

**Understanding the Lived Experiences of Women with Interstitial Cystitis (IC):
A Qualitative Study of Women's Sexual Experience**

Hannah Richardson

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Supervisor: Dr. Peggy J. Kleinplatz

Faculty of Education
University of Ottawa

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Abstract

Women who complain of pain related to the urinary bladder, with persistent urges to void and increased urinary frequency, often endure years of invasive investigations to receive the label of interstitial cystitis (IC), an “orphan disease” which has no known cause and no known cure. Despite women’s reports, the existence of IC as a medical condition is still questioned. Few studies have aimed to explore the sexual experiences of women dealing with the lengthy diagnostic process and “treatment” of IC. The general experience of women dealing with this condition has been linked to themes of diagnostic uncertainty, limiting life, self-management and negative effects on interpersonal relationships. The current research aimed to understand the lived experiences of women with IC as they relate to their sexuality and their lives in general. Ten key informants, that is, women who had been diagnosed with IC were recruited to participate in individual, semi-structured interviews. Research team members used an iterative process of reviewing interview transcripts to uncover common themes of participant experiences. The current findings indicate the adverse experiences of women dealing with IC, which were linked to themes of negative physician-patient interactions, severely limited sexual relationships, restricted quality of life and the necessity for self-management of symptoms. These findings are relevant for how physicians fail to consider, discuss and prioritize the sexuality of women with bladder pain.

Keywords: phenomenology, interstitial cystitis, sexuality, women

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Understanding the Lived Experiences of Women with Interstitial Cystitis (IC): A Qualitative Study of Women's Sexual Experience

Introduction

Interstitial cystitis (IC) is a term unfamiliar to many people and its existence as a medical condition is questioned today. Women who complain of pain related to the urinary bladder, with persistent urges to void and increased urinary frequency wait years to receive a label of a medical condition called interstitial cystitis, which has no known cause and no known cure. Women with IC are told frequently that they have different diagnoses including recurrent urinary tract infections, hypersensitive bladder, vulvodynia, dyspareunia, chronic pelvic pain, endometriosis or painful bladder syndrome (Skove et al., 2019). Women with IC must advocate for themselves, undergo uncomfortable diagnostic tests and are told that their symptoms are all in their head, leading to feelings of isolation and self-stigmatization (Rabin, 2001). While there are several diagnostic tests used for IC including urinalysis, urine culture, potassium sensitivity testing and such invasive procedures as cystoscopy and biopsy of the bladder, none of these tests can diagnose IC definitively (Hanno et al., 2011). Because there are no specific diagnostic criteria for IC, the diagnosis is made after other conditions have been excluded (Skove et al., 2019). This condition does not fit into the medical model with a definite etiology, diagnostic testing, treatment or disease course (Gillenwater & Wein, 1988). Consequently, patients are stigmatized frequently by their physicians (King et al., 2003; Volpe et al., 2021). This stigmatization can lead to significant delays in “diagnosis” and “treatment”.

Despite treatment advances and research progress, the lived experiences of women with IC remain poorly understood. IC is defined by the Canadian Urological Association's (CUA) 2016 guidelines as “an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms for more than six weeks

duration, in the absence of infection or other identifiable causes” (Cox et al., 2016, p. E136).

Common symptoms of IC include pelvic pain, pain in the genitals/genital area, urinary urgency and frequency and pressure in the bladder (Hanno et al., 2015; Payne et al., 2007).

IC has been linked to increased levels of sexual dysfunction in various quantitative studies and a few qualitative studies (Azevedo et al., 2005; Gardella et al., 2011; Hung et al., 2014; Lee et al., 2015; Ottem et al., 2007; Volpe et al., 2021). IC has been linked to dyspareunia (i.e., pain during or following sexual intercourse; Schultz et al., 2005), altered sexual desire and orgasm frequency and insufficient lubrication (Gardella et al., 2011; Gupta et al., 2015; Hung et al., 2014; Lee et al., 2015; Ottem et al., 2007). Sexual dysfunction among female patients has been reported to affect their quality of life negatively but IC pain and diminished sexual functioning have not been a target of medical treatment (Azevedo et al., 2005; Bogart et al., 2011). Despite this growing link, few studies have examined the relationship between sexual functioning and IC using qualitative methodology, with many studies measuring sexual functioning primarily through self-report questionnaires like the Female Sexual Functioning Index (FSFI; Rosen et al., 2000) or with unvalidated measures (McKernan et al., 2018; Mellado et al., 2019). This type of research may not be capturing accurately the individual complexities associated with IC and could be painting a narrow picture of how IC affects individuals’ sexuality.

A particular phenomenon that has yet to be investigated concerns the lived experiences of women with IC in relation to their sexuality. The way people experience and express their sexuality is “different for each individual and can be influenced by biologic, psychological, social, cultural and religious factors” (Southard & Keller, 2009, p. 213). Sexuality has been defined inconsistently in the literature according to a recent systematic review by Macleod and McCabe (2020), with a commonly cited definition being, “a central aspect of being human

throughout life [that] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction” (WHO, 2017).

Understanding the lived experiences of women with IC in relation to their sexuality could help patients, the community and physicians gain a deeper understanding of the psychological and physical effects that IC has on women’s sex lives and identify the individual complexities associated with this condition. Furthermore, the information gathered from exploring the lived experiences of women with IC may aid physicians in implementing specific assessments and interventions for this population. This qualitative research study aimed to explicate the experiences of women with IC to readers who are unaware of IC and its effects on sexuality and to future patients who might consider seeking care for this condition.

In the Literature Review, previous studies on IC and the lived experiences of individuals with IC are summarized. First, I describe sexual dysfunctions and the etiology of sexual dysfunctions. Next, I describe literature on the psychosocial effects of IC and current qualitative studies examining the lived experiences of individuals with IC. Finally, I provide the purpose statement and justification for this study along with the main research question.

In the Methods section I outline the methods used to conduct this study. This section includes a description of descriptive phenomenology and why this method of research was chosen. I outline the participant recruitment process and the interview prompts that were used to elicit participants’ experiences. Finally, I outline the process of uncovering the emerging themes.

In the Results section I summarize participants’ characteristics and information about their experiences with IC. I outline and describe the main themes and subthemes that emerged to describe participants’ experiences. The descriptions are accompanied by direct quotes (i.e., rich text) from participants to illustrate their experiences.

In the Discussion section I discuss the results of this study along with contributions to the

literature, clinical implications, limitations, strengths, directions for future research and the conclusion.

Literature Review

Sexual Dysfunction

In the *DSM-5*, sexual dysfunctions are described as “a clinically significant disturbance in a person’s ability to respond sexually or to experience sexual pleasure” (APA, 2013, p. 423). These include difficulties in experiencing sexual desire, sexual arousal and/or orgasm. In the *DSM-5* the following sexual dysfunctions are identified for women: female orgasmic disorder (i.e., female anorgasmia), female sexual interest/arousal disorder, genito-pelvic pain/penetration disorder, substance/medication-induced sexual dysfunction, other specified sexual dysfunction and unspecified sexual dysfunction (APA, 2013).

Etiology of Sexual Dysfunctions

In the *DSM-5*, it is suggested that there are several factors (i.e., partner factors, relationship factors, individual vulnerability factors, psychiatric comorbidity or stressors, cultural/religious factors) that can impede sexual functioning, including medical factors relevant to prognosis, course or treatment (APA, 2013, p. 423). It is important to note that a combination of these factors can induce sexual dysfunction but for the purposes of this study, sexual dysfunction experienced as a result of IC is the focus.

Sexual Dysfunction in IC

Most studies examining the sexual functioning of women with IC have demonstrated a higher prevalence of sexual dysfunction among women with IC compared to women in the general population (Tonyali & Yilmaz, 2017). The physiological underpinnings of IC have not been established, though several mechanisms have been proposed in recent research.

Inflammation, urothelial dysfunction, mast cell activation and autoimmunity are thought to act in disease pathogenesis (Tonyali & Yilmaz, 2017; Rubin & Malphrus, 2018).

A population-based representative survey called the RAND Interstitial Cystitis Epidemiology Study, demonstrated that compared to 43% of the general population, 88% of women with IC reported one or more symptoms of sexual dysfunction (Bogart et al., 2011). Women in this study (N= 1469) responded over the phone to measures of IC symptoms, sexual behaviour and dysfunction and physical and psychological health (Bogart et al., 2011). Women reported higher rates of sexual dysfunction, including difficulties with libido, arousal and orgasm. Despite having a high prevalence of sexual difficulties, the majority of women did not seek medical help for these symptoms (Bogart et al., 2011).

Gardella and colleagues (2011) conducted a case control study examining the prevalence of sexual dysfunction and vulvodynia among 47 women with IC and 188 age-matched controls. The rates of spontaneous or provoked vulvodynia among women with IC were 23% and 74%, respectively. The rate of dyspareunia was significantly higher in IC patients compared to controls (87.2 vs. 5.9%) and 23% of women with IC, as compared to 9% of controls, reported no sexual activity in the year preceding the study (Gardella et al., 2011).

Other studies have found that women with IC report higher levels of dyspareunia, pelvic pain, fear of pain during intercourse and lower levels of sexual desire and orgasm compared to women without IC (Lee et al., 2015; Ottem et al., 2007; Peters et al., 2007; Yoon & Yoon, 2010). In summary, the majority of studies to date have demonstrated that IC affects women's sexual functioning negatively (Kirkham & Swainston, 2022). However, these studies have focused on quantifying the elements of this condition (i.e., through self-report measures) rather than exploring the nuanced experience of this condition using rich, detailed interviews to elicit detailed description. No qualitative studies to date have aimed to examine the broader effects of

IC on women's sexuality. To address this, the current research explores the lived experiences of women with IC with a focus on their sexuality.

Qualitative Studies

Only four qualitative studies to date have investigated the lived experiences of women with IC. These qualitative findings illustrate the complex nature of women's experiences and the physical and psychological effects of IC on women's daily lives.

Linton (2007) investigated the general lived experiences of women with IC. Five women were interviewed using an unstructured approach and were asked "What is it like to live with IC?." Their descriptions revealed the following eight themes: (1) unpredictable course of the disease, (2) changing sense of self and self-esteem, (3) pain, (4) loss of employment and income, (5) being dismissed and discounted by others, (6) social isolation, (7) depression and suicidal ideation and (8) becoming empowered.

Kirkham and Swainston (2022) conducted a phenomenological research study exploring the lived experiences of women with IC/painful bladder syndrome (PBS). Twenty women with IC were asked to e-mail in a written account of their experience of living with IC and were asked "Please describe your experience of IC" (no prompts were given). The transcripts were analyzed using thematic analysis (Braun & Clarke, 2019) and revealed the following four core themes: (1) diagnostic uncertainty (i.e., diagnostic delay, increasing frustration), (2) restrictions and limitations on life (i.e., the loss of a normal life, effect on activities of daily living), (3) self-management (i.e., researching options, trial-and-error) and (4) interpersonal relationships and social support (i.e., painful experiences during sexual intercourse, loss of intimacy within sexual relationships and the understanding of others about their condition and the limitations it brought).

Chien and colleagues (2023) conducted a descriptive phenomenological study examining women's life experiences with IC. Four major themes were identified: torment, restriction, acceptance and empowerment. Women in this study endured physical and psychological distress and loneliness, experienced obstacles and limitations in daily living because of their symptoms, accepted reality and considered their symptoms as a part of everyday life and developed coping strategies for IC (Chien et al., 2023). Unlike the experiences of IC patients documented in other studies, the authors found that most women believed that only medical professionals could understand women's suffering as compared to family and friends. In addition, the authors indicated that women obtained self-care information primarily from medical professionals. The authors highlighted the importance of considering cultural factors when caring for patients with IC and indicated that these findings may be attributable to differences in referral systems used in different countries (Chien et al., 2023).

Gonzalez and colleagues (2023) conducted a digital ethnography study examining women's experiences with IC. The following themes emerged from their qualitative analysis: online community engagement, triggers and disease etiologies, medical comorbidities, effects on quality of life, patient experience with medical care and alternative therapies and self-management strategies (Gonzalez et al., 2023). Gonzalez and colleagues (2023) found that women with IC had to manage their symptoms on their own and utilized strategies including acupuncture, homeopathy, pelvic floor physical therapy, elimination diets, hot baths and medical marijuana. Women who engaged with online communities connected with peers who gave them guidance and information about self-management strategies and IC diagnosis, symptoms and treatment (Gonzalez et al., 2023).

