

Chronic Pelvic Pain Patients Perception about their Experience with the First Health Care Provider Among the Patients who Follow in Wasser Pain Management Center in Mount Sinai Hospital

Maram Alshareef^{1*}, Denise Pandeuro², Kethmini Amarasinghe², Kareena Gurbaxani² and Allan Gordon²

¹Faculty of Medicine, Umm Alqura University, Saudi Arabia

²Wasser Pain Management Centre, Mount Sinai Hospital, Toronto, Ontario, Canada

*Corresponding Author: Maram Alshareef, Faculty of Medicine, Umm Alqura University, Saudi Arabia.

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Abstract

Aims: Chronic pelvic pain is a common condition observed in primary health care, yet no research has surveyed the experience of these individuals within the health system. In order to address this gap, the current study explored patients' experiences when consulting for the first time with a health care provider to communicate symptoms of Chronic Pelvic Pain.

Methods: Thirty individuals (M age = 40, + 12; 27 females) with CPP completed a 10 to 15 minutes anonymous qualitative questionnaire while awaiting their medical appointment at the Wasser Pain Management Centre. Participants were asked to provide demographic information, pain duration, pain onset, the medical specialty of their initial Health Care Provider, and to report their feelings associated with expressing their symptoms as well as their overall satisfaction.

Results: The average pain duration was 5 years and 70% of patients were unsure how their pain began. The majority of patients indicated that their first Health Care Provider was a family physician or gynecologist. Sixty percent reported a negative experience while expressing their symptoms such as feeling uncomfortable and hesitant and 67% reported feeling disappointed with the quality of health care obtained from the providers. Patients were most disappointed with the level of dismissiveness and the lack of knowledge and personalized care received. The average overall satisfaction reported was 3.93 out of 10.

Conclusions: These findings highlight the urgent need to provide early education regarding adequate diagnostic approaches for Health Care Provider. Adopting a supportive and empathic therapeutic environment is critical for facilitating optimal health care for individuals with Chronic Pelvic Pain.

Keywords: Chronic Pelvic Pain; Patient Perception; Health Care Provider

Introduction

Chronic pelvic pain (CPP) is one of the most common symptomologies observed by healthcare practitioners in Primary Health Care (HCP) [1]. CPP is defined as pain occurring below the umbilicus, including the abdomen, pelvic, genital organs, and thighs in both men and women that can either be intermittent or continuous for a minimum of 3 to 6 months [1,2]. The prevalence of this problem seems to be high in females and the rate is similar to other common chronic problems seen in PHC, like asthma, headache, and back pain [4]. The prevalence of CPP in women for dysmenorrhea and dyspareunia are between 16.8 to 81% and up to 21.8% respectively, whereas the non-hormonal pelvic region pain was between 2.1 to 24% [3]. CPP results in approximately 20% of gynecology consultations and contributes to 45% of the reduced work productivity [5,6]. The prevalence of CPP in males varies between 2.7 to 16% and it is about 8% of urology visit per year [7,8].

The etiology of CPP is not always clear and that can lead patients to visit multiple healthcare providers in search of an accurate diagnosis [11]. A study conducted in 1995 showed that of the 598 employed participants, 15% reported time lost from paid work and 45% reported reduced work productivity due to pain. According to [29], stated that an estimated amount of \$881.5 million dollars was spent in that year to help the outpatient population with CPP condition [9-11]. A retrospective analytic research was conducted to explore duration of symptoms, diagnosis patterns, and the process of referral for women with chronic pelvic pain. One-third of the women who had CPP for several years did not receive an appropriate diagnosis; in addition, only 40% of the patients received a referral to secondary care or a specialist [14].

CPP affects several aspects of patient's life varies from disruption of the daily activity, interpersonal relationship to the sexual difficulties [12]. A research on patient experience suggested that patients' satisfaction depends greatly on factors that are external to the health care system [20]. These external factors that were indicated to impact participant satisfaction include health status, patient expectation and type of care received [21]. This finding highlights the importance of the overall health care provider experience. A systematic review examined the relationship between healthcare provider experience and the quality of care they offered to patients. Over half of the studies reviewed displayed a negative association between the experience of the healthcare provider and the health care provider's performance in treating the patient. An interesting finding of this systematic review showed a 2% positive association between the health care provider's experience and the performance in the healthcare setting. It was suggested that health care providers with several years of practice were more likely to be less informed and that could potentially lead to poorer patient health outcomes [27]. Patients experiencing other chronic pain conditions such as fibromyalgia have indicated difficulties they experienced with health care providers, including the lack of care and understanding that negatively impacts their health and quality of life [28]. No research exists looking at CPP and the patient experience within the healthcare system. In order to assess the perceptions of the patients with this complex diagnosis, we have conducted a qualitative study. The current study explores patients' experiences when consulting with their first health care provider to communicate symptoms of CPP.

