the link were brought to a page that included the IRB-approved digital study consent form, which required them to agree to proceed to the 20-30-minute IRB-approved survey. If patients did not agree to the digital form, they were redirected to the end of the survey. Inclusion criteria included (1) a self-reported diagnosis of endometriosis, (2) an age of at least 18 years, and (3) residing within the United States. Patients who completed the survey could enter a raffle to receive one of six $25 Amazon gift cards. This study was approved by the Rutgers University IRB (Protocol #: Pro201900348).
Patients were first asked their demographic information, followed by some health-related information such as how long ago their symptoms began, how long ago they began seeking care for their symptoms, whether they were diagnosed via diagnostic laparoscopy, time since surgical diagnosis (if relevant), whether they received a clinical diagnosis of endometriosis prior to their surgical diagnosis of endometriosis, and time since clinical diagnosis (if relevant). Patients were also asked to report their symptoms, whether they had endometriosis-associated fertility problems, to rate their overall health, their average pain level in the past seven days, their average fatigue level in the past seven days, what their worst endometriosis symptom was, and then their average level of their worst symptom in the past seven days. Patients were also asked out of how many of the past 30 days their symptoms interfered with their normal daily functioning.

Patients were then brought to a separate section of the survey related to their experiences with clinicians in relation to their communication about patients’ symptoms. They were asked a single open-ended question:

Please describe a specific interaction you had with a doctor that took place before your diagnosis of endometriosis in which your doctor said, implied, and/or did one or more things that you felt were dismissive of your endometriosis symptoms and/or you. As best you can, please include specifically what the doctor said. If there has been more than one interaction, please choose the most memorable.

Phase II analyzes the responses to this open-ended question.

After describing a specific healthcare interaction, patients completed a series of close-ended questions that pertained to the specific interaction they were asked to describe. Questions included the type of clinician with whom the interaction occurred, how long ago the interaction occurred, whether the interaction was typical of those with clinicians prior to their eventual diagnosis, approximately how many interactions similar
to the one described occurred prior to their eventual diagnosis, over how much time these types of interactions occurred, and how long after the interaction they received an endometriosis diagnosis. Then, patients filled out two subsequent scales that were developed and piloted in this study: symptom invalidation and personalized symptom invalidation. Other constructs measured included patient satisfaction with the clinician, perceived supportive communication from the clinician, cognitive-affective reactions to their interaction with the clinician, symptom uncertainty at the time of the interaction, symptom threat at the time of the interaction, self-esteem, social support, and depression.

Phase III reports on the scale assessing symptom invalidation, along with patient satisfaction with the clinician, perceived supportive communication from the clinician, and cognitive-affective reactions to their interaction with the clinician. Phase IV reports on the scale assessing symptom invalidation, along with a handful of items from the cognitive-affective reactions to their interaction.

**Phase II Participants**

1008 (58%) patients from the United States and abroad responded to the open-ended question as part of the survey. Responses were coded as “relevant” for 830 patients (i.e., the sample for this study), and as “not relevant” (and therefore excluded from analysis) for 178 patients. Responses that were deemed “not relevant” were those that reported 1) experiences being diagnosed in a matter-of-fact manner, 2) positive experiences, or 3) dissatisfaction or incompetence but lacked the experience of invalidation. In terms of demographic characteristics, 62% (n = 526) reported residing within the United States and the remaining 37.8% reported residing abroad. Mean reported age was 33.8 ($SD = 7.9$; range = 18 to 64), with 90.3% identifying as non-
Hispanic white. Most of the sample reported their sexual orientation as heterosexual (84.4%). The sample was well educated, as 63.1% patients reported having at least an undergraduate degree. 75.4% reported a personal annual income of more than $40,000.

Full demographic characteristics can be found in Table 1.

Table 1 Sample Characteristics of Respondents with Included Responses from Phase II

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>( M = 33.8 ) (( SD = 7.9 ))</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic Asian</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>Hispanic Native Hawaiian or Pacific Islander</td>
<td>2 (0.2%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>11 (1.4%)</td>
</tr>
<tr>
<td>Hispanic mixed race</td>
<td>2 (0.2%)</td>
</tr>
<tr>
<td>Non-Hispanic American Indian/Alaskan Native</td>
<td>2 (0.2%)</td>
</tr>
<tr>
<td>Non-Hispanic Asian</td>
<td>19 (2.3%)</td>
</tr>
<tr>
<td>Non-Hispanic black or African American</td>
<td>19 (2.3%)</td>
</tr>
<tr>
<td>Non-Hispanic Native Hawaiian/Pacific Islander</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>735 (90.3%)</td>
</tr>
<tr>
<td>Non-Hispanic mixed race</td>
<td>22 (2.7%)</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>710 (84.4%)</td>
</tr>
<tr>
<td>Lesbian</td>
<td>2 (1.1%)</td>
</tr>
<tr>
<td>Bisexual</td>
<td>14 (7.8%)</td>
</tr>
<tr>
<td>Queer</td>
<td>4 (2.2%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (0.6%)</td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
</tr>
<tr>
<td>Single/ Never married</td>
<td>149 (17.7%)</td>
</tr>
<tr>
<td>Dating</td>
<td>146 (17.4%)</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>81 (9.6%)</td>
</tr>
<tr>
<td>Married or in a Civil Union</td>
<td>426 (50.6%)</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>40 (4.8%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>9 (1.1%)</td>
</tr>
<tr>
<td>High school diploma or equivalent</td>
<td>70 (8.3%)</td>
</tr>
<tr>
<td>Business/Trade/Technical school</td>
<td>40 (4.8%)</td>
</tr>
<tr>
<td>Some college/2-year degree</td>
<td>192 (22.8%)</td>
</tr>
<tr>
<td>College degree</td>
<td>304 (36.1%)</td>
</tr>
</tbody>
</table>
In terms of health-related characteristics, 37.4% reported having endometriosis-associated infertility, 12.9% reported not having endometriosis-associated infertility, and 49.8% reported that they did not know if they had endometriosis-associated infertility. On a 0-100 scale, the mean average level of pain in the past seven days was 49.2, the average level of fatigue in the past seven days was 64.9, and the average level of their worst reported symptom in the past seven days was 58.3. The average number of days with which their symptoms interfered was 11.2. On average, patients reported their self-rated health as being fair (2.5 of 5). Full health-related characteristics can also be found in Table 1.

Phase III and IV Participants

Data from patients who resided in the United States at the time of the survey and who filled out the PSIS in its entirety were included as part of this analysis (N = 533). Patients’ ages ranged from 18 to 85, with a mean age of 34.2 (SD = 8.1). A majority of the sample identified as non-Hispanic white (85.0%) and roughly half the sample identified as being married or in a civil union. In terms of education, nearly two-thirds of the sample reported having at least a college degree (65.2%). In terms of personal annual income, roughly three-quarters (75.3%) of the sample reported making more than
$40,000 per year. Currently, there are no known demographic predilections that exist in the context of endometriosis (Center for Endometriosis Care, 2023). As such, a comparison of demographic characteristics between those in this survey and those with endometriosis more generally cannot be made. Full sample characteristics are in Table 2.

**Table 2** Sample Characteristics of Respondents from Phase III and Phase IV

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Respondents (N = 533)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>$M = 34.2$ ($SD = 8.1$)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic Asian</td>
<td>0.1%</td>
</tr>
<tr>
<td>Hispanic Native Hawaiian/Pacific Islander</td>
<td>0.3%</td>
</tr>
<tr>
<td>Hispanic White</td>
<td>1.3%</td>
</tr>
<tr>
<td>Hispanic Mixed Race</td>
<td>0.3%</td>
</tr>
<tr>
<td>Non-Hispanic American Indian/Alaskan Native</td>
<td>0.1%</td>
</tr>
<tr>
<td>Non-Hispanic Asian</td>
<td>2.9%</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>1.6%</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>90.1%</td>
</tr>
<tr>
<td>Non-Hispanic Mixed Race</td>
<td>3.2%</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>86.4%</td>
</tr>
<tr>
<td>Lesbian</td>
<td>2.1%</td>
</tr>
<tr>
<td>Gay</td>
<td>0.2%</td>
</tr>
<tr>
<td>Bisexual</td>
<td>8.7%</td>
</tr>
<tr>
<td>Queer</td>
<td>1.6%</td>
</tr>
<tr>
<td>Other</td>
<td>1.1%</td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
</tr>
<tr>
<td>Single/Never married</td>
<td>14.4%</td>
</tr>
<tr>
<td>Casually dating multiple partners</td>
<td>1.8%</td>
</tr>
<tr>
<td>Monogamously dating one partner</td>
<td>13.5%</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>7.7%</td>
</tr>
<tr>
<td>Married or in a Civil Union</td>
<td>56.6%</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>6.1%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>0.5%</td>
</tr>
<tr>
<td>High school diploma or equivalent</td>
<td>6.3%</td>
</tr>
<tr>
<td>Business/Trade/Technical school</td>
<td>2.7%</td>
</tr>
</tbody>
</table>
### Variables and Measures

**Cognitive/Affective Experiences of Invalidation**

Items reflecting invalidation of symptoms as perceived by patients were constructed for the purpose of this study. Patients were instructed: ‘Thinking about the interaction you described above, how much do you agree or disagree with the following statements regarding your doctor’s treatment of your symptoms during this interaction?’ A sample item includes: ‘My doctor did not dismiss my symptoms’ (reverse scored). Six items were used, and patients were asked to respond to each item using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with higher scores indicating greater invalidation of symptoms. A sample item includes: ‘My doctor passed my symptoms off.’ Internal consistency for these items was very good ($\alpha = .88$). The scale mean was 3.98 ($SD = 1.00$). For Phase III, which piloted and tested a self-report measure, this scale was used to assess for convergent validity.

**Cognitive/Affective Responses to Institutional Betrayal**

Cognitive/affective experiences of institutional betrayal were assessed using the cognitive/affective reactions subscale of the Institutional Betrayal in the Medical System scale (Tamaian & Klest, 2018), which comprises 20 items. Patients were asked to rate the extent to which their list of 20 items impacted them at that time of the interaction they described earlier in the survey on a five-point Likert scale ranging from 0 (not at all) to 4 (extremely). Higher scores indicated greater cognitive/affective responses to institutional
betrayal. An example item includes ‘Made me feel helpless.’ This scale has previously demonstrated excellent internal consistency ($\alpha = .99$). Internal consistency for these items was excellent ($\alpha = .98$). The scale mean was 3.73 ($SD = 1.18$). For Phase III, this scale was used to assess for convergent validity. For Phase IV, only a handful of items from this scale was used. Particularly, to assess healthcare-related anxiety and trauma as a result of the invalidating interaction, the scale item ‘scared/terrified’ was tested as an outcome. To assess for loss of trust or feelings of betrayal as a result of the invalidating interaction, the scale item ‘less trusting of the medical system’ was tested as one outcome. To assess for frustration and anger toward clinicians and the healthcare system as a result of the invalidating interaction, the scale item ‘angry’ was tested as an outcome. To assess for delays, breaks, or terminations in care as a result of the invalidating interaction, the scale items ‘cautious about seeking care’ and ‘reluctant to seek further medical care’ were averaged together, the total of which was tested as an outcome.

**Supportive Message Quality from Clinicians**

Supportive message quality from clinicians was assessed using the 12-item semantic-differential Helpful, Supportive, and Sensitive Scale (Goldsmith et al., 2000). Responses were captured on a 6-point semantic differential scale. Higher scores indicated greater perceived support from the clinician. This scale has previously demonstrated good to excellent internal consistency (for helpful, $\alpha = .89$; supportive, $\alpha = .92$; and sensitive, $\alpha = .92$). Internal consistency for the three subscales of helpful, supportive, and sensitive were excellent ($\alpha = .92$, $\alpha = .93$, $\alpha = .93$, respectively). The mean for the helpful subscale was 2.42 ($SD = 1.31$). The mean for the supportive subscale was 2.25 ($SD = 1.33$). The
mean for the *sensitive* subscale was 2.3 (*SD* = 1.33). For Phase III, this scale was used to assess for convergent validity.

**Satisfaction with Interaction**

Patients’ overall satisfaction with their interaction with the clinician was assessed using the following question: ‘How satisfied were you with the overall interaction you had with this doctor?’ to which patients could respond very dissatisfied, somewhat dissatisfied, neither satisfied nor dissatisfied, somewhat satisfied, and very satisfied. A higher score indicated greater satisfaction with the interaction. For Phase III, this question item was used to assess for convergent validity.

**Phase II Data Analysis**

**Data screening.** The data analyzed for the qualitative portion of Phase II (RQ2 and RQ3) stemmed from the open-ended responses to the aforementioned single open-ended question. Although there was a total of 1747 patients who initiated the survey, 661 (37.8%) of these patients terminated the survey before answering the open-ended question on which this study is based. Of those who did not terminate the survey early (n=1086), 44 (4.0%) did not respond to the question, yielding 1042 responses. Furthermore, two patients wrote “none” as their response, one patient wrote “NA” as their response, and one patient wrote “1” as their response. These responses were discarded, leaving a total of 1038 responses to be further analyzed for appropriateness and inclusion in the final data set.

Importantly, the exclusion criteria for eliminating responses to yield the final data set were initially very inclusive, because the phenomenon being studied (i.e., symptom invalidation) still lacks a standardized conceptual term and definition (Bontempo, 2022b).
To remedy his, however, the two coders consulted the literature on invalidating environments (Linehan, 1993) and illness representations (Leventhal et al., 1997) and to inform the joint deductive-inductive coding process, which also concurrently served to meet the aim of the study. In particular, the literature on illness representations served to maintain a focus on the features of invalidation, while the literature on emotional invalidation and invalidating environments served to maintain a focus on invalidation as a unique process. Accordingly, the boundaries of the phenomenon of symptom invalidation were drawn iteratively during the coding process.

During the conceptualization and coding process, we were cognizant of the fact that any negative experience with a clinician reported by a patient was not the same as a negative experience that constituted invalidation of patients’ symptoms. For example, patients may have reported on a negative outcome of a procedure, a negative interaction that exemplified general dissatisfaction, or being dissatisfied that clinicians did not have an answer for the patient concerning their diagnosis but such experiences, while certainly unfavorable, are not cases of symptom invalidation. Thus, it was determined that one of the boundary conditions for symptom invalidation was that experiences report on invalidation, or the process by which a patient’s symptoms and related experiences are deemed not “real” or of value by clinicians. Aligning with this definition was paramount to ensure that patients’ comments on any negative experience they may have had in the healthcare setting but that did not constitute invalidation were not included in the study.

Data analysis. Responses were coded both deductively and inductively simultaneously using a highly iterative process by two coders already familiar with the phenomenon of symptom invalidation in the context of endometriosis (AB and LM) and
have published work on the value of trust in clinicians on the healthcare experiences of patients with endometriosis (see Mikesell & Bontempo, 2022). To answer RQ2 (“How well do the five established illness representation features (a) identity, (b) cause, (c) timeline, (d) consequences, and (e) control/cure map onto patients’ reported experiences of invalidation?”), the first author constructed a codebook according to the five dimensions of illness representations according to Leventhal and colleagues: identity, cause, timeline, consequences, and control. Reflecting the literature and self-report measures on illness representations, identity was separated into “identity label” and “identity symptoms,” “cause” was separated into “external cause” and “internal cause,” and control was separated into “self-efficacy” and “response efficacy,” thus yielding eight a priori codes. Instead of maintaining the original five domains as practiced by Leventhal and colleagues, including these additional subcategories would allow for more nuanced coding and, if no nuances existed, could be collapsed back into the original five categories of Leventhal and colleagues. These eight a priori categories served as the deductive portion of the data analysis and were essential for answering RQ2.

To answer RQ3 (“What additional features in addition to the five established features of illness representations do patients describe that are reflective of symptom invalidation?”), in addition to coding the eight aforementioned categories, an “other/uncertain” category was created, which was designated for cases that did not adequately align with any of the eight illness representation categories but seemed to still reflect invalidation of patients’ symptoms in some meaningful way. All “other” cases were captured within this same coding category after a first pass through the data and then each case examined for conceptual likeness and distinctions among and across cases.
Once enough instances of a new domain were present, it would only be then that the new domain would be given an appropriate label. This other/uncertain category served as the inductive portion of the data analysis and was essential for answering RQ3.

In coding the data, a mixed deductive-inductive thematic analysis approach was utilized. Thematic analysis, as a guide, identifies verbal indicators of a meaningful experience or event (i.e., units of analysis) in the identification of conceptual themes (Ryan & Bernard, 2003). For the present dataset, the unit of analysis was each patient response, given that patients were asked to describe one memorable interaction. However, despite these instructions, patients often reported more than one interaction (e.g., “Dr. A said…” and “Dr. B said…”) or a generalization of many interactions (e.g., “Most doctors said…”). For simplicity’s sake, instead of designating each interaction as the unit of analysis, patients who did not report just one interaction were assigned a code to indicate such to be included in post-hoc analysis after the fact.

**Data coding.** The coding process began with my advisor and I familiarizing ourselves with the codebook to be used for data analysis. After doing so, we independently coded roughly 15 responses in the data set using the eight a priori categories of illness representations to capture the features of the invalidating messages. This was utilized to answer RQ2. We were also mindful of the “other/uncertain” category in the codebook, which was utilized to help answer RQ3. After this first round of coding, AB refined the codebook, which LM looked over, before proceeding to another round of coding. 10 iterations of this coding process took place from which we coded a total of 150 responses from the data set to finalize the first draft of the codebook. With each of the 10 iterations, new decisions were made regarding the codebook.
Following these 10 iterations, AB and LM then coded another subset of the data (n=50) to calculate interrater reliability, with k ranging between .554 and .783. Then AB and LM discussed the discrepancies in their first round of interrater reliability coding. Another 200 responses were coded for interrater reliability. Within this second round of coding, the interrater reliability was still not satisfactory (k ranged between .453 and .838), with only one value being satisfactory (i.e., \textit{internal cause}). AB and LM again discussed the discrepancies in their second round of interrater reliability coding, after which AB and LM re-coded the first 100 responses from their interrater reliability coding. Within this third round of coding, interrater reliability was somewhat satisfactory (k ranged between .637 and .941), with all but three values being satisfactory (i.e., \textit{identity label, identity - symptoms, symptom experiences, external cause, internal cause, response efficacy, and investigative}). AB and LM again discussed discrepancies and recoded the next 250 responses. Within this fourth and final round of coding, interrater reliability was again somewhat satisfactory (k ranged between .707 and .905). Roughly 15\% of the data were used for establishing interrater reliability. From here, formal data analysis commenced.

After having achieved sufficient interrater reliability, AB then went on to code the 1038 that resulted from the initial screening of the responses. During this process of coding, AB consulted LM when challenges surfaced in the data coding.

\textbf{Phase III Data Analysis}

Data analyses were conducted using the IBM Statistical Package for Social Sciences (SPSS) program, Version 28 (IBM, 2022). The \textit{Statistics} package was used for exploratory factor analysis and the \textit{AMOS} package was used for confirmatory factor
analysis. Kaiser-Meyer-Olkin’s sampling adequacy test (KMO) and Bartlett’s test of sphericity were used to examine the appropriateness of the data for factor analysis. Following recommended best practices (Carpenter, 2018), exploratory analysis was conducted using a common factor model with principal axis factoring. As the scale dimensions were expected to be correlated, an oblique rotation (Promax) was used. A parallel analysis test (Horn, 1965) was conducted to determine the appropriate number of factors to extract. This approach is an improvement on the use of Keiser’s rule suggesting that only the factors with eigenvalue larger than 1 should be retained. Parallel analysis compares the eigenvalues from observed data to those obtained from multiple random datasets of the same size. Factor loadings and cross-loadings from the exploratory analysis were reviewed and used (along with theory-driven examination of the items) to construct the factors. The cut-off level for a minimum acceptable factor loading was set at 0.4.

Confirmatory factor analyses (CFA) were conducted to confirm the findings from the exploratory factor analysis. Goodness of fit for the models was determined by examining the Comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA), and the Standardized Root Mean Square Residual (SRMR). Satisfactory models were expected to have CFI above 0.9, as well as RMSEA and SRMR lower than 0.08. Factor loadings were expected to be significant at the 0.05 level.

**Phase IV Data Analysis**

Each of the aforementioned items—scared/terrified, less trusting of the medical system, angry, and cautious and reluctant to seek further medical care—served as the dependent variable in the regression analysis. Demographic variables were entered into
Step 1 as covariates of the model (age, race/ethnicity, education, income) and the PSIS (i.e., invalidation) was entered into Step 2 of the model.
CHAPTER FOUR: EXAMINING THE NEGATIVE SEQUELAE OF INVALIDATING EXPERIENCES

The goal of this phase is to provide a systematic review of the extant qualitative literature that documents patient-reported invalidation of their symptoms by clinicians. The illness contexts that will be reviewed are Ehlers Danlos syndrome (EDS), endometriosis, irritable bowel syndrome (IBS), long COVID, lupus, undiagnosed illness, and postural orthostatic tachycardia syndrome (POTS). A total of 1108 articles (EDS: 43; endometriosis: 195; IBS: 231; long COVID: 88; lupus: 208; undiagnosed illness: 333; POTS: 10) were initially retrieved from the electronic database searches. At the end of the selection and identification process, 59 articles were included in this review (EDS: 7; endometriosis: 16; IBS: 3; long COVID: 16; lupus: 6; undiagnosed illness: 13; POTS: 1).

Among these 59 articles, there were 54 qualitative studies—four studies produced two related articles and one study produced three related articles. Also among these 59 articles, there were two that were not original investigations—one conducted secondary analyses of patient blogs and one conducted a secondary analysis of an online support forum. Thirty-two studies (59%) used interviews as its methodology, eight studies (15%) used mixed-method online surveys, four studies (7%) used focus groups, and one study (2%) used mixed-method paper surveys. Six studies used more than one method—four studies (7%) used interviews and focus groups, one study used interviews and diary-keeping, and one study used interviews and ethnographic observations. Furthermore, one study did a secondary analysis of a memoir and analyzed one interview, one study had patients submit stories online to covid19-recovery.org, and one study had patients submit creative writing pieces to an online repository.
Thirty articles (51%) focused on the broader patient experience with the illness. Some aspects relevant to the broader patient experience that were discussed in these articles were the physical and psychosocial impacts of the illness and methods of coping with the illness. Twenty-three articles (39%) focused on the healthcare interactions and experiences among patients with clinicians. A smaller number of articles (n=6; 10%) focused on specific types of illness experiences such as experiences with prolonged uncertainty in diagnosis, childbearing in the context of the illness, and the role online patient communities play in the illness experience.

Nearly half of the studies originated in the United Kingdom (n=27; 50%). Fifteen studies were conducted in Europe: five were from Sweden (9.3%); two from Denmark (3.7%), Italy (3.7%), and Switzerland (3.78%); and one from France (1.9%), Norway (1.9%), Poland (1.9%), and Spain (1.9%). North American studies represented the United States (n=5, 9.3%), Canada (n=2; 3.7%), and the US territory, Puerto Rico (n=1; 1.9%). Finally, four studies (7.4%) were conducted in Australia. Characteristics of the included articles are provided in Table 3.
### Table 3 Characteristics of Included Articles (n = 59).