Psychosocial Effects of IC

In the literature thus far, IC has been understood as a biopsychosocial disorder, whereby biological (physiological), psychological and social factors interact to produce the symptoms experienced in IC (Cashman & Biers, 2018; Dellis et al., 2019; Tripp, 2018). A number of psychosocial factors such as comorbid depression, anxiety, quality of life and trauma-related symptoms have been shown to “accompany and intensify” IC (McKernan et al., 2018, p. 2) and be implicated in the experience of IC (Doggweiler et al., 2017; Malde et al., 2018; Windgassen & McKernan, 2020). Most studies published on IC have focused on its pathophysiology, symptom presentation and physiological treatments targeted at symptom control (McKernan et al., Mellado et al., 2019; Pazin et al., 2016). Although there is an emerging body of research that has begun to examine the psychosocial effects of IC, many of these studies gain data through self-report measures, rather than aiming to understand the personal and individual experiences of individuals living with IC through qualitative analysis and inquiry. Inconsistent terminologies and disease classification have slowed research progress in this regard (Windgassen & McKernan, 2020). A systematic review by McKernan and colleagues (2018) identified only 34 articles that have examined the psychosocial factors affecting individuals with an IC diagnosis.

The predominance of psychological research in the field of IC has focused on assessing employment status (Beckett et al., 2014), anxiety and depression (McKernan et al., 2018), sexual functioning (Bogart et al., 2011) and quality of life (Michael et al., 2000). IC has been linked to negative outcomes such as depression, anxiety, suicidal ideation, stress and sleep disorders – with these comorbidities exacerbating symptoms (Bosch & Bosch, 2014; Hepner et al., 2012; Tripp et al., 2016; Watkins et al., 2011).

Patients with IC report elevated rates of psychosocial comorbidity compared to individuals without IC (McKernan et al., 2018). These psychosocial factors as well as the burden

of symptoms can affect IC patients' physical, mental and day-to-day functioning such as travel, ability to participate in daily activities, sleep, diet and sexual functioning (Nickel et al., 2018; Vasudevan & Moldwin, 2017). In this study, there was a consideration of psychosocial factors (i.e., depression, anxiety, quality of life and trauma-related symptoms) that may be implicated, or affect, individuals' lived experiences with IC.

Depression

Individuals with IC have reported elevated levels of depression in both cross-sectional (Clemens et al., 2008; Hepner et al., 2012; Koziol et al., 1993; Magni et al., 1998; Meure, 2018; Tripp et al., 2016) and longitudinal (Crawford, 2017; Crawford et al., 2019; Tripp et al., 2018) studies. Many studies have found that women with IC are more likely to be diagnosed with depression than women in the general population and are more likely to experience suicidal ideation, feelings of helplessness and increased pain (Chuang et al., 2015; Clemens et al., 2008; McKernan et al., 2018; Novi et al., 2005). As of 2018, depression has been identified in up to 70% of IC cases, with female patients being two to seven times more likely to be diagnosed with depression than those in the general population (Chuang et al., 2015; Clemens et al., 2008; McKernan et al., 2018; Novi et al., 2005). Individuals with IC are at a higher risk of developing subsequent depression, anxiety and insomnia than those in the general population (Chuang et al., 2015; Novi et al., 2005). In addition, women with IC who have depression or panic attacks report heightened levels of pain and deteriorating physical and psychological functioning compared to women without depression or panic (Watkins et al., 2011). The presence of helplessness, a symptom of depression, has been associated with more severe psychological problems among IC patients (Tripp et al., 2009; Watkins et al., 2011).

Among general chronic pain populations, depression assessed at baseline has been linked to worse outcomes in pain, but it has been unclear whether baseline pain affects future depression

or what variables might mediate the relationship between pain and depression (Williams & Schäfer, 2016). Within IC populations, catastrophizing and depression have been associated with decreased physical and mental quality of life (Katz et al., 2017; Nickel et al., 2010; Tripp et al., 2009). In a study by Tripp and colleagues (2016), 190 women with IC and 117 members of the community without IC completed self-report measures of pain, depression, catastrophizing and suicidal ideation. Compared to 6% of controls without IC, 23% of women with IC endorsed suicidal ideation in the past two weeks (Tripp et al., 2016). This suicidal ideation was associated with greater pain and decreased psychological functioning (Tripp et al., 2016).

Anxiety

The majority of studies on anxiety and IC have assessed symptoms of anxiety through self-report measures, with two studies evaluating clinical diagnoses given during medical record review and one study using a structured and validated clinical interview assessing for the presence of an anxiety disorder (McKernan et al., 2018). As of 2018, the prevalence rates of anxiety symptoms among individuals with IC ranged from 14% to 52% (McKernan et al., 2018). Regarding diagnosed anxiety disorders, individuals with IC are four times more likely to have pre-existing anxiety disorders prior to developing IC (Chung et al., 2014) and are two times more likely to develop an anxiety disorder following an IC diagnosis (Chuang et al., 2015).

Weisman and colleagues (2004), wanted to determine whether patients diagnosed with IC and their first-degree relatives had an increased rate of panic disorder and panic attacks compared to patients without IC. Participants included 67 individuals with IC and 79 individuals with other urologic disorders and 815 first-degree relatives. Compared to patients with other urologic disorders, patients with IC had a significantly higher lifetime prevalence of panic disorder after controlling for age and sex (Weisman et al., 2004). More specifically, panic disorder was identified in 26% of cases, indicating that women with IC are four times more likely than those

with other urological diseases to develop panic disorder in their lifetime and have first degree relatives that have panic disorder (McKernan et al., 2018; Weisman et al., 2004).

Quality of Life

IC has been linked to decreases in numerous aspects of quality of life, including work productivity, emotional changes, sleep, sexual dysfunction and mobility (Vasudevan & Moldwin, 2017). Preliminary studies have demonstrated that female patients with IC report a lower overall quality of life compared to patients with end-stage renal disease (Hanno et al., 1990; Michael et al., 2000). In a comprehensive study on IC patients and quality of life, Michael and colleagues (2000) demonstrated that compared to healthy controls, individuals with IC scored lower across five of the seven health-related quality of life variables, including physical role, bodily pain, vitality, social functioning and psychological health (Michael et al., 2000).

Overall, both physical and mental quality of life are significantly affected among IC patients (McKernan et al., 2018). Decreases in health-related quality of life are exacerbated by deteriorating psychological health, sexual functioning, sleep hygiene, work productivity and mobility (Ahangari, 2014; Beckett et al., 2014; Michael et al., 2000; Vasudevan & Moldwin, 2017). There however, remains a paucity of research of a qualitative nature that has examined the psychological effects of IC on quality of life.

Trauma

Previous research has demonstrated a higher prevalence of abuse and historical trauma among individuals with IC compared to the general population (McKernan et al., 2016; Peters et al., 2007). McKernan and colleagues (2019) were the first to examine the prevalence of post-traumatic stress disorder (PTSD) among individuals with IC. Approximately 42% of individuals with IC met provisional diagnostic criteria for PTSD, which was significantly higher than a group of individuals with a general chronic pain condition (McKernan et al., 2019). Among the 42% of

individuals meeting provisional diagnostic criteria for PTSD, there were elevated rates of reported sexual abuse and childhood trauma. Compared to individuals with a general pain condition, individuals with IC reported poorer outcomes including higher pain severity, more emotional distress and decreases to their quality of life (McKernan et al., 2019).

Women with IC who have experienced childhood trauma have been more likely to experience symptoms of dissociation and heightened anxiety (Chui et al., 2017) compared to individuals with acute cystitis who have no history of childhood trauma. Preliminary research has suggested that among women with IC who have experienced sexual abuse, they report sensory pain (Nickel et al., 2011; Seth & Teichman, 2008), less daytime frequency and nocturia and larger voided volumes (Seth & Teichman, 2008) and difficulties with sexual functioning (Nickel et al., 2011; Seth & Teichman, 2008). These preliminary findings suggest a modest relationship between trauma exposure and heightened IC symptom and pain severity, however, few research studies have been conducted in this area (McKernan et al., 2018; Windgassen & McKernan, 2020). Although there are concerns of under-reporting with individuals who have experienced sexual trauma and abuse, it is recommended that trauma and abuse exposure be assessed and screened for in clinical settings such as public health clinics, community clinics, primary care settings, urgent care clinics or urogynecology clinics (McKernan et al., 2018). More research in this area is needed to expand the understanding of IC and trauma exposure.

Current Study

Purpose Statement

The economic burden of IC is substantial, costing health care systems upwards of \$750 million annually (McKernan et al., 2018; Payne et al., 2007). Current studies suggest that

between three to eight million American women have symptoms consistent with a diagnosis of IC (Berry et al., 2010; Konkle et al., 2012).

Both the Canadian and American Urological Associations (AUA) suggest that first-line treatments for IC should be non-invasive in nature and should be used to establish “symptom control and improve quality of life” (McKernan et al., 2020, p. 4). First-line treatments include patient education about IC, dietary modification, bladder training, pain management and stress management (McKernan et al., 2020). The AUA recognizes that there is a need for psychosocial interventions as first-line treatments for IC (Hanno et al., 2015). However, the interventions listed in the CUA and AUA guidelines have been difficult to implement in actual practice and are underutilized (McKernan et al., 2018). It is unknown if the recommended therapies listed in these guidelines (i.e., stress management/general relaxation, pain management, patient education, self-care/behavioural modification) meet patients’ needs sufficiently (Hanno et al., 2015; McKernan et al., 2018). Furthermore, there are a paucity of randomized controlled trials evaluating how these interventions work and for whom or how they might target certain consequences of IC, such as difficulties with sexual functioning (McKernan et al., 2018).

Despite treatment advances and research progress, the lived experiences of women with IC remain poorly understood. Although there has been some research that has examined the lived experiences of women with IC and the sexual functioning of women with IC, there is still much research to be conducted to explain the lived experiences of women with IC in relation to its effects on women’s sexual experiences. Furthermore, it is recommended that future studies focus on understanding patient experiences in the formulation, assessment and treatment of IC (Kanter et al., 2017).

Through an in-depth discussion of women’s lived experiences, the hope is that a detailed description about this condition and women’s journey to diagnosis will contribute to the

literature. Given that many women who undergo this journey are left feeling alone and stigmatized, the current study will contribute to the literature by identifying the common elements of women's experience with this isolating condition that is only diagnosed by exclusion. This study will be the first qualitative study conducted to date that has explored the lived experiences of women with IC with a focus on their sexuality. The purpose of this descriptive phenomenological study was to explore the lived experiences of women with IC. More specifically, this study explored the lived experiences of women with IC in relation to their sexuality and their lives in general. For the purposes of this study, I defined sexuality in any way the participants in the current study saw or defined their sexuality but considered how sexuality has been defined in the current literature (MacLeod & McCabe, 2020).

Research Question

The central question that was investigated in this study is as follows: What are the lived experiences of women with interstitial cystitis as they relate to women's sexuality and their lives in general?

Methods

Research Design

Descriptive Phenomenology

Descriptive phenomenology, informed by Husserl (1970), was used as the methodological framework for this study (Laverty, 2003; Lopez & Willis, 2004). Phenomenology refers to the study of lived experience (Polkinghorne, 1989). When adopting phenomenology as a research method, the researcher seeks to understand participant experiences about a particular phenomenon. In this study, the phenomenon is IC and the sexuality of women living with IC. Traditionally, researchers in phenomenological studies conduct in-depth interviews to collect

information about participants' subjective lived experiences of a phenomenon. The interviews are then transcribed, reviewed and analyzed in an attempt to understand the participant experiences (Lopez & Willis, 2004).

There are philosophical perspectives that are unique to descriptive phenomenology that shape how the research is conducted. Supporters of descriptive phenomenology hold that there are common elements, or essences, among all the individuals who experience a particular phenomenon, which are generally presented as themes (Lopez & Willis, 2004; Natanson, 1973). The purpose of descriptive phenomenological studies is to attempt to uncover and describe the common themes of the participant experiences with a particular phenomenon (Polkinghorne, 1983). The goal of the current study was to discover and come to an understanding of the lived experiences of IC related to women's sexuality and their lives in general. The process of uncovering these elements of experience consisted of reviewing and analyzing the participant narratives many times in an iterative process (Laverty, 2003; Lopez & Willis, 2004; Mahrer, 2004; Mahrer & Boulet, 1999; VanKaam, 1966). Direct quotes from the participant interview transcripts are presented as support for the emerging themes. The process of uncovering emerging themes for this study is outlined in more detail in the following section (see pages 20-23).