Methodology

Chronic Pelvic Pain - Methods Participants

The sample was a convenient sample taken by comprised 30 participants with CPP recruited from the Wasser Pain Management Centre, a multidisciplinary pain center in Toronto. The mean age of participants was 40 (± 12) and the majority of participants were female (90%). Inclusion criteria consisted of females or males diagnosed with chronic pelvic pain over 18 years of age. Participants who were unable to read and speak English were excluded. Demographic information is provided in the results section.

Procedure

A health care practitioner at the Wasser Pain Management Centre reviewed daily scheduled appointments and provided a list of eligible candidates to the research coordinator. Participants were approached while awaiting their medical appointment and presented with an information letter that described the study by one of the research team members. Survey completion time was approximately 10 to 15 minutes and participants were informed that the survey was anonymous and to place it into a confidential box in the waiting area of the clinic upon completion.

Materials

The research team in the center could not find a survey that explore patients' perceptions regarding their first health care provider experience as this study was the first to conduct so they developed a qualitative survey to explore the patients experience with their first HCP. Demographic information, pain onset, pain duration, descriptors of pain (e.g. aching, burning, piercing, etc.), and self-reported most bothersome symptoms were included in the survey. Participants were asked to provide information describing their first health care provider experience regarding their pelvic or genital pain. Participants were asked to provide feedback on how they felt when they expressed

their symptoms to their health care provider (e.g. hesitant, easy, uncomfortable, etc.). Participants were also asked to provide details regarding their health care provider response and the feelings associated with this response. Data was gathered pertaining to the type of first HCP (e.g. family physician, gynecologist, pain specialist), satisfaction indicated on a numeric scale ranging from 0 (not satisfied) to 10 (extremely satisfied) with this HCP. Patients were asked about the number of total HCPs they visited, management options offered, preferred health care provider and treatment options provided. Lastly, participants were asked to provide a detailed description of the impact the pain condition has on three domains affecting their life: physical, psychological, as well as sexual.

Results

This is a qualitative study where the research team coded the data by and use the thematic analysis especially on the questions where it required the patients to describe their experience and their feelings before, during and after the experience. Data were read independently by two members of the team then the common themes were used to analyze the participants perceptions with the first HCP. Overall, thirty participants indicated that they consulted with a health practitioner to discuss the pain they were experiencing in their pelvic region. Ninety percent of the sample was female (n = 27). The demographic information reveals an 18.5% of the participants were Caucasian (Table 1). Half of the sample was either married or in a domestic relationship (n = 15). On average, participants experienced pain for 5 years (range 0.25 - 26 years). Approximately 37% of the sample indicated that their pain from the onset was sudden and “just began”, 33.3% indicated that the source of pain was “unknown”, 16.7% indicated that their pain began “after surgery” and 16.7% indicated “other reasons”.

Variable	N (%)
Ethnicity	18.5 (61.7)
White	18.5 (61.7)
Black	3 (10)
Latin American	1 (3.33)
South East Asian	1.5 (5)
Aboriginal	0.5 (1.67)
Korean	1 (3.33)
South Asian	1 (3.33)
Filipino	1 (3.33)
Portuguese	1 (3.33)
Chinese	0 (0)
Japanese	0 (0)
Arab/West Asian	0 (0)
Prefer not to Answer	1 (3.33)
Marital Status	
Single	10 (33)
Married/Domestic	15 (50)
Separated	1 (3.33)
Divorced	2 (6.67)
Widow	1 (3.33)

Table 1: Summary of Demographic Information.

The most five pain descriptors reported by participants include: tenderness aching, burning, stabbing and tightness (Table 2). It is important to note that some participants responded with more than one descriptor.

Pain Descriptor	N (%)
Tenderness	23 (76.7)
Aching	21 (70)
Burning	18 (60)
Stabbing	17 (56.7)
Tightness	16 (53.3)

Table 2: Pain Descriptors.