<table>
<thead>
<tr>
<th>Authors and Year of Publication</th>
<th>Country of Analysis</th>
<th>Illness context</th>
<th>Study Aim(s)</th>
<th>Sample size (n) (age range in years)</th>
<th>Data Collection Method</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baz et al. (2023)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To understand the barriers faced in accessing primary, secondary and specialist healthcare support for people with LC</td>
<td>40 (18-69)</td>
<td>Interviews</td>
<td>Reflexive thematic analysis</td>
</tr>
<tr>
<td>Bennett et al. (2021)</td>
<td>United Kingdom</td>
<td>EDS</td>
<td>To identify the psychosocial impact by examining participants’ lived experiences; and identify characteristics of effective coping</td>
<td>17 (age range not reported)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Berglund et al. (2000)</td>
<td>Sweden</td>
<td>EDS</td>
<td>To explore how individuals with different symptoms of EDS describe their symptoms and perceive their daily life</td>
<td>11 (21-67)</td>
<td>Interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Berglund et al. (2010)</td>
<td>Sweden</td>
<td>EDS</td>
<td>To describe encounters in health-care situations when individuals suffering from EDS experienced that their dignity was not fully upheld</td>
<td>32 (age range not reported)</td>
<td>Mixed-methods online survey</td>
<td>Content analysis</td>
</tr>
<tr>
<td>Burton et al. (2022)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To explore factors affecting mental health and well-being from the perspective of people with long COVID</td>
<td>21 (26-70)</td>
<td>Semi-structured interviews</td>
<td>Reflexive thematic analysis</td>
</tr>
<tr>
<td>Buttery et al. (2021)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To investigate the experience of people who continue to be unwell after acute COVID-19, often referred to as ‘long COVID’, both in terms of their symptoms and their interactions with healthcare</td>
<td>3290 (18-75)</td>
<td>Mixed-methods online survey</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Callan et al. (2022)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To explore the lived experience of ‘brain fog’— the wide variety of neurocognitive symptoms that can follow COVID-19</td>
<td>50 (29-74)</td>
<td>Focus groups</td>
<td>Constant comparative method</td>
</tr>
<tr>
<td>Chauvet et al. (2018)</td>
<td>France</td>
<td>Endo</td>
<td>To analyse open comments associated with a validation scale study, in order to ascertain whether the questionnaires allowed an adequate exploration of patient preoccupations and in so doing define important quality of life themes not assessed in HRQoL scales</td>
<td>265 (age range not reported)</td>
<td>Mixed-methods online survey</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Cheston (2022)</td>
<td>United Kingdom</td>
<td>MUS</td>
<td>To understand, theorize and, ultimately, propose means of alleviating the shame experienced by women whose symptoms are seen to be ‘medically unexplained’</td>
<td>2 (age range not reported)</td>
<td>Secondary analysis; semi-structured interview</td>
<td>Thematic and literary analysis</td>
</tr>
<tr>
<td>Name</td>
<td>Country</td>
<td>Condition</td>
<td>Summary</td>
<td>Participants</td>
<td>Methodology</td>
<td>Analysis Method</td>
</tr>
<tr>
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<tr>
<td>Cox, Henderson, et al. (2003)</td>
<td>Australia</td>
<td>Endo</td>
<td>To identify the information needs of women facing laparoscopy for endometriosis</td>
<td>61 (20-64)</td>
<td>Mixed-methods paper survey</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Cox, Ski, et al. (2003)</td>
<td>Australia</td>
<td>Endo</td>
<td>To identify the information and support needs of women experiencing endometriosis</td>
<td>465 (age range not reported)</td>
<td>Mixed-methods paper survey</td>
<td>Analysis not reported</td>
</tr>
<tr>
<td>Day (2022)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To explore the roles that online peer support groups take on, and the impact they have on patients experiencing and recovering from long COVID in the United Kingdom</td>
<td>11 (20-59)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Denny (2004)</td>
<td>United Kingdom</td>
<td>Endo</td>
<td>To explore women’s experiences of living with the pain of endometriosis and examine delay in the diagnosis of the disease</td>
<td>20 (20-47)</td>
<td>In-depth interviews</td>
<td>Content analysis</td>
</tr>
<tr>
<td>Denny (2009)</td>
<td>United Kingdom</td>
<td>Endo</td>
<td>To explore women’s experience of living with endometriosis</td>
<td>30 (age range not reported)</td>
<td>Semi-structured interviews; diary-keeping</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Denny &amp; Mann (2008)</td>
<td>United Kingdom</td>
<td>Endo</td>
<td>To explore the experience of women with endometriosis in the primary care setting</td>
<td>30 (19-44)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Facchin et al. (2018)</td>
<td>Italy</td>
<td>Endo</td>
<td>To develop a grounded theory of how endometriosis affects psychological health</td>
<td>74 (24-50)</td>
<td>Open interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Grogan et al. (2018)</td>
<td>United Kingdom</td>
<td>Endo</td>
<td>To understand women’s experiences of endometriosis and its impact on their lives and relationships</td>
<td>34 (22-56)</td>
<td>Open-ended online questionnaires</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Grundström et al. (2018)</td>
<td>Sweden</td>
<td>Endo</td>
<td>To identify and describe the experience of healthcare encounters among women with endometriosis</td>
<td>9 (23-55)</td>
<td>Interviews</td>
<td>Interpretive phenomenological analysis</td>
</tr>
<tr>
<td>Grundström et al. (2020)</td>
<td>Sweden</td>
<td>Endo</td>
<td>To identify and describe endometriosis healthcare experiences based on affected individuals’ blog posts</td>
<td>16 (22-34)</td>
<td>N/A*</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Hale et al. (2006)</td>
<td>United Kingdom</td>
<td>Lupus</td>
<td>To examine the perceptions of patients with systemic lupus erythematosus (SLE) about their health care provision in the United Kingdom</td>
<td>10 (26-68)</td>
<td>Semi-structured interviews</td>
<td>Interpretive phenomenological analysis</td>
</tr>
<tr>
<td>Halverson et al. (2021)</td>
<td>United States</td>
<td>EDS</td>
<td>To investigate the lived experiences of patients who have received clinical diagnoses of hEDS</td>
<td>22 (19-60)</td>
<td>In-depth, semi-structured interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Firstname et al. (Year)</td>
<td>Country</td>
<td>Diagnosis</td>
<td>Research Question</td>
<td>Sample Size</td>
<td>Data Collection Method</td>
<td>Data Analysis Method</td>
</tr>
<tr>
<td>-------------------------</td>
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</tr>
<tr>
<td>Halverson et al. (2023)</td>
<td>United States</td>
<td>EDS</td>
<td>To understand the origins of their trauma and how that trauma might be addressed</td>
<td>26 (19-60)</td>
<td>In-depth interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Hållstam et al. (2018)</td>
<td>Sweden</td>
<td>Endo</td>
<td>To examine women’s experience of painful endometriosis including long-term aspects, social consequences, impact of treatment and development of own coping strategies</td>
<td>13 (24-48)</td>
<td>Semi-structured interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Ireson et al. (2022)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To explore the physical and epistemic challenges of living with Long Covid</td>
<td>66 (age range not reported)</td>
<td>Patient stories submitted online to covid19-recovery.org</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Jackes et al. (2022)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To explore the experience of those living with long COVID</td>
<td>8 (age not reported)</td>
<td>Semi-structured focus groups</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Knoop &amp; Dunwoody (in press)</td>
<td>United Kingdom</td>
<td>POTS</td>
<td>To explore the lives of those living with a medical diagnosis of POTS.</td>
<td>6 (20-42)</td>
<td>Interviews</td>
<td>Interpretive phenomenological analysis</td>
</tr>
<tr>
<td>Kornelsen et al. (2016)</td>
<td>Canada</td>
<td>MUS</td>
<td>To explore patients’ experiences of prolonged uncertainty in diagnosis</td>
<td>38 (age range not reported)</td>
<td>Open-ended interviews</td>
<td>‘Open coding approach’ (grounded theory)</td>
</tr>
<tr>
<td>Ladds et al. (2020)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To document such patients’ lived experience, including accessing and receiving healthcare and ideas for improving services</td>
<td>114 (27-73)</td>
<td>Narrative interviews, focus groups</td>
<td>Constant comparative method</td>
</tr>
<tr>
<td>Lan Le et al. (2022)</td>
<td>Canada</td>
<td>MUS</td>
<td>To understand the experiences of patients who experience multiple persistent symptoms or high health anxiety and their physicians when they interact</td>
<td>18 (age range not reported)</td>
<td>Interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Langhinrichsen-Rohling et al. (2021)</td>
<td>United States</td>
<td>EDS</td>
<td>To determine patients’ self-reported prevalence of healthcare institutional betrayal and its link with their expressed symptoms, provider perceptions, unmet needs, and on-going healthcare-related expectations</td>
<td>104</td>
<td>Mixed methods online survey</td>
<td>Content analysis</td>
</tr>
<tr>
<td>Lian &amp; Robson (2017)</td>
<td>Norway</td>
<td>MUS</td>
<td>To explore the interactional dynamics of clinical encounters riddled by medical uncertainty, as experienced by people living with long-term medically unexplained fatigue in Norway</td>
<td>256 (16-72)</td>
<td>Mixed-methods online survey</td>
<td>Thematic approach (Braun &amp; Clarke, 2006) inspired by a grounded theory strategy Charmaz,</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Condition</td>
<td>Objective</td>
<td>Sample Size</td>
<td>Methodology</td>
<td>Analysis Method</td>
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<td>-----------------------</td>
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<td>---------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Loft et al. (2022)</td>
<td>Denmark</td>
<td>LC</td>
<td>To explore the experiences of patients living with long-term cognitive sequelae (LTCS),</td>
<td>19 (25-63)</td>
<td>In-depth interviews</td>
<td>Ricoeur’s interpretation theory</td>
</tr>
<tr>
<td>Matias-González et al. (2021)</td>
<td>Puerto Rico</td>
<td>Endo</td>
<td>To document stigma experiences among Latina women living with endometriosis.</td>
<td>50 (age range not reported)</td>
<td>Focus groups</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Moretti et al. (2022)</td>
<td>Italy</td>
<td>LC</td>
<td>To explore the illness experienced by patients suffering from Long-COVID in Italy</td>
<td>17 (31-59)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Moulin et al. (2015)</td>
<td>Switzerland</td>
<td>MUS</td>
<td>To understand the experiences with, and perceptions of, the healthcare of adolescents who have MUS and their parents</td>
<td>10 (12-20)</td>
<td>Interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Nettleton et al. (2004) ★</td>
<td>United Kingdom</td>
<td>MUS</td>
<td>To explore the narratives told by neurology outpatients in the UK who have endured profound illness symptoms and yet have no clinical diagnosis</td>
<td>18 (28-67)</td>
<td>In-depth interviews</td>
<td>Draws upon the work of Frank (1995)</td>
</tr>
<tr>
<td>Nettleton et al. (2005) ★</td>
<td>United Kingdom</td>
<td>MUS</td>
<td>To explore the narratives of patients, who live with medically unexplained symptoms (MUS) and who have not secured a diagnostic label.</td>
<td>18 (28-67)</td>
<td>In-depth interviews</td>
<td>Draws upon the work of Frank (1995)</td>
</tr>
<tr>
<td>Nettleton (2006) ★</td>
<td>United Kingdom</td>
<td>MUS</td>
<td>To contribute to an emerging literature on the sociology of medically unexplained symptoms (MUS) by reporting on a small qualitative study into such experiences</td>
<td>18 (28-67)</td>
<td>In-depth interviews</td>
<td>Draws upon the work of Frank (1995)</td>
</tr>
<tr>
<td>Pearson et al. (2022)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To elicit creative expressions from participants with lived experience of Long Covid.</td>
<td>28 (age range not reported)</td>
<td>Online repository where participants could submit their pieces of creative writing</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Peters et al. (1998)●</td>
<td>United Kingdom</td>
<td>MUS</td>
<td>We first explored patients' use of medical ideas and language in their understanding of symptoms. Secondly, we</td>
<td>68 (25-69)</td>
<td>Interviews</td>
<td>Thematic analysis</td>
</tr>
</tbody>
</table>
sought to understand the part played by medical ideas in their requirements and evaluation of interactions with doctors.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Overview</th>
<th>Sample Size</th>
<th>Methodology</th>
<th>Analysis Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peters et al. (2009)</td>
<td>United Kingdom</td>
<td>MUS</td>
<td>To identify potential barriers to reattribution and the improvement of clinical outcome by analysing patients’ experiences of consultations, and furthermore, to establish if barriers are particular to the reattribution model or to MUS management more generally</td>
<td>23 (32-84)</td>
<td>In-depth interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Pezaro et al. (2020)</td>
<td>United Kingdom</td>
<td>EDS</td>
<td>To arrive at a deeper biopsychosocial understanding of childbearing in the context of hEDS/HSD</td>
<td>40 (22-55)</td>
<td>Narrative interviews</td>
<td>Thematic narrative analysis</td>
</tr>
<tr>
<td>Risør et al. (2009)</td>
<td>Denmark</td>
<td>MUS</td>
<td>To analyse the social construction of illness explanations among patients with MUS, and to illustrate the use of explanatory idioms as being dependent on space, time and setting, legitimizing each idiom</td>
<td>9 (20-58)</td>
<td>Semi-structured interviews</td>
<td>Thematic content analysis</td>
</tr>
<tr>
<td>Rowe et al. (2021)</td>
<td>Australia</td>
<td>Endo</td>
<td>To compare women’s and health professionals’ perceptions of quality of endometriosis health care and opportunities for improvements</td>
<td>46 (21-62)</td>
<td>Focus groups</td>
<td>Framework Analysis technique</td>
</tr>
<tr>
<td>Rushforth et al. (2021)</td>
<td>United Kingdom</td>
<td>LC</td>
<td>To explore long Covid’s rapid emergence and unique status among illnesses, using a dataset of narrative interviews and focus groups with people with long Covid</td>
<td>114 (27-73)</td>
<td>Narrative interviews and focus groups</td>
<td>Drawing on socio-narratology (Frank), therapeutic emplotment (Mattingly) and polyphonia (Bakhtin)</td>
</tr>
<tr>
<td>Russell et al. (2022)</td>
<td>United States</td>
<td>LC</td>
<td>To explore the subjective experiences of Long COVID and the ways in which interviewees' understandings of their illness were shaped by social interactions</td>
<td>20 (20-64)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Salmon et al. (1999)</td>
<td>United Kingdom</td>
<td>MUS</td>
<td>To describe, from the perspective of patients, distinguishing features of doctors’ attempts to explain the symptoms of somatisation disorders</td>
<td>228 (age range not reported)</td>
<td>Interviews</td>
<td>Analysis not reported</td>
</tr>
<tr>
<td>Samper-Pardo et al. (2023)</td>
<td>Spain</td>
<td>LC</td>
<td>To increase understanding about the emotional well-being of people diagnosed with long COVID</td>
<td>35 (age range not reported)</td>
<td>Interviews; focus groups</td>
<td>Inductive thematic content analysis</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Disease</td>
<td>Objective</td>
<td>Sample size</td>
<td>Data collection methods</td>
<td>Analysis</td>
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<tr>
<td>Sloan et al. (2021)</td>
<td>United Kingdom</td>
<td>Lupus</td>
<td>To identify unmet needs, values, concerns and preferences, thus enabling patient-centred improvements to be considered</td>
<td>N/A**</td>
<td>N/A**</td>
<td>Thematic analysis</td>
</tr>
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<td>Sloan, Harwood, et al. (2020)</td>
<td>United Kingdom</td>
<td>Lupus</td>
<td>To explore patient experiences and views of their symptoms, delays in diagnosis, misdiagnoses and medical support, to identify common experiences, preferences and unmet needs</td>
<td>182 (age range not reported)</td>
<td>Mixed-method online survey</td>
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<td>Sloan, Naughton, et al. (2020)</td>
<td>United Kingdom</td>
<td>Lupus</td>
<td>To explore the impact of patient–physician interactions, pre- and postdiagnosis, on lupus and UCTD patients’ psychological well-being, cognition and health-care seeking behaviour</td>
<td>21 (18-69)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
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<td>Sowińska &amp; Czachowski (2018)</td>
<td>Poland</td>
<td>MUS</td>
<td>To explore Polish patients’ perspectives on living with MUS</td>
<td>20 (18-57)</td>
<td>Semi-structured interviews</td>
<td>Content analysis</td>
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<td>Stockl (2007)</td>
<td>United Kingdom</td>
<td>Lupus</td>
<td>To explore SLE as one example of complex syndromes that the clinical practice of late modernity seems to bring about</td>
<td>30 (age range not reported)</td>
<td>Semistructured interviews; Ethnographic observations</td>
<td>Grounded theory</td>
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<td>Taylor et al. (2020)</td>
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<td>13 (age range not reported)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
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<tr>
<td>Tunnicliffe et al. (2016)</td>
<td>Australia</td>
<td>Lupus</td>
<td>To describe the experiences and perspectives of adolescents and young adults diagnosed with juvenile-onset SLE to inform strategies for improving treatment and health outcomes</td>
<td>26 (14-26)</td>
<td>Semi-structured interviews; focus groups</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Tunnicliffe et al. (2016)</td>
<td>Australia</td>
<td>Lupus</td>
<td>To describe the experiences and perspectives of adolescents and young adults diagnosed with juvenile-onset SLE to inform strategies for improving treatment and health outcomes</td>
<td>26 (14-26)</td>
<td>Semi-structured interviews; focus groups</td>
<td>Thematic analysis</td>
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<tr>
<td>Tunnicliffe et al. (2016)</td>
<td>Australia</td>
<td>Lupus</td>
<td>To describe the experiences and perspectives of adolescents and young adults diagnosed with juvenile-onset SLE to inform strategies for improving treatment and health outcomes</td>
<td>26 (14-26)</td>
<td>Semi-structured interviews; focus groups</td>
<td>Thematic analysis</td>
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<td>Wren &amp; Mercer (2022)</td>
<td>United Kingdom</td>
<td>Endo</td>
<td>To explore nine young women’s experiences of the diagnostic process and the significance of support during this period</td>
<td>9 (age range not reported)</td>
<td>Semi-structured interviews</td>
<td>Interpretative phenomenological analysis</td>
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<td>Wurz et al. (2022)</td>
<td>Switzerland</td>
<td>LC</td>
<td>To better understand and explore individuals’ experiences with long COVID and commonly reported symptoms, using qualitative data collected from open-ended survey responses.</td>
<td>169 (40-49)</td>
<td>Open-ended survey responses</td>
<td>Reflexive thematic analysis</td>
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<td>Condition</td>
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<td>Young et al. (2020)</td>
<td>Australia</td>
<td>Endo</td>
<td>To examine women’s experiences of navigating knowledge and power within medical encounters for endometriosis</td>
<td>26 (20-51)</td>
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<td>Zale et al. (2020)</td>
<td>United States</td>
<td>Endo</td>
<td>To understand healthcare provider perceptions and patient experiences with endometriosis in the United States</td>
<td>12 (20-43)</td>
<td>Interviews</td>
<td>Thematic analysis</td>
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</tbody>
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*This study consisted of secondary data analysis of online blogs, thus this information is not relevant. **This study consisted of secondary data analysis of an online community forum, thus this information is not relevant. ※✦★◼ Symbols indicate data generated by the same study.
Negative Sequelae of Symptom Invalidation

The thematic analysis led to the identification of six distinct but interrelated negative sequelae: (1) negative affect, negative self-esteem, depression, and suicidal ideation; (2) healthcare-related anxiety or trauma; (3) loss of trust in specific clinicians, clinicians generally, or the broader healthcare system; (4) frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system; (5) symptom underreporting; and (6) delays, breaks, or terminations in care. See Table 4 for a matrix table displaying which articles reported on each sequela.

Negative Affect, Negative Self-Esteem, Depression, and Suicidal Ideation

Thirty-three (56%) of the articles reported negative affect. Negative affect clustered around four main types of language. The first language cluster centered feelings of isolation such as “abandoned” (Burton et al., 2022; Buttery et al., 2021; Halverson et al., 2023; Jackes et al., 2022; Moretti et al., 2022; Sloan et al., 2021), “neglected” (Baz et al., 2023); “isolated” (Grogan et al., 2018; Moretti et al., 2022), “alone” (Cox, Ski, et al., 2003; Grundström et al., 2018, 2020), and “invisible” (Wurz et al., 2022). The second language cluster emphasized feelings of dissatisfaction including “let down” (Buttery et al., 2021; Day, 2022; Peters et al., 1998; Taylor et al., 2020) or “disappointed” (Berglund et al., 2000; Grogan et al., 2018, 2020; Hållstam et al., 2018; Risør et al., 2009; Taylor et al., 2020) by clinicians or the healthcare system more broadly. The third language cluster highlighted feelings of embarrassment including “shame” (Cheston, 2022; Moulin et al., 2015; Nettleton et al., 2004, 2005; Sloan et al., 2021), “guilt” (Björkman et al., 2013; Sloan et al., 2021; Sloan, Harwood, et al., 2020), “humiliation” (Berglund et al., 2010; Håkanson et al., 2010; Hållstam et al., 2018), “embarrassment” (Håkanson et al., 2010;
Peters et al., 1998), “stupid” (Burton et al., 2022; Cox, Ski, et al., 2003). Demonstrating this third cluster, one patient with endometriosis in Cox, Ski, et al.’s (2003) study noted, “Nobody was even interested in thinking about what it could have been, and each time I felt more alone and stupid about the whole thing” (p. 205). Invalidation can make an individual question their own experiences (Linehan, 1993), which, in turn, can make one feel “stupid” for not knowing any “better,” as this example demonstrates. Such feelings went as far as patients “taking the blame” for clinical encounters that yielded no results owing to being asymptomatic at the time of the appointment (Håkanson et al., 2010) and when psychosomatic explanatory models were used, which evoked feelings of internal attributions of control for their suffering (Björkman et al., 2013). Patients have been reported feeling like they are wasting clinicians’ time (Björkman et al., 2016) and even apologizing for seeking care (Håkanson et al., 2010). The fourth language cluster accentuated resignation including “discouraged” (Moretti et al., 2022), “hopeless” (Baz et al., 2023; Callan et al., 2022; Grundström et al., 2018; Langhinrichsen-Rohling et al., 2021; Pezaro et al., 2020), and “helpless” (Pearson et al., 2022; Wurz et al., 2022).

Four (7%) articles reported negative self-esteem. Self-esteem refers to “a person’s appraisal of his or her value” (Leary & Baumeister, 2000, p. 1). Self-esteem includes feelings of worthlessness that are portrayed in these studies (Cox, Henderson, et al., 2003; Sloan et al., 2021; Sloan, Naughton, et al., 2020). Similarly, appraisals of self-worth were also seen in reference to patients’ “personal weakness” (Sowińska & Czachowski, 2018) and “moral failing” (Denny, 2009). More explicitly, Cox, Henderson, et al. (2003) commented that the “damage” done to the self-esteem of patients with endometriosis is “quite significant” owing to the invalidation they received from
clinicians. Negative self-esteem among patients can also be gauged by authors’ references to patients’ self-worth or value, or lack thereof. For example, one patient with endometriosis in Cox, Henderson, et al. (2003) reported that she felt “worthless,” and Sloan et al. (2021) reported feelings of “worthlessness” among their patients with lupus.

Three (5%) articles discussed depression resulting from invalidation. Depression was attributed to negative self-esteem, manifesting as feelings of worthlessness and self-hate (Halverson et al., 2021; Sloan et al., 2021). Negative self-esteem was further attributable to the doubt of clinicians (Halverson et al., 2021) and one’s own self-doubt regarding the “realness” of patients’ symptoms (Halverson et al., 2021) and, in general, the absence of diagnosis and support from clinicians. In one case, one patient with long COVID reported depression as a result of nobody “listening” to them (Ireson et al., 2022), which strongly reflects one characteristic of invalidation.