Descriptive phenomenologists believe that it is essential to try to achieve "transcendental subjectivity" or remain as unbiased as possible throughout the research process (Laverty, 2003; Lopez & Willis, 2004; Natanson, 1973). To achieve transcendental subjectivity, the researcher constantly and consciously attempts to shed preconceptions and personal biases about the phenomenon (Laverty, 2003; Lopez & Willis, 2004). This process is referred to as bracketing or epoche (Natanson, 1973). In bracketing, the researchers' previous thoughts, biases, presuppositions, assumptions, judgments and beliefs about a phenomenon are set aside in the

hopes of approaching the phenomenon from a fresh and naïve perspective (Husserl, 1970; Laverly, 2003; Osborne, 1994; Wertz, 2005). This is a process that involves, “suspending one’s judgement or bracketing particular beliefs about the phenomena in order to see it clearly” (Laverly, 2003, p. 23). The purpose of this is to allow the essence or structure of the participants’ experience to emerge with minimal influence from the researcher (Laverly, 2003; Lopez & Willis, 2004; Natanson, 1973).

To check and eliminate biases in this study, the researcher collaborated with others in this field to describe the emerging themes as outlined by VanKaam (1966). The biases of the researcher and team members were discussed and bracketed out – a technique that underlies the desire for scientific rigor when doing descriptive phenomenology (Laverly, 2003; LeVasseur, 2003). To attempt to bracket biases about the sexuality of women, the researcher and multiple members of the Optimal Sexual Experiences (OSE) Research Team of the University of Ottawa utilized an iterative process of discussion and returning to the data. The process of having the researcher and research team members constantly challenge one another was advantageous in identifying biases we might have had. This iterative process involved research team members meeting weekly to discuss potential emerging themes and returning to the data (Laverly, 2003; VanKaam, 1966). Finally, in an attempt to achieve confirmability of the results (Lincoln & Guba, 1985), the emerging themes were reviewed by another team member who was excluded from the weekly meetings, until the final stage. The processes of collaborative bracketing and having an external reviewer check is outlined in more detail in the following section (see pages 20-23).

Little is known or understood about people who have IC. It was essential to gain a better understanding of what individuals with IC experience to create more awareness of this condition. Therefore, descriptive phenomenology was an appropriate methodological approach for this study because it offered an open and exploratory approach to understanding individuals’

experiences. Descriptive phenomenology has also been shown to be useful in understanding patient experiences in health sciences and psychology (Arikan Dönmez et al., 2021; Heath et al., 2015; Lloyd et al., 2014; Lopez & Willis, 2004; Penner et al., 2012; Sundler et al., 2019). For example, phenomenology has been used to uncover peoples' experiences with sexual difficulties, optimal sexual experiences and other chronic pain conditions (Kleinplatz et al., 2013; Shallcross et al., 2019).

Participants

As there is no desire in descriptive phenomenological research to generalize to other populations or settings (Laverty, 2003; Lopez & Willis, 2004), the recruitment of a random sample of participants is neither desired nor advised. Rather, key informants, who have expert knowledge regarding the phenomenon being studied and who were able to describe their experiences thoroughly, were invited to participate (Moustakas, 1994; Polkinghorne, 1994). In the current study, the phenomenon was the sexuality of women living with IC or symptoms consistent with a diagnosis of IC. In order to participate in this research study, participants needed to (1) be able to read, write and speak English, (2) have a diagnosis of IC or symptoms consistent with a diagnosis of IC, (3) be willing to have their interview audio-recorded for data analysis purposes and (4) have access to a telephone or a computer. Ten women with IC were recruited to participate in the study (see Appendix A for recruitment statement).

Participants were recruited through online advertising. Information about the research study was distributed via email to online support groups for individuals with IC. The email contained an overview of the study and its procedures and was distributed within online support groups. Anyone interested in the study was asked to contact the researcher directly either via email or telephone to arrange an individual interview.

This sample size of 10 participants is consistent with recommendations from the literature. Polkinghorne (1989) recommends 5 to 25 participants and Dukes (1984) recommends 3 to 10 participants for phenomenological studies. A smaller sample size is recommended for phenomenological studies because of the detailed and time-intensive analysis required to describe the experiences of the participants (Smith et al., 2009).

Materials and Measures

This study required a computer or mobile device and an Internet connection to conduct the interviews. With informed consent, an audio-recording device was used to record the interviews to ensure accurate transcription and description of emerging themes. The semi-structured interview prompts (see Appendix B) were used during the interview to collect information from participants.

Interview Prompts

The principal method for gathering data in descriptive phenomenology is through the unstructured or semi-structured interview (Langdrige, 2007; Moustakas, 1994; Polkinghorne, 1994). The semi-structured interview was chosen as the method for collecting data for this study because in-depth interviews are considered an optimal way to understand individuals' lived experiences (Creswell, 2007; McCracken, 1988). In addition, it has been argued that semi-structured interviews may give participants more control over the interview process (Corbin & Morse, 2003). The current study's semi-structured interview protocol consisted of five open-ended questions with two specific prompts designed to invite women to talk openly about their experiences with IC and its effect on their sexuality. The researcher used additional prompts as needed to help participants clarify or elaborate on their experiences or to articulate their experiences and reflections more deeply (Smith et al., 2009).

Procedure

The following protocol was approved by the Research Ethics Board at the University of Ottawa in July, 2022. Semi-structured interviews were conducted by the researcher, Hannah Richardson, BA, between September and October of 2022. At the time of the study, the researcher was a female graduate student with previous training in descriptive phenomenological research methodology through a qualitative research class and as part of the OSE Research Team. The interviews were conducted using a version of Zoom that is compliant with the Personal Health Information Protection Act (PHIPA) and were audio-recorded with informed consent. Women were informed that the interviews would be audio-recorded for adequate analysis and that their identities would be protected using pseudonyms. Each participant chose her own pseudonym for protection of confidentiality. Participants read the Informed Consent document (see Appendix C). Then the researcher reviewed the document with the participants. Women were given the opportunity to make comments and/or ask questions about the informed consent document. Once informed consent was given by each woman, the researcher proceeded with the one-on-one interviews. The researcher then asked participants questions from the semi-structured interview protocol. Informed consent was additionally obtained verbally (1) prior to the audio recording of the semi-structured interview and (2) following the interview to see if participants would like to keep their data or withdraw from the study. Participants were informed that they could withdraw from the study at any time. Interviews ranged between 23 min and 63 min in duration (\bar{x} = 33 min).

Process of Uncovering Emerging Themes

An iterative and collaborative approach was employed for the current study, which is consistent with descriptive phenomenological research methods (Laverly, 2003; Lopez & Willis,

2004; Sundler et al., 2019; VanKaam, 1966). The study of the interview data was conducted within a research team of seven members at scheduled, weekly meetings. Eight team members from the OSE Research Team of the University of Ottawa worked together to uncover and identify the themes during the research process. Members of the OSE research team are all licensed therapists or graduate students under their supervision with a particular interest in sexuality research and/or therapy for sexual difficulties. The team members have been trained previously in this descriptive phenomenological method. This collaborative form of analysis is one of the ways to establish transcendental subjectivity in descriptive phenomenological analysis (Lavery, 2003).

This study utilized the process outlined by Van Kaam (1966) in which the researcher and the other experts (1) reviewed each other's codes and themes of the transcripts collaboratively, (2) discussed emerging codes and themes until consensus was reached, (3) wrote out the description or an initial list of emerging themes (4) applied the themes to other transcripts and (5) revised again collaboratively until consensus was reached about the final list of themes that fully, accurately and faithfully captured the participants' experiences. A total of eight members from the research team (including the researcher and the thesis supervisor) took part in the process. Seven members (including the researcher and the thesis supervisor) uncovered and described the emerging themes. In an attempt to establish confirmability, the remaining member of the team, who had not been involved thusfar in the weekly meetings, then conducted an external reviewer check to help revise the themes at the final stage of the process.

In the first stage of uncovering the emerging themes, each interview was transcribed verbatim by the researcher. The transcripts included verbal and non-verbal behaviour and emotion. All identifying information was removed from the transcripts. Initially, the researcher read and re-read each interview transcript many times to get a general sense of women's

narratives. Then, the researcher de-identified and distributed the confidential transcripts to the other six team members. Next, the researcher and the six team members read the first interview transcript independently to identify emerging themes associated with each unit of meaning in the transcript. The researcher and the six team members then met to describe their initial list of prospective themes from each unit of meaning in the first transcript. During the weekly meetings, seven team members shared their preliminary impressions as to the emerging themes. In order to build consensus while minimizing social influence (Asch, 1951), the sequence for offering input went from the least to most experienced team members. That is, the person newest to phenomenological research methodology spoke first. Each member provided input in order of (in)experience, from the least to most experienced. This sequence is designed to enable participation while allowing individuals to contribute candidly and reduce social pressures for unanimity. The seven team members asked each other questions, discussed and returned repeatedly to the transcript in an iterative process until a consensus was reached for each theme. The process for the first transcript was repeated for the first six transcripts. The first stage of the process was completed over the course of 10 meetings (20 hours).

During the next stage, the team members independently began to identify which emerging themes appeared from the first six transcripts. The team then read transcripts seven and eight to decide whether the emerging themes captured in transcripts one to six also captured the experiences in transcripts seven and eight as well. Over the next six meetings (12 hours), the themes were refined collaboratively by team members until a consensus was reached and an initial list of themes compiled.

In rare cases, when comments were considered to come from a place of bias or when there were disagreements related to the themes, the comments and themes were re-evaluated among the group in an iterative process by talking to one another and looking, again, at the transcripts until a

consensus was reached. This iterative process was utilized to reduce bias and allow the themes to emerge.

In the final stage of the process, the remaining team member who had not been involved in the first 16 weekly meetings, was given the last two de-identified transcripts and the initial list of emerging themes. This team member read and re-read transcripts nine and 10 to evaluate whether the list of emerging themes fully captured women's experiences. The purpose of this external reviewer check was to (1) attempt to achieve dependability, confirmability and credibility of the results (Lincoln & Guba, 1985), (2) identify any additional biases during the process and (3) help the team members revise and refine their understanding of emerging themes to bring women's experiences into clearer focus. This team member then brought their comments and questions about the list of themes to the other seven team members. Over the next three meetings (3.5 hours), the comments and questions about the themes were discussed among all eight team members until a consensus was reached. At this point, the list of emerging themes was finalized.

The team members had a total of 19 collaborative meetings (35.5 hours). The entire process was iterative and collaborative. The collaborative part of this process allowed team members to question each other's understanding of women's experiences to minimize biases. This process involved a continuous repetition of looking at each woman's experience in relation to the whole experience and looking at the whole experience in relation to each woman's experience. During this process, the team members looked for connections among the prospective themes to see which themes appeared together. During the process of theme refinement, the team members referred back to the themes and direct quotations from the transcripts to ensure that the themes were qualitatively different from one another. This collaborative and iterative process was

utilized to ensure that team members had captured women's experiences fully, accurately, and faithfully.

This collaborative process has been conducted in previous studies by the OSE Research Team (Kleinplatz & Ménard, 2007; Kleinplatz, Ménard, Paradis et al., 2009; Kleinplatz, Ménard, Paquet et al., 2009; Kleinplatz et al., 2013; Ménard et al., 2015; Rice et al., 2022, etc.). The collaborative process in all of these previous studies required considerable discussion and the constant iterative process of returning to the data, discussion and refinement until consensus was achieved.

