Why is chronic pelvic pain under-recognized and under-treated?

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Abstract:

Chronic pelvic pain syndrome is one of the most common health conditions affecting women worldwide. However, despite its prevalence, it is under-diagnosed, under treated, and poorly understood. Often times, a specific etiology cannot be found, and patients may present with symptoms from multiple organs. A majority of these patients have comorbid conditions such as irritable bowel syndrome and chronic fatigue syndrome, further complicating their management. Besides the lack of awareness, bias within health care towards patients presenting with chronic pain still remains a major barrier for those seeking appropriate diagnosis and treatment.

Introduction:

Chronic pelvic pain syndrome (CPPS) is a common, but not well-known, condition that affects approximately one in seven women each year in the United States.[1] Despite having a prevalence like that of other common conditions, such as migraine headaches and chronic back pain, CPPS is underdiagnosed and under treated, leaving many to suffer through the disabling effects of this condition.[1] Chronic pelvic pain is a broad term for any chronic pain lasting at least six months located in the pelvis, lower abdomen, low back, medial aspect of thigh, inguinal area, and perineum.[2] Unfortunately, it is associated with many comorbidities including autoimmune diseases, major depressive disorder, and pelvic inflammatory disease. This condition has a significant effect on quality of life; however, it is estimated that fifty percent of cases remain undiagnosed.[1] CPPS can cause severe and disabling pain that hinders many normal daily activities and affects sexual health. It is the most common reason for referral to women's health services and is estimated to cost $881.5 million each year for its outpatient management.[2] However, despite its prevalence, the awareness of this condition is low among the general population, medical community, and health practitioners.

Etiologies and Pathophysiology:

The exact cause of CPPS is unknown, however, many conditions are implicated including those from a gynecologic, urologic, gastrointestinal, musculoskeletal, neurologic, and psychosocial origin (Table 1). The expansive nature of this condition is one of the many difficulties in diagnosing and treating patients suffering from CPPS. In fact, for 80% of patients, the origin of the pain is not gynecologic. Despite this, it is responsible for 40% of laparoscopies and 12% of hysterectomies in the United States annually.[3] Most patients have multiple coexisting pelvic pain syndromes and therefore have many overlapping symptoms (Table 2), further complicating diagnosis. For example, 48% of women who have Interstitial cystitis (bladder pain) also have endometriosis and 30-75% of women with Interstitial cystitis also have irritable bowel syndrome.[3]

The leading theory for the connection between the bladder and the colon is Viscero-viscero cross sensitization theory. This theory suggests that because the bladder and colon share neural pathways, a disease in one organ can affect the other. The bladder and colon have inputs that converge into similar areas of the spinal cord, allowing them to coordinate function. Hence why you are able to prevent yourself from urinating when defecating. However, inflammation or disease in one organ, the colon for example, alters the sensory pathways shared by the bladder, therefore causing dysregulation of the neural pathway for the bladder. As a result, there can be an abnormal perception of a normal stimulus.[4]

Other theories for CPPS are the same as those for chronic pain which include central and peripheral sensitization. Central sensitization is when there is increased membrane excitability to normal stimuli as a result of neural plasticity of the central nervous system after exposure to prolonged inflammation and disease. Therefore, the body develops a lower threshold for pain compared to normal. Peripheral sensitization is increased sensitivity in the afferent nerve secondary to trauma or injury.[5] Both have been implicated in many types of chronic pain syndromes including CPPS. As a result, the source of pain for these patients can be nociceptive, inflammatory, and/or neuropathic pain.[2]

Table 1.

Etiologies of CPPS by location:	
Gynecological	Primary dysmenorrhea, Mittelschmerz, Endometriosis, Adenomyosis, Uterine leiomyomata, Cervical stenosis or obstructive abnormality, Pelvic venous congestion syndrome, Ovarian remnant/residual ovary syndrome, Pelvic adhesions, PID,

	Endosalpingiosis, Vulvodynia, Vestibulodynia, Clitorodynia
Urinary Tract	Interstitial Cystitis, Urethral pain
Gastrointestinal	Irritable bowel syndrome, Inflammatory bowel disease, Chronic constipation
Intra-Abdominal Female Genitals	Ovary (unilateral or bilateral) Pelvic congestion syndrome (pressure, heaviness, dull aching pain in pelvis and/or in the back
Musculoskeletal	Pelvic floor muscle dysfunction, Myofascial pain
Neurological	Pudendal neuralgia, Nerve entrapment, Herniated disc
Psychosocial	Depression, Physical/sexual abuse, Psychological stress, Substance abuse

Note. Adapted from Paiva S, Carneiro MM. Complementary and Alternative Medicine in the Treatment of Chronic Pelvic Pain in Women: What Is the Evidence?. *ISRN Pain*. 2013;2013:469575. Published 2013 Nov 28. doi:10.1155/2013/469575

Table 2.