Two (3%) articles discussed suicidal ideation. In one article, one patient with EDS stated: “I can see that [doubt] causing someone to spiral downwards and decide: This doctor thinks I’m making it all up. I’m just going to end it now and kill myself” (Halverson et al., 2021, p. 419). In the other article, a patient with lupus stated: “I’ve been in a very low place too when nobody seemed to understand what was wrong with me and worse still didn’t seem to care!! I felt worthless. I too thought of ending my life and had to get emergency counselling as well as medication for severe depression” (Sloan et al., 2021, p. 724). All these other sequelae that have been reported thus far seem to contribute to this suicidal ideation, particularly if these sequelae are persistent.

**Healthcare-Related Anxiety or Trauma**
11 (19%) articles discussed healthcare-related anxiety or trauma. This was often a concern for patients with illnesses for which there could be serious consequences if not handled appropriately, such as lupus and EDS (Sloan, Naughton, et al., 2020; Halverson, 2021). Feelings of anxiety or trauma were especially prevalent when clinicians did not listen to patients and treat them as the experts of their own illness and bodies. In some cases, anxiety was so great that patients withdrew from their consultant’s care (Pezaro et al., 2020), no longer continued receiving care (Halverson et al., 2023) and instead engaged in “self-care” tactics (Berglund et al., 2010) so as to avoid any potentially physically (or emotionally) harmful healthcare encounters. Two articles described post-traumatic stress disorder—referred to as “medical post-traumatic stress disorder” (Sloan, Naughton, et al., 2020) and “complex post-traumatic stress disorder” (Halverson et al., 2021). An underlying fear was that clinicians were going to be dismissive of patients, so when they were accessing healthcare services, they often felt “nervous” or “scared” (Young et al., 2020). Patients even became fearful of certain clinicians (Lian & Robson, 2017), hospitals (Grundström et al., 2020), and healthcare services more broadly (Lian & Robson, 2017), owing to their previous negative experiences.

**Loss of Trust in Specific Clinicians, Clinicians Generally, or the Broader Healthcare System**

Twenty-one (36%) articles reported loss of trust in specific clinicians, clinicians generally, or the broader healthcare system. Trust is defined as “the optimistic acceptance of a vulnerable situation in which the truster believes the trustee will care for the truster’s interests” (Hall et al., 2001, p. 615). Trust comprises five main domains: competence, fidelity, honesty, confidentiality, and global trust (Hall et al., 2001). The specific domain
of trust that appears to be lost across these studies is competence, or “avoiding mistakes and producing the best achievable results” (Hall et al., 2001, p. 621). This was especially prevalent when patients discussed being misdiagnosed. Misdiagnoses—especially those that are psychological in nature—are experienced as invalidating to patients (i.e., a lack of fidelity) because clinicians fail to “listen to” and “take seriously” the patients’ symptoms. However, “not listening” and “not taking seriously” patients’ symptoms also presumably leads to misdiagnoses (i.e., a lack of competence). Some noted mental health misdiagnoses were particularly negatively impactful on trust in clinicians (Sloan et al., 2021; Sloan, Harwood, et al., 2020; Sloan, Naughton, et al., 2020; Salmon et al., 1999).

Two studies noted a loss of trust in clinicians’ ability to interpret patient symptoms (Sloan, Naughton, et al., 2020; Stockl, 2007) rather than in the healthcare system more broadly. Some patients distrusted clinicians and therefore their IBS diagnosis, signaling an implicit distrust in clinicians’ interpretations of their symptoms and leaving patients feeling as if there was something more wrong with them other than IBS (Björkman et al., 2013). Men, especially, doubted their “rubbish” diagnosis of IBS (Björkman et al., 2013).

Some patients noted that trust was most difficult at the start, before actually meeting clinicians (Halverson et al., 2021), though others noted that this distrust persisted even after diagnosis (Sloan et al., 2021) and transferred to clinicians with whom patients already had an existing relationship (“a previously valued family doctor service”; Ladds et al., 2020). As is demonstrated, invalidation has the power to even upend pre-existing relationships patients have with established clinicians and thus disrupt continuity of care.
Frustration and Anger Toward Specific Clinicians, Clinicians Generally, or the Broader Healthcare System

Thirty-two (54%) articles reported frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system. Especially post diagnosis, this loss of trust can reportedly lead to feelings of frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system. There were several ways frustration and anger were phrased throughout the studies, ranging from mere “annoyance” (Baz et al., 2023; Nettleton et al., 2005) to “resentment” (Tunnicliffe et al., 2016), “hostility” (Peters et al., 2000), and “hate” (Sloan et al., 2021). One patient’s case actually escalated to a desire for physical aggression: “I was extremely angry, to the point that I felt as though I was willing to punch all the doctors” (Facchin et al., 2018, p. 543). The most common language, however, was “frustrated” and “angry.”

The target of patients’ frustration and anger varied. Sometimes, the target was a specific clinician (Buttery et al., 2021; Facchin et al., 2018; Kornelsen et al., 2016; Lan Le et al., 2022; Peters et al., 2000, 2009; Rushforth et al., 2021; Russell et al., 2022; Sloan et al., 2021; Taylor et al., 2021). Sometimes it was clinicians in general (Chauvet et al., 2018; Day, 2022; Grundström et al., 2020; Lian & Robson, 2017; Moretti et al., 2022; Samper-Pardo et al., 2023; Sloan et al., 2021). Other times, it was the healthcare system more broadly (Moretti et al., 2022; Moulin et al., 2015; Samper-Pardo et al., 2023; Stockl, 2007).

Frustration and anger were often experienced as a result of being diagnosed—upon patients finally having a name to their illness and the legitimacy and self-confidence they were seeking. With this renewed self-confidence and their accompanying diagnosis,
many patients (except in the case of undiagnosed illness) were frustrated or angry that they had been misdiagnosed or their diagnosis had been delayed (Knoop & Dunwoody, 2022; Moulin et al., 2015; Tunnicliffe et al., 2016). This was especially the case for mental health misdiagnoses (Buttery et al., 2021; Callan et al., 2022; Grogan et al., 2018; Russell et al., 2022) and for when such misdiagnoses caused patients to doubt their own bodily experiences (Knoop & Dunwoody, 2022). Some patients believed that declaring patients’ symptoms to be anxiety allowed clinicians to stop further investigation (Day, 2022; Kornelsen et al., 2016), which was unsettling to patients. One patient, in contrast, experienced anger when she was told her symptoms were “normal,” stating “In the end I got so mad at her (the doctor) and I said: Do you really think it’s normal that I have diarrhoea and go to the toilet eleven times a day?” (Björkman et al., 2013, p. 1339).

Although it is crucial to not conflate misdiagnosis with invalidation, many patients perceived their missed diagnoses or misdiagnoses as due to invalidating clinician behavior, such as not listening to and dismissing what the patient told them. Some patients appeared more upset over the way they had been treated rather than their diagnosis having been delayed. In particular, patients with long COVID reported a lack of understanding and support from clinicians (Burton et al., 2022) and others reported that their symptoms were “not taken seriously” or not “taken as a symptom requiring a medical intervention” (Ireson et al., 2022, p. 1759). For these patients, because their symptoms were not taken seriously, they could not secure any relief from their suffering.

Frustration and anger were especially prominent for patients who perceived they had unjustly lost something as a result of being misdiagnosed or having their diagnosis missed, such as with patients with lupus and endometriosis. Some patients with lupus
harbored “resentment” regarding their delayed diagnosis, as had they been diagnosed earlier, their illness might not have gotten so severe (Tunnicliffe et al., 2016). Similarly, patients with endometriosis were particularly concerned when they felt that their endometriosis could have been treated earlier, sparing relationships with others (Denny, 2004) as well as their fertility (Denny & Mann, 2008).

**Symptom Underreporting**

Nine (15%) articles reported symptom underreporting. The symptoms underreported came in two forms: 1) somatic symptoms and 2) mental health and cognitive problems (Sloan, Naughton, et al., 2020; Taylor et al., 2021). For the former, patients had already experienced invalidation of those symptoms, so to avoid further invalidation, patients chose not to disclose these somatic symptoms (Sloan, Naughton, et al., 2020). For the latter, patients were concerned that the mental health problems they reported would not be perceived by clinicians as the cause of their somatic symptoms but rather as a condition comorbid with their somatic-based illness (i.e., sinus tachycardia; Taylor et al., 2021).

Some patients reportedly were concerned not only about having their symptoms be invalidated—they were also concerned about the stigma associated with their would-be relayed concerns, sometimes introducing an element of shame. For example, Sloan, Naughton, et al. (2020) introduced one reason for the lack of disclosure as a “fear of stigma,” while patients in Salmon et al. (1999) and Peters et al. (1997) described concerns that the clinician “[will] just laugh.” Patients in Nettleton (2006) similarly described their concern with “wasting” clinicians’ “time” by presenting the full array of
their symptoms, which could potentially result in embarrassment or shame in patients, which circles back to the first theme that describes negative affect.

**Delays, Breaks, or Terminations in Care**

Nineteen (32%) articles reported delays, breaks, or terminations in care. Some patients spoke of “hesitation” when going to see clinicians, even when urgent care was needed (Berglund et al., 2010). Other patients “refuse” to see or “never went back” to the clinicians who had invalidated their symptoms (Jackes et al., 2022; Halverson et al., 2021, 2023; Pezaro et al., 2020), sometimes leaving them to find a new clinician (Berglund et al., 2010; Loft et al., 2022). Sometimes, this behavior of “refusing” or “never going back” referred not just to the clinicians who had invalidated them but generalized to clinicians (Peters et al., 2009) or the healthcare system (Halverson et al., 2023) more broadly. Some patients spoke about how they “raised the bar” regarding what required clinical intervention; for example, some patients reporting only not seeking help “unless its desperate” (Bennet et al., 2021) or seeking help “only if my life is at risk” (Berglund et al., 2010). One patient with EDS did not abandon the medical system but merely noted having to “take time off” from seeing clinicians (Halverson et al., 2023). To “get by,” however, patients spoke of engaging in “self-care practices” so as to avoid seeing a clinician (Baz et al., 2023; Berglund et al., 2010; Sloan, Naughton, et al., 2020).

Some patients spoke of prioritizing their mental health over their physical health, indicating that by not turning to the healthcare system, they would endure physical suffering. This was acceptable to them, however, if that meant they could avoid invalidation from clinicians. Some patients with endometriosis, in their blogs, detailed how they stayed home “trying to endure extreme pain” rather than going to seek care
(Grundström et al., 2020). In fact, one patient with unexplained illness explained how going to see clinicians would actually “jeopardize” their health, stating, “because if I do really need medical care it’s just going to be blamed on some kind of psychosomatic issue” (Kornelsen et al., 2016). One patient with endometriosis described delaying her treatment:

In general it’s just really frustrating how women are treated in the medical world as patients who are being dramatic . . . I was honestly afraid of having a surgery only to be told, ‘it’s not endometriosis, just deal with it, we all have cramps’. So I definitely delayed treatment myself because I didn’t want to be ‘overdramatic’ about anything. (Zale et al., 2020, p. 5).

In describing her reasoning for delaying treatment, she reveals her expectation that she would have been treated as being ‘overdramatic’ upon seeking care.
<table>
<thead>
<tr>
<th>Author(s)</th>
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<th>Illness</th>
<th>Negative Affect</th>
<th>Self-Esteem</th>
<th>Depression</th>
<th>Suicidal Ideation</th>
<th>Healthcare Anxiety &amp; Trauma</th>
<th>Loss of Trust</th>
<th>Frustration &amp; Anger</th>
<th>Not Disclosing Information</th>
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<td>Matias-González et al.</td>
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<td>Rowe et al.</td>
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<td>Rushforth et al.</td>
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<td>Russell et al.</td>
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<td>Salmon et al.</td>
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<td>Sloan et al.</td>
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<td>Sloan, Naughton, et al.</td>
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<td>Young et al.</td>
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The table above lists the authors and their respective years, types of studies, and their frequencies of occurrence.
Note: Endo = Endometriosis. LC = long COVID. X = Presence of sequela within study. - = Absence of sequela within study. Frequency = the proportion of primary studies in which a sequela was present (see Sandelowski & Barroso, 2010).

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<th>Frequency</th>
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Figure 14 Relationships between Sequelae
Relationships Between Sequelae

The sequelae that have been identified are not siloed from one another—many of these sequelae are interrelated and, as described in the literature, demonstrate effects on other sequelae (see Figure 8). Many of the sequelae are shown to be related in some way to the loss of trust in specific clinicians, clinicians generally, or the broader healthcare system. This loss of trust can directly lead to delays, breaks, and terminations in care; symptom underreporting; as well as healthcare-related anxiety or trauma. Furthermore, healthcare-related anxiety appears to mediate the relationship between loss of trust and both symptom under-reporting and delays, breaks, and terminations in care. The psychological fallout is complex, the nuance of which must be fully appreciated to understand the outcome processes of invalidation.

As an example, fear is seen as preceding the delaying of care. For example, one patient in Zale et al. (2020) described how, owing to her fear of being dismissed, she delayed treatment. She stated, “In general it’s just really frustrating how women are treated in the medical world as patients who are being dramatic . . . I was honestly afraid of having a surgery only to be told, ‘it’s not endometriosis, just deal with it, we all have cramps’. So I definitely delayed treatment myself because I didn’t want to be ‘overdramatic’ about anything” (p. 5). Furthermore, trust is seen as preceding symptom underreporting and healthcare system avoidance. As an example, Sloan, Naughton, et al. (2020) noted how “persisting insecurity and distrust” appeared to be correlated with symptom underreporting and healthcare avoidance (i.e., delays, breaks, or terminations in care). Additionally, distrust is seen as preceding healthcare-related anxiety. For example, one patient with EDS noted that their distrust in medical providers in general makes
going to appointments with new clinicians distressful and anxiety-provoking (Halverson et al., 2021). See Figure 14 for a diagram of the relationships between sequelae.

**Chapter Summary**

Analysis of the data from this chapter revealed that negative sequelae of invalidating experiences include negative affect, negative self-esteem, depression, and suicidal ideation; healthcare-related anxiety or trauma; loss of trust in specific clinicians, clinicians generally, or the broader healthcare system; frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system; symptom underreporting; and delays, breaks, or terminations in care. Phase I also found that many of these sequelae are related to and influence each other. Specifically, many of the sequelae showed relationships with patients’ loss of trust. This loss of trust can directly lead to delays, breaks, and terminations in care; symptom underreporting; as well as healthcare-related anxiety or trauma. Furthermore, healthcare-related anxiety appears to mediate the relationship between loss of trust and both symptom under-reporting and delays, breaks, and terminations in care.
CHAPTER FIVE: ELUCIDATING SYMPTOM INVALIDATION

Having helped establish the significance of symptom invalidation by having examined the negative sequelae associated with interactions resembling symptom invalidation in extant work (Chapter 4), I turned to the open-ended comments of patients’ experiences with symptom invalidation to discover what constitutes symptom invalidation and consider how to more precisely conceptualize it. The purpose of this chapter is thus to elucidate the specific features of clinicians’ messages that can lead to cognitive/affective experiences of invalidation. What is well known from the extant work is that there is likely a latent, global construct of invalidation that is cognitive/affective in nature. Examples of this construct include having one’s symptoms being “dismissed,” not “taken seriously,” not “listened to,” “ignored,” “passed off,” and “discounted” (see Bontempo, 2022b). As important as this global construct is concerning what should be a patient-centered healthcare culture, it fails to inform us about what occurred communicatively in the healthcare interaction that led to such cognitive/affective experiences of invalidation. It is important, then, to examine via patient reports what has transpired communicatively in the healthcare interaction to more easily identify this type of communication when it manifests.

In this chapter, I report on findings from RQ2 and RQ3. RQ2 explores how well the established illness representation features map onto patients’ reported experiences of invalidation. RQ3 explores whether there are additional features that do not currently exist within the established features of illness representations that are reflective of symptom invalidation. First, however, I offer a few explanations that should be taken into
consideration prior to presenting the results. A list of all the themes and example quotes for each are found in Table 5.

**Some Initial Explanations**

Two important points should be raised prior to delving into the results. The first point is that although there are five domains to illness representations as conceptualized by Leventhal and colleagues, some of these domains have been split into two subdomains as they were in the self-report questionnaires used to assess illness representations. More specifically, identity label and identity symptoms have been separated as has been done in the relevant self-report questionnaires, specifically, the revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). These questionnaires ask patients to first rate whether or not they have experienced the listed symptoms using a yes/no format. Then, patients are asked whether or not they believe each symptom is associated with their illness also using a yes/no format (Moss-Morris et al., 2002). This is consistent with the way *identity symptoms* was originally intended by Leventhal and colleagues—a specific matching of symptoms with an identity label rather than just a list of symptoms that are experienced by patients (Moss-Morris et al., 2002). This conceptualization of matching symptoms to illness label is reflected in the codebook for the present analysis (Appendix F). Specifically, the *identity symptoms* construct as applied to the context of invalidation is clinician’s failure to acknowledge one or more symptoms as related to the patient’s illness.

Furthermore, *cause* has been divided into two separate constructs in some of the work that has been conducted. For example, *internal cause* and *external cause* were separated out in the work by Lau and Hartman (1983). Additionally, for the scoring
instructions for the cause category from the original IPQ, Weinman et al. (1996) stated:

“For the cause scale it is not appropriate to sum all of the items as each item represents a specific causal belief, although some researchers may find it appropriate to combine items for their needs (e.g., external vs internal causal factors)” (Weinman et al., 1996, p. 2). Because there appears to be a distinction relating to internal cause and external cause, especially how they relate to the role of locus of control, they were distinguished in the analysis.

Additionally, self-efficacy and response efficacy—both components of control—have been divided to represent two distinct components of control, as they were in the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). The rationale for dividing these into two separate components in the IPQ-R and in the present analysis is predicated on the fact that prior work shows that self-efficacy and response efficacy are two related but distinct constructs. Specifically, re-analysis of these control data in past work using factor analyses demonstrated that the items loaded onto two separate factors (self-efficacy and response efficacy) and that the two were found to be only weakly correlated with each other (Horne, 1997; Moss-Morris et al., 2002). Self-efficacy was concerned with personal control and self-efficacy beliefs, whereas response efficacy was concerned with beliefs in the treatment or recommended advice (i.e., outcome expectancies) (Moss-Morris et al., 2002).

In consideration of the above discussion, eight categories (i.e., identity label, identity symptoms, internal cause, external cause, timeline, consequences, self-efficacy, and response efficacy) are presented below, rather than the original five proposed by Leventhal and colleagues (i.e., identity, cause, timeline, consequences, and control).
A second point for consideration is that *illness identity* does not exist as a code among these labels. This absence of a code is because in its original formulation, *illness identity* refers to etiology or cause of the illness—in this case, endometriosis. This conceptualization is problematic for two reasons. First, the etiology of endometriosis is still unknown, though there are many theories. For example, perhaps the most popular theory of etiology though it has been debunked is the theory of retrograde menstruation or “Sampson’s Theory” (Sampson, 1925). This theory stipulates that endometriosis is a product of “reflux menstruation,” wherein normal endometrium—the tissue that makes up the lining of the uterus—is “showered backwards” into the peritoneum and ovaries, in which locations it takes hold and implants. As such, in the original conceptualization of illness representations, retrograde menstruation would serve as a perceived cause. Additionally, because the open-ended survey question asked patients to reflect on an interaction prior to diagnosis, the illness, in theory, would have been unknown to them at the time (though some patients report knowing they had endometriosis prior to a clinician diagnosing them). To account for these factors, *cause* as a label is treated as illness identity. That is, *cause* refers to cause of the symptoms rather than of the illness (i.e., the etiology). Thus, if a patient’s symptoms are dismissed as IBS, this would be coded under *cause* rather than illness identity.

**Patients’ Reported Experiences Reflecting the Domains of Illness Representation**

**Identity Label**

*Identity label* refers to whether a diagnostic label applies for the patient’s given symptoms and whether endometriosis is the diagnostic label accounting for the patient’s
given symptoms. Invalidation can thus occur when the patient believes that there is a
diagnosis for their symptoms, but the clinician does not. As an example:

I described my severe pain with menstrual cycles and with sexual intercourse. I
also pointed out exactly where it hurt in my abdomen. I described other symptoms
such as fatigue. My physician thought all of these things did not warrant concern
and told me that I was young and looked healthy therefore nothing is wrong with
me.

This patient provides an elaborate account of the abnormalities of her body and thus
makes clear that she expects a medically relevant label for her symptoms. However, the
clinician reportedly denies a label altogether when they conclude that “nothing is wrong”
with her. The patient and the clinician, then, are demonstrating divergence. Her belief
that something is wrong is deemed not valid from the perspective of the clinician, which
is the first characteristic of invalidation (i.e., that patients are wrong in their analysis of
their experiences; Linehan, 1993).

Invalidation can also occur when the patient believes that endometriosis is the
diagnosis responsible for the symptoms she is experiencing, but the clinician does not. As
an example:

I was 15 and had been experiencing endo symptoms for at least a year. My mom
took me to an OBGYN and I explained my symptoms and asked if it might be
endometriosis. I had an aunt who had it, but didn’t know much about diagnosis
and treatment. He immediately told me that I didn’t have [endometriosis].

This patient communicates to the clinician that she has a family history of endometriosis
(given that there is a seven- to tenfold increased familial risk for endometriosis; Malinak
et al., 1980; Matalliotakis et al., 2008). The patient, believing her symptoms could be
emblematic of endometriosis, is told she does not have endometriosis without even a
pelvic examination (evident from the patient’s description of the clinician coming to his
conclusion “immediately”), which is clinically indicated when patients report
dysmenorrhea (American College of Obstetricians and Gynecologists, 2018). The clinician demonstrates a divergence in identity label when he tells her that she does not have endometriosis. The patient’s belief that her symptoms could be emblematic of endometriosis is implicitly deemed not valid by the clinician, which represents the first characteristic of invalidation (Linehan, 1993).

Related to understanding patient experiences when clinicians deem symptoms as medically unexplained, and thus as nothing wrong, it may seem reasonable, that if there is no evidence from tests for clinicians to ground a diagnosis, to conclude that nothing is wrong. However, patients’ symptoms do not cease to exist simply because specific tests come back normal. This may indicate that the correct test(s) were not performed, which happens frequently with endometriosis (see Ballard et al., 2006). As importantly, when clinicians find themselves uncertain of the underlying cause once testing comes back unremarkable, this does not warrant validating patients’ somatic experiences—after all, the symptoms nevertheless persist. It should not come as a surprise that patients want an illness label should they find themselves with unexplained symptoms, according to the Leventhal and colleagues symmetry rule, which again states that labels create a pressure for identifying somatic experiences associated with that label and somatic experiences create a pressure for identifying a diagnostic label associated with those symptoms (Leventhal et al., 1997). Indeed, patients with unexplained illness (those participating in research at a time during which they had undiagnosed symptoms, similar to patients with endometriosis prior to their diagnosis) have stated that more than anything else, they wanted to have their symptoms acknowledged by clinicians and valued clinicians who listened to them and appeared to accept there was something wrong with them and thus in
need of support (Nettleton. 2006). Put simply, patients want their somatic experiences validated independent of what diagnostic testing shows.