Results

Participants

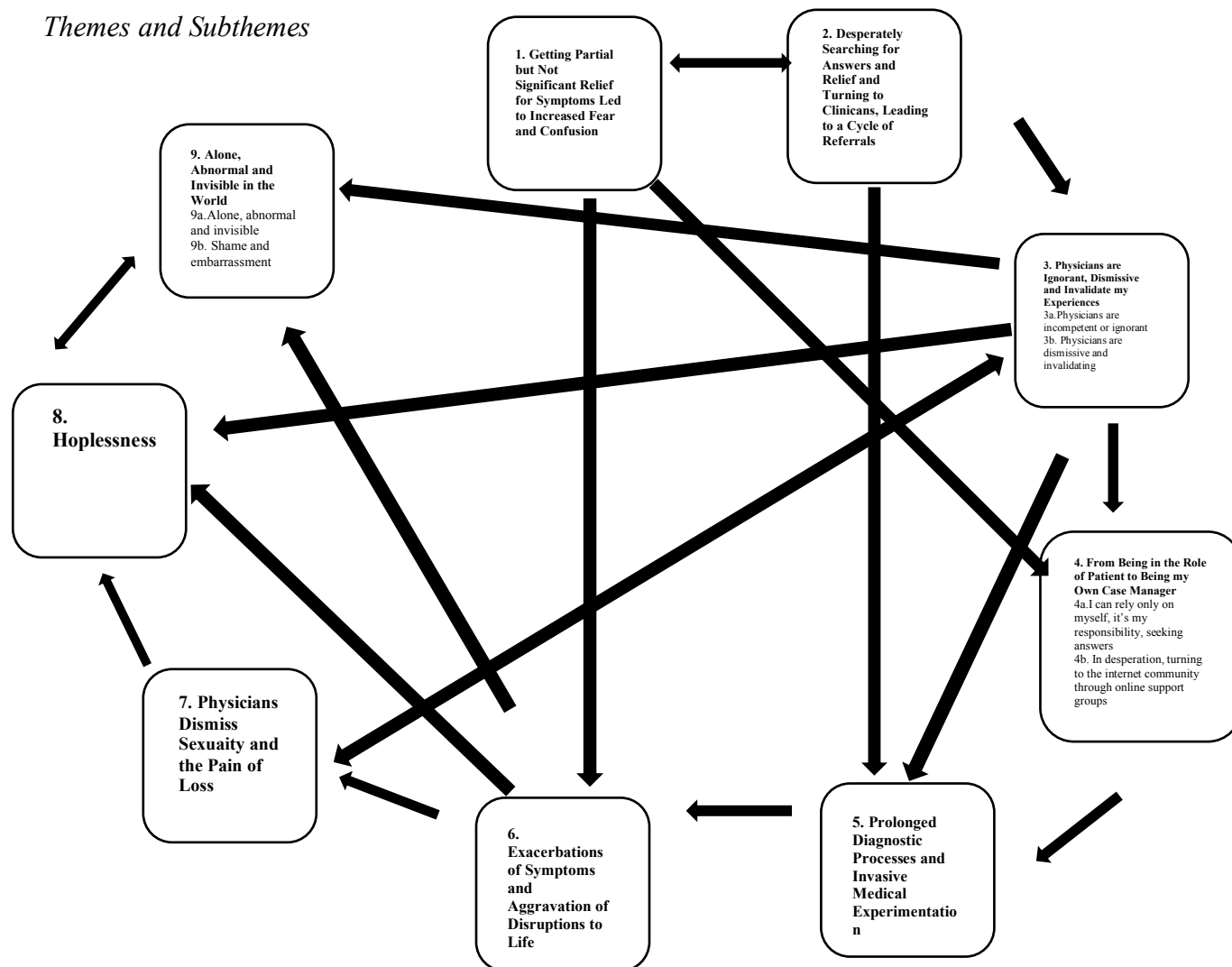
Ten women who were diagnosed with IC or who had symptoms consistent with a diagnosis of IC were selected for the current research. Women from North America were recruited as participants through social media platforms and social media groups. The age range of participants was 23 to 40 years, with an average age of 29. All 10 participants were in relationships. Five participants were married and one participant was engaged. Women had symptoms of IC or symptoms consistent with a diagnosis of IC for a period ranging from 1 to 10 years. One participant had a diagnosis of endometriosis in addition to having a diagnosis of IC.

Themes: Introductory Summary

In the interviews, women described their experiences with IC and how IC affected their lives in general and their sexuality. The author and members of the OSE research team used a descriptive phenomenological approach to uncover and describe the themes that characterized women's experiences with IC and how IC affected their sexuality. In descriptive phenomenological research, the names of themes consist of more than one word or descriptor to

capture fully all the elements of each theme (Mahrer, 2004; Mahrer & Boulet, 1999). In this study, nine themes and six subthemes emerged and are outlined in the figure below:

Figure 1



Note: Arrows indicate the impact of one theme on another.

1. Getting Partial but Not Significant Relief for Debilitating Symptoms Led to Increased Fear and Confusion.

2. Desperately Searching for Answers and Relief and Turning to Clinicians, Leading to a Cycle of Referrals.

3. Physicians are Ignorant and Dismiss and Invalidate My Experiences.
 - a. Physicians are incompetent or ignorant.
 - b. Physicians are dismissive and invalidating.
4. From Being in the Role of Patient to Being My Own Case Manager.
 - a. I can rely only on myself, it's my responsibility, seeking answers.
 - b. In desperation, turning to internet community through online support groups.
5. Prolonged Diagnostic Processes and Invasive Medical Experimentation.
6. Exacerbation of Symptoms and Disruptions to Life.
7. Physicians Dismiss Sexuality and the Pain of Loss.
8. Hopelessness.
9. Alone, Abnormal and Invisible in The World.
 - a. Alone, abnormal and invisible.
 - b. Shame and embarrassment.

The results include a description of each theme using direct quotations from the interview transcripts. Square brackets within the quotes indicate that words were removed to maintain participants' anonymity. Ideally, in descriptive phenomenological studies, pseudonyms are used to assist the reader in following the detailed and individual stories of each participant involved in a study. In the case of the current study, women's voices were quite distinctive and their information quite identifying even when using pseudonyms. In consultation with the research team and the Ethics application, the determination was made to err on the side of caution and to protect the identity of women by using their words without pseudonyms. Therefore, the reader should be aware that representative quotes from each participant are distributed throughout the results section in equal proportion.

1. Getting Partial but Not Significant Relief for Debilitating Symptoms Led to Increased Fear and Confusion

All women experienced debilitating symptoms for which they tried to get relief. When women did not get significant relief, this led them to question and fear what was happening to them. Women said that the onset of their symptoms ranged from adolescence to their mid-twenties. Women noted the following symptoms: urinary urgency and frequency; nocturia; burning, irritation and pain with urination; vaginal tension and pain during and after sexual intercourse and orgasm; pelvic pain and discomfort; and abdominal pain and discomfort. Women stated that their symptoms were intermittent in nature, showed up in flares, came on suddenly and were triggered by intercourse, exercise and diet. One participant experienced a flare-up of UTI symptoms which persisted for several weeks:

So, um, the first flare I experienced for about two to three months, um, and this was consistent every single day ... It was nocturia – so, peeing at least 10 to 15 times a night My pelvic muscles felt really bad. At night I just could not sleep because I kept having to pee or I would feel the burning and the pain.

All women reported significant pain and UTI symptoms which prompted a need to seek medical treatment. As one stated:

I was just – experiencing symptoms of UTIs. So, nocturia was ... unfortunately a thing as well as significant pain. So, for about two to three months I just lost a lot of sleep. I then prompted immediately to try to seek health care ... It was just quite scary, um, couldn't really find what I was looking for.

One participant described intense pain in her vaginal area and perineum:

I will experience burning shards-of-glass pain in the, um, the labia minora and then down to the perineum The, um, the pain for me goes right into kind of the opening of the

vagina So, kind of from the urethra down ... sometimes there can almost be anal involvement with the – and around the anus that is feeling painful.

Most women felt pain during intercourse. One stated:

Pain during sex was definitely a thing. Um ... just, um, shooting pains during sex – the big thing and then often after sex ... feeling that UTI kind of thing.

Similarly, another participant had pain when she engaged in sexual activity:

I think it's my urethra's more inflamed and so any sort of thing near my clitoris is painful. Um, and then some days that's less so. Um, sometimes penetration feels good and sometimes it feels bad and sometimes the positions can really vary ... Pretty much as soon as I come down from the orgasm its pain.

Women wanted relief from their symptoms. Some women noted that certain medications helped alleviate symptoms. One woman reported that a particular medication, Uribel, dulled her pain:

I think it just dulls my pain enough that I don't really have to think about it ... I'll take it and I'll almost feel like a normal person [chuckles]. Um, until I use the restroom and my pee is a different color but, um, yeah it's pretty good, um, I like it. It helps me not have to think about it.

Another participant noted that a particular medication, Ditropan, helped alleviate but not eliminate her symptoms. This medication led to feelings of numbness in her vaginal area:

Um, I was on Ditropan ... I was able to kind of see, 'Oh yeah, this is definitely calming my bladder' um, but it was not a cure-all. Um, I went up at one point and I did not – it numbed me there and I did not enjoy that. So, um, it greatly impacted my sex life so I was, like, 'Hm, I'm gonna go back down.'

The lack of relief from symptoms caused women to question and fear what was happening to them. One woman described the sensations that she felt in her pelvic floor area. She felt confused and distressed:

I would get these – what I described as a ‘crack of lightning’ through just my – I get my pelvic floor more in the front area now ... I just really didn't quite understand, um, the difference in what was happening to my body You're just ... like, ‘Oh my God, what's happening?’

Another woman who wanted relief stated that she was confused by her symptoms:

So right now, I think they're – the IC thing – question – is still open because ... I don't understand why I – why I'm peeing so much, I really don't.

One participant questioned whether her symptoms were IC or an infection:

I still just don't know which symptoms are my infection and which is interstitial cystitis and if once – or if these infections will ever go away cause it seems like they won't. Um, if the – once the infections go away will my symptoms with IC lessen? Or stop completely?

Some women reported that having trustworthy partners who were understanding about and supportive of IC symptoms, helped to alleviate symptoms. Some participants reported that exploring sexually via mutual masturbation with their romantic partners and via sex toys resulted in less pain than engaging in intercourse. One woman said that being with someone she trusted helped her relax her pelvic floor muscles and lessen symptom flares:

Um, and it has been really nice I think being with someone I trust – now the flare-ups don't really happen that often during sex anymore ... I don't know maybe my pelvic floor has relaxed because I trust him. Um, and it's nice that he finally, um – he's the first person who could make me orgasm.

Another woman stated that having an understanding partner made her experience with IC easier:

Um, I mean he's awesome so, that definitely makes it a little easier. But I can definitely see if you were single or if you didn't have an understanding partner it would be something that would be impossible essentially.

Most participants felt fearful when they engaged in sexual activity. One said she had to manage the consequences of having sex or anticipate the consequences of sexual activity:

It was fear. I got to the point where, I wouldn't even, um, masturbate anymore because I was so scared ... At the time I was like, 'All I know is I'm just scared to do anything.' I was very scared of it. Um, hesitant with it. I sort of was either, um, dealing with the consequences or trying to sort of plan around them.

2. Desperately Searching for Answers and Relief and Turning to Clinicians, Leading to a Cycle of Referrals

Because women experienced partial but not significant relief from their symptoms, they felt desperate. To find relief, women stated that they turned to the medical system. While seeking help, women saw many different clinicians including emergency room physicians, family physicians, urologists, gynecologists, urogynecologists, nurse practitioners, physician assistants and physiotherapists. When participants spoke to clinicians, women felt frustrated that clinicians did not have answers and gave referrals to other clinicians. This cycle of referrals meant women had to wait for answers and relief for a long time, sometimes for months or years. Most women felt desperate and noted that they were willing to try anything to get relief. As one stated:

I tried acupuncture on my bladder and, um, one of those TENS machines. I would sit with it on my abdomen and in hopes that that would help and, um, yeah, you get kind of desperate ... And then I did – my acupuncturist sold me Chinese medication pills. You'll try anything really, yeah.

To try to find answers, one woman visited the emergency department repeatedly:

But then after a while the symptoms would persist and I – they would do urinalysis and nothing would come up but they would keep giving me antibiotics anyways And I kept going to urgent care, um, and trying to get an answer but they would just send me home with antibiotics.

Most women said that they needed relief but were unable to find answers. One reported:

Sometimes I just needed immediate relief and I couldn't find it anywhere. So, I just went to a walk-in clinic thinking that I could just find someone who could hear me out.

Many participants reported that they saw multiple physicians over several years. For example, one said:

So, I had probably seen in the span of five years, uh, I wanna say probably seven different doctors, um, who just had no answers.

Similarly, one woman stated that she saw physicians, nurses and specialists throughout her journey:

I couldn't get into my doctors' so I saw, um, a nurse practitioner Then, there was the ER resident and their attending doctor and they were a mess too ... Then I talked to the urologist and then I saw a nurse practitioner at the urologist, um, in, um, [home city] and then I talked to a urogynecologist.

Furthermore, most women stated that they met with multiple physicians to try to get a diagnosis.

One said:

I've been seen by my family doctor, uh, many ER physicians and some doctors from walk-in clinics as – sometimes I just needed immediate relief and I couldn't find it anywhere ... Now, again, I'm looking for a diagnosis and now they're gonna send me to a second urologist and a gynecologist.

3. Physicians are Ignorant, Dismissive and Invalidate My Experiences

In their searches for relief, women met with multiple clinicians. Women indicated that the majority of their interactions with physicians (i.e., emergency room doctors, family physicians, urologists, gynecologists, urogynecologists) physician assistants and nurse practitioners resulted in negative experiences. Each subtheme includes a description of women's interactions with physicians and the effects that these interactions had on women. The two subthemes are as follows:

3a. Physicians are incompetent or ignorant.