The most 5 bothersome symptoms experienced by the patients include: burning (26.6%), pain during sex (16.7%) pain during urination (13.3%) frequency of urination (13.3%) and sharp/shooting pain, pain in the abdomen, pain while sitting/standing/walking, excessive bleeding, difficulty in bowel movement, pressure which all count (3%) of the most bothersome symptoms that patients reported (Table 3). It is important to note that some participants reported more than one symptom as most bothersome.

Symptom	N (%)
Burning	8 (26.7)
Pain during sex	5 (16.7)
Pain during urination	4 (13.3)
Frequency of urination	4 (13.3)
Sharp/shooting pain	3(10)
Pain in abdomen	3 (10)
Pain when sitting/standing/walking	3 (10)
Excessive blood	3 (10)
Difficulty in bowl movement	3 (10)
Pressure	3 (10)
Constant arousal	2 (6.67)
Uncontrollable menstrual cycle: Excessive pain	2 (6.67)
Throbbing	2 (6.67)

Table 3: Most bothersome symptoms.

Participants were asked to describe their feelings when they initially expressed their symptoms to their first HCP. Fourteen participants (46.7%) reported feeling “uncomfortable and uneasy”, six participants (20%) reported feeling “hesitant” to report their symptoms, and 3 participants (10%) reported feeling “apprehensive, nervous, and scared”. Four participants (13.3%) reported having a negative impact on their self-image as they stated feeling “embarrassed and humiliated”. While 40% (n = 12) reported a positive experience stating that the feeling of expressing their symptoms was “easy”.

Participants were asked to report their feelings after they consulted with their health care provider for their pelvic pain condition. The participants express that as the following: “uncomfortable” (13.3%), “upset” (13.3%), “embarrassed” (13.3%), “disappointed” (10%), “frustrated” (10%), and “terrible” (6.67%). nine participants (30%) reported they were fine, one (3.33%) were hopeful and two (6.67%) were happy.

Eight participants (26.7%) reported feeling “easy” and three participants (10%) reported feeling “fine”. In addition, (36.64%) of the sample reported neutral feelings about when they met with their first health care provider. Three participants reported feeling “scared” (10%), two participants indicated that they felt “concerned and nervous” (6.67%), four participants indicated that they felt “confused” (13.3%), and two participants (6.67%) reported feeling “surprised”.

Participants were asked to report how they felt about their first health care provider’s response and management approach. Eight participants (26.7%) indicated that the health care provider was dismissive. Six participants (20%) indicated that the healthcare provider was unsupportive. Six participants (20%) also indicated that the health care provider was uninformed of the condition. It is important to note that some individuals indicated more than one descriptor item to explain their perception. Contrasting the negative perceptions, 16 participants (53.3%) indicated a positive response from their health care provider. Seven participants (23.3%) indicated that they felt their health care provider was “supportive” after the consultation. Five participants (16.7%) reported that the health care provider suggested more testing for a better diagnose of the condition. Four participants (13.3%) indicated that the health care provider referred them to a specialist.

The survey included a question pertaining to how the participant felt about the health care provider’s response. Four participants (13.3%) of the sample expressed feeling “uncomfortable” with the response of the health care provider, four participants (13.3%) reported feeling “confused” about the health care provider’s response, four participants (13.3%) reported that they felt “not understood” with the response of the health care provider. Five participants (16.7%) reported feeling “frustrated” with the HCP’s response, three participants (10%) reported feeling “upset”, one participant (3.33%) felt “disappointed”, one participant (3.33%) felt “shocked”, and one participant (3.33%) felt “helpless”, In contrast, twelve (40%) participants reported feeling positive. Nine participants (30%) reported feeling “fine” with the response of the health care provider, one participant (3.33%) reported feeling “hopeful” of the health care provider’s response, and two participants [2] reported feeling happy about the health care provider’s response.

Participants were asked to report the management options offered by the health care provider. Twenty-one participants (70%) were prescribed medication, twenty participants (66.7%) were referred to other specialists, four participants (13.3%) were provided with “other” treatment options, three participants (10%) were provided with alternative treatment options, and three participants (10%) were provided no treatment option. It is important to note that some participants responded with more than one treatment option as suggested by their health care provider. The participants, on average, reported 3.93 on a scale ranging from 0 to 10 (0 representing no satisfaction and 10 representing complete satisfaction) to indicate their satisfaction with their health care provider.