**Identity Symptoms**

*Identity symptoms* refers to what symptoms are specifically associated with a given identity label. Invalidation can occur when the patient is experiencing one or more symptoms that she believes are attributable to their agreed-upon illness label, but the clinician does not believe the symptoms are attributable to that label. In these cases, there is a divergence between to what illness the patient and clinician are attributing the symptoms, as in the case below:

I was struggling with Severe back pain over the last few weeks before the appointment, he asked me which symptom affected me the most so I stressed how painful my back had been lately, he blank face told me that back pain is not a gynaecological issue multiple times, even though I knew full well it is, for some reason he made me doubt myself.

This patient, knowing she has a diagnosis of endometriosis, knows that back pain can be a symptom of endometriosis. Having endometriosis, this patient expects that, in addition to more classical endometriosis symptoms explained by the diagnostic label, other abnormal experiences such as back pain can, too, be accounted for by endometriosis. However, the clinician rejects the associations. The patient and the clinician are clearly misaligned, and there is a divergence in beliefs about the reported symptom. This excerpt especially resonates with invalidation when the patient states “for some reason he made me doubt myself,” as one of the consequences of invalidation is that it fails to teach an individual when to trust their own emotional and cognitive responses as reflections of valid interpretations of events (Linehan, 1993). Furthermore, this desire to have all symptoms explained by a diagnosis is consistent with Leventhal’s work on the symmetry
rule, which states that when given a label, individuals will search for corresponding symptoms and when experiencing symptoms, patients will search for a label (Leventhal et al., 1980). Although this patient already has a diagnosis of endometriosis, her illness representation is incomplete and thus not fully coherent without this other symptom being accounted for. This sense of coherence is meaningful, being that illness coherence was a domain of illness representations added in the IPQ-R. It is referred to as “a type of metacognition reflecting the way in which the patient evaluates the coherence or usefulness of his or her illness representation” (Moss-Morris et al., 2002, p. 2).

**Internal Cause**

*Internal cause* refers to the internal factors that contribute to the symptoms the patient is experiencing. These can include psychological factors and environmental factors. Here, because *cause* is divided into internal factors and external factors, invalidation seems to most often occur when the clinician believes that there is an internal (psychological) cause for the patient’s symptoms, while the patient often believes there is an external (physical) cause for her symptoms.

The most frequent internal cause reportedly communicated by clinicians that was perceived by patients as invalidating was that the pain and other symptoms were related to some psychological process. Some of these determinants are vague and refer to something “psychological” in an unspecified way. For example, symptoms are reportedly labelled by clinicians as “psychological,” “mental,” “psychosomatic,” and “all in their head.” The clinicians also reportedly communicates that the patient’s symptoms are related to more specific psychological processes, such as ongoing anxiety, depression, hypochondriasis, premenstrual dysphoric disorder, and posttraumatic stress syndrome.
Some clinicians reportedly do not label patients with mental health conditions but rather speak of what sounds similar to conversion disorder in the American Psychiatric Association’s Diagnostic Manual of Mental Disorders 5—physical manifestation of emotional pain. One patient most clearly explains this process when she details that she was told “that [her] symptoms were a result of depression manifesting physical symptoms.”

Internal causes were also communicated implicitly when the clinician referred patients for or encouraged patients to seek out mental health evaluations and care from counselors, psychologists, and psychiatrists, and when they told patients they should be on or prescribed for them psychotropic medication. Underlying this discourse is the belief that the patient is mentally unwell and is in need of psychological evaluation and/or intervention.

For all misattributions of cause to psychological determinants, the clinician is reportedly communicating to the patient that she is wrong in her description and interpretation of her own experiences, which is reflective of the first invalidation characteristic (Linehan, 1993). More concretely, patients are presumed to be wrong in believing there is a physical (external), gynecological issue causing their symptoms. This kind of discourse to patients also communicates that psychological processes, instead, are at play, misattributing patients’ experiences to “socially unacceptable personality traits” (i.e., mental illness), which is consistent with the second invalidation characteristic (Linehan, 1993).

It is worth noting that many of these psychological processes communicated to patients were communicated after some diagnostic testing had been performed. In many
cases, these were tests that were *nondiscriminatory* in the diagnosis of endometriosis such as transvaginal ultrasound, computed tomography, and magnetic resonance imaging (Ballard et al., 2006; Simoens et al., 2007). In these instances, there are two conflicting information sources for clinicians: the patient’s story and the results of diagnostic testing. When these two information sources are at odds, the clinician reportedly defaults to trusting diagnostic testing over the word of the patient. The word of the patient in these reported cases is not viewed by clinicians as a valid portrayal of the patient’s somatic reality; instead, it is viewed as flawed and thus invalid.

*External Cause*

*External cause* refers to factors contributing to the symptoms the patient is experiencing that are external. Patients make clear that what they want is their symptoms to be attributed to an external cause rather than an internal cause—and rightfully so, as the cause of their symptoms is external (i.e., ectopically located endometrial-like lesions).

However, there are some instances in which clinicians reportedly ascribe an external cause for patients’ suffering but it is, nevertheless, viewed as invalidating. The most prominent example is when the external cause communicated by the clinician was that the patient is “just” experiencing normal menstruation. Sometimes, the clinician reportedly positioned the patient’s experiences with “normal menstruation” as the result of the patient’s low pain thresholds or low tolerances of pain—concurrently ascribing a character flaw to patients, which is the second characteristic of invalidation. As an example:

> When I was about sixteen, my doctor told me that the severe, debilitating pelvic pain that I was experiencing was completely normal. Even though both my mother and aunt have surgically-confirmed endometriosis, the doctor said that there was no way that I had it. She said that I was just experiencing normal period
pain and that I just thought it was worse than it was because I have a low pain tolerance.

The patient here describes “debilitating” pelvic pain, which was deemed “completely normal” by the clinician. However, to account for the patient’s concerns, the clinician essentially says the patient is mistaking her own experience (“I just thought it was worse…”), juxtaposing it with the “bodily reality” of the clinical scenario as viewed by the clinician. Thus, invalidation is relevant because the clinician is reportedly now telling the patient she is wrong in describing her own experiences, which is the first characteristic of invalidating environments. Additionally, the patient is told that the confusion regarding the normality of her experiences is due to having a low pain tolerance—again ascribing a character flaw to the patient, the second characteristic of invalidating environments. This invalidation is reinforced when the patient uses the graduation device ‘just’ in the reported dialogue of the clinician. The use of ‘just,’ here, functions to downgrade the evaluation of the pain by the clinician, which helps to construe the pain as normal and thus not worthy of further consideration.

Additional external causes that the clinician uses to explain the patient’s symptoms are also experienced as invalidating such as irritable bowel syndrome (IBS) or sexually transmitted infections (STDs) and/or resulting pelvic inflammatory disease (PID). Even though these causes are external, the patient rejected these as causes for her symptoms. IBS, for example, is considered by some as “medically unexplained symptoms.” Medically unexplained symptoms are medically contested conditions and are stigmatizing, particularly owing to their perceived relationship to mental illness. As such, patients often view it as invalidating. Thus, as such cases demonstrate, not all external causes are perceived similarly and, in these cases, patients’ notions of external causes
diverge from that of clinicians’ working diagnosis of IBS. As an example of a diagnosis of IBS, one patient wrote:

> When I was 14 years old I had an endoscopy and [colonoscopy] performed by a Pediatric Gastroenterologist. When both tests came back negative he dismissed my symptoms and told me that he didn’t know what was wrong with me. Gave me a stereotypical diagnosis of IBS and sent me on my way.

First, the patient refers to her IBS diagnosis as a “stereotypical diagnosis,” which suggests the patient and clinician are not aligned on this diagnosis and that the diagnosis is perhaps unthoughtful or not carefully accounting for her experiences. Second, the patient also conveys that she perceives this diagnosis as dismissive since she describes a literal dismissal by the clinician (e.g., “sent me on my way”) after she mentions she is given this “stereotypical diagnosis.”

Being diagnosed with IBS can be perceived as both a positive experience and a negative experience. IBS is a disorder that is made using the Rome IV diagnostic criteria and thus is not a diagnosis that should be made as a diagnosis of exclusion (Lacy et al., 2021). For those who are diagnosed using the Rome IV diagnostic criteria, it is reasonable that patients would experience this diagnosis positively. However, for those who are diagnosed because there were no findings during the clinician’s investigation (i.e., was a diagnosis of exclusions)—or if the clinician failed to investigate at all—these patients may perceive this diagnosis negatively. It may not be the diagnosis per se that is perceived negatively; rather, it may be the lack of care and attention that went into investigating patients’ symptoms, if an investigation took place at all. For example:

> I saw a GP and they just said I had IBS and did nothing. They did blood tests to check for diabetes, anemic, thyroid etc but they all came back clear so they put down my pain to having IBS
Although IBS occurs more frequently in those with endometriosis (Chiaffarino et al., 2021), it may also be that a diagnosis of IBS does not account for all symptoms of endometriosis experienced by the patient. For example, heavy, frequent, and painful menstrual bleeding are not symptoms of IBS. Pain during intercourse is similarly not a symptom of IBS. As such, when patients are given solely a diagnosis of IBS, they are aware that it does not account for all of their symptoms. For example:

I was sent to a gastroenterologist. I was describing my symptoms extensively - the doctor cherry picked about 4 of them that happened to match IBS and gave me that as a blanket diagnosis.

As another point of consideration, it may be how the clinician frames the diagnosis of IBS that predicts whether or not the IBS diagnosis is one that is invalidating. If the clinician frames it as one that is the result of psychological sequelae, it is reasonable that patients would find this invalidating. For example, a few of such framings are as follows.

A doctor once told me ‘you’re a teenage women who over dramatises, causing you unnecessary stress and upsetting your bowels.

I was seeking treatment for chronic bowel pain [and] was told I was just depressed and had IBS from being depressed

You have teen anxiety. I am a stomach doctor and I know your IBS symptoms are teen stress and you should take Xanax. I was 14 at the time and had no idea what Xanax was and my mom said no thankfully.

Patients’ symptoms were also misattributed to sexually transmitted diseases (STDs) and pelvic inflammatory disease (PID) as a result of alleged STDs. To provide context, PID is a disease in which there is an upward migration of an infection from the lower genital tract (e.g., the vagina and cervix) to the upper genital tract (e.g., uterus, fallopian tubes, ovaries, and pelvic peritoneum), from which the associated organs become inflamed (Brunham et al., 2015). Symptoms of PID include lower abdominal
pain, mild pelvic pain, increased vaginal discharge, irregular menstrual bleeding, fever, pain with intercourse, painful and frequent urination, abdominal tenderness, pelvic organ tenderness, uterine tenderness, adnexal tenderness, cervical motion tenderness, and inflammation (CDC, 2021). PID can lead to chronic pelvic pain, infertility, and ectopic pregnancy (Soper, 2010). PID, like endometriosis, can only be diagnosed definitively via laparoscopy (Brunham et al., 2015), though is roughly half less common than endometriosis (4.4% vs. 10%) (Kreisel et al., 2017).

As an example of a diagnosis of STD/PID, one patient wrote:

I went to ER for what was later believed to be a twisted ovarian cyst. I was told that I had pelvic inflammatory disease caused by an STD. I said that was impossible because I had never been sexually active. I was told that I must have an std without knowing it.

In this excerpt, it is clear the STD/PID diagnosis of the clinician is incorrect and diverges from that of the patient. The patient’s account, however, is reportedly disregarded by the clinician, which is demonstrated when they maintain that the patient has PID caused by an STD. This, here, is a denial or rejection (i.e., invalidation) of the patient’s somatic reality, with the added insult of being labeled with a stigmatized illness (an STD). Furthermore, it is an insult to the patient’s intellect to suggest that the patient “must” have an STD without her own awareness.

Patients were also advised of having rather benign conditions, and again used the graduation device “just” in the reported dialogue used by the clinician to minimize the severity of their conditions and thus normalize their experiences. For example, patients were reportedly told that they “just have painful periods,” that they “just had not started ovulating yet,” “that they “just have an ovarian cyst,” that they are “just constipated,” that it is “just gas” The use of this device again downplays patients’ concerns and shows that
patients perceive clinicians to be positioning their concerns as not worthy of further consideration or investigation. Furthermore, often these downgraded causes would not be accompanied by an investigation that would rule them either in or out. This therefore demonstrates perceived “lazy” behavior of clinicians, which makes patients feel like their symptoms are not worthy of time and attention and thus not of value.

**Timeline**

Invalidation can occur when the patient’s reality of when symptoms began is contested by the clinician’s idea of when symptoms “should” begin. An example of this type of invalidation is as follows: “[I was told] Your periods don’t get worse as you get older.” In this excerpt, it can be inferred that the patient reported to the clinician that her menstrual periods were getting worse—something that has happened over time—but the clinician holds different beliefs about the expected course of menstruation. By not acknowledging the patient’s actual reported experience, regardless of what beliefs the clinician may have about timeline, the clinician is invalidating her lived experience of worsened menstrual periods over time.

Invalidation can also occur when the course of their symptoms is contested by the clinician’s idea of how symptoms “should” present—acutely, episodically/cyclically, or chronically. An example is: “I was told it couldn’t be endometriosis because my pain was intermittent and cyclical, not 24/7.” The patient here is experiencing endometriosis as intermittent and cyclical. However, because the time course of endometriosis is viewed differently by the clinician, the patient is implicitly told that she is wrong for thinking that what she was experiencing was due to endometriosis. Here, the patient and the clinician have different ideas of what constitutes the timeline for endometriosis.
In the literature, cases of invalidation related to timeline are also reported to occur when the patient’s reality of when symptoms end is contested by the clinician’s idea of when symptoms “should” end. In this type of instance, the patient’s and the clinician’s illness representations are undoubtedly at odds. There were no examples of this manifestation in the data, however.

Consequences

In terms of consequences, invalidation can occur when clinicians downplay or minimize the severity of patients’ symptoms and/or the impairing effects it has on their quality of life. In these instances, clinicians acknowledge that patients are experiencing symptoms; however, what is contested here is the severity of those symptoms. Patients reported a variety of consequences of their symptoms, including, for example, lightheadedness, nausea, vomiting, and passing out. These consequences also facilitated further consequences; in particular, impaired physical functioning and impaired motility. Patients also explained that these consequences had an effect on their ability to go to or function well at school and/or work, engage in sexual intercourse, or engage in other life activities. Despite the significant impact endometriosis was reported to have on patients’ everyday lives, their concerns were not taken seriously. In these instances, the significance of these consequences is disputed by the lack of response patients reported receiving from their clinician. There is no acknowledgement of the patients’ symptoms or recognition that they are seriously detrimental to patients. As an example:

After trying 4 types of oral contraceptives, my doctor still refused to refer [me] to a gynecologist. I presented him with a record of all of my days of bleeding and other symptoms, combined with evidence of the clinical significance of my symptoms (i.e. missing days at work, struggling to function at work or school, feeling ill and depressed). He replied that, “many young women I work with
experience these symptoms. It does not mean anything is wrong, just that we have not found the right birth control to manage your symptoms. Doing any further testing (i.e. I had asked for a hormone panel and referral to a gynecologist) is not necessary and will not make a difference”

This patient shows the level of conviction she has in the seriousness of her symptoms, carefully documenting her symptomatic experiences and their impact in an effort to convince the clinician that her symptoms have a significant impact on her life. However, despite the amount of effort that the patient puts into trying to convey her illness representation to the clinician, she is met with the clinician’s very different illness representation. The clinician goes as far as denying there is an identity label attached to her experiences when they say to her, “It does not mean anything is wrong” and “refuses” further action (testing, referral). Thus, not only is the clinician denying the consequences that the patient is experiencing, but they are denying that something is wrong altogether, which also positions identity-label as part of this patients’ invalidating experience. Furthermore, the patient invokes the term “refused” when she reports that the clinician would not provide her a referral to a gynecologist, which displays a degree of unwillingness as perceived by the patient.

**Control - Self-efficacy**

In terms of self-efficacy, invalidation can occur when clinicians take a “mind over matter” stance on “treating” patients’ symptoms. This often was conveyed when patients described clinicians communicating how they needed to learn to “live with it,” “toughen up,” “suck it up,” “deal with it,” “get over it,” “get used to it,” “get on with life” and “move on,” “put up with it,” “grin and bear it,” and “accept it.” These suggestions to patients are insensitive to the suffering of the patient and assume a degree of ease with
which one can overcome their suffering. Not only are these suggestions insufficient in helping patients cope with endometriosis, but in none of these cases did clinician provide recommendations on how to carry out these “recommendations,” nor are any other solutions offered to the patient. As such, these types of recommendations minimize the degree of patient suffering, particularly in cases when no other treatment or management is offered. Had better management or treatment strategies been offered, this may validate the suffering patients’ experience. An example of the recommendation to “deal with it” includes: “I remember my family doctor at age 16, after being on my bathroom floor in tears, telling me that my pain tolerance was very low and I was going to have to learn how to deal with pain; because this was what being a woman was like.” This patient is told that she is “going to have to learn how to deal with pain,” that is, it is her responsibility to figure out how to manage this and thus an instance of self-efficacy at work. She then reports being told a reason she needed to engage in self-efficacious behavior – “because this is what being a woman was like” – which normalizes the experiences of the patient positioning her pain as not exceptional or thus worthy of medical attention and also implies that her suffering is going to ensue indefinitely. Not only is this reported communication from the clinician insensitive, but it negates the significance of her suffering—and again, the validity—of her experience.

Invalidation was also experienced when clinicians gave lifestyle recommendations to patients as a way to control their symptoms. Patients reported recommendations that included adjusting their diet, exercising more, drinking more water, getting some rest, taking hot baths or using heating pads, trying meditation, and reducing stress and relaxing such as by getting a mindfulness coloring book and
practicing breathing exercises. The *direct contact rule* allows us to better understand how these lifestyle recommendations can lead to feelings of invalidation. Again, the direct contact rule assumes direct contact of the therapy with the pathogenic agent (Leventhal et al., 1997), with more direct contact with the pathogenic agent (i.e., endometriosis) being viewed as more legitimate and potent forms of treatment, thereby validating the suffering of the patient. Thus, the more removed the treatment recommendation is from the actual identity label, the more invalidating the recommendation may be. An example includes the following:

I told the doctor I was experiencing severe menstrual cramps and had passed out from my cramps multiple times in the past calendar year. I was about 30 lbs heavier than I was the previous year (I had started grad school and was struggling with the transition), and I was told to lose weight. When I argued I’d had severe cramping since I was 16 and this wasn’t a change to my cycle due to weight, the doctor replied if I lost weight and quit grad school, the symptoms would go away.

The patient seems to suggest that the severity of her suffering is not truly being appreciated when being given advice to lose weight and quit graduate school. These recommendations, for her, are far removed from being in direct contact with the problem she is experiencing (i.e., severe menstrual cramps that cause syncope). From the patient perspective, losing weight and quitting graduate school are unlikely to alleviate her suffering owing to how far removed they are from the actual problem, and thus she questions in her report how the clinician can be taking her symptoms seriously, invalidating her experiences.

**Control - Response efficacy**

Response efficacy refers to a patient’s belief in the recommended advice or treatment, or the outcome expectancies of recommended advice or treatment. In contrast
to self-efficacy, it focuses more on the outcome of the recommended response than it does on the patients’ ability to engage in the recommended response. For example, invalidation can occur when the patient is not prescribed any treatment option for their symptoms. As an example:

I visited an ER in Croatia (where I was living at the time and after I had a surgical diagnosis of endometriosis) and I was in severe pain with nausea and could barely walk or talk and the doctor dismissed my pain as menstrual cramps and refused to provide pain killers. He openly disparaged my decision to come into the ER as wasting his time.

In this excerpt, the patient believes their situation calls for painkiller-level pain medication, which is not granted to her by the clinician. The patient even uses the term “refused” to suggest a form of conflict between them because it indicates that she had made an explicit request for medication that was denied. The implicit message here is that the patient is inappropriately interpreting the severity of her pain.

Invalidation can also occur when patients are prescribed low potency treatment options that they do not believe are compatible with the severity of the symptoms they are experiencing. This type of invalidation is shown in the following two examples:

I was told everyone has cramps even though I complained about how much school I was missing and other important aspects of my life because of how much pain I was in. I was pretty much dismissed with some prescription strength ibuprofen of 800 milligrams which did nothing.

The pain was so out of control and I was forced to wait for hours [in the emergency department] before my pain was taken seriously. I was questioned relentlessly by the doctors about my history of ER visits. When they finally agreed to administer pain meds they offered Torodal - a COMPLETE joke when suffering from the type of severe pain I have. I wasn’t given another option. It did nothing to help my pain. I ended up back in the ER and was finally given morphine.

In both cases, these patients believe their symptoms are being minimized owing to the potency (or lack thereof) of the pain medication prescribed to them. Both cases also
embody the dose-dependent rule for illness representations explained earlier, which underscores the notion that “the more severe or intractable the symptom, the greater the dose or strength of the treatment required” (Leventhal et al., 1997, p. 30). This is especially apparent in the second excerpt, when the patient indicates what she believes she needs—morphine—in order for her pain to subside. Thus, these patients appear to compare the seriousness of their symptoms (i.e., consequences) with the type and potency of the treatment prescribed.

Invalidation can also occur when patients are prescribed treatments—regardless of the potency of the treatment—without also having their symptoms investigated. In many of these cases, patients felt like a nuisance to clinicians and explained situations in which they were physically dismissed by the clinician. Although at first glance it may appear that patients would be satisfied being prescribed treatments—especially those of high potency such as prescription pain killers for the reasons explained earlier—their dissatisfaction with only being prescribed these treatments informs us that there is something else missing, which is an illness label (i.e., diagnosis). For example, one patient describes, “I went to a female nurse practitioner for a routine pap, told her about my pain and was given a prescription for 800mg IBU. No additional questions asked, no tests done, no nothing.” In this excerpt, the patient communicates her pain to the clinician but, instead of having her symptoms investigated (“no additional questions asked, no tests done, no nothing”), she is given prescription-strength ibuprofen. The patient mentions that a pap smear at the appointment was routine, which downplays the pap smear as a step the clinician is taking in investigating her symptoms. However, although the clinician is prescribing her prescription-strength pain medication, which would appear to
validate the patient’s symptoms, the failure to investigate her symptoms seems to render the prescription a feeble attempt at treatment and perhaps a way to quickly deal with her pain. Another example of this type of invalidation is as follows: “I went to the [emergency room] crying and dizzy with pain from cramping. I was told (at 23 years old) menstrual cramps were just a normal part of life. I was given pain killers and sent home.” In this excerpt, one might reason, based on the dose-dependent rule, that the patient would be satisfied with prescription medication, given that “the unavailability of these medications without an expert’s prescription, sustains the view of their special power” (Leventhal et al., 1997, p. 30). Pain killers are, by and large, the most powerful pain medication available. However, the prescription alone does not validate this patient. She makes it clear that she feels invalidated by the absence of an illness label or an attempt to identify one, which she is denied when the clinician states there is no label (this is “just a normal part of life”) and describes being quite literally dismissed when she is “sent home.” The assumption here is that more should have been done by the emergency department clinicians, instead of sending the patient home and without a diagnosis. Patients often felt they were cared about, and not just cared for, when they are given both an illness label and acceptable treatment for their symptoms. As such, without clinicians’ effort to investigate an illness label, prescribing medication as a response to address symptoms is experienced by patients as a thoughtless remedy for what they are experiencing. Clinicians’ not taking the time to investigate patients’ symptoms and physically dismissing patients with a quick “fix” fails to acknowledge patients’ suffering as worthy of anything more can be invalidating to patients.
One last, unique demonstration of invalidation in the context of response efficacy is when patients were advised by clinicians to get pregnant to treat or even “cure” their symptoms. This was especially invalidating when patients were told this at a young age—often before they even reached their 20s in age. Pregnancy is not a medically sound treatment option (Leeners et al., 2018) and was often reported to have been recommended to patients for whom it would have been inappropriate—those who were in their teens, those who had already been trying but were unable to conceive, and those who did not desire having children.
Table 5 Questions Guiding Coding from Research Questions 2 and 3 with Examples

Themes from Research Question 2

**Identity - label**
Does the HCP fail to acknowledge the patient’s beliefs regarding a) whether or not there is an illness label or, if not, b) what that label is (i.e., endometriosis)?