3b. Physicians are dismissive and invalidating.

All participants asked for help from physicians at least three times. Women received various responses from physicians. First, women said that physicians did not have basic knowledge about IC. Because of this, women were referred to other physicians. Second, women reported that they were dismissed, turned away and were told that what they were experiencing was "in their head." When women described their experiences with IC, they reported that physicians' responses were ignorant, dismissive and invalidating.

3a. Physicians are incompetent or ignorant. Women said that physicians did not know what to do, did not know about IC or did not know about the diagnostic processes and treatment for IC. One participant said that when she was accessing multiple physicians, she felt frustrated because they gave up on her and told her they did not know what to do:

The reason why I've seen so many different doctors is because it feels like if you do not have the most basic of problems ... they're kind of done with you at that point ... I've literally had doctors tell me, 'Well I don't know what to tell you [...]' It feels like they just give up on you.

Many participants were told that they could not be helped by physicians. One woman stated:

Every single time I go to a doctor they'll just usually shrug their shoulders and be like, 'I can't help you. Go to the next person' and I'm, um, still feeling all these symptoms, right?

Another woman felt frustration about physicians' lack of knowledge:

I feel mad at the doctors who don't even know what it is – how – I mean I don't know ... I kind of feel like you really have to look into it yourself out of your own interest ... So, it just makes me mad that these doctors really only know about the general stuff and not everything else that can happen in the body.

3b. Physicians are dismissive and invalidating. Women wanted relief. When participants spoke with physicians, the messages women received were: Your symptoms are not significant, your symptoms are “in your head” or are not possible, your symptoms will diminish and your sexual functioning is not important. One woman reported that her physicians thought her symptoms would go away:

Mm, so, at first, I was given a couple of different medications to try. The doctors were pretty – they seemed to just think it would go away on its own. I just had to wait it out.

Many participants were told that what they were experiencing was in their head or not real. One said:

He wouldn't say whether or not he believed it's IC. His PA believes I have it but he's just convinced that a lot of this is in my head.

Women reported that they fought to be believed by physicians. One woman stated that physicians treated her as a drug-seeker and she tried to convince them that she was not crazy:

I'm treated as a drug-seeker and I'm like, 'Guys, look at this biblical tome of medical records that I can give you access to 'cause I keep it in a PDF so that people can – if I need to share it with someone like, 'Here it is, um, I'm not crazy.'

One participant was told by her physicians that she could not have IC:

So, they were like, ‘Well you're too young you can't have IC because you're too young.

You can't have IC cause you never had kids.’

Most women stated that their physicians dismissed their sexual symptoms. One woman felt frustrated and said:

I would say one of the frustrations of it is going to a provider like a urogynecologist or a urologist you're told all the time that ... these are the professionals you can talk to about these kind of issues that you're having and I feel like I've just been totally dismissed and like they don't want to talk to me about these things.

One woman was told by her physician that all he could do was write a prescription for her:

He offered to write me a script for some sort of mental health medication. He said, ‘I can't help you manage it or anything but I can write you a script for something like that.’

4. From Being in the Role of Patient to Being my Own Case Manager

Women felt that their experiences and symptoms were being dismissed and invalidated by physicians. This led to a shift in the amount of energy and effort women devoted to the medical system (i.e., their role as a patient). Women had to rely on themselves to try to manage their symptoms and to look for relief. Participants devoted time, energy and focus to assessing their needs and to monitoring, adjusting and evaluating information about IC and its treatment.

Women searched for relief and turned to the Internet, in particular, to online support groups for individuals with IC. Many participants maintained some contact with physicians and the medical system while awaiting a diagnosis. The two subthemes are as follows:

4a. I can rely only on myself, it's my responsibility, seeking answers.

4b. In desperation, turning to the internet community through online support groups.

4a. I can rely only on myself, it's my responsibility, seeking answers. Participants were not getting significant relief from their symptoms and not getting the support they needed

from the medical system and physicians. Women were dismissed and invalidated by physicians and women were unable to get a diagnosis. Participants concluded that they could rely only on themselves to get relief from their symptoms. Women reported that out of desperation, they devoted more time and energy to trying to finding relief on their own. Participants continued to seek answers desperately and to explore as many options as possible that might provide relief. Through their searches, women gained some understanding and perspective of their experiences and learned more information about IC. Many women searched for relief on the Internet. As one reported:

I've tried so many things and whatnot. The Internet led me to things, like, um, D-Mannose, um, supplements. Um, led me to Prelief, which is also a supplement of sorts. Um, I took a lot of baths I learned a lot about the sensitivity to fragrances and things like that. Um, as far as sex – lube and things like that – I learned things to avoid – I just didn't know anything about stuff like that. I didn't realize how fragrance things are – or what was really in foods that could irritate you.

To try to get relief, most women said they conducted online searches about treatments and made changes to their lifestyles. One woman stated:

I just started researching, uh, treatment options So, I was able to see a pelvic floor specialist ... I changed my diet. Um, uh, stopped drinking coffee and tea for – well, I drank nothing but water, um, and then slowly started introducing the things back ... after that I just sort of did ... pelvic floor stretches essentially.

One woman noted the effort and awareness it had taken to manage her IC symptoms and vaginismus:

Yeah, so Pyridium is always in my house it's ... I always have it in the medicine cabinet and then I also – um, five percent lidocaine topical ointment for the vaginismus element

of it. Um, I will say that, um, after the loss of the second pregnancy I have had increased instances of actual UTIs.

Many participants recounted an all-consuming process of trying multiple treatments to get relief.

One indicated:

Um, the aloe vera I've done off and on I guess another thing I've tried is diet Um, hydroxyzine I think ... Physical therapy ... but that's not been consistent and then the Zyrtec and the Hiprex I've been on since [2020s] so about three-ish months there too.

In her search, one woman said she learned about medical terminology and assessment information related to IC:

Um, in the more recent years of it – because I know I learned a lot about stuff like, um what is it? Hydrodistension, things like that – about cystoscopies – things like that. Um, certainly about Hunner lesions and, uh, all these different sort of, uh, I guess terms kind of linked to IC, and the umbrella kind of broadened.

Another woman noted her increased attention to her symptoms, symptom triggers and patterns of symptom flares:

I kept noticing after that two-to-three-month long flare, um, every month thereon I'd experience a week of IC-like symptoms during my period and then it would slowly subside Um, I find that my triggers ... are coffee, um, some acidic juices I get triggered after sex for sure, a little mini flare.

4b. In desperation, turning to the internet community through online support groups. When women participated in online support groups, they felt supported and validated by group members, developed a sense of community, gained some understanding of and perspective on their experiences with IC and learned more information about IC. One participant felt grateful because members of the online support group were interested in understanding more about IC:

I mean I just am so grateful that anyone has an interest in it Um, but I – just like the fact that there's any acknowledgment of the condition or interest in finding out more about it I think is amazing.

Another woman recounted what she took away from the discussions in the support groups:

I just feel like it's such an under studied mystery – medical mystery. I'm in a [social media group] where we all talk – the interstitial cystitis [group] – and there are a lot of people posing what they think their origin story is with it and it's so vastly different for everyone.

Some women stated that they found support and accessed resources through online support groups. As one reported:

So, I learned, um, a lot from there and then I started to find a lot more stuff. [Social media group] is where I then – I found more resources in the last two years from [social media group].

Similarly, another woman reported that online support groups provided her with helpful information and support:

Um, I know that I think I first saw your post on the [social media group] for IC. So, I have my notifications turned on for that thing because a lot of times they can give me helpful things – or try this or try that or avoid this. So, that really helps, um, just having small little support systems off there on the Internet.

5. Prolonged Diagnostic Processes and Invasive Medical Experimentation

Women reported significant delays in and obstacles to obtaining a diagnosis of IC. Nine of the ten participants received a formal diagnosis of IC from physicians. At the time of the interview, one woman was waiting for a diagnosis. For the women who had received a diagnosis, the average time from experiencing the initial symptoms until receiving a diagnosis was three

years and this interval ranged from two weeks to six years. In addition, women reported that they underwent invasive diagnostic screenings and invasive treatments that were recommended by physicians. One participant reported that she waited between six and eight months to get a diagnosis:

But, um, they kind of weren't – they didn't really give me an official diagnosis But then it took I think, at least six months if not longer than that to actually speak with a urologist. So, um, yeah, it was probably I'd say at least six to eight months before I got the diagnosis.

Despite meeting with multiple physicians, most women noted that they did not receive formal diagnoses. One stated:

So, uh, I ended up going back to my family doctor and, um, they started to look for a specialist and a urologist specifically for me to look for a diagnosis for interstitial cystitis and – so it was honestly just a web of different healthcare individuals. I had very – a lot of difficulty and ... I don't have a diagnosis yet.

Most participants indicated that it took multiple years before they received formal diagnoses. As one indicated:

Yeah, um, so I was undiagnosed from [early to late teens].

One woman felt frustration about her journey to diagnosis:

Um, it was a little frustrating because ... I didn't necessarily need to have diagnosed via a laparoscopy It had been discussed and then ruled out at some point for reasons that I didn't fully understand. So, I think there was some frustration with having pursued it from such a different angle for so long.

Most women reported that they sought diagnoses and encountered uncertainty. At the time of the interview, one woman reported:

They told me I had chronic BV which was not going away with treatment and the medicine that I would take for BV ... that would then give me a yeast infection So, that was back and forth until [2020s] when they finally tested for urea plasma, which is, I think what I still currently have.

Another woman stated that her physician reacted in the following way after she told her she suspected IC:

I don't know what this [physician's] deal was, 'I'll decide if you have IC' um, but you're not gonna get along with everyone you meet and maybe there's something else going on for her that day. Um, I just decided that was not someone who was going to be able to collaborate with me in my care.

Participants reported that physicians recommended invasive treatments. Women said that they were the subjects of experimentation and reported that the treatments recommended by physicians led to aggravated symptoms. Some women were not even offered treatment nor provided adequate screening or diagnostic testing. Participants had trusted initially that physicians would offer appropriate treatment to these women in a timely manner. Most women stated that their physicians recommended a variety of treatments including antibiotics, tricyclics for modulating pain, antihistamines, antispasmodics, anticonvulsants, Botox, vitamin supplements, bladder instillations, physiotherapy and suggested that women make changes to their diets and lifestyles. Women reported that the majority of treatments led to increased pain and aggravated symptoms (i.e., numbness, infection, nausea, sleep difficulties, pelvic and abdominal pain and changes to their sexual functioning) which had adverse effects on their daily functioning.

Some physicians recommended that women attend pelvic floor physical therapy sessions. Some women stated that they experienced partial but not significant relief from such sessions.

Women said that participating in pelvic floor physiotherapy sessions led to decreases in their pelvic pain, symptom flares and pain during and after sexual activity. Many women reported that pelvic floor physical therapy helped to alleviate their symptoms but did not fully eliminate symptoms. As one indicated:

I want to say that the pelvic floor physical therapy has been really good for me, too. Um, so a lot of the ways that I alleviate my symptoms right now is just doing ... some of the pelvic floor exercises and that's helped subside the flares although it doesn't truly eliminate the issue for me.

Similarly, another participant stated that she had some relief from physical therapy, but that it was not helpful overall:

I've done it off and on for almost two years now and have kind of found I can get to a certain point where I relax – somewhat relax the muscles. But I haven't been able to get fully relaxed, so. Um, yeah, they tried to do stuff with ... bladder training and all that – stretching and stuff. But I didn't really find it that helpful.

Some women reported that physicians did not disclose potential side effects of treatments, nor did they provide a justification for recommending treatments. Women reported that the treatments led to aggravated symptoms. One participant said that when she spoke to a family physician, he did not offer her treatment:

There were no treatments offered. I was just told to drink nothing but water and that was it.

Another woman reported that physicians did not screen her for IC or try to rule out other conditions:

I just kept the – they weren't even testing my urine. They were just throwing antibiotics at me and I kept going back saying that it wasn't working.

One woman who was examined by a physician did not know what she was being examined for and was not told about the results of the examination:

At the time the doctor just wasn't explaining anything to me and I didn't have pants on, um, so I thought he would come back and talk to me again once I put my pants on He just left and was like, 'Ok now I'll schedule an appointment ... and then ... like, 'Wait what's going on?'