Most common symptoms experienced by patients with CPPS:

Gynecological:	Abnormal bleeding, painful menstruation, pain with intercourse, discharge, burning, voiding/defacatory pain, abdominal/pelvic pain (can be a stabbing pain)
Urinary tract:	-Interstitial Cystitis: recurrent chronic pelvic pain, pressure/discomfort perceived to be in the bladder accompanied by urinary urgency and frequency -Urethral pain without history of current infection but can occur after urinary tract infection.
Gastrointestinal:	Constipation, diarrhea, pain with defecation, bleeding, cramping, abdominal pain, rectal pain/pressure
Musculoskeletal:	Abdominal/pelvic pain, pain with sitting or movement, pain with sex, pain that is unilateral or bilateral., pain with voiding or defecation
Psychological:	Anxiety, low mood, frustration, sleep disturbance, hopelessness, difficulty concentrating, pain impairing enjoyment, low sex drive, inability to become aroused, difficulty reaching orgasm.

Note. Obtained from Doggweiler R, Whitmore KE, Meijlink JM, et al. A standard for terminology in chronic pelvic pain syndromes: A report from the chronic pelvic pain working group of the international continence society. *Neurourol Urodyn*. 2017;36(4):984-1008. doi:10.1002/nau.23072

Approach to diagnosing CPPS:

The first and most important step in diagnosing CPPS is obtaining a thorough history of the patient. This should assess the patient's perception of their pain/discomfort, duration, triggers, and modality (if the pain is persistent or recurrent).[2] It is important to employ a trauma-informed care as a history of sexual and physical abuse is common in this population.[5] This allows for improved patient-physician interactions and aids with obtaining an accurate history, which is crucial for determining the underlying etiology. Pelvic pain and psychology are closely interrelated. Because many of these patients are victims of physical and/or sexual abuse, understanding this relationship is crucial to managing these patients. Trauma can augment pain, especially in the genitalia. This can manifest as vaginismus (unconscious contraction of vaginal muscles, causing painful penetrative sex) and dyspareunia (pain with sex). A history of trauma is an obstacle for many which prevents them from pursing treatment. Moreover, it can also make the physical exam portion of a patient visit particularly traumatizing. Using trauma informed care can aid in mitigating these obstacles.

The next step in diagnosing CPPS is the generalized physical exam, a complete pelvic exam, palpation of the lower abdomen, assessment of the lumbar, and sacral spine and assessment of bladder fullness/tenderness. A full gynecological consultation with work up and tests is also necessary.[5] During the physical exam, other treatable diseases presenting with similar symptoms should be ruled out. For example, patients who present with anal pain should be assessed for anal fissures, abscesses or hemorrhoids. Some patients may require further diagnostic testing studies conducted by specialists such as a cystoscopy for suspected interstitial cystitis. For patients with musculoskeletal complaints, pain mapping can be done, which may be helpful in identifying trigger points and referred pain.[2]

Barriers to diagnosis:

Many of the barriers to diagnosing chronic pelvic pain are the same as those with chronic pain due to other conditions. It has been well documented that negative stereotypes and bias plays a major role in the relationship between patients and health care personnel when it comes to chronic pain. Diagnosing CPPS requires a high degree of suspicion, however, bias towards chronic pain can hinder this. These biases and negative stereotypes are even more prevalent when it comes to black patients, who are a considerable percentage of women with CPPS. Research has shown that clinicians tend to distrust reported symptoms from patients and place more emphasis on psychosocial contributions and are less likely to consider medical interventions. Studies have also shown that when patients report higher levels of pain severity, clinicians are even more likely to discount the pain severity and the contributions of medical causes.[6] This can lead to undertreatment when patients with high pain severity require more aggressive intervention.

Many clinicians need medical evidence to validate a patient’s reported symptoms. Notably, however, due to the difficulty in obtaining tangible evidence of CPPS, many of these patients will not receive the necessary care. One proposed potential mechanism underlying this trend in health care is that patients who report high levels of pain without evidence violate social norms where society tends to value “stoicism” in response to adversity.[6] Thus, these patients may be viewed negatively and seen as inflating their symptoms. Another theory is that clinical burden underlies this bias due to the challenge that physicians face when managing complex medical conditions. Studies show that health care providers find managing chronic pain conditions to be difficult and unrewarding due to the apparent difficulty in treating such conditions. This mindset is thought to be further exacerbated when clinicians read case descriptions of a typical patient with chronic pain which may reinforce the existing negative stereotypes. These stereotypes depict these patients as untrustworthy, drug seeking, depressed and unlikely to improve.[6]

However, studies also show that patients who report moderate pain and have supporting medical evidence are also still viewed negatively similarly to those reporting high pain severity.[6] Despite the effort to educate and increase awareness of these negative stereotypes of chronic pain patients, this bias has not significantly improved. One possible solution is the implementation of multidisciplinary treatment. Multidisciplinary treatment can help to mitigate these difficulties and biases by reducing the burden on an individual clinician. Many providers have felt the stress brought on by time restrictions imposed by health insurance and hospitals. Time restrictions in addition to the complex nature of CPPS makes it difficult for providers to feel as if they have adequate time to extract an accurate diagnosis and to come up with a management pan. This can create negative feelings towards managing these patients and therefore plays a role in the development of bias and increases the chance of a provider abandoning these patients. Though this approach provides some relief for an individual clinician, it will likely increase the burden on the patient who would then need to see multiple clinicians. This is particularly troublesome because this is an issue that CPPS already patients face and it causes significant financial difficulties.