**Example:**
“[The clinician] Told me I was too young and low risk for anything major.”

**Identity – symptoms**
Does the HCP fail to acknowledge the patient’s beliefs regarding the symptom(s) associated with the illness label/diagnosis?

**Example:**
“[The clinician] blank face told me that back pain is not a gynaecological issue multiple times, even though I knew full well it is.”

**Internal cause**
Do the cause(s) or explanation(s) offered by the HCP regarding the patient’s symptom(s) refer to internal attributions (i.e., “patient’s fault”)?

**Example:**
“[The clinician] told me my crippling pain was my fault for not eating breakfast and walked out of the room.”

**External cause**
Do the cause(s) or explanation(s) offered by the HCP regarding the patient’s symptom(s) refer to external attributions (i.e., “not patient’s fault”)?

**Example:**
“Before diagnosis I was a teenager (diagnosed at 15). So my doctors assumed my pain was the stomach flu or at most a cyst”

**Timeline**
Does the HCP fail to acknowledge the patient’s beliefs regarding the course or timescale of the patient’s symptom(s)?

**Example:**
“[I was told] Your periods don’t get worse as you get older”

**Consequences**
Does the HCP fail to acknowledge the patient’s beliefs regarding the impact of the symptoms on overall quality of life or how they may affect functional capacity?

**Example:**
“The doctor brushed what I said off and did not take into consideration that I was having to call out of work and school due to the level of pain.”

**Control - Self-efficacy**
Does the HCP fail to acknowledge the patient’s beliefs regarding (a) whether and/or (b) to what degree their symptom(s) is/are curable or controllable via the performance of the coping behaviors?

Example:
“I was also told…if I lost 10-20 pounds I’d probably get pregnant.”

Control- Response efficacy
Does the HCP fail to acknowledge the patient’s beliefs regarding (a) whether (b) to what degree their symptom(s) is/are curable or controllable via the efficacy of having performed the coping behaviors, and/or (c) a willingness to prescribe a management or treatment option desired by the patient?

Example:
“My female primary care doctor would just say “some women feel more pain with their periods then others” and push NSAIDS and birth control on me.”

Themes from Research Question 3
Secondary gains
Does the HCP fail to acknowledge that the patient is experiencing symptoms AND is attributing that reason to a negative personality trait?

Example: “The doctor told me I was exaggerating the amount of pain to get attention.”

Symptom experiences
Does the HCP fail to acknowledge the patient’s beliefs regarding the presence, quality, location, and/or prioritization of the symptom(s) according to the patient?

Example: “You’re only 12. You can’t be experiencing this much pain.”

Investigative experiences
Does the HCP fail to investigate or otherwise act on the patient’s symptoms?

Example: “Honestly my biggest issue was that no dr prior to dx even bothered to ask questions about my pain. They knew I’d been hospitalized for pain, assumed a cyst burst each month and gave me rx nsaids…”

Additional Message Features Reflective of Symptom Invalidation

RQ3 asked: “Are there additional features that do not currently exist within the five established features of illness representations that are reflective of symptom invalidation?” Data analysis for RQ3 demonstrated that there were two other categories that may account for unique message features—secondary gains and symptom experiences. Additionally, another category of invalidation that emerged did not as explicitly describe message features per se, but focused on the clinical actions of the
clinician and how they engaged in practice to identify a cause for the patient’s symptoms. I refer to these as *investigative experiences*, which includes whether clinicians were perceived to sufficiently and appropriately interview patients and ask probing questions before giving patients’ their assessment of the problem, complete a thorough physical exam, order diagnostic blood or imagining tests, give patients a referral, follow up with patients following a referral, prescribe the necessary medication, and instruct patients to make a follow-up appointment with them. A discussion of this category will follow the discussion of secondary gains and symptom experiences, respectively.

**Secondary Gains**

The first additional message feature of illness representations is what Sigmund Freud called *secondary gains* (Dusenbury, 2018). Secondary gains pertains to clinicians’ communicated beliefs that patients are falsely presenting as ill with ulterior motives to achieve secondary gains, motives that do not involve seeking treatment for a legitimate medical concern but that are likely hostile or manipulative in nature. In these instances of secondary gains, clinicians make evident that they believe that the underlying reason patients are presenting to them is psychological; however, the difference between these cases and those of *internal cause* (which also positions symptoms as stemming from psychological issues) is that clinicians, in the case of secondary gains, make it evident that they not only do not believe that there is something physically wrong with the patient but also that the patients themselves do not believe there is something physically wrong.

Examples of these secondary gains include seeking attention, seeking pain medication, and/or getting out of school/work, such as in the examples below:
I was told because I’d witnessed my brother die from [juvenile] [Huntington’s] disease that I was wasn’t in pain that I was just attention seeking because of things that went on with my brother.

More than once I entered an emergency room for severe pain and was treated as if I was lying/attempting to get opioids. I had a doctor insist that no matter how bad I “claimed” to be in pain, she would not give me painkillers so I should be more honest so she could “actually help” me.

I have had multiple doctors tell me and my mom that my pain wasn’t real and I “just didn’t want to go to school.

In these examples, not only do patients believe that the clinician does not believe they have legitimate medical concerns, but they are being labelled—as an attention seeker, as a drug seeker, as a truant—which aligns squarely with invalidation as defined by Linehan (1993), in that invalidation first tells a person they are wrong in what they are experiencing and that their behavior is attributed to negative personality traits. It should be noted that in addition to being labeled attention-seeking, inherent in this communication is that these patients are lying, which is yet another character flaw.

**Symptom Experiences**

The second additional domain of illness representations is what I am calling symptom experiences and it also serves as health-related features that can be invalidated by clinicians. Symptom experiences pertains to beliefs about the presence, location, and/or quality of the patient’s symptom(s). Invalidation was perceived to occur when there was a failure of the clinician to acknowledge the patients’ beliefs about their symptom experiences—or the presence (symptom presence), quality (symptom quality), and/or location (symptom location) of the symptom(s). Symptom presence refers to whether or not the clinician believes that one or more symptoms are present or are being experienced by the patient. Clinician communication about the presence of the symptom
that are made without also referencing some character flaw were captured here rather than secondary gains (i.e., exaggerating symptoms for attention), as the presence of the symptom is being foregrounded in such talk rather than any character flaw that may be responsible for patients’ asserting the presence of their symptom. An example of symptom presence includes: “I was told that…it wasn’t possible to have week long cycles every other week.”

Symptom severity refers to the degree of the symptom experienced by the patient (e.g., pain). It should be noted that responses about the quality of the symptoms that are made by the clinician without also referencing some negative personality trait would be coded here rather than secondary gains (i.e., exaggerating symptoms for attention). An example of symptom severity includes: “You’re only 12. You can’t be experiencing this much pain.”

In the examples for both symptom presence and symptom severity, the clinician’s reported response to the patient positions the patient as wrong in her presentation of her own symptoms. In fact, the patient’s lived reality of her bodily symptoms is reported to be quite literally denied (“it’s not possible” for symptom presence and “you can’t be experiencing” for symptom severity) by the clinician in a way that is absolute as opposed to using less definitive phrasing, such as “you shouldn’t be,” which is a primary feature of invalidation. What is notable from these examples is that patients are reporting that clinicians are dictating the reality for them, again asserting authority over what is and is not possible.

Symptom location refers to whether the clinician and the patient are in alignment regarding the location of the symptom being experienced. An example of symptom
location includes: “I had continued to go in for extreme lower back pain, they diagnosed me with “we tendions” even though I kept saying my pain was very internal.” In this example, although it is not clear what is meant by “we tendions,” the patient contrasts this presumed body system with the true location of her pain (“my pain was very internal”). Presumably, then, “we tendions” is something that is perceived as more external owing to the patient’s contrasting it to an “internal” problem. What is clear here is a divergence in beliefs about from where the pain is originating. What is also evident is that the patient reports that the clinician is denying her beliefs about the origin of her symptoms—she denies her lived experiences with her pain by implicitly telling her that she is wrong in how she is interpreting her own bodily experiences, a key characteristic of invalidation.

The three examples above present data that would have not otherwise been captured by the coding had inductive thematic coding not taken place. In the first example, although initially it may appear that this example would be captured by identity - symptoms, given the focus on the symptoms, according to the literature on illness representations, identity - symptoms is reserved for attributing specific symptoms to an identity label, such as attributing pelvic pain, fatigue, and infertility (symptoms) to endometriosis (label). This code does not take into consideration the denial of the presence of a symptom—in this case, week-long cycles. In the second example, although at first it may appear that these examples could be captured by consequences given the focus on the severity of the symptoms, consequences is reserved for the impact of an illness on everyday functioning and interference with aspects of their life. It does not take into consideration the denial of the severity of a symptom—in this case, pain. In the third
example, although initially it may seem as though this coding unit would be captured by *identity - symptoms*, given the focus on the symptoms, *identity - symptoms* is reserved for attributing specific symptoms to an identity label, such as attributing heavy menstrual bleeding and painful intercourse (symptoms) to endometriosis (label). This code does not take into consideration the denial of the location of a symptom. Although these are not better represented by the a priori themes representative of illness representations, they are included here as they still appear to be a part of the patients’ beliefs about their illness.

**Investigative Experiences**

This additional category that is not one of the domains of illness representations was the *investigative experiences* category. *Investigative experiences* constitutes the clinical actions of the clinician. Investigative experiences refers to any part of the appointment that would yield further insight into patients’ symptoms, such as asking questions as part of the history, performing pelvic examinations, performing blood and/or diagnostic imagining, performing laparoscopy, and referring patients out to specialists. Patients perceived these particular clinical actions as indicative of clinicians’ positioning of their symptoms and overall illness experience and often as something that complements clinicians’ verbal communication. For example, if a clinician tells a patient that they don’t know what is wrong with the patient but engages in none of the aforementioned clinical actions, the overall encounter may be perceived as dismissive. However, if a clinician tells a patient they don’t know what is wrong with the patient but refers the patient to a colleague, the overall encounter is less likely to be perceived as dismissive (Bontempo, 2023). By failing to investigate patients’ symptoms, clinicians
failed to validate patients’ symptoms and related experiences owing to a lack of responsiveness.

One way symptoms were deemed not worthy of investigation is when clinicians reportedly failed to ask questions as part of taking a history from patients: “Honestly my biggest issue was that no dr prior to [diagnosis] even bothered to ask questions about my pain. They knew I’d been hospitalized for pain, assumed a cyst burst each month and gave me [prescription] nsails.” The patient describes not being asked any questions about her pain. The patient appears to attribute this to laziness or poor judgment, when she states that the clinicians “assumed.” It appears that bursting ovarian cysts was the working diagnosis of clinicians, yet there is no mention of testing to actually rule it or other, differential diagnoses out. The patient also states that no clinician even “bothered” to ask questions, signifying that this was perceived by the patient as a choice of the clinicians, which further solidifies the presumed “lazy” behavior of the clinician. It appears that writing a prescription was presumed to be enough action in the perceived view of the clinician to treat this patient.

Another way patients were reportedly treated as if their symptoms were not worthy of investigation was when clinicians reportedly failed to perform pelvic and/or other physical examinations on patients. For example: “We were told that my severe pain and heavy bleeding that had been going on for a year non stop was “normal”, that i just had not started ovulating yet, and I must have a low pain tolerance, and be exaggerating the amount of blood. The doctor did not even examine me.” In this example, the patient demonstrates that the clinician arrives at a (false) conclusion about her symptoms without even examining her. Indeed, when patients are symptomatic, the American College of
Obstetricians and Gynecologists (2018) guidelines state that clinicians should perform a pelvic examination on patients. It is made apparent in this excerpt that a pelvic exam did not transpire. Although the history of the presenting illness is a powerful clinical tool in achieving diagnosis (American College of Obstetricians and Gynecologists, 2018), pelvic exams are nevertheless standard for further evaluating patients’ presenting concerns and validate for the patient that there is something worthy of clinicians’ time to evaluate, even though endometriosis cannot be diagnosed via pelvic exam (see Simoens et al., 2007).

One last way patients were reportedly treated as if their symptoms were not worthy of attention was when clinicians reportedly “refused” to refer patients out to specialists for further investigation into their symptoms. Should clinicians end up uncertain about the cause of their patients’ symptoms, clinicians are recommended to refer patients out (American College of Obstetricians and Gynecologists, 2007, 2020). However, this appears to not always be the case:

After numerous attempts to get my family doctor (a general practitioner) to send me for an ultrasound and/or to a gynecologist and/or gastroenterologist numerous times, in order to deal with terrible pelvic pain, chronic severe constipation and bloating/pelvic inflammation (to the point that I looked 6 months pregnant), she refused.

In this excerpt, the patient uses the word “refuse” in discussing their clinician’s alleged response to their request for a referral (or lack thereof), for which it is apparent that the patient made a request. By incorporating the word “refuse,” the patient is priming a type of intentionality of the clinician to not help the patient. Furthermore, clinicians reportedly fail to legitimize their symptoms by “refusing” to refer the patient out for more appropriate or specialized care.
Chapter Summary

RQ2 and RQ3 yielded specific features of messages—that of the illness label and its symptoms, the cause, the timeline, the consequences, and control over the illness—that likely contribute a significant amount of variance to these cognitive/affective experiences of invalidation. What was demonstrated was that patients experience invalidation in a variety of ways: it can be related to how clinicians identify the diagnosis and symptoms, communicate the cause of the symptoms, convey understanding of the timeline of patients’ illness, treat the consequences of the illness, and communicate their understanding of control over the symptoms. In addition to these forms of communication, patients also experienced clinical decisions (or lack thereof) as invalidating, especially with respect to investigating symptoms (e.g., not taking a history or asking probing questions, not performing a physical exam, not ordering appropriate testing, not referring patients out to specialists). Thus, taken together, it appears that both clinicians’ verbal and nonverbal communication as well as their clinical decisions jointly influence patients’ cognitive/affective experiences of invalidation.
CHAPTER SIX: VALIDATING A SELF-REPORT MEASURE TO ASSESS SYMPTOM INVALIDATION

Having helped establish the importance of symptom invalidation by having examined the negative sequelae associated with interactions resembling symptom invalidation in extant work (Chapter 4) and, further, elucidating what is at the core of symptom invalidation as a concept (Chapter 5), I investigated the close-ended survey responses gauging patients’ experiences with symptom invalidation to ascertain whether or not symptom invalidation is a concept that can be measured quantitatively.

**Exploratory Factor Analysis**

The scale proposed here demonstrated good internal consistency ($\alpha = .88$). Both the KMO test score of .87 and the Bartlett sphericity test ($\chi^2 = 2986, df = 15, p < .001$) indicated that factor analysis was appropriate for the invalidation items used in this study. The parallel analysis test used to assess the appropriate number of factors suggested extracting one factor—this is also the number of factors expected based on the literature driving the scale construction. An exploratory factor analysis with principal axis factoring and a Promax rotation was conducted. The resulting factor loadings are presented in Table 8. The total explained variance for the model was 61%.
Table 6 PSIS Item Statistics and Factor Loadings

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>SD</th>
<th>Factor loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSIS 1 My doctor did not dismiss my symptoms. (R)</td>
<td>3.98</td>
<td>1.38</td>
<td>.650</td>
</tr>
<tr>
<td>PSIS 2 My doctor passed my symptoms off.</td>
<td>4.01</td>
<td>1.36</td>
<td>.645</td>
</tr>
<tr>
<td>PSIS 3 My doctor took my symptoms seriously. (R)</td>
<td>4.13</td>
<td>1.17</td>
<td>.898</td>
</tr>
<tr>
<td>PSIS 4 My doctor challenged my symptoms.</td>
<td>3.51</td>
<td>1.36</td>
<td>.491</td>
</tr>
<tr>
<td>PSIS 5 My doctor validated my symptoms.</td>
<td>3.81</td>
<td>1.27</td>
<td>.834</td>
</tr>
<tr>
<td>PSIS 6 My doctor did not treat my symptoms as important.</td>
<td>4.14</td>
<td>1.19</td>
<td>.832</td>
</tr>
</tbody>
</table>

Confirmatory Factor Analysis

Confirmatory factor analysis with maximum likelihood estimation to was subsequently performed. The initial CFA model did not initially provide an adequate fit to the data ($\chi^2 = 117, df = 14, p = .001, CFI = .96, GFI = .99, RMSEA = .12, 90\% CI = [.10, .14], SRMR = .04$). Based on modification indices, one item was removed from the CFA (‘My doctor rejected my symptoms’), which resulted in a satisfactory model fit to the data ($\chi^2 = 23, p = .006, df = 9, CFI = .10, GFI = .99, RMSEA = .04, 90\% CI = [.02, .08], SRMR = .02$).

Figure 15 Confirmatory Factor Analysis of the PSIS
Convergent Validity

Convergent validity was assessed by conducting bivariate correlations of the 6-item scale and relevant constructs: patient satisfaction with the healthcare interaction, supportive message quality from the clinician, and cognitive/affective reactions to institutional betrayal in the medical system. Convergent validity of the scale was confirmed via significant zero-order correlations with patient satisfaction with the healthcare interaction ($r = -.708, p < .001$), supportive message quality from the clinician ($r = -.760, p < .001$), and cognitive/affective reactions to institutional betrayal in the medical system ($r = -.742, p < .001$). These correlations indicated that patients in this study who report higher levels of invalidation of their symptoms are more likely to report lower levels of satisfaction with the healthcare interaction and supportive message quality from the clinician and higher levels of cognitive/affective reactions to institutional betrayal in the medical system.

Chapter Summary

This chapter demonstrated that the PSIS, a brief (6-item) measure, is a psychometrically sound self-report scale that can reliably measure the perceived invalidation of one’s symptoms by clinicians in the context of endometriosis. Supporting the convergent validity of the PSIS, correlations indicated that patients with endometriosis who perceived greater invalidation from their clinician also reported lower patient satisfaction and lower supportive message quality from the clinician and higher institutional betrayal from the clinician.
CHAPTER SEVEN: TESTING THE NEGATIVE SEQUELAE OF SYMPTOM INVALIDATION

Having ascertained whether symptom invalidation is something that can be measured quantitatively (Chapter 6), I sought to test whether the PSIS developed in Chapter 6 is correlated with some of the negative sequelae uncovered in Chapter 4. Demonstrating that the PSIS has predictive validity is integral to connecting symptom invalidation to psychological and possibly indirect physical harm.

Hierarchical linear regressions were computed to test the relationship between symptom invalidation and some of the negative sequelae described earlier as part of a secondary analysis: negative affect, negative self-esteem, depression, and suicidal ideation; healthcare-related anxiety or trauma; loss of trust in specific clinicians, clinicians generally, or the broader healthcare system; frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system; symptom underreporting; and delays, breaks, or terminations in care. Because this is a secondary analysis, the “fit” of some of the variables to how they were conceived from the systematic review are not perfect.

Sequela: Scared/Terrified

Table 7 Hierarchical Linear Regression for Hypothesis 1 (N = 512)

<table>
<thead>
<tr>
<th>Scared/terrified</th>
<th>$R^2$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invalidation Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>.04</td>
<td>.00</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td></td>
<td>-.05</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td>-.15**</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td>-.03</td>
</tr>
<tr>
<td>Step 2</td>
<td>.21</td>
<td>.43**</td>
</tr>
<tr>
<td>Invalidation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Note. Cell entries are adjusted $R^2$ statistics and standardized coefficients.
*p < .01. **p < .001.

For Hypothesis 1, the results obtained from the hierarchical linear regression model assessing the impact of invalidation on being scared/terrified (i.e., healthcare-related anxiety and trauma) as a response yielded a significant model, $R^2 = .21$, $F(5, 507) = 53.23$, $p < .001$, thus the full model accounted for a total of 21% of the variance in being scared/terrified as a sequela of symptom invalidation. Being scared/terrified (i.e., healthcare-related anxiety and trauma) was predicted by education ($\beta = -.15$, $p < .001$), and invalidation ($\beta = .43$, $p < .001$). That is, those who were less educated and experienced greater invalidation reported being more scared/terrified (i.e., healthcare-related anxiety and trauma) as a result of the reported invalidation. Inclusion of invalidation into Step 2 of the model explained an additional 17.8% of the variance, which remains significant ($p < .001$). See Table 8 for further details.

**Sequela: Less Trusting of the Medical System**

**Table 8 Hierarchical Linear Regression for Hypothesis 2 (N = 512)**

<table>
<thead>
<tr>
<th>Invalidation Model</th>
<th>Less trusting of medical system</th>
<th>$R^2$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td></td>
<td>-.01</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td>-.13**</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td>-.03</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td>.44</td>
<td>.64*</td>
</tr>
<tr>
<td>Invalidation</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Cell entries are adjusted $R^2$ statistics and standardized coefficients. *p < .01. **p < .001.
For Hypothesis 2, the results obtained from the hierarchical linear regression model assessing the impact of invalidation on being less trusting of the medical system as a response yielded a significant model, $R^2 = .44$, $F(5, 507) = 78.23$, $p < .001$, thus the full model accounted for a total of 44% of the variance in being less trusting of the medical system as a sequela of symptom invalidation. Being less trusting of the medical system was predicted by education ($\beta = -.13$, $p < .001$), and invalidation ($\beta = .64$, $p < .001$). Inclusion of invalidation into Step 2 of the model explained an additional 40.3% of the variance, which remains significant ($p < .001$). See Table 9 for further details.

**Sequela: Angry**

**Table 9** Hierarchical Linear Regression for Hypothesis 3 (N = 512)

<table>
<thead>
<tr>
<th>Invalidation Model</th>
<th>Anger $R^2$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>.02</td>
<td>.03</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>-.09*</td>
</tr>
<tr>
<td>Caucasian</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td>-.04</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td>-.03</td>
</tr>
<tr>
<td>Step 2</td>
<td>.40</td>
<td>.62**</td>
</tr>
<tr>
<td>Invalidation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Cell entries are adjusted $R^2$ statistics and standardized coefficients. *$p < .01$. **$p < .001$.

For Hypothesis 3, the results obtained from the hierarchical linear regression model assessing the impact of invalidation on anger (i.e., frustration and anger toward clinicians and the healthcare system) as a response yielded a significant model, $R^2 = .40$, $F(5, 507) = 67.29$, $p < .001$ thus the full model accounted for a total of 40% of the variance in anger as a sequela of symptom invalidation. Anger (i.e., frustration and anger toward clinicians and the healthcare system) was predicted by race/ethnicity ($\beta = -.09$, $p$
<.01), and invalidation ($\beta = .62, p < .001$). Inclusion of invalidation into Step 2 of the model explained an additional 37.8% of the variance, which remains significant ($p < .001$). See Table 10 for further details.