One woman recounted her experience with bladder instillation treatment, which involved having a catheter inserted into her urethra:

So, they would, um, basically put a catheter into my urethra, um, and then fill up my bladder with this solution. I believe it was some sort of baking soda solution, um, and there were other medications, I think. An anti-inflammatory and a little small dose of an antibiotic in there as well. Um, and it – they said it was meant to strengthen the bladder lining, um, and that maybe extending the bladder physically, would help alleviate some symptoms. Um, ultimately, I think just the insertion of the catheter was too painful for me, um, to continue with that treatment.

Participants reported minimal or no relief from the treatments. Women reported that physicians offered treatments simultaneously or one after the other with minimal or no relief. Despite being offered multiple treatments, women noted that the treatments did not work for them. As one woman stated:

It started with the BV medicine and then ... the anti-fungals ... But then when the BV treatment wouldn't work, they gave me antibiotic gel to insert in there and then for the urea plasma I was given doxycycline But for the IC they ... he gave me, um, amitriptyline which is an antidepressant a lot of medicines throughout my life, no matter what it is ... don't really work on me.

Another woman reported that her parents pushed her to go back to physicians and to what she described as a time-consuming “guinea pig phase” of treatment:

My parents continuously try to push me to try new treatments and they try to push me back into the guinea pig phase and I'm kind of, like, ‘Why? I’m a [...] right now, I don't really have time to be in and out of the doctor's office anymore. I don't have – I don't have time to try all that.’

6. Exacerbation of Symptoms and Aggravation of Disruptions to Life

Participants described an ongoing cycle of waiting for relief and experiencing aggravated symptoms. Women reported that invasive medical experimentation and delays in diagnosis exacerbated their symptoms. The exacerbated symptoms, in turn, led to aggravated disruptions and changes to their sex lives, interpersonal relationships, daily functioning and to their physical and mental states.

Women used phrases such as “broad effects”, “long journey,” “change”, “cannot do it anymore,” “scared”, “suicidal thoughts”, “horrendous”, “deter my life” and “non-existent sex life” to describe their physical or mental states. One participant said that the antibiotics prescribed to her led to an infection, specifically *clostridioides difficile* (i.e., *C. diff*):

So, I went to pelvic floor PT last year, um, for a few months and then I actually came down with a gut infection called *C. diff* from antibiotics. So, I had to take a break from PT because that – the recovery from that, even after not having the infection anymore, lasted for months.

Another participant reported that the medication prescribed by her physician led to numbness in her arms and legs:

Um, and the gabapentin – I kind of take either 100 milligrams or 200 milligrams depending on how I'm feeling that day and how I need to feel the next day ... At one

point they prescribed to me up to 300 but I was finding I would get numb, um, my legs, my hands ... I do a lot of, uh, [movement] for my work. So, that was kind of scary.

Most participants indicated that IC had changed the course of their lives. One stated:

It has completely changed the course of my life. I, um, was very high achieving academically. I went to a really good school or college. But interstitial cystitis – the inability to deal with it – and then just being in the transition of being away at – I think any [student] would have a lot of, um – just needing time to adjust. But then my adjustment was focused on then dealing with being in pain all the time and being in the hospital and being so far. I mean, it amplified all of those feelings of distance. It was very distracting. So, I wasn't doing my course work the way that I wanted to and so I had to leave and, um, I was really adrift when I got home. I mean that was – I had plans for myself and there was no plan b, right? And so here I have this new situation where I'm having to deal with, um, the mental health issues that come along with your dream coming apart and just being in pain all of the time, not being able to control your body – all these sorts of things.

Another woman reported that having IC shaped her personality:

I'm sure it's shaped my personality, too. Uh, just being anybody who has a chronic illness or chronic pain. Even someone with as much support – which is a ton – as I have, um, it does change you to be in pain all the time. Or be afraid of when the thing is gonna come back and what you're able to do.

Most participants said that their chronic symptoms affected their lives terribly in several ways.

One reported:

Um, terribly for a very long time. Um, there were, um, a number of years where I spent almost every day in the bathtub. Um, where I would not even have sex anymore God!

It's been a long journey ... it gave me a really bad relationship with food for a long time.

Um, I became so scared of everything.

Many participants stated that their exacerbated symptoms had negative effects on their abilities to work and attend school. One woman reported that the management of her symptoms became so overwhelming that she had to drop out of school:

So, I was, um, my symptoms actually prompted me to leave my school [...] and come back home [...] after three semesters, um, because it was too much for me to manage with student health and being in kind of a more rural place.

Another participant said that her symptoms became so severe that she was unable to work:

Stuff wasn't helping and I was not able to work for almost two months because the symptoms were so severe.

Women reported that exacerbated symptoms led to aggravated disruptions and changes to their sex lives and romantic relationships. Women reported pain during and after intercourse, the loss of sexual intimacy in their relationships and feeling isolated in their sexual relationships.

One woman stated that her symptoms "robbed" her of the ability to enjoy her sex life with her current partner as compared to the way she had been accustomed to with her previous partners:

I'm upset that I can't enjoy my full sex life from what I used to be able to do with previous partners ... I wish I could have done with my [current partner] instead But after the symptoms, I feel robbed of the fact that I can't fully enjoy it with my [current partner] and it makes me pretty upset because this is the person that I want to be able to give myself to and yet I can't I just want to emphasize that I guess the combination of the physical pain and the mental inability to have sex has drastically decreased my libido.

Most women said that pain during and after intercourse led to adverse effects on their daily functioning. One stated:

Um, it's affected pretty much everything. Um, the first thing it started affecting was my sex life because it's – [sighs] first is just the burning. But then there's the after sex where you can't sleep because all you feel is pressure on your bladder and you're just laying awake all night and you gotta put a heating pad on and sometimes even take pain medicine ... I can't really ... do it at the moment and if I do choose to do it I'm basically choosing – I know I'm gonna be in pain after. So, it's – you want to do it but you know it's gonna be painful.

Furthermore, another woman reported that her sex life had become “non-existent”:

It's pretty non-existent at this point. I've – this year I've tried, um, external stuff a couple times . . . but not penetrative sex. Um, just to see if maybe it's – because I know penetration is a big trigger, but just to see if other things are doable without causing a flare. Because early on in my diagnosis I could still do those things and I wouldn't really get a flare from them. But now – doing those things I have a flare for a few days after. Um, so it's just – I don't really know how I am going to resume intercourse at this point. Either way it's – I am playing Russian roulette and I'm going to have some kind of pain after this. So, is it worth it? There's always that question.

7. Physicians Dismiss Sexuality and the Pain of Loss

Participants described the adverse effects that their exacerbated symptoms had on their sexuality. Women suffered from the losses in their romantic relationships. Participants did not believe that physicians understood the debilitating nature of IC or the effects that it had on women's sex lives and sexual functioning. As a result, women emphasized the need for

physicians to prioritize the management of the sexual difficulties that accompany IC. One participant reported that she lost a year of her life trying to treat IC:

I kind of feel like I lost a year of my life trying to treat the condition and even then, I'm not 100% to where I was before.

Some participants reported a history of sexual trauma. One woman suggested that physicians should consider how a history of sexual trauma might influence women's experience of IC:

Yeah, so I think, um, I think it might be something to consider in the future that there might be a sexual trauma component, um, that might play into people's experiences.

Another participant reported that one of her physicians was "at the end of his rope" with her. She wanted her physician to pay more attention to the losses and effects that accompany IC:

My provider has even told me he's at the end of his rope with me So, feeling like I'm on my own in all of this and also feeling like a really bad partner because I haven't been able to have intercourse over for over a year because my flares have been so bad ... It's really made a big impact on my mental health and physical health I wish providers would pay attention to that aspect of it a little bit more, because it is important and it's something that's not easy to talk about or bring up with a provider.

One woman reported that physicians should be more aware of the cost of the medications and treatments that they offer. She wished that she had more financial support for treatments while at school:

Um, also the cost of trying all these different medications. Some of them were \$100 just to try them what would have been really helpful would have been if they were able to give some extra financial support ... I would be willing to pay to get extra benefits ... what they offer is not enough.

8. Hopelessness

As a result of the invasive medical experimentation, delays in diagnosis, exacerbation of symptoms, aggravated effects on their lives and lack of consistent and significant relief, women felt hopeless about their situations. One participant bemoaned that her lack of relief from pain led to hopelessness. She relayed that she had been close to thoughts of suicide:

Uh – [sighs] I mean you can't – you're in pain all the time. So, you can't really do anything ... it's frustrating because there's no relief really I don't wanna say that I had suicidal thoughts but it wasn't – it was probably close, to be honest.

Another woman said that getting better did not feel possible:

I want to get better. I feel, like, even though my [partner] has never made me feel this way I feel like I'm on a clock of trying to get this figured out before being left ... I don't know how long it's acceptable for this sort of thing to be happening But I don't think I'm going to get it figured out.

Most participants felt hopeless because they could not find relief and because of their interactions with physicians. One reported:

It can just get really – feel just really hopeless I guess cause it feels like nothing's working still at this point and ... they'll act like nothing's even wrong with me and so I just have to deal with it ... and not a lot of people know about it and so you don't really know what to do ... It's just been very stressful overall.

Similarly, another woman felt hopeless because of a lack of response from physicians:

So many people with so much expertise were kind of just, like, 'Uh' [shrugs shoulders] um, it was just – you felt kind of helpless and hopeless ... But it being kind of this really A) invisible thing, right? I'm not limping – and then B) it has to do with your genitals.

9. Alone, Abnormal and Invisible in the World

As a result of their entire experiences, women felt alone in the world, that they were abnormal and that their experiences of suffering were invisible. Many women described IC as an invisible illness. Women expressed a lot of shame and embarrassment about their symptoms and reported withdrawing from their interpersonal relationships and social lives. Some participants also felt alone in their relationships with their romantic partners. Ultimately, participants felt lonely, abnormal and alienated in the world. The two subthemes are as follows:

9a. Alone, abnormal and invisible.

9b. Shame and embarrassment.

9a. Alone, abnormal and invisible. Women felt alone and abnormal and reported that their suffering was invisible. One woman stated that because of IC, she felt lonely and as though she were a bad partner:

When you have an illness like this that's under studied and not really understood you just feel really alone for the entire experience. And then on top of that feeling like a bad partner and it just – yeah, I don't know.

Similarly, another woman felt alone and as though she were bad partner because she had not engaged in intercourse in over one year:

So, feeling, like, I'm on my own in all of this and also feeling, like, a really bad partner because I haven't been able to have intercourse over for over a year because my flares have been so bad and non-stop.

One participant recounted the loneliness she felt after she asked a physician for support in improving her sex life:

Um, but I was just tearing up and saying, 'I just want to be able to have sex with my [partner]' and ... the provider just looked uncomfortable and looked away and was just,

like, 'Yeah, I know' and then that was it [chuckles]. There was no advice ... or support or anything there and that's one of the loneliest parts of all of it.

Another woman reported that having IC made her feel abnormal in comparison to peers:

It makes me feel abnormal and also just jealous every single day of normal people with normal bodies. I see people on social media and they're out with their boyfriends and I just know, like, 'Oh, I bet you have sex every single night and your life is perfect' So, it makes me very insecure, very jealous, very mad.

Many women described IC as an invisible illness. One said:

With it being kind of an invisible illness, you're sometimes not sure whether people actually take you seriously or whether people will believe you.

9b. Shame and embarrassment. Many participants felt ashamed about and embarrassed by their symptoms. One participant felt embarrassed when she communicated to her professors that she could not attend class because of her symptoms:

I was kind of in and out of class a lot, um, and I – it was a little bit embarrassing for me to email my professors and say, 'Hey, um so I have this pain condition and I can't come to class right now.'

Another woman felt ashamed and self-conscious about her body:

Body image wise I don't feel great either ... even though I work out and I still try to feel good about my body as much as possible. There are times where I can't work out and that affects me in my body image ... the fact that ... I always have to constantly go to the washroom – it makes me feel really gross about my body.

Similarly, another participant felt self-conscious about her urinary urgency and frequency. She feared that others would notice her symptoms:

I feel I spend a lot of time making sure . . . like, ‘Oh, I hope that there's a bathroom there’ . . . having to make sure that I can get away to do that. So, that's a weird kind of side effect of this thing is that I feel somewhat self-conscious sometimes about people noticing that.

Discussion

The purpose of this study was to explore the lived experiences of women who have been diagnosed with IC or who have symptoms consistent with IC. More specifically, this study explored women’s experiences with how IC had affected their lives and their sexuality.

The meaning of participants’ experiences is presented in the discussion. First, a summary of the dominant research themes is provided. Then, participants’ experiences with IC and its general effect on their lives are discussed. Then, participants’ experiences with their physicians are discussed. Then, participants’ experiences with IC and its effect on their sexuality are discussed. Finally, a discussion of contributions to the literature, clinical implications, limitations, strengths and directions for future research is provided.