Participants indicated the level of interference in physical, psychological, and sexual aspects of their life due chronic pelvic pain condition. Twenty-seven participants (76.57%) reported having psychological distress that was due to their pain. Psychological distress included: negative self-image (33.3%), anxiety (13.3%), general negative impact (13.3%), depression (10%), and stress (6.67%). Fifteen participants (49.97%) reported interference in their sex life, which involved a decrease in libido (13.3%), decreased frequency of intercourse (10%), presence of pain during intercourse (10%), fear (6.67%), interpersonal issues (6.67%), and negative self-image (3.33%). Seven participants (23.34%) reported interference in the physical aspects of their life, including involvement in daily activities (10%), their work life (6.67%), and disruption in their sex life (6.67%). The average overall satisfaction reported was 3.93 out of 10.

	Negative	N (%)	Positive	N (%)
Initial feelings about expressing symptoms to HCP	Uncomfortable and uneasy	14 (46.7)	Easy	12 (40)
	Hesitant	6 (20)		
	Apprehensive, Nervous and scared	3 (10)		
	Embarrassed and humiliated	4 (13.3)		
Feelings after Expressing symptoms to HCP	Uncomfortable	4 (13.3)	Fine	9 (30.0)
	Confused	4 (13.3)	Hopeful	1 (3.33)
	Not understood	4 (13.3)	Happy	2 (6.67)
	Frustrated	5 (16.7)		
	Upset	3 (10)		
	Disappointed	1 (3.33)		
	Shocked	1 (3.33)		
	Helpless	1 (3.33)		

Table 4: Feelings Associated with Health Care Provider.

Discussion

The study is the first to explore CCP patients’ experience with their first HCP and how that might affect the course and the progression of the patients’ symptoms and condition. Majority of the patients recruited were female might be because of the prevalence of CPP which is more common in female than male in addition to the pain physiological and pathological pathway is different between them [22,33]. The average overall satisfaction reported was 3.93 out of 10. The study found twenty-three participants (76.59%) reported negative feelings toward the health care provider’s response. This may indicate the dismissiveness they perceived during the consultation. Chronic pelvic pain patient need the HCP to show personal interest and care, they wanted to receive a detailed explanation and education regarding their conditions. They need reassurance after a proper workup that eliminate serious diseases [31].

60% of the patients had difficulty prior to express their symptoms for the first time to their HCP because they felt ashamed, hesitant or being afraid of being perceived negatively. It becomes more complicated if the HCP is different in gender. The patients were shocked by the response of the health care provider as most of them were dismissing or ignoring the complaint or even labelled these patients as having psychological or infectious diseases. In general, HCP showed a lack of the important knowledge, skills, and attitude to manage chronic pain especially neuropathic pain [24]. However, knowledge about CPP is important for most HCP especially family physician because 60% of the patients in our study had family physician as first HCP. Family Physician acknowledge the need for more training in regard to chronic pain as well as other health care providers [18,19].

The important factor in treating chronic pelvic pain patients is the relationship with the patients. It’s important to keep it supportive and reassuring to an appropriate extent [25] its known, the diagnosis of CPP is challenging due to multiple potential sources of pain and the areas of malfunction that women with CPP experience were not directly associated with pain variables. More importantly, the functional impairments were associated with anxiety and depression stating that CPP impacts the health of patients on a broader level [19]. An optimal approach to the management of CPP would involve focusing on the pain as well as the overall mental health of the patient. In order to achieve this, a comfortable and nurturing healthcare provider experience would be necessary.

If the family physicians have enough training in CPP they can be able to diagnose and save the patients from frustration and stress and improve their quality of life especially when we know that family physician are trained in the psychosocial (holistic) approach [26]. They could be able to manage the patient, and this would improve the outcome and give the patients answer to their most important question. "What do I have? what is the diagnosis?" when patients have this answer they start to accept their chronic pain symptoms and try the options to manage or cope with it. We noticed the patients who get to know their diagnosis earlier they seem less distress than those who visited all the specialist.

Practically we noticed when the patients understand their conditions they respond better to the management options which enable them to cope better with their lives, improve the function and prevent the consequence of catastrophe in CPP [26].

Conclusion

In conclusion, this study suggests that chronic pain management should better be taught to the medical students and family physicians. They should have a clear approach to diagnose and manage chronic pelvic pain conditions which will reduce the condition impacts and cost on government and patients and lead to better outcome.

Limitations

This is the first study to explore CPP satisfactions with the first health care provider and it is a retrospective study. A cohort study may be needed for better knowledge about the association between chronicity and complexity of CPP and first health care provider consultation.

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