**Sequela: Cautious and Reluctant to Seek Further Care**

For Hypothesis 4, the results obtained from the hierarchical linear regression model assessing the impact of invalidation on being cautious and reluctant to seek care as a response yielded a significant model, $R^2 = .46$, $F(5, 507) = 79.02, p < .001$, thus the full model accounted for a total of 46% of the variance in caution/reluctance to seek care as a sequela of symptom invalidation. Being cautious and reluctant to seek care was predicted by education ($\beta = -.09, p = .01$), and invalidation ($\beta = .66, p < .001$). Inclusion of invalidation into Step 2 of the model explained an additional 42.3% of the variance, which remains significant ($p < .001$). See Table 11 for further details.

**Table 10** Hierarchical Linear Regression for Hypothesis 4 (N = 512)

<table>
<thead>
<tr>
<th>Invalidation Model</th>
<th>$R^2$ $\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>.03</td>
</tr>
<tr>
<td>Age</td>
<td>-.02</td>
</tr>
<tr>
<td>Caucasian</td>
<td>-.03</td>
</tr>
<tr>
<td>Education</td>
<td>-.08*</td>
</tr>
<tr>
<td>Income</td>
<td>-.06</td>
</tr>
<tr>
<td>Step 2</td>
<td>.46</td>
</tr>
<tr>
<td>Invalidation</td>
<td>.66**</td>
</tr>
</tbody>
</table>

*Note. Cell entries are adjusted $R^2$ statistics and standardized coefficients. *$p < .01$. **$p < .001$.

**Chapter Summary**
This chapter demonstrated that the PSIS allows for the more systematic and consistent documentation of negative health outcomes, as the PSIS allows for quantification of invalidation, which can be used to test against the negative health outcomes of interest, as is done via secondary analysis in this chapter. For example, this chapter demonstrated that perceived invalidation is significantly correlated with all measures of negative sequelae—specifically, being scared/terrified, less trusting of the medical system, angry, and cautious and reluctant to seek further medical care.
CHAPTER EIGHT: DISCUSSION

The goal of this dissertation is multi-faceted: (a) to establish the importance of invalidation by elucidating the negative sequelae invalidating experiences impose on patients (Phase I), (b) to explicate the concept of symptom invalidation as it takes place between patients and clinicians (Phase II), (c) to validate a reliable self-report measure of symptom invalidation based on the findings of (b) (Phase III), and finally (d) to document the negative consequences of symptom invalidation using this self-report measure from (c) as part of a secondary analysis (Phase IV). A discussion for each of the four phases is provided below.

Phase I

Phase I found that negative sequelae of invalidating experiences include negative affect, negative self-esteem, depression, and suicidal ideation; healthcare-related anxiety or trauma; loss of trust in specific clinicians, clinicians generally, or the broader healthcare system; frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system; symptom underreporting; and delays, breaks, or terminations in care. Phase I also found that many of these sequelae are related to and influence each other. Specifically, many of the sequelae showed relationships with patients’ loss of trust. This loss of trust can directly lead to delays, breaks, and terminations in care; symptom underreporting; as well as healthcare-related anxiety or trauma. Furthermore, healthcare-related anxiety appears to mediate the relationship between loss of trust and both symptom under-reporting and delays, breaks, and terminations in care. The psychological fallout is complex, the nuance of which must be fully appreciated to understand the outcome processes of invalidating experiences.
All of these sequelae warrant concern. First, although a full discussion of whether or not invalidation of patient symptoms can contribute to post-traumatic stress disorder (PTSD) is beyond the scope of this paper, feelings of endangerment (Sloan, Naughton, et al., 2020) and helplessness are often necessary precursors to the development of PTSD (American Psychiatric Association, 2013). In fact, perceived betrayal by clinicians, which can occur as a result of invalidation of patient symptoms, was shown to be positivity correlated with PTSD among a sample of Canadian adults with chronic health conditions (Tamaian & Klest, 2018).

Second, regarding loss of trust, concern lies in the fact that loss of trust detracts from the many positive correlates of trust in the patient-provider relationship for patient health outcomes, such as patient satisfaction, adherence to treatment protocols, and health-related quality of life (see Chandra et al., 2018). Furthermore, perceived betrayal by clinicians, or what is called institutional betrayal in the medical system, has been positively associated with the mental health outcomes of anxiety, depression, disassociation, and post-traumatic stress as well as with delay in care among a sample of Canadian adults with chronic health conditions (Tamaian & Klest, 2018). Indeed, trust is a reciprocal process and a feature of a relationship, and does not live in only the patient or only the clinician; thus, if clinicians do not trust what patients are reporting to them regarding their own bodily experiences, patients will be less likely to trust clinicians, in return.

Third, regarding frustration and anger, it must be noted that anger is the discrete emotion underlying betrayal, and betrayal is inextricably linked with trust (Mechanic, 1998). Importantly, as Hall et al. (2001) note, “one of the hallmarks of trust is that its
violation tends to produce an emotional reaction of moral outrage or indignation, rather than mere disappointment in the failure to achieve expected results” (p. 617; as cited in Baier, 1986 and Lagenspetz & Akademi, 1992).

Fourth, regarding symptom underreporting, feelings like this link back to the negative affect that have been reported to result from these interactions; particularly, embarrassment, guilt, and shame. Specifically, not disclosing health information that the patient believes will be invalidated by the clinician may in fact be a coping mechanism so as not to have to experience this embarrassment, guilt, or shame. It may help to accomplish the goals of preserving one’s sense of self while also attaining the care they need. A subtheme of distrusting clinicians among a sample of patients with EDS was “risking bad health,” which reflected how patients did not express their needs to clinicians nor showed them how they truly were suffering (Berglund et al., 2010). In these instances, an honest exchange of information from patient to clinician does not occur. It is reasonable to think symptom underreporting to clinicians is a conscious or subconscious “compromise” for patients, a compromise between delaying, breaking from, or terminating care seeking (to be discussed below) and care seeking that involves full disclosure of all relevant health information.

Fifth, similar to symptom underreporting to clinicians, decisions to delay, break from, or terminate care may link back to the negative affect that has been reported to result from these interactions. Particularly, delaying, taking a break from, or terminating care may be a coping mechanism. Although the patient would not simultaneously be working toward accomplishing the goal of attaining the care they need, delaying,
breaking from, or terminating seeking care may help accomplish the goal of preserving the patients’ sense of self-worth by avoiding potentially invalidating encounters.

Concern regarding this domain lies in the fact that this presumed patient coping strategy of postponing or stopping care prevents continuity of care (Reid, 2002), which is an established predictor of high-quality patient care (Starfield et al., 1977; Van Walraven et al., 2010). Further, such delays and terminations inevitably add to diagnostic delay, which has implications not only for calculating and more comprehensively understanding diagnostic delay but also for the initiation of treatment. Additionally, such breaks from care are a critical concern for patients who have progressive chronic illnesses, such as lupus which can involve multi-organ damage (Tsokos, 2020), and endometriosis which can involve loss of ovarian reserve from ovarian endometriosis or extrapelvic organ damage or loss, such as of the kidney(s) (Nezhat & Nezhat, 1993; Nezhat et al., 1992). This may also hold true for non-examined illnesses with progressive courses and deleterious outcomes if left uncared for such as neurodegeneration in progressive multiple sclerosis (Mahad et al., 2015) or metastasis in cancer (Chaffer et al., 2011).

Indeed, invalidation has been demonstrated in patients with multiple sclerosis (Edwards et al., 2008) and cancer survivors (Street et al., 2019).

Finally, the impact of invalidation on patients’ mental health, particularly their reports of suicidal ideation warrants serious reflection. Although only reported in two studies, suicide is a stigmatized topic, and a recent meta-analysis demonstrates only 50-60% of individuals experiencing suicidal ideation disclose this to others. Additionally, disclosure is higher when it is to family members rather than friends or clinicians
(Hallford et al., 2023). As such, suicidal ideation is likely to have been experienced at higher rates than was disclosed to the research teams of the reviewed studies.

**Phase II**

Phase II found that the patients with endometriosis experience invalidation in a variety of ways: it can be related to how clinicians identify the diagnosis and symptoms, communicate the cause of the patient’s symptoms, convey their understanding of the timeline of a patient’s illness, treat the consequences of the illness, communicate their understanding of control over the symptoms, communicate judgments of whether or not patients are presenting to the clinical encounter for secondary gains, and how symptoms are experienced by patients. In addition to these forms of communication, patients also experienced clinician actions (or lack thereof) as invalidating, especially with respect to not investigating symptoms (e.g., not asking questions, not performing a physical examination, not ordering appropriate testing, not referring patients out to other clinicians).

There therefore appears to be a strong communicative and a strong action-oriented component to symptom invalidation. These findings, as a whole, are in line with Linehan’s (1997) work on validation. Linehan states that there are two types of validation: topographical validation and functional validation. Topographical validation is more explicit and is posited as validation by words, whereas functional validation is more implicit and is posited as validation by deeds. Thus, the reverse is true for invalidation. In theory, topographical invalidation is explicit and is invalidation by words, and functional invalidation is implicit and is invalidation by deeds. Indeed, both are necessary, being that if both are not present, it may appear that an individual is not taking
the individual’s experiences seriously (Linehan, 1997). Similarly, the work on doctorability (Heritage & Robinson, 2006) suggests that moving from the problem presentation portion of the medical visit to the history-taking portion of the visit validates the patient’s belief that their presenting problem is worthy of medical investigation. Heritage and Robinson (2006) state, “After this point, patients can surrender control of the encounter in exchange for the medical questioning that, by taking the concerns seriously, prospectively overwrites the doctorability of their problems” (p. 64). In this phase of the dissertation, the failure of any history taking by clinicians was cited as a demonstration of invalidation of the symptoms described to clinicians. Patients often spoke of healthcare interactions in which clinicians did not ask probing questions about their symptoms after the problem presentation portion of the visit. Taken together, the clinical actions of clinicians in the medical encounters, too, is perhaps equally vital to patients’ perceptions of invalidation.

The results from Phase II also demonstrate the nuances that comprise invalidation and what distinguishes invalidation from other, likely related constructs such as components of trust and satisfaction. Regarding trust, for example, Hall et al. (2001) posit that there are five domains of trust. One domain is competence, which includes avoiding cognitive and technical errors to produce the best achievable results. Another domain is fidelity, which includes pursuing patient’s best interest, not taking advantage of vulnerability. A third domain includes honesty, which includes avoiding intentional falsehoods. A fourth domain is confidentiality, which includes proper use of sensitive or private information. The last domain includes global trust, which includes trust that is not reducible to component parts. Some of these domains are seen in the responses not
analyzed for this study, being that they reflected the construct of trust and not symptom invalidation. A proportion of patients described experiences of (in)competence and/or (in)fidelity rather than invalidation. Although invalidating experiences focused on the treatment of symptoms as not “real” or of value to clinicians, incompetence identified failures in clinical reasoning, for example, examining the wrong organ system (“they were always looking into my bowels but never at my reproductive organs”). Infidelity manifested rather than symptom invalidation when a patient said the clinician talked over her (“First Dr talked over me when I was trying to explain my symptoms”).

In comparison to trust, which is a “forward-looking evaluation of an ongoing relationship” (Hall et al., 2001, p. 617), satisfaction is an “assessment of one or more past events” (Murray & Holmes, 1997, as cited in Hall et al., 2001) and tends to be more outcome based. For example, one patient stated “I have not had a dismissive interaction. Just long waits to see a GYN surgeon.” In this quote, the patient is able to distinguish between invalidation and dissatisfaction with “long waits to see a GYN surgeon”. In sum, although the instructions for this question of the survey asked patients to detail instances of dismissal, these nonconforming responses demonstrate constructs seemingly related to invalidation and reinforce the boundary conditions of invalidation set forth.

**Phase III and IV**

Phase III found that the PSIS, a brief (6-item) measure, is a psychometrically sound self-report scale that can reliably measure the perceived invalidation of one’s symptoms by clinicians in the context of endometriosis. Supporting the convergent validity of the PSIS, correlations indicated that patients with endometriosis who perceived greater invalidation from their clinician also reported lower patient satisfaction
and lower supportive message quality from the clinician and higher institutional betrayal from the clinician.

Phase IV found that perceived invalidation is significantly correlated with all negative sequelae items—specifically, being scared/terrified, less trusting of the medical system, angry, and cautious and reluctant to seek further medical care. Being able to quantitively and robustly test these observations based on prior qualitative work can help substantiate the claims regarding these negative sequelae while also controlling for potential covariates such as age, gender, race/ethnicity, education, and income. Doing so would, in turn, help gather the data needed to establish the real and practical import of this work.

This scale is likely appropriate for other illness contexts, especially given the literature from which the scale from Phase III drew examined various illness contexts. Future research will work to assess this scale with other patient populations who, too, seek legitimacy from the medical community but often report feeling unheard.

**Limitations**

This dissertation is not without important limitations that affect the interpretation of its findings. First, there were a few limitations regarding the larger study from which Phases II (analysis of patients’ open-ended responses), III (validation of a self-report measure), and IV (secondary analysis testing the association between invalidation and negative sequelae) were drawn. For example, the study utilized convenience sampling and comprised recruitment that was almost entirely online via support groups or health-related organizations. As such, the findings of Phase II, III, and IV are not applicable to all patients with endometriosis, especially given the large demographic profile of patients
from this study—well educated, non-Hispanic white. Although it can be argued that those who participated in this study were more highly motivated, owing to having had negative experiences and therefore skewing patient responses, including more patients from these other demographic groups may skew these results further in the same direction due to the well-documented disparities historically marginalized populations experience in healthcare. Additionally, the study sample was composed of patients who self-identified as having endometriosis. Surgical reports were not obtained from any clinics or patients themselves and thus we were unable to confirm patients’ self-identified diagnosis. The study, however, was anonymous, which precluded the ability to conduct any medical record review to provide such verification. Furthermore, some criteria by which we assess qualitative research such as sincerity, credibility, and resonance have been questioned with the use of open-ended survey questions (LaDonna et al., 2018). Accordingly, the findings of Phase II (analysis of patients’ open-ended responses) may provide a limited understanding of patients’ complete experiences that could better be gauged using interviews with patients in which follow up questions can be asked or illness narratives that often contextualize patients’ experiences more thoroughly.

One limitation of Phase II (analysis of patients’ open-ended responses) is that although I asked about patients’ perceptions of invalidation at the time of the healthcare interaction, I was only able to capture patients’ retrospective accounts of invalidation at the time that they responded to the survey. It could very well be that patients did not find a given interaction invalidating at the time it happened but did so at the time of taking the survey. Of course, all patients had been diagnosed with endometriosis during the time of the data collection and thus what we do not know in many instances is whether or not
patients felt invalidated at the time of the interaction. For example, a clinician may have told a patient that their pain during menstruation is normal and could be especially bad for certain individuals, which the patient may have believed at the time. Thus, the clinician and the patient’s idea of the cause of the patient’s symptoms were initially aligned. Upon learning, perhaps, five years later that pain during menstruation and “really bad periods” in the way they were experiencing are not normal, the patient then may experience a sense of invalidation upon possibly realizing that their symptoms had not been taken seriously enough.

A second limitation specific to Phase I (analysis of patients’ open-ended responses) is that many patients did not follow directions by describing more than one interaction for the open-ended question. This lack of adherence to the survey directions complicated the coding process. For example, instead of reporting one interaction with one clinician, some patients described more than one interaction with the same clinician, more than one interaction with more than one clinician, a generalized description that applied to multiple doctors more broadly, and patients’ overall diagnostic journey (from beginning of treatment seeking to diagnosis). This made coding difficult, as the units of analysis varied significantly.

A third limitation specific to Phase II (analysis of patients’ open-ended responses) is that not all patients described instances of symptom invalidation—they varied from describing clinicians’ incompetence, to infidelity, to general dissatisfaction. Again, *competence* refers to “avoiding mistakes and producing the best achievable results” (Hall et al., 2001, p. 621), while *fidelity* refers to “pursuing a patient’s best interests and not taking advantage of his or her vulnerability” (Hall et al., 2001, p. 621). Although
(in)competence and (in)fidelity could arguably lead to dissatisfaction in either case (e.g., “the clinician was incompetent, therefore I was less satisfied with my care”), general dissatisfaction also took the form of negative outcomes experienced by the patient that could not be attributed to (in)competence and (in)fidelity alone. Indeed, satisfaction is distinguished from trust and its core components (e.g., competence, fidelity) by the fact that satisfaction is generally future-oriented and outcome based, whereas trust is more relational (Hall et al., 2001). For example, a patient can be dissatisfied with the outcome of trying a new medication, realizing it does not help improve symptoms and comes with a host of side effects. This scenario is not contingent on the competence or fidelity of the prescribing clinician. Two examples from the current data set are: “Gave me birth control for PMS it honestly made everything worse” and “I had been going to my primary dr for years talking of conceiving and nothing had been happening after years of trying.” In the first example, the failure of the birth control pills to control the pain is not contingent on the competence of the clinician, nor is the second patient’s inability to conceive “after years of trying.” Despite the limited number of usable responses, these responses helped establish the boundary conditions of symptom invalidation by providing contrasting cases for comparison.

A fourth limitation specific to Phase II (analysis of patients’ open-ended responses) is that patients may have been influenced by how the question they were asked to respond to was framed. Although some participants noted that they did not experience invalidating experiences, asking patients in this study to recall a negative interaction likely biases patients’ responses. As such, the responses in this data set are skewed to be negatively valanced. The overarching aim of the study comprising Phases II, III, and IV
was to develop and validate a self-report measure. Thus, when validating a self-report measure, it is important to have variance in responses (Devellis & Thorpe, 2022). However, having responses that only report on negative experiences limits the variance of responses captured by the PSIS. As such, the prompt for Phase II (analysis of patients’ open-ended responses) likely affected the psychometrics of the scale developed in Phase III (validation of a self-report measure). A fifth limitation specific to Phase II (analysis of patients’ open-ended responses) is that many of the patient responses lacked context or detail. In such cases, I took a conservative approach and did not include them as part of the sample unless there were clear indicators that they were describing experiences of symptom invalidation.

One limitation of Phase III (validation of a self-report measure) is that the PSIS was developed using only six items (dismissed, passed off, not taken seriously, invalidation, rejected, and challenged), though one item was discarded during the scale validation process (i.e., rejected). Additional descriptors of invalidation exist in the literature and may have been relevant to scale development. For example, “brushed off,” “minimized,” “trivialized,” “fobbed off” could have also served as additional items to be tested with the model.

Another limitation of Phase III (validation of a self-report measure) is that the PSIS captures cognitive/affective experiences of invalidation. Although there is use in being able to measure such experiences quantitatively, it does not capture the communication processes that contribute to such cognitive/affective experiences of invalidation. As such, the PSIS demonstrates that patients can feel invalidated by clinicians, but it does not elucidate how, as is demonstrated in Chapter 5. It is just as
important to understand the communication underlying invalidation as it is to understand feelings of invalidation. With that said, future work should seek to correlate communicative processes that contribute to such cognitive/affective experiences of symptom validation so that communication scholars can advise clinicians on how to best communicate with patients about their symptoms, especially when they might perceive them differently than the patient. This dissertation thus provides the foundation for developing this future work to help mitigate the negative impact of symptom invalidation.

One limitation of Phase IV (secondary analysis testing the association between invalidation and negative sequelae) is that the investigation into the negative sequelae of invalidation was done as a secondary analysis of items from the cognitive/affective subscale of the Institutional Betrayal in the Medical System, which did not encompass all of the sequelae identified in the review in Phase I; in particular, there were no items from the cognitive/affective subscale to gauge negative self-esteem, depression, suicidal ideation, and symptom underreporting. Additionally, there were a few sequelae that did not accurately map onto a few items from the cognitive/affective subscale. Thus, the level of precision of these items was not ideal. For example, to document the sequela of delays, breaks, and terminations in care, two items were used that were averaged together. These two items were “cautious about seeking care” and “reluctant to seek further medical care.” These items, however, should not be conflated with actual delays, breaks, or terminations in care—they are instead a reflection of patients’ motivational state related to seeking care and are not patients’ actual behavior.
Another limitation of Phase IV (secondary analysis testing the association between invalidation and negative sequelae) is that the measure used to gauge negative sequelae—the cognitive/affective response to Institutional Betrayal in the Medical System (Tamaian & Klest, 2018) is subject to recall bias, in that patients were asked to reflect back on an interaction and were asked to remember their cognitive/affective responses to symptom invalidation. For some patients, this could have been many years ago, so the strength of cognitive/affective reactions may be different than they were at the actual time of the interaction.
Implications

There are several implications of this dissertation that are both of theoretical and practical value.

Theoretical Implications

As noted in Chapter 1, there is a proliferation of research on a phenomenon that closely resemble and possibly overlap with symptom invalidation (e.g., disenfranchising talk, Hintz, 2022). However, most of this work on a phenomenon resembling symptom invalidation has not truly interrogated what this phenomenon is and is not and what its boundary conditions are. Instead, what symptom invalidation is as a concept is oftentimes glossed over. For example, Hildenbrand et al. (2021) conducted a study on patients’ perceptions of clinicians’ “dismissive” communication. In particular, “participants were asked if they ever felt they had a health problem that was dismissed or ignored by a health care provider, with response options of ‘Yes’ or ‘No’” (p. 3). It is unclear whether the terms “dismissed” and “ignored” are conceptually the same and why both terms were used in the question posed to participants. Participants were then prompted to detail what the clinician said and what happened in the interaction. Of the 871 participants who completed their open-ended question, 797 remained relevant and thus able to be coded. Thus, 74 responses were excluded because they were irrelevant (e.g., participants just wrote “Health problem” or “Yes”). However, of those that were relevant, it is not clear how it was determined whether the relevant responses that were coded were consistent with the authors’ definition of dismissal or ignoring. For instance, it is unclear how a dismissive interaction was distinct from other relevant concepts such as clinician incompetence or general dissatisfaction that do not go as far as actually dismissing the
patients’ symptoms. This dissertation fills this gap by interrogating all of the responses of the patients to determine whether or not they meet the threshold of invalidation.

Furthermore, there are many concepts that appear to be similar to symptom invalidation, yet how symptom invalidation can be distinguished from other constructs has remained largely unexplored. For example, as discussed in Chapter 2, Kool et al. (2009) defined invalidation as “…the perception of cognitive, affective, and behavioral responses of others that are perceived as denying, lecturing, overprotecting, not supporting and not acknowledging with respect to the condition of the patient” (Kool et al., 2009, 2010; p. 1990) and largely draw from the social support literature. For example, they cite the stress-buffering model of social support (Cohen & Wills, 1985) as an argument for why invalidation—or more accurately, validation—is important in dyadic communication, including with clinicians. They state that “…invalidation may be harmful for additional reasons besides a lack of social support” (p. 1651). Here, Kool et al. appear to be equating invalidation with social support. Additionally, they refer to their clusters of lecturing and overprotecting as cases of “negative support,” which is an accurate depiction of these clusters. However, negative support should not be conflated with invalidation. Understanding where symptom invalidation ends and other related constructs begin is paramount to advancing this work.