Summary: Women’s Lived Experiences

Women’s responses to the interview questions were powerful, vivid, meaningful and incredibly painful. Women deserved much better and were harmed. The current findings indicate the generally adverse experiences of women dealing with IC, which include themes of negative physician-patient interactions, severely limited sexual relationships, restricted quality of life and the necessity for self-management of symptoms.

Women with IC experienced debilitating pain, urinary and bladder symptoms and sexual dysfunction for which they could not get relief. Participants indicated that sexual dysfunction and losses within their sexual relationships were critical problems that accompany IC and which they wanted resolved. Desperate to find relief, participants met frequently with various physicians.

Participants reported that most of their physicians and specialists were incompetent and ignorant about how to recognize, diagnose and screen for IC; treat IC or symptoms consistent with a diagnosis of IC; and lacked knowledge about the physical, emotional and sexual effects of IC.

Women's Experiences with IC and its Effect on their Lives in General: Restricted Quality of Life

Women's suffering was immense and debilitating. Women noted that invasive and ineffective treatments, delays in diagnosis, their interactions with physicians, exacerbated symptoms and a lack of symptom relief led to disruptions and changes to many domains in their lives. These included their tasks of daily life, sleep quality, ability to exercise, sex lives, interpersonal relationships, work and academic performances and to their eating patterns, physical and mental states. The exacerbated symptoms created circumstances in which women had to take time off work, drop out of school and restrict their diet and daily routines. Women said that having prolonged IC symptoms changed aspects of their personalities and led to suicidal ideation and periods of low mood.

These findings reflect problems identified in the literature, including the effects of IC on individuals' ability to function in one's daily life and ability to work (Beckett et al., 2014; Vasudevan & Moldwin, 2017) to their psychological states (Chuang et al., 2015; Clemens et al., 2008; Tripp et al., 2016; Watkins et al., 2011) and to their physical functioning and vitality (Rothrock et al., 2002). Women were left in perpetual survival mode in which they were desperate about getting better. Most women reported that because their symptoms were present for so long, they were fearful of symptoms flaring, recurring or getting worse. As a result, participants said they felt frustrated, hopeless, lonely, ashamed, embarrassed, abnormal and felt their experiences of suffering were invisible.

While previous quantitative work has struggled to attribute causality to psychological problems and IC (Beckett et al., 2014; Watkins et al., 2011), women in the current study indicated that IC was a cause of their inability to function in their daily lives, psychological distress, physical pain and sexual difficulties. Although mental health professionals are largely unaware of IC, patients with IC would benefit from increased access to psychotherapy (Watkins et al. 2011).

Women's Experiences with their Physicians: Compounding IC Symptoms and Suffering

Women indicated that they suffered immensely and needlessly not only because of their IC but because of their interactions with physicians. Commonly, the lived experiences and wishes of individuals with IC regarding their health are overlooked or are not considered by medical professionals (Kirkham & Swainston, 2022; McManimen et al., 2019; Milton, 2008). Generally, women's experiences were as follows: physicians dismissed, invalidated and ignored women's experiences with IC; physicians did not want to hear about suffering; physicians recommended treatments that led to increased pain and aggravated symptoms; and physicians did not prioritize the management of pain during and after intercourse or any other sexual difficulties.

Physicians who dismiss, disregard or ignore the feelings and experiences of their patients can compound patients' suffering and symptoms, increase patient depression and can erode patients' sense of self and reality (Gertsman et al., 2023; Kirkham & Swainston, 2022; McManimen et al., 2019; Merone et al., 2022; Milton, 2008; Vasudevan & Moldwin, 2017). Participants said that physicians did not understand the debilitating nature of IC or the effects that it had on women's sex lives and sexual functioning. When women tried to explain that their sexual difficulties were critical issues that needed to be resolved immediately, they reported being silenced by physicians.

Physician Silencing of Women Living with Persistent Sexual Difficulties

Sexuality is seen as a critical aspect of overall health, however, that importance is not reflected in medical practice (Higgins et al., 2006; Higgins et al., 2008; Quinn et al., 2011; Stevenson, 2004; Urry et al., 2019).

The majority of women in this study were between the ages of 23-29 but felt utterly hopeless and despondent about the future of their sex lives. Women tried to assert to physicians that having sex or talking about sex is important when connecting with people and is an important part of personal and interpersonal development. When participants disclosed their sexual difficulties to physicians, women were told, “it’s not that big of a deal,” “this isn’t happening to you,” “so what,” “we can’t do anything about it,” or “what you’re experiencing is not possible.” Physicians who lack awareness of the persistent sexual difficulties that can accompany IC may continue to dismiss patients’ sexual difficulties and therefore approach treatment inappropriately (Bogart et al., 2011). This could leave patients trapped in a system where they are not getting effective pain relief, coping strategies or treatment for their sexual difficulties.

“Gaslighting” is “a type of psychological abuse aimed at making victims seem or feel ‘crazy,’ creating a ‘surreal’ interpersonal environment” (Sweet, 2019, p. 851). The phenomenon of medical “gaslighting” occurs “when health care professionals downplay or blow-off symptoms” (Sebring, 2021, p. 1952). Women in the current study noticed a contradiction between what they were experiencing and what they were told they were experiencing and were left to try to make sense of their situations on their own. Participants said that they felt crazy and were told that what they were experiencing was in their head or not real.

Sebring (2021) and Sweet (2019) argue that medical “gaslighting” results from a paternalistic power imbalance that exists between physicians and patients, which values

“biomedical expertise over lived experience” (Sebring, 2021, p. 1952). The power imbalance comes from the ideology that science and medicine are “the ultimate source of objective, indisputable knowledge and truth” (Sebring, 2021, p. 1957). Physicians who are governed by this ideology believe that their knowledge is final, which leaves little room for the perspectives of patients. Women noted that instead of acknowledging and listening to their needs, physicians pushed their ideologies, ideas and “medical expertise” onto women. Assigning validity to the voices of women might broaden the understanding of women’s health, illness and disease (Maltreud, 1999).

Prolonged Periods of Waiting: Delays in IC Diagnoses and Diagnostic Uncertainty

There are no universally accepted clinical criteria for the diagnosis of IC. Therefore, IC is a diagnosis of exclusion (Perry, 2023). Due to non-specific symptoms that overlap with other gynecologic, urologic and gastrointestinal problems, long delays in diagnosis and diagnostic uncertainty are prevalent among patients with IC and similar pain conditions like endometriosis (Perry, 2023; Skove et al., 2019; Surrey et al., 2020).

Nine of the ten participants received a formal diagnosis of IC from physicians. At the time of the interview, one woman was waiting for a diagnosis. Women indicated that they went through a cycle of referrals because physicians did not have answers. For the women who had received a diagnosis, the average time from experiencing the initial symptoms until receiving a diagnosis was three years and this interval ranged from two weeks to six years. In pursuit of symptom relief and treatment, some women stated that they sought diagnoses and encountered uncertainty and were told they might have the following conditions or infections: sexually transmitted infections, endometriosis, bacterial vaginosis, yeast infections, urinary tract infections or irritable bowel syndrome.

Similarly, Chien and colleagues (2023) reported that most women in their study sought medical treatment from multiple specialists before receiving a diagnosis. In addition, Kirkham and Swainston (2022) reported that women in their study felt frustrated with their experience of diagnosis because they underwent a lengthy process of being re-referred, retested and saw multiple physicians from different specialties (Kirkham & Swainston, 2022). If diagnosed or managed inappropriately, individuals with IC may have increased symptom burden resulting in negative effects to their daily functioning and quality of life (Daniels et al., 2018; Perry, 2023).

Current IC Treatments Are Ineffective: Implications for Current Treatment Guidelines

Despite the available Canadian Urological Association (CUA) and American Urological Association (AUA) treatment guidelines (Cox et al., 2016; Hanno et al., 2015) current treatments show limited efficacy, are confusing for patients to navigate, are invasive, time-consuming, expensive and have not been shown to reduce symptoms significantly over time (Dellis & Papatsoris, 2019; Gonzalez et al., 2023; Kirkham & Swainston, 2022; Theoharides, 2007).

Women felt that they were being perceived as though they were objects to be “treated” instead of humans who were experiencing immense pain, who had needs, desires, feelings, thoughts and who had important problems that deserved attention. Women in this study stated that physicians either did not recommend any treatments or ended up recommending a variety of treatments including antibiotics, tricyclics for modulating pain, antihistamines, antispasmodics, anticonvulsants, Botox, vitamin supplements, bladder instillations, physiotherapy and suggested women make changes to their diets and lifestyles. Treatments were recommended that were invasive, caused increased pain and exacerbated participants’ symptoms (i.e., numbness, infection, nausea, sleep difficulties, pelvic and abdominal pain and changes to their sexual functioning). Similarly, Gonzalez and colleagues (2023) found that women who had IC reported

that physicians engaged in both undertreatment and overtreatment of IC and overused and prescribed antibiotics (Gonzalez et al., 2023). Some women indicated that physicians did not follow up appropriately on women's responses to treatments (Gonzalez et al., 2023, p. 212). In addition, Kirkham and Swainston (2022) found that participants who had IC underwent numerous medical tests and tried multiple medical interventions that were unsuccessful in reducing pain. Women were dissatisfied with treatment options and were reluctant to undergo future treatments (Kirkham & Swainston, 2022).

There is evidence suggesting that improvements and changes need to be made to current IC treatment guidelines, which should focus on reducing women's pain and sexual difficulties (Chen et al., 2021). This may help ensure that patients are not trapped in a cycle of hopelessness, physical suffering and negative emotions (Chien et al., 2023).

The Necessity for Self-Management of IC Symptoms and the Importance of Online Communities

Individuals who have chronic illnesses including IC face common challenges which include:

...recognizing symptoms and taking appropriate actions, using medications effectively, managing complex regimens, developing strategies to deal with the psychological consequences of the illness and interacting with the medical system over time (Schulman-Green et al., 2012, p. 2).

The necessity for self-management of symptoms among patients with IC is common, as individuals report that they do not get the support they need from medical professionals (Gonzalez et al., 2023; Kirkham & Swainston, 2022; Meijlink, 2017). Similarly to other qualitative studies (Gonzalez et al., 2023; Kirkham & Swainston, 2022), participants indicated

that they had to manage their symptoms on their own and searched for relief on the Internet and in online support groups for individuals with IC. Women reported that they gained an understanding and perspective of their experiences and learned more about IC and current treatment options online.

To prevent patients from having to rely on themselves to manage their IC, they would benefit from having increased access to relevant resources and information pertaining to IC and pain management which might improve their ability to cope with IC. Evidence from the current study and the literature shows the importance of online networks in providing support and resources to individuals who have IC.

Women's Experiences with IC and their Sexuality

Changes to Women's Sexual Functioning and Losses in their Sexual Relationships

Similar to previous quantitative (Azevedo et al., 2005; Gardella et al., 2011; Hung et al., 2014; Lee et al., 2015; Ottem et al., 2007; Schultz et al., 2005; Tonyali & Yilmaz, 2017; Tripp et al., 2009; Volpe et al., 2021) and qualitative research findings (Kirkham & Swainston, 2022), women in the current study experienced problems during sexual intercourse including vaginismus and pain during and after orgasm and intercourse. Women in the current study reported reductions and losses of sexual intimacy and closeness with their partners; feeling isolated in their sexual relationships; and a feared loss of sexuality for the future. Participants indicated that the pain they experienced during and after sexual activity led them to reduce the frequency of their sexual activity significantly in both partnered and solo sex. Women sacrificed their own sexual desires and pleasures to manage their pain because they believed that they needed to regulate and manage their own responses during sex to please their romantic partners. Some women reported that they had not been able to engage in any sexual activity at all or had

been unable to have sexual intercourse for years because of the pain they were experiencing.

Most participants said that their sexual problems were alleviated partially after they engaged in pelvic floor physical therapy sessions. Pelvic floor physical therapy has been recommended as an adjunctive treatment for women overcoming anxiety related to vaginal penetration and for women presenting with vaginismus and dyspareunia (Rosenbaum, 2005). Some women in this study indicated that the support and understanding of their romantic partners and exploring sexually via mutual masturbation with their romantic partners and via sex toys alleviated some of their sexual problems. In studies examining couples in which one member of the couple has chronic pain, research has demonstrated a positive relationship between spousal validation and relationship satisfaction (Cano et al., 2008; Johansen & Cano, 2007; Leong et al., 2011). A review conducted by Rosen and colleagues (2014, p. 3) showed that empathic partners:

...may facilitate women's emotional regulation by creating a validating emotional climate in which both partners are better equipped to process and cope with their pain-related stressors (e.g., decreased frequency of sexual intercourse), leading to improved pain and psychosexual adjustment.