This dissertation also fills a gap in that there is not a standardized conceptual term yet, with recent work calling for conceptual standardization (Bontempo, 2022b). Indeed, this work argues that there is too much variability in how the phenomenon that I am calling symptom invalidation is referred to. Specifically, there were more than 25 different terms spanning 33 articles reviewed, and there was not only a lack of
consistency in describing this phenomenon across studies but also within the same studies. For example, as I mentioned above, Hildenbrand et al. (2021) use the words “dismissed” and “ignored,” but it is unclear whether these two words are describing the same process, hence the need for precise and standardized terminology. Such a standardization will help to better streamline the output of work on symptom invalidation and prevent siloed work. It will allow for systematic reviews to be published for which outlining the identification and search process is crucial.

**Practice Outcomes**

This dissertation, specifically Phase I (the systematic review of negative sequelae of invalidation) and Phase IV (secondary analysis testing the association between invalidation and negative sequelae) have implications for patient health outcomes. Research demonstrates that patient-centered care is linked to positive health outcomes such as survival, cure/remission, reduced suffering, increased emotional well-being, pain control, functional ability, and vitality both directly and indirectly through mechanisms such as increased patient understanding, increased satisfaction, clinician-patient agreement, increased trust, feeling “known,” patient involvement in their care, increased rapport, increased motivation, access to care, quality medical decisions, commitment to treatment, trust in the healthcare system, social support, self-care skills, and increased emotional management (Street et al., 2009). In theory, symptom invalidation, which is the antithesis to patient-centered care, precludes patients from achieving these positive health outcomes. It also has the added harm of what was discovered in Phase I (the systematic review of negative sequelae of invalidation)—negative affect, negative self-esteem, depression, and suicidal ideation; healthcare-related anxiety or trauma; loss of
trust in specific clinicians, clinicians generally, or the broader healthcare system; frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system; symptom underreporting; and delays, breaks, or terminations in care. The PSIS that was developed and validated in Phase III allows us to correlate invalidation to indirect and direct health outcomes to test these assumptions. Demonstrating the negative sequelae in this way illuminates the importance of this scale and, consequently, the very real harm of symptom invalidation.

A second implication of this dissertation is that Phase II (analysis of patients’ open-ended responses) allows us to better understand how symptom invalidation manifests in the patient-clinician interaction. Achieving such an understanding is paramount to understanding the verbal and nonverbal communication and behavior of clinicians that can lead to perceptions of invalidation by patients. Identifying this communication and behavior of clinicians can help establish patient-centered protocols that are intended to protect against invalidation and instead promote validation. These protocols are essential for communication skills training programs, with a special focus on (in)validation.

**Future Directions**

There are several future directions for this dissertation. First, clinician perspectives should be gauged. Most of the research on invalidation in the context of endometriosis, for example, focuses on the perspectives of patients. Only a few studies—those of Berterö et al. (2019), Grundström et al. (2016), Rowe et al. (2019), Van Der Zanden et al. (2019), Young et al. (2017), and Zale et al. (2020)—have sought to incorporate the perspectives of clinicians concerning the quality of care for patients with
endometriosis. Clinicians can offer valuable insight into the standard of care for patients with endometriosis that might not have been considered by patients or even researchers. For example, interviews with clinicians completed by Berterö et al. (2019) demonstrated that clinicians withhold an endometriosis diagnosis from their patients until it is time for a laparoscopy, as they view this as a way to protect them from worrying. Although not detailed in Berterö et al. (2019), in place of being honest with patients, as a way to ease their worrying, clinicians might offer reassurance. However, research has demonstrated that reassurance is often perceived as invalidating by patients (Dowrick et al., 2004; Salmon et al., 1999). Patients, however, appear to view this as a matter of incompetence on the part of the clinician, which can undermine patients’ trust in these clinicians. This is just one demonstration of how our understanding of the perspectives of and problems in care for patients with endometriosis remains limited without the perspectives of clinicians.

Second, future research should examine patient-clinician interactions in real time to better understand the verbal and nonverbal communication that takes places that patients perceive as invalidating as well as the clinical actions of the clinicians. In addition to observing these interactions, it is critical to ask patients to reflect on the interaction soon after it has transpired to achieve a more precise understanding of the language that is being used by clinicians as well as the behavior of clinicians in the consultation to map what specific discourse is invalidating and, just as importantly, what specific discourse is validating. It is also critical to ask clinicians to reflect on the interaction to describe what was transpiring during the times when invalidation was being perceived as occurring by patients, including a list of the clinicians’ differential diagnoses.
as well as a rating of their diagnostic uncertainty to elucidate whether invalidation transpires under conditions of uncertainty to avoid disclosing such uncertainty.

Third, it is important to examine symptom invalidation in other patient populations—especially those that are medically marginalized. It is likely that such findings will emerge for other difficult-to-diagnose or contested patient populations, such as those with Ehlers Danlos syndrome (EDS), fibromyalgia, irritable bowel syndrome (IBS), myalgic encephalomyelitis (ME/CFS), postural orthostatic tachycardia syndrome (POTS), long COVID, mast cell activation syndrome (MCAS), systemic lupus erythematosus (lupus), myasthenia gravis, and an array of other autoimmune conditions, especially those for which patients are primarily female. It is especially important that, unlike Phase I of this dissertation (analysis of patients’ open-ended responses), patients are asked to describe a memorable interaction with a clinician—either positive or negative—to reduce bias as well as learn what validating clinician communication looks like in the context of patients’ symptoms.

Fourth, the PSIS, though it proved to be valid and reliable, is a measure of cognitive/affective experiences of invalidation. It does not shed light on the specific verbal and nonverbal communication of clinicians that reportedly contributes to these cognitive/affective experiences of invalidation. It also does not shed light on the behaviors of clinicians that reportedly contribute to these cognitive/affective experiences of invalidation. To this end, it is quite nonspecific. As such, it would be deeply beneficial to understand the communication and behaviors of clinicians that reportedly lead to such cognitive/affective experiences of invalidation. Appreciating that invalidation occurs is
important, but what is equally important is if we can achieve an understanding of what kinds of communication lead to invalidation.

As such, the creation of one or more scales to gauge the communication behavior of clinicians that most often elicit such a reaction is warranted. In constructing this scale, it would be useful to use the specific message features uncovered in Phase II of this dissertation (analysis of patients’ open-ended responses) as well and develop sample items from the raw data analyzed in Phase II (analysis of patients’ open-ended responses). It is expected that invalidation presents in various ways based on the various message features uncovered in Phase II (analysis of patients’ open-ended responses). Using these as domains of invalidation—for example, invalidation of one’s symptoms associated with the illness, invalidation of the timeline associated with the illness, invalidation of—serves as a launching point for understanding the underlying structure of such a scale.

Fifth, it is important to note that symptom invalidation is similar to several other communication constructs that were not gauged in this survey. Related communication constructs include low verbal person-centeredness, hurtful communication, and (lack of) active empathic listening. Although in this dissertation the construct of symptom invalidation was adapted from the conceptual frameworks of invalidating environments and illness representations, drawing from these other communication-specific frameworks may also prove fruitful. Verbal person centeredness (VPC) (Burleson, 1994) refers to the degree to which messages “explicitly acknowledge, elaborate, legitimize, and contextualize the feelings and perspective of a distressed person” (Bodie et al., 2012, p. 3). Low VPC messages are messages that “deny the other’s feelings and perspective by
criticizing or challenging their legitimacy, or by telling the other how to act and feel” (Burleson, 1994, p. 3). Legitimacy is indeed at the heart of invalidation, as something that is deemed not valid is also deemed not legitimate.

Hurtful communication is considered communication that results in hurt among the receiver, with *hurt* being defined as a specific emotion that results from an emotional injury (Folkes, 1982; L’Abate, 1977). In other words, “People feel hurt when they believe that another individual, or group of individuals, communicated or behaved in a way that caused them emotional pain” (Vangelisti & Hampel, 2010). Hurt is one emotion that patients feel when they have been invalidated (e.g., Cox, Henderson, et al., 2003; Denny, 2009).

One last related construct is AEL, which has been defined as “the active and emotional involvement of a listener during a given interaction—an involvement that is conscious on the part of the listener but is also perceived by the speaker” (Bodie, 2011, p. 278). Listening is critical in diagnostic consultations, especially during the history of the presenting illness portion of the appointment.

All three of these constructs do not yet have a corresponding self-report measure that has been developed for the patient-provider context. Validating a scale for each of these constructs in the patient-clinician context may prove beneficial.

Lastly, a more robust way to test the sequelae of symptom invalidation is to develop measurement items reflective of the sequelae the systematic review demonstrated. In Phase IV (secondary analysis testing the association between invalidation and negative sequelae), such investigation was done as a secondary analysis of items from the cognitive/affective subscale of the Institutional Betrayal in the Medical
System (Tamaian & Klest, 2018), which did not encompass all the sequelae identified in the review in Phase I (the systematic review of negative sequelae of invalidation) nor did it precisely map on to the sequelae that were uncovered during the systematic review. Asking patients more intentionally about their experiences with the sequelae identified from Phase I (the systematic review of negative sequelae of invalidation) and with question items generated specifically for this purpose is recommended to develop a more precise understanding of the effects of symptom invalidation.

**Conclusion**

I saw the same GYN for about 3 years and she constantly pushed various birth controls on me. After about the 5th different one, I decided to make an appointment to try to see other options. I always explained my symptoms and she always brushed it off as my body just trying to regulate itself with my cycle and that maybe the birth controls weren’t strong enough. So when I made a new appointment, the other doctor from the practice was the only one available. After meeting with him once, explaining my symptoms and how many different forms of birth control I had tried, he instantly suggested endometriosis. I was scheduled for surgery approximately 10 days later and my diagnosis was confirmed.

This excerpt is different from the excerpt provided in the introduction in two important ways. At the end of the excerpt, a diagnosis was made, and a diagnosis was made via the simple yet perhaps taken-for-granted act of communication. The clinician in this excerpt reportedly did not have to utilize technology and state-of-the-art equipment to diagnose this patient—all he did was listen as the patient shared with him her story. After all, it was the great physician, Sir William Osler who said, “Listen to your patient; he is telling you the diagnosis.” There is hope that this reported interaction with this clinician becomes the standard of care for patients presenting with endometriosis symptoms.

Reflecting on this dissertation, we have learned that invalidation can lead to negative sequelae, such as negative affect, negative self-esteem, depression, and suicidal
ideation among others. We also learned that many of these sequelae are related to each other and as such, the psychological fallout is complex, the nuance of which must be fully appreciated to understand the outcome processes of invalidation.

We also learned that we can measure the construct of invalidation in a reliable and valid manner. Using the developed scale, we learned that interactions emblematic of invalidation lead to outcomes similar to the negative sequelae described in the literature, such as being scared/terrified (in the case of healthcare-related anxiety or trauma as an outcome), being less trusting of the medical system (in the case of loss of trust in clinicians), being angry (in the case of frustration and anger toward specific clinicians, clinicians generally, or the broader healthcare system), and being cautious and reluctant to seek further medical care (in the case of delays, break, or terminations in care).

Overall, we have explored and interrogated many patients’ accounts of symptom invalidation. We have borne witness to these experiences. Nikunen (2019) distinguishes between the practice of sharing and witnessing. The latter constitutes a level of moral engagement that can be a consequence of lived or felt experiences. She states, “Witnessing refers to the act of seeing something important and bearing responsibility to something that one has seen” (p. 94). Indeed, this dissertation allows for such witnessing and an ultimate appreciation of the stories that were encountered. It is first through witnessing these stories that we can advocate for these patients who have been invalidated and whose lived experiences have been so readily denied to them.
APPENDICES

Appendix A: Sample Study Recruitment Email

Sample Recruitment Email

Dear [endometriosis organization],

My name is Allyson Boniempo, and I am a doctoral student studying health communication at Rutgers University in New Brunswick, NJ. I am interested in helping other women with endometriosis through various research efforts and health campaigns.

As part of my studies, I am conducting a brief, anonymous, online survey on endometriosis. This study is really going to try to get at the heart of patient-provider interactions with which endometriosis patients are unsatisfied, focusing on patients’ reports of what exactly is being said by providers that is dismissive, invalidating, etc. (important for future provider communication intervention efforts), the process by which such communication by providers can adversely affect patients’ mental health (to try to make the case that there are negative consequences of such physician communication behavior, and why this should be taken seriously), and the impact of endometriosis on romantic partners. Participants will have the opportunity to enter their email in a draw for a chance to win one of six $25 Amazon gift cards.

If feasible, I am very interested in recruiting participants through [endometriosis organization]. We have an image with overlayed recruiting text that can be posted on [endometriosis organization]-associated websites and/or social media sites such as the [endometriosis organization] Facebook page.

Please let me know if you have any other questions. I very much look forward to hearing from you.

Sincerely,

Allyson C. Boniempo, M.C.L.S.
Appendix B: Study Recruitment Material

Endometriosis Patients Wanted for Research Survey

Rutgers University is seeking endometriosis patients both in the US and international to participate in a brief (30-minute max.) and anonymous IRB-approved online survey regarding the dismissal or invalidation of your medical symptoms that you may have experienced by healthcare providers and/or your romantic partner, and how this invalidation may be related to your physical and mental health. We are very interested in your experiences and struggles as patients. Subjects will have the opportunity to enter their email in a drawing for a chance to win one of six $25 Amazon gift cards.

To participate in this study, you must:

- Be at least 18 years of age
- Have a diagnosis of endometriosis

If you meet these criteria and would like to participate, please access the survey at:

[survey link here]

If you would like more information, please contact Allyson Bon Tempo at:

allyson.bontempo@rutgers.edu

School of Communication and Information, Rutgers University
4 Huntington Street, New Brunswick, NJ 08901
Appendix C: Study Consent Form

CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: Invalidation of Medical Symptoms by Healthcare Providers and Partners of Individuals with Endometriosis
Principal Investigator: Allyson Bontempo, M.C.I.S., Email: allyson.bontempo@rutgers.edu

This consent form is part of an informed consent process for a research study and will provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. After all of your questions have been answered and you wish to take part in the research study, you will be asked to click on the “I Agree” button at the bottom of this page to continue with the study. If you decide not to continue with the study, just close this window or click “I do not Agree” at the bottom of this page.

Who is conducting this research study and what is it about?
You are being asked to take part in research conducted by Allyson Bontempo who is a graduate student in the School of Communication and Information at Rutgers University. The purpose of this research is to better understand a problem many endometriosis patients have reported regarding their interactions with physicians—patient-physician conflict. The purpose of this research is to closely examine physicians’ dismissal of endometriosis patients’ symptoms before endometriosis patients were diagnosed, as reported by patients, and to examine any relationship symptom dismissal may have with patients’ physical and psychological health outcomes. If you are involved in a romantic relationship, you will also be asked questions about the ways your romantic partner helps you cope with your diagnosis and the quality of your relationship.

What will I be asked to do if I take part?
The survey will take about 30 minutes to complete. We anticipate 300 subjects will take part in the study.

What are the risks and/or discomforts I might experience if I take part in the study?
The only foreseeable risks to participating in this study would be that some questions may make you feel uncomfortable. If that happens, you can skip those questions or withdraw from the study altogether. If you decide to quit at any time before you have finished the survey, your answers will NOT be recorded. If you are experiencing depression, anxiety, or another mental health issue and would like to seek live help or locate treatment services in your area, please contact the Substance Abuse and Mental Health Services Administration (SAMHSA) referral hotline at 1-877-SAMHSA (1-877-726-4372). Please note that this resource is free, anonymous, and available Monday through Friday from 8 a.m. to 8 p.m. EST.

Are there any benefits to me if I choose to take part in this study?
There are no direct benefits to you for taking part in this research. You will be contributing to knowledge about physicians’ dismissal of endometriosis patients’ symptoms before they were
eventually diagnosed, knowledge that will allow us to work toward addressing this problem in the future.

Will I be paid to take part in this study?
You will have the opportunity at the end of the survey to enter your email address into a drawing for a chance to win one of six $25 Amazon gift cards. The raffle will take place once the data collection process is complete, and winners will be emailed with the Amazon gift card code. Please note that your email address will not be linked to your survey data in any way.

How will information about me be kept private or confidential?
This research is completely anonymous. Anonymous means that the research records will not include identifiable information about you. You will be completing this survey in an online format and your responses will be stored on a secure server with no identifying information about you.

The research team and the Institutional Review Board (a committee that reviews research studies in order to protect research participants) at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. All study data will be kept for at least three years and will be destroyed upon the completion of publication of study results, as stated in the study protocol.

What will happen to information I provide in the research after the study is over?
The information collected about you for this research will not be used by or distributed to investigators for other research.

What will happen if I do not want to take part or decide later not to stay in the study?
Your participation is voluntary. If you choose to take part now, you may change your mind and withdraw later. If you do not click on the 'submit' button after completing the form, your responses will not be recorded. You may also choose to skip any questions that you do not wish to answer. However, once you click the 'submit' button at the end of the form, your responses cannot be withdrawn as we will not know which ones are yours.

Who can I call if I have questions?
If you have questions about taking part in this study, you can contact the Principal Investigator: Allyson Bontempo at allyson.bontempo@rutgers.edu. You can also contact my faculty advisor Dr. Jen Theiss at 4 Huntington Street, New Brunswick, NJ 08901, jitheiss@rutgers.edu, 848-932-8719. If you have questions about your rights as a research subject, you can call the IRB Director at: New Brunswick/Piscataway ArtsSci IRB (832)233-2866 or the Rutgers Human Subjects Protection Program at (973) 972-1149 in Newark.

Please print out this consent form if you would like a copy of it for your files.

If you do not wish to take part in the research, close this website address. If you wish take part in the research, follow the directions below:
By beginning this research, I acknowledge that I am 18 years of age or older and have read and understand the information. I agree to take part in the research, with the knowledge that I am free to withdraw my participation in the research without penalty.

Click on the "I Agree" button to confirm your agreement to take part in the research.
Appendix D: Study Survey

Demographics

The following questions ask you about some of your demographic information.

What is your age in years? ________

What is your biological sex?
- Male
- Female
- Transsexual

How would you characterize your sexual orientation?
- Heterosexual
- Lesbian
- Gay
- Bisexual
- Queer
- Other ________

What is your race/ethnicity? (mark all that apply)
- American Indian or Alaskan Native
- Asian
- Black or African American
- Hispanic or Latino/a
- Native Hawaiian or Pacific Islander
- White / Caucasian

What is your relationship status?
- Single/Never married
- Casually dating multiple partners
- Monogamously dating one partner
- Cohabiting
- Married or in a Civil Union
- Separated/Divorced
- Widowed

What is your educational background?
- Some high school
- High school diploma or equivalent (GED)
- Business/Trade/Technical school
- Some college/2-year degree
- College degree (BA, BS)
- Graduate degree (MA, MS, JD, MBA, PhD, MD)
What is your annual household income?
- < $10,000
- $10,000 to $25,000
- $25,001 to $40,000
- $40,001 to $75,000
- $75,001 to $100,000
- $100,001 to $150,000
- > $150,000

What kind of health insurance do you have?
- Employer-sponsored health insurance
- Health insurance through Affordable Care Act
- Medicare
- Medicaid
- None
- I live outside of the U.S.
- Other: ___________

Where do you live?
- Inside the U.S.
  - State of residence? ________________
- Outside the U.S.
  - What country? ________________

Endometriosis-Related Information
The following questions ask you about some of your endometriosis-related health information.

How long ago did your endometriosis symptoms start?
- _______ months/years

How long ago did you begin seeking medical care to look for a diagnosis for your symptoms?
- _______ months/years

Have you been given a definitive diagnosis of endometriosis through surgery (vs. endometriosis being suspected but not confirmed)?
- Yes
- No

How long ago did you receive your surgical diagnosis of endometriosis?
- _______ (months/years)

What stage was your endometriosis when you were first surgically diagnosed?
- Stage I
- Stage II
Stage III
Stage IV
Don't know/Don't remember

Were you given a diagnosis of endometriosis by a physician before you received your surgical diagnosis of endometriosis (e.g., your doctor suspected you had endometriosis)?

Yes         No

How long ago did you receive your suspected, non-surgical diagnosis of endometriosis?

__________ months/years

Have you ever had any of the following symptoms associated with your endometriosis? (Mark all that apply)

- Severe cramping
- Chronic pelvic pain
- Excessive bleeding
- Frequent bleeding
- Cysts
- Painful sexual intercourse
- Back pain
- Leg pain
- Bloating
- Constipation
- Diarrhea
- Nausea
- Painful bowel movements
- Rectal pain
- Blood in stool
- Frequent urination
- Painful urination
- Blood in urine
- Headache
- Fatigue
- Other

Do you have endometriosis-associated subfertility or infertility?

Yes         No

The following questions ask about your general physical health.

How would you rate your overall health?

Poor
Fair
Good
Very good
Excellent

How would you rate your average level of pain in the past 7 days from 0 (no pain) to 100 (worst pain possible)?
0---------------------------------------------------------------100

How would you rate your average level of fatigue in the past 7 days from 0 (no fatigue) to 100 (worst pain possible)?
0---------------------------------------------------------------100

What is your most bothersome endometriosis symptom?

How would you rate the average level of that symptom in the past 7 days from 0 (the best) to 100 (the worst)?
0---------------------------------------------------------------100

During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

_____ days
Physician Validation of Medical Symptoms

The following questions ask you about your interactions with doctors during your search for a diagnosis, as well as some questions related to that experience.

Please describe a specific interaction you had with a doctor that took place before your diagnosis of endometriosis in which your doctor said, implied, and/or did one or more things that you felt were dismissive of your endometriosis symptoms and/or you. As best you can, please include specifically what the doctor said. If there has been more than one interaction, please choose the most memorable. If there has not been a specific interaction that you had with a doctor in relation to this, please check “N/A” below.

N/A

What kind of health care provider was this?
- Primary care doctor
- Gynecologist
- Internist
- Nurse practitioner
- Other _______

How long ago did this interaction occur? _______ (months/years)

Was this conversation typical of the interactions you had with your physician(s) prior to your eventual diagnosis of endometriosis?
- Yes
- No

How many interactions similar to the one you just described occurred before your eventual diagnosis of endometriosis? (If you do not remember exactly, please give the best estimate.) _______ interactions

If this kind of interaction occurred more than once, over how many months and/or years did these interactions occur? (For example, you may have had four of these interactions with doctors over the span of three years.) _______

How long after this interaction did you receive your official diagnosis? _______ (months/years)

Thinking about the interaction you described above, how much do you agree or disagree with the following statements regarding this doctor’s treatment of your symptoms during this interaction?
1 = Strongly disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly agree

During your diagnostic consultation with this doctor:
1. My doctor did not dismiss my symptoms.  R
2. My doctor passed my symptoms off.
3. My doctor took my symptoms seriously.  R
5. My doctor rejected my symptoms.
6. My doctor validated my symptoms.  R
7. My doctor acknowledged that my symptoms were abnormal.  R
8. My doctor said there was nothing physically wrong with me.
9. My doctor said my symptoms were part of normal bodily functioning.
10. My doctor did not treat my symptoms as important.
11. My doctor believed my symptoms were real.  R
12. My doctor said my symptoms were psychological or somatic.
13. My doctor said my symptoms were not just anxiety.  R
14. My doctor said my symptoms were just depression.
15. My doctor said my symptoms were not just all in my head/mind.  R

Thinking about the interaction you described above, how much do you agree or disagree with the following statements regarding this doctor's treatment of you during this interaction?

1 = Strongly disagree  2 = Disagree  3 = Neutral  4 = Agree  5 = Strongly agree

During your diagnostic consultation with this doctor:

1. My doctor dismissed me.
2. My doctor did not pass me off.  R
3. My doctor did not take me seriously.
4. My doctor did not challenge me.  R
5. My doctor rejected me.
6. My doctor invalidated me.
7. My doctor treated me as important.  R
8. My doctor did not believe me.
9. My doctor listened to me.  R
10. My doctor did not hear me as I discussed my symptoms.
11. My doctor thought I was just anxious.
12. My doctor did not think I was just depressed.  R
13. My doctor implied I was crazy.

Thinking about the interaction you described above, please rate the extent to which this experience impacted you at that time.

0 = Not at all  1 = Slightly  2 = Somewhat  3 = Moderately  4 = Extremely

1. Made me feel betrayed.
2. Made me feel cautious about seeking care.
3. Made me feel reluctant to seek further medical care.
4. Made me feel angry.
5. Made me feel sad.
6. Made me feel hurt.
7. Made me feel disrespected.
8. Made me feel ignored.
9. Made me feel dismissed.
10. Made me feel disappointed.
11. Made me feel helpless.
12. Made me feel desperate.
13. Made me feel humiliated.
14. Made me feel ashamed.
15. Made me feel like the medical providers didn’t really care about me.
16. Made me feel scared/terrified.
17. Made me feel lonely/alone.
18. Made me feel guilty.
19. Made me feel disempowered.
20. Made me feel less trusting of the medical system.

The following questions ask you about the doctor’s behavior during the conversation you described above. Using the pairs of words below, please indicate how the doctor acted during that conversation.

| Helpful     | 1 2 3 4 5 6 | Hurtful     |
| Useful      | 1 2 3 4 5 6 | Useful      |
| Ignorant    | 1 2 3 4 5 6 | Knowledgeable |
| Selfish     | 1 2 3 4 5 6 | Generous |
| Supportive  | 1 2 3 4 5 6 | Unsupportive |
| Upsetting   | 1 2 3 4 5 6 | Reassuring |
| Comforting  | 1 2 3 4 5 6 | Distressing |
| Encouraging | 1 2 3 4 5 6 | Discouraging |
| Sensitive   | 1 2 3 4 5 6 | Insensitive |
| Heartless   | 1 2 3 4 5 6 | Compassionate |
| Considerate | 1 2 3 4 5 6 | Inconsiderate |
| Understanding | 1 2 3 4 5 6 | Misunderstanding |

How satisfied were you with the overall interaction you had with this doctor?
- Very dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Very satisfied

Symptom Uncertainty
Thinking about the interaction you described above, how much do you agree or disagree with the following statements regarding your uncertainty about your symptoms at that time?

1 = Strongly disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly agree
1. I suspected I had endometriosis.
2. This unknown aspect of my symptoms weighed heavily on my mind.
3. I had a lot of questions on my mind about my symptoms.
4. My uncertainty about my symptoms was relatively minor. R
5. I felt like I didn’t have a clear understanding of my symptoms.
6. The uncertainty I felt about my symptoms was prominent in my daily life.

Symptom Threat
Thinking about the interaction you described above, how much do you agree or disagree with the following statements regarding the threat of your symptoms at that time?

1 = Strongly disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly agree
1. I thought my symptoms were a serious threat.
2. I did not believe my symptoms were dangerous. R
3. I thought my symptoms were harmful.
4. I did not think my symptoms were life-threatening. R

Emotional Response to Diagnosis
The following statements ask you to reflect on how you felt after you received an official diagnosis of endometriosis from the doctor who diagnosed you. Please indicate how much you agree or disagree with each item.

1 2 3 4 5 6
STONGLY DISAGREE

STONGLY AGREE

At the time of my diagnosis, I felt...

Vindicated ............................................1 2 3 4 5 6
Relieved ..................................................1 2 3 4 5 6
Scared ....................................................1 2 3 4 5 6
Disappointed ...........................................1 2 3 4 5 6
Hopeful ...................................................1 2 3 4 5 6
Validated ...............................................1 2 3 4 5 6
Frustrated ...............................................1 2 3 4 5 6
Appreciative ..........................................1 2 3 4 5 6
Heartbroken ..........................................1 2 3 4 5 6
Valued ....................................................1 2 3 4 5 6
Important ...............................................1 2 3 4 5 6
Grateful ...................................................1 2 3 4 5 6
Angry ......................................................1 2 3 4 5 6
Rosenberg Self-Esteem Scale

Please record the appropriate answer for each item, depending on whether you strongly agree, agree, disagree, or strongly disagree with it.

1 = Strongly agree  2 = Agree  3 = Disagree  4 = Strongly disagree

1. On the whole, I am satisfied with myself.
2. At times I think I am no good at all.
3. I feel that I have a number of good qualities.
4. I am able to do things as well as most other people.
5. I feel I do not have much to be proud of.
6. I certainly feel useless at times.
7. I feel that I am a person of worth.
8. I wish I could have more respect for myself.
9. All in all, I am inclined to think that I am a failure.
10. I take a positive attitude toward myself.

Modified Medical Outcomes Study Social Support Survey (mMOS-SS)

If you needed it, how often is someone available...

1. To help you if you were confined to bed?
2. To take you to the doctor if you need it?
3. To prepare your meals if you are unable to do it yourself?
4. To help with daily chores if you were sick?
5. To have a good time with?
6. To turn to for suggestions about how to deal with a personal problem?
7. Who understands your problems?
8. To love you and make you feel wanted?

CES-D (Depression)

Please indicate your response based on how you have felt and behaved during the past week.

1 = Rarely or none of the time (<=1 day)
2 = Some or a little of the time (1-2 days)
3 = Occasionally or a moderate amount of the time (3-4 days)
4 = Most or all of the time (5-7 days)

1. I was bothered by things that don’t usually bother me.
2. I did not feel like eating, my appetite was poor.
3. I felt that I could not shake off the blues even with the help of my family or friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not get "going."
Appendix E: Study Debriefing Form

Thank you very much for taking the time to complete our survey! Your responses will help us to closely examine physician dismissal of endometriosis patients’ symptoms before patients are diagnosed, and any relationship this may have with physical and psychological patient health outcomes.

If you are experiencing depression, anxiety, or another mental health issue and would like to seek live help or locate treatment services in your area, please contact the SAMHSA referral helpline at 1-877-SAMHSA7 (1-877-726-4727). Please note that this resource is free, anonymous, and available Monday through Friday from 8 a.m. to 8 p.m. EST.

If you have any questions about the study or study procedures, you may contact myself at allyson.bontempo@rutgers.edu. You can also contact my faculty advisor Dr. Jen Theiss at 4 Huntington Street, New Brunswick, NJ 08901, jtheiss@rutgers.edu, 848-932-8719.

Please read below for additional opportunities.

☐ I would like to be entered into a raffle for a chance to win one (1) of six (6) $25 Amazon gift cards.
   As soon as we stop recruiting subjects for our survey, we will randomly select the email addresses of those subjects who choose to enter their information into the drawing. We will then email the winners to notify them, along with the gift card codes. Please click here to provide us with your email address if you would like to be included in the drawing. Please note that there will be no way to link your email address to your survey responses.

☐ I would like to receive a brief summary of the survey results when the study is complete.
   Please click here to provide us with your email address. Please note that there will be no way to link your email address to your survey responses.

☐ I would like to be notified of future studies to participate in.
   If you change your mind at a later time and would like us to remove it from our list, you may send Allyson an email. Please click here to provide us with your email address. Please note that there will be no way to link your email address to your survey responses.

Thank you so much for your time and for helping us to better understand your experiences and struggles.
## Appendix F: Codebook for Phase I Coding

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Label</th>
<th>Possible Codes</th>
<th>Notes / Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relevance Check</td>
<td>Relevance Check</td>
<td>0. Interaction is not relevant/codable 1. Interaction is relevant/codable</td>
<td>Initially, trim (and count) dataset for responses that: 1. Contain something along the lines of &quot;N/A,&quot; &quot;none,&quot; &quot;none before diagnosis,&quot; etc. 2. Are nonspecific/do not report on an actual interaction (&quot;I’ve had this happen to me,&quot; &quot;I’ve been dismissed by 9 doctors&quot;)</td>
</tr>
</tbody>
</table>

### ILLNESS REPRESENTATION INFORMATION

**Identity:** beliefs about the illness label and its accompanying symptoms

| Identity-Label | Does the HCP fail to acknowledge the patient’s beliefs regarding a) whether or not there is an illness label or, if not, b) what that label is (i.e., endometriosis)? | 0. No 1. Yes | Examples:  
- "Natropath 1 - prescribed breathing exercises and said "I don't have to have endometriosis""
- "Told me I was too young and low risk for anything major."
- "...when I brought up my adenomyosis symptoms, she said I was too young to have that..."  

**Note #1:** Explicit suggestions that symptoms are normal are coded here. These may be double coded with “external cause.” Examples of relevant language include periods ae “normal,” “meant to hurt,” are “supposed to hurt.” May reference “all women,” “most women,” or “some women.” May also include language such “there isn’t anything wrong,” “there’s nothing wrong.”  
- “Periods are meant to hurt”  
- “Period pain is normal” |

| Identity-Symptoms | Does the HCP fail to acknowledge the patient’s beliefs regarding the symptom(s) associated with the illness label/diagnosis? | 0. No 1. Yes | Examples:  
- “Current doctor said she has never heard of connection between endometriosis and fatigue.” |
<table>
<thead>
<tr>
<th>Symptom_experiences</th>
<th>Does the HCP fail to acknowledge the patient's beliefs regarding the presence, quality, location, and/or prioritization of the symptom(s) according to the patient?</th>
<th>0. No</th>
<th>1. Yes</th>
</tr>
</thead>
</table>

**Examples:**
- “...he blank face told me that back pain is not a gynaecological issue multiple times, even though I knew full well it is”
- “my previous obgyn kept telling me there is no link between my ovarian cysts to digestive issues”

**Note #1:** Comments about the presence or severity of pain that are made without also referencing some negative personality trait of the patient would be coded here, such as:
- "Didn't believe the amount of pain I was in"
- "The pain can't be that bad"
- She said 'I couldn't have that much pain (after laparoscopy) because there was only very little endometriosis seen"
- "Doctor was laughing and said “Periods are uncomfortable but hardly painful, take some paracetamol and you'll be fine”"
- "I was referred to a male gynaecologist who told me there was no possible way I could be having the symptoms or blood loss that I was having without being sick or looking ill”
- "No one believed I had endo until I became bloated enough that I was afraid I had ovarian..."
cancer, and even then the OBGYN who eyeballed me said “you’re not bloated”

<table>
<thead>
<tr>
<th>Secondary_gains</th>
<th>Does the HCP fail to acknowledge that the patient is experiencing symptoms AND is attributing that reason to a negative personality trait?</th>
<th>0. No 1. Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Examples:</td>
<td></td>
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<tr>
<td></td>
<td>• “The doctor told me I was exaggerating the amount of pain to get attention.”</td>
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<tr>
<td></td>
<td>• “I was told I was making it up for attention, and it is a common issue with spoiled women”</td>
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<td></td>
<td>• “More than once I entered an emergency room for severe pain and was treated as if I was lying/attempting to get opioids. I had a doctor insist that no matter how bad I “claimed” to be in pain, she would not give me painkillers so I should be more honest so she could “actually help” me.”</td>
<td></td>
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<tr>
<td></td>
<td>• “There were multiple interactions….”faking it to get off school”</td>
<td></td>
</tr>
</tbody>
</table>

Note #1: Instances in which respondents state “they told me I wasn't in pain” will remain coded as Id-Symptoms B because it is a generalized statement, but then once some negative personality trait gets pulled in (attention seeking, medication seeking, missing school), it would get coded as appointment reason.

**Cause: beliefs about the determinants of symptoms, as having both internal and external causes**

<table>
<thead>
<tr>
<th>Cause-External</th>
<th>Do the cause(s) or explanation(s) offered by the HCP regarding the patient’s symptom(s) refer to external attributions (i.e., “not patient’s fault”)? AKA: Is the cause or explanation something the patient does not have control over?</th>
<th>0. No 1. Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Examples:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• “I have had a doctor tell me that i had i.b.s, i had a doctor suggest that i had a sexually transmitted infection…”</td>
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<tr>
<td></td>
<td>• “Before diagnosis I was a teenager (diagnosed at 15). So my doctors assumed my pain was the stomach flu or at most a cyst”</td>
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<td></td>
<td>• “I was told that I had pelvic inflammatory disease caused by an STD.”</td>
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<tr>
<td></td>
<td>• “Told me it was related to muscle tension.”</td>
<td></td>
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<td></td>
<td>• “I remember a physician telling me that my global pain, back pain etc. might be due to wearing flat shoes.”</td>
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</tbody>
</table>
• “She told me I just had a hemorrhoid, which she couldn’t find.”

Note #1: References to menstruation, “bad” periods, etc., are coded here. If the response reports being told that “painful periods are normal,” the painful periods would be coded using this code and the reference to painful periods being normal would be coded under identity-label.

Note #2: If someone said “I came to my doctor with intense period pain and he said it’s normal”, don’t code because she is not framing the invalidation as one of causal misattribution -- she's said she came with period pain. But code as identity-label because she is indicating here that this is the invalidating experience, that her period pain was brushed off as being normal.

Note #3: External factors are things that the patient does not have control over. External reasons can include factors such as contagious disease, food poisoning, the weather, unavoidable accidents, bad medicine, chronic illness.

<table>
<thead>
<tr>
<th>Cause-Internal</th>
<th>Do the cause(s) or explanation(s) offered by the HCP regarding the patient’s symptom(s) refer to internal attributions (i.e., “patient’s fault”)? AKA: Is the cause or explanation something the patient does have control over?</th>
<th>0. No 1. Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>These may include explanations from the HCP regarding as to the reason why the patient was supposedly misunderstanding their symptom(s) or presenting to the HCP (e.g., a low pain threshold or tolerance, hypochondriasis, distorted thinking from depression, conversion disorder (i.e., physical manifestations of psychological pain), other psychiatric problems)</td>
<td></td>
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</tr>
</tbody>
</table>
so we believe she might be suffering some sort of mental health problem."

• "I have had doctors ask if I had a 'low pain threshold'"

• "Stated my pain during intercourse was due to...us not properly lubricating during intercourse."

• "...he told me my crippling pain was my fault for not eating breakfast and walked out of the room."

• "Told me that I must have anxiety that causes me to be more sensitive to pain"

Note #1: Informal suggestions and formal referrals to see a mental health specialist (psychologist, psychiatrist, counselor, therapist, social worker, etc.) should be coded here as "psychological" AND not concurrently under control/cure.

Note #2: Informal suggestions, unaccepted offers, and accepted offers for psychotropic medications (psych meds, mental health meds, SSRIs, etc.) should be coded here as "psychological" AND not concurrently under control/cure.

Note #3: Internal factors are things that the patient does have control over. Internal reasons can include factors such as not getting enough sleep, not taking care of oneself, poor eating habits, stress and nerves, substance abuse.

Note #4: To be included here are implicatures, even if something was not explicitly stated but a respondent says that a clinician "implied" something or "made them feel" a certain way.

• "Made me feel like a drug seeker"

• "Implied I was crazy and imagining pain"
### Timeline: beliefs about rate or age of onset of symptoms, expected duration (acute, episodic/cyclical, chronic) of symptoms, and expected rate of decline of symptoms

| Timeline | Does the HCP fail to acknowledge the patient’s beliefs regarding the course or timescale of the patient’s symptom(s)? | 0. No  
1. Yes  
Enter "-99" if nothing falls under this category. | **Examples:**  
**Generic:**  
- “The HCP didn’t acknowledge that my symptoms are chronic rather than just cyclical (with menstruation).”  
- “The HCP didn’t acknowledge that endometriosis can still exist post hysterectomy.”  
- “The HCP didn’t acknowledge that the pain is persistent.”  
**From dataset:**  
- “[I was told] Your periods don’t get worse as you get older”  
- When my father brought me back to his office [after surgery] a week later when I was dying in pain he told me he didn’t know what was causing it because he’d cured me.  
- “The pain was probably just a cyst. there’s nothing I can do about it, it’ll go away on its own most likely”  

**Note #1:** Comments about endometriosis/its symptoms persisting post hysterectomy are coded here and NOT under Identity-Label.

### Consequences: beliefs about the symptoms’ impact on life functions, including expected physical, cognitive, and social disruption

| Consequences | Does the HCP fail to acknowledge the patient’s beliefs regarding the impact of the symptoms on overall quality of life or how they may affect functional capacity? | 0. No  
1. Yes | **Examples:**  
- “It took me four months to get in for appointment, only to be turned away by the clinic’s doctor. Told me I was too young and low risk for anything major. I had been bleeding for seven months straight and in pain at this point.”  
- “The doctor brushed what I said off and did not take into consideration that I was having to call out of work and school due to the level of pain.”
• “And that he had a kidney stone once and passed out. So passing out from pain is no big deal and not an emergency.”
• “When I was 15 my primary care doctor told me that the cramps making me vomit and dizzy were “normal””

**Note #1:** If control/cure response efficacy is coded because the recommended management, treatment, or cure offered to the patient actively minimizes or invalidates the patient’s symptoms or their severity, DO NOT also code as consequences. Consequences is reserved more for reflections of functional capacity, etc.

<table>
<thead>
<tr>
<th>Control/Cure: beliefs about whether symptoms are preventable, curable, or controllable</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Control-Self-efficacy</strong></td>
</tr>
<tr>
<td>Does the HCP fail to acknowledge the patient’s beliefs regarding (a) whether and/or (b) to what degree their symptom(s) is/are curable or controllable via the performance of the coping behaviors?</td>
</tr>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td><strong>Control- Self-efficacy_TXT</strong></td>
</tr>
<tr>
<td>What is/are the coping behaviors offered by the HCP to address the patient’s symptoms and/or their misinterpretation of their symptoms?</td>
</tr>
<tr>
<td><strong>Examples:</strong></td>
</tr>
<tr>
<td>• “The HCP said I needed to learn to live with it.”</td>
</tr>
<tr>
<td>• “The HCP said I need not worry so much.”</td>
</tr>
<tr>
<td>• &quot;I was also told in the same appointment that…I needed to learn to deal with it because it really is not that bad!””</td>
</tr>
<tr>
<td>• &quot;I was also told…if I lost 10-20 pounds I’d probably get pregnant.”</td>
</tr>
<tr>
<td>• “The first doctor I went to see told me…that I needed to change my diet”</td>
</tr>
<tr>
<td><strong>Control-Response-efficacy</strong></td>
</tr>
<tr>
<td>Does the HCP fail to acknowledge the patient’s beliefs regarding (a) whether (b) to what degree their symptom(s) is/are curable or controllable via the efficacy of having performed the</td>
</tr>
<tr>
<td>1. Yes</td>
</tr>
</tbody>
</table>
coping behaviors, and/or (c) a willingness to prescribe a management or treatment option desired by the patient?

| Note #2: Suggestions for pregnancy are always coded, even without any context. |
| Note #3: In cases when the patient writes only what management, treatment, or cure option was recommended (even if it was perceived as problematic), do NOT code as control/cure - response efficacy because there is not enough information to determine whether the patient is merely reporting on HCP incompetence or HCP invalidation (or both). |
| Note #4: There are patient comments where it may seem that they're dissatisfied with getting strong meds (e.g., opioids). We can also see this when they say "just." For these, they are dissatisfied with having medication "thrown at them" without the clinician looking into the root cause. If the latter part is not stated ("they weren't trying to get to the root cause"), only code under response efficacy. |
| Note #5: If a respondent writes in "just" (or "simply" or "only", etc.) before whatever the recommendation is, we can assume that it's | indication ("eat broccoli" vs. "get a hysterectomy"), where the latter may not be accurate but is not actively minimizing or invalidating their symptoms) or (b) are not practical solutions that can realistically manage/treat/cure the symptoms either in and of itself or by virtue of not taking into consideration the larger biopsychosocial context of the patient ("get pregnant" when having been already trying to get pregnant for 3 years (vs. get a hysterectomy", where the latter may not be accurate of considerate of the patient’s biopsychosocial context (e.g., but it is treatment option nonetheless). |
invalidating since it’s an indicator that whatever is being discussed is insufficient or inadequate.

**Note #6:** Symptoms that persist after hysterectomy and laparoscopy are coded as timeline. However, these can be coded as response efficacy as well since it details the level of “curativeness” of these procedures.

<table>
<thead>
<tr>
<th><strong>Control- Response-efficacy</strong></th>
<th><strong>Text</strong></th>
<th><strong>Examples:</strong></th>
</tr>
</thead>
</table>
| **What is/are the management, treatments, or cures offered (or not offered or denied) by the HCP to address the patient’s symptoms and/or their misinterpretation of their symptoms?** | Enter “-99” if nothing falls under this category. | From dataset:  
- “The HCP said he didn’t want to do exploratory surgery on ‘someone so young.’”  
- “After my first surgery my HCP told me my best course of action would be to become pregnant (even though I’d been trying unsuccessfully to get pregnant for 3 years).”  
- “She recommended miralax and gave me no pain medication”  
- “My female primary care doctor would just say ‘some women feel more pain with their periods then others’ and push NSAIDS and birth control on me.” |

<table>
<thead>
<tr>
<th><strong>Investigative</strong></th>
<th><strong>Text</strong></th>
<th><strong>Examples:</strong></th>
</tr>
</thead>
</table>
| **Does the HCP fail to investigate or otherwise act on the patient’s symptoms?** | 0. No  
1. Yes | From dataset:  
- “I asked for further testing, which was deemed not necessary.”  
- “Honestly my biggest issue was that no dr prior to dx even bothered to ask questions about my pain. They knew I’d been hospitalized for pain, assumed a cyst burst each month and gave me rx nsaid…”  
- “Every time i would explain my excruciating pain, they would dismiss me and tell me i had a low threshold for pain. No one ever conducted any scans or tests…” Also then told me I was ‘expecting’ too much out of our
health care by wanting to further my search for an answer to my problems I was having.”

- “A separate gyn doctor just prescribed BC pills without looking further into the pain”

**Note #1:** These may include reports of the HCP failing to perform comprehensive questioning of the history of the symptoms, a pelvic exam, or other diagnostic testing.

**Note #2:** There are patient comments where it may seem that they’re dissatisfied with getting strong meds (e.g., opioids). We can also see this when they say “just.” For these, they are dissatisfied with having medication “thrown at them” without the clinician looking into the root cause. If the latter part is not stated (“they weren’t trying to get to the root cause”), do NOT code as investigative but instead as response efficacy.

### DIAGNOSTIC TESTING

<table>
<thead>
<tr>
<th>Diagnostic Testing</th>
<th>When, in terms of diagnostic testing/medical investigation, did the patient explicitly report this interaction occurred?</th>
<th>0. No diagnostic testing/medical investigation performed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Misalignment reported before diagnostic testing/medical investigation</td>
<td>1. Misalignment reported before diagnostic testing/medical investigation</td>
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<tr>
<td></td>
<td>2. Misalignment reported after diagnostic testing/medical investigation</td>
<td>2. Misalignment reported after diagnostic testing/medical investigation</td>
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<tr>
<td></td>
<td>3. Diagnostic testing/medical investigation implied (i.e., they report having a</td>
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<tr>
<td></td>
<td>Note #1: A manual pelvic exam is the standard of care for annual visits and thus does not count as diagnostic testing.</td>
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<tr>
<td>Diagnosis</td>
<td>Are post diagnosis</td>
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<td>-----------</td>
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<td></td>
</tr>
<tr>
<td>Enter &quot;-99&quot; if diagnostic testing/medical investigation not explicitly reported</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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