IC has adverse effects on women's sexual functioning. Pelvic floor physical therapy and couples and sex therapy are likely to be appropriate treatments for women with IC and should be considered by physicians.

Contributions to the Literature

Few qualitative studies have explored the lived experiences of women with IC and its effect on their sexuality. By continuing to share women's experiences with the persistent difficulties that accompany IC, the hope is that IC will become recognized by individuals, physicians, mental health professionals and researchers who are unaware of IC. In addition,

sharing these findings may lead to more research on the lived experiences of individuals with this condition. Participants in this study indicated that there is a culture of silence and dismissal that exists around sexual difficulties and IC in the medical community. Findings from this study may help to break the silence and stigma that surrounds IC and sexual difficulties.

Clinical Implications

Women in this study reported that their suffering would not have been as overwhelming if only their physicians had treated them with empathy, kindness, caring and compassion. It is absurd, disturbing and inconceivable that women were met with apathy, silence, dismissal and ignorance related to their IC, the resultant suffering and to important parts of their lives.

Women experienced extreme mental and physical pain and were faced with a lack of care and no relief. None of the women in this study were referred to psychological support services to help them manage the suffering associated with their condition. Mental health professionals, including couples and sex therapists, are largely unaware of IC, the suffering that accompanies this condition or the effects that IC has on women's sexual functioning and their relationships. By sharing women's experiences of this very real and debilitating condition, the hope is that psychologists, sexologists and therapists will understand the gravity of women's pain so that they might create empathic and compassionate spaces for these individuals.

Women indicated that they felt dismissed when they tried to express their sexual needs to physicians. Women said that physicians did not place emphasis on patients' experiences, women's sexual functioning and intimacy in their relationships. Some participants indicated that better training for physicians in the recognition and management of IC might have reduced their suffering during the process of assessing for and treating IC. It might have reduced the number of referrals to other physicians, reduced delays in diagnosis and prevented women from having to

manage their symptoms alone. Chronic pain conditions, such as IC, are notoriously difficult to treat. Clinicians estimate that current treatments for chronic pain populations only help one in three to one in four people (Odling-Smee, 2023). Researchers suggest that there should be increased efforts to match or tailor the right treatments to people in pain which could make pain control options more effective (Odling-Smee, 2023).

Women's suffering would not have been as overwhelming if they did not have to wait months or years for diagnoses and information and resources related to their condition. Women who have IC might benefit from having a supporter such as a patient-navigator or a case manager to help them navigate their conditions and the medical system. Patient navigators are professionals who "seek to proactively guide patients through the healthcare continuum to facilitate timely access to care and foster self-management and autonomy through education and emotional support" (Kelly et al., 2019, p. 28). Case managers also provide emotional and informational support to their patients and fill gaps in the medical system by acting as care providers. Case management is defined by the Case Management Society of America (CMSA, 2016, p. 11) as, "a collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost-effective outcomes." Case managers are found commonly across many social and health settings whereas patient navigators exist primarily in the oncology care setting (Kelly et al., 2019).

Key informants reported that they gained support and learned about IC resources from online support groups and patient advocacy forums for people with IC. Other than these online forums and chat groups, there were few websites about IC that patients could navigate easily. Future efforts could target the creation of patient-led websites for IC that value grass-roots

advocacy, including resources and information and raising awareness about IC. Current websites exist for other unknown conditions such as the patient-led website for post-SSRI sexual dysfunction, PSSD Canada (Rice, 2023).

Some participants in this study reported a history of sexual trauma and indicated that physicians should consider how such a history might affect women's experience of IC. Therapists who are aware of IC and who have experience in helping women and couples with sexual dysfunction, loss and trauma may be helpful for people who have IC (Cano et al., 2008; Johansen & Cano, 2007; Leong et al., 2011; Rosen et al., 2014). In addition, some participants in the current study reported that physicians should be more aware of the cost of the medications and treatments they prescribe.

Delimitations

The current study had specific boundaries related to the primary research question: "What are the lived experiences of women who have interstitial cystitis as they relate to women's sexuality and their lives in general?" The current study did not explore the lived experiences of men with IC, individuals with IC who have other gender identities (e.g., transgender, agender, Two-Spirit, genderqueer, non-binary) or individuals with other urologic conditions. Researchers who are interested in those experiences should investigate them. In addition, this study focused on the effects of IC on participants' sexuality as opposed to women's experiences with IC and other phenomena (e.g., therapy, treatment, employment, schooling). Women who were recruited into this study had to read, write and speak English; were recruited only using social media; and had to have access to a telephone or computer for interviews to be conducted on Zoom. This study did not include people who do not use social media or who lack access to a telephone, computer or Zoom.

Limitations

Although this study provided some new insights into the experiences of women with IC, it is important to note that there are some limitations of this study. Purposive sampling was utilized to recruit key informants who have expert knowledge regarding the phenomenon being studied and who could describe their experiences in depth. The researcher chose participants on a first-come, first-served basis. As it happened, the study sample skewed young in terms of age. All but one participant (n=10) were aged 23-39. As a result, the experiences of IC among older women or women who have experienced IC for longer periods may not be captured accurately in this study. Researchers who are interested in the experiences of older women with IC or women who have experienced IC for longer periods should investigate these experiences, too.

Strengths

The current study has some strengths. The process of identifying emerging themes was iterative, rigorous and in line with descriptive phenomenological research. In an attempt to achieve dependability, confirmability and credibility of the results, the emerging themes were reviewed by another expert who was not involved in the process. The identification of themes was conducted using multiple experts in the field in an attempt to establish transcendental subjectivity (Laverty, 2003; VanKaam, 1966). All eight experts had conducted research and/or worked in areas related to sexuality using a phenomenological lens. All have a history of conducting this form of descriptive phenomenology in previous projects of the OSE Research Team. The individual who participated as an external reviewer has been a member of the research team for over 10 years and has extensive experience using this methodology. (The external reviewer was not the thesis supervisor.) The distinct approach to phenomenology that

was utilized in this study involved: an iterative and collaborative process of discussion; a return to the data; and experts checking each other's biases on the participants' experiences to establish dependability, confirmability and credibility of these findings (Lincoln & Guba, 1985).

Directions for Future Research

Future research should continue to investigate the physiological mechanisms and etiology of IC. Researchers should also examine the interactions between physicians and patients who have IC and barriers that physicians face when working with IC patients. In addition, future research should investigate the effectiveness of current IC treatments, how current treatments affect patients' sexual response and psychological treatments to target the physical, psychological and sexual difficulties that accompany IC.

Conclusion

These findings may contribute to a deepened understanding of the lived experiences of women with IC and help to increase physicians' understanding and awareness of the negative effects that accompany IC. This research could serve to improve IC patients' physical, psychological and sexual needs that are, at best, underserved in current treatment approaches. By continuing to share the stories of individuals with IC, the hope is that the suffering and the sexual effects that accompany this condition will become recognized, understood and treated by mental health professionals, physicians and medical researchers.

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Appendix A

Recruitment Statement

My name is Hannah Richardson and I am a graduate student at the University of Ottawa in the M.A. Counselling Psychology program in the Faculty of Education. I am currently recruiting participants for my Master's thesis project under the supervision of Dr. Peggy J. Kleinplatz, Professor, Faculty of Medicine and cross-appointed to the Faculty of Education, University of Ottawa. The purpose of my study is to explore the lived experiences of women with interstitial cystitis (IC). Participation in this study will consist of completing a telephone or video interview with the researcher (Hannah Richardson) for approximately one hour. During this interview, participants will be asked to reflect on their experiences of how interstitial cystitis has affected their sexuality and sex lives. In order to be eligible for participation, participants must be (1) be able to read, write and speak English, (2) have symptoms consistent with a diagnosis of IC, (3) willing to have their interview audio-recorded for data analysis purposes and (4) have access to a telephone or a computer. I hope that this study will raise awareness of this condition and future patients who receive a diagnosis of IC give voice to those who have suffered from IC. If you meet the above criteria and are interested in participating in this study or have any questions about the study, please contact me. Should you have any additional concerns, please contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562 5387 or ethics@uottawa.ca. Your participation is greatly appreciated.

Appendix B

Interview Protocol Prompts

1. What prompted you to seek health care treatment that led to a diagnosis of interstitial cystitis (IC)/symptoms consistent with a diagnosis of IC?
2. How long have you been wrestling with these symptoms/feeling pain?
 - a. If applicable, could you describe what treatments were offered to you by relevant health care practitioners?
 - i. Are you taking any medication for interstitial cystitis? What, if any, impact have they had?
3. How has this condition affected you and your life?
4. How would you describe your current sex life?
5. How has interstitial cystitis affected your sex life?

Appendix C

Consent Form

Title of Study: Understanding the Lived Experiences of Women with Interstitial Cystitis (IC): A Qualitative Analysis of Individuals' Sexuality

Principal Investigator:

Hannah M. Richardson

Graduate Student

Faculty of Education

University of Ottawa

Ottawa, ON

Supervisor:

Dr. Peggy J. Kleinplatz

Professor, Faculty of Medicine

Cross Appointed, Faculty of Education

University of Ottawa

Ottawa, ON

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Hannah M. Richardson to complete her Master's thesis under the supervision of Dr. Peggy J. Kleinplatz.

Purpose of the Study: The purpose of the study is to explore the lived experiences of women who have been diagnosed with interstitial cystitis (IC) or who have symptoms consistent with a diagnosis of IC. More specifically, this study will examine the experiences of women living with IC and how the IC has affected their sexuality.

Participation: My participation will consist essentially of completing a telephone or video interview with the researcher for approximately one hour during which I will be asked to reflect on my experiences of living with interstitial cystitis (IC) and its effects on my sexuality, if applicable. I do not have to answer any questions that I do not want to answer. The interview has been scheduled for a time that is convenient for me. I am free to withdraw from the interview at any time and to withdraw my data at any time, too.

Risks: By participating in this study, I am aware that I will be volunteering some personal information. Given the nature of this research, there is a risk that I will feel emotional discomfort before, during or after the interview. I have received assurance from the researcher that every effort will be made to minimize these risks. As such, I know that I am free to refuse to answer any questions that may cause such discomfort and I know that any information collected from me during the interview will be kept confidential and anonymous. Furthermore, if I do feel any emotional discomfort, I know that I may contact Dr. Peggy J. Kleinplatz, a registered clinical psychologist, at the previously listed number.

Benefits: This research is not specifically designed to benefit participants. However, the hope is that this will be an opportunity for participants to share their stories and shed light on this condition, thereby helping other/future women dealing with IC.

Anonymity: I have received assurance from the researcher that the information I will share will remain anonymous. Anonymity will be protected in the following manner: I have been asked to

provide a pseudonym to ensure that any information I disclose remains anonymous during data analysis and for publication purposes.

Confidentiality: I have received assurance from the researcher that the information I will share will remain strictly confidential and will be used solely for the purposes of this research. The only people who will have access to the research data (i.e., the interview transcripts) are the researcher, Hannah M. Richardson and the Supervisor, Dr. Peggy J. Kleinplatz. Members of the Optimal Sexual Experiences Research Team will see only de-identified transcripts for data analysis purposes. I understand that the contents will be used only for data analysis purposes and that some direct quotations from my interview may be cited in the final research paper and future publication. Any identifying information, such as my real name and contact information (i.e., email address and/or telephone number) will be known only to the researcher. Finally, in order to minimize the risk of security breaches and to help ensure your confidentiality we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you have completed the interview.

Conservation of data: Any information taken and printed from the questionnaires will be kept in a locked filing cabinet in the office of Dr. Peggy J. Kleinplatz of the University of Ottawa for a period of 5 years at which time, they will be destroyed. All electronic data (i.e., the interview transcript, a copy of the consent form and the audio-recording of the interview) will be kept on the password-protected computer of the researcher in password-protected files for a period of 5 years before deleting.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will not be used for the study. It will be conserved and destroyed/deleted in the same manner as described above.

Acceptance: I, (Name of participant) agree to participate in the above research study conducted by Hannah M. Richardson of the Faculty of Education, University of Ottawa, whose research is under the supervision of Dr. Peggy J. Kleinplatz. If I have any questions about the study, I may contact the researcher or her supervisor. If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, tel.: (613) 562-5387 or ethics@uottawa.ca There are two copies of the consent form, one of which is mine to keep.

Participant's signature: *(Signature)* Date: *(Date)*

Researcher's signature: *(Signature)* Date: *(Date)*