One study on thirty (30) CPPS patients at a pain management center found 76.59% reported negative feelings towards the health care providers' responses. They desired for the provider to show more personal interest and to conduct a proper workup to eliminate the potential of serious diseases as the cause. Moreover, they wanted health care providers to provide them with a thorough explanation of their condition. Also 60% of these patients had difficulty expressing their symptoms to providers due to feelings of shame and fear of being perceived negatively.[7] There is a lot of room for improvement in physician-patient relationships as this affects the patient's time to diagnosis and accuracy of diagnosis. Improving this relationship begins at the level of medical education. In one study, residents consistently reported feeling overwhelmed by CPPS patients, perceived a lack of time to see these patients, and indicated a desire to learn more about this area.[8]

Treatment:

Pharmacological management

Due to the many possible etiologies of CPPS, the treatment requires a multimodal approach based on the underlying pathology. Management of CPPS should address the physiological aspect of pain as well as the psychological aspect (Figure 1). In general, both a pharmacological and nonpharmacological approach is used to treat pain. The initial treatment for pain begins with over the counter ("OTC") analgesics such as NSAIDs, which also address inflammation. Further management of pain depends on the source of the pain. For example, if the pain is from a gynecological source, hormone replacement therapy, such as oral contraceptives and intrauterine devices, can be used in addition to OTC analgesics. For those with neuropathic and muscular pain, topical agents can be used in addition to neuromodulators.

Neuromodulation involves manipulating the central pain processing pathway using medications that alter circulating neurotransmitters. An imbalance of these transmitters is thought to be an underlying source of pain. These neuromodulators including tricyclic antidepressants (“TCA”) and serotonin-norepinephrine reuptake inhibitors (“SNRIs”), gabapentin and pregabalin. TCAs and SNRIs also function as antidepressants which would be particularly beneficial for patients with a coexisting mood disorder. In addition, other adjuvant pharmacotherapies such as medical marijuana and diazepam suppositories (for high tone pelvic floor disorder) can be attempted for those who do not respond to first line pharmacological therapies.[5] If the pain is still uncontrolled, it is advisable to refer the patient to a pain specialist to manage use of opioid analgesics.

Some patients may benefit from peripheral nerve blocks, neuromodulation of sacral nerves, local steroid injections, radiofrequency ablation, peripheral nerve blocks, and Botox injections. Botox injections and trigger point injections are particularly important for this patient population, in which pain with sex is one of the most distressing and frustrating symptoms. Trigger point injections with a local anesthetic like lidocaine can be used for short term pain relief. They relieve hypertonicity and pain in pelvic floor or abdominal wall muscles, providing relief from pelvic pain in general and from pain with sex. Trigger point injections can also be both diagnostic and therapeutic for myofascial pain syndrome. Finally, education is equally as important for these patients. It is important that they understand that many patients can and do find some relief. However, the provider should have an in-depth discussion about the proposed etiology and what the patient should reasonably expect in terms of pain relief.

Nonpharmacological management

Another important aspect of pain management in these patients includes nonpharmacological treatments such as pelvic floor physical therapy, cognitive behavioral therapy (CBT), exercise, yoga, and acupuncture. Pelvic floor physical therapy is very helpful for those with pelvic floor muscle dysfunction, which many of these patients have. Addressing mood disorders and psychological factors is crucial because there is evidence that depression and pain have a close relationship. The presence of depression could worsen pain and vise versa.[5] One study with 118 participants investigating the effect of CBT on these symptoms found that it reduced pain severity, pain during intercourse, and increased sexual satisfaction.[5] However, CBT is time intensive, hence why patients should be referred for CBT early in their treatment to obtain maximal benefit. Exercise has been shown in multiple studies to aid in reducing chronic pain overall. Studies on patients with CPPS who do yoga have also shown a reduction in pain and an increase in quality of life.[5]

Role of Opiate medications:

Like many other chronic pain conditions, opiate medications have been commonly prescribed to CPPS patients despite little evidence of its effectiveness. Whether or not to prescribe opiates to this patient population is particularly difficult for providers to decide for these patients because they have many chronic pain syndromes all coexisting and contributing to chronic pain. Often times, CPPS patients will present with a history of having received long-term narcotic prescriptions from other providers.[9] In these cases, establishing boundaries and setting goals with these patients is important. While the pain relief provided by opiates cannot be disregarded for some, the role of opioid therapy for chronic pain is not well supported and carries major risks. Employing a screening tool for opioid misuse and using strategies to minimize the possibility of opioid abuse is paramount for these patients. This can include patient contracts, regular drug testing, pill counts and only having a single provider and pharmacy for all opioid prescriptions[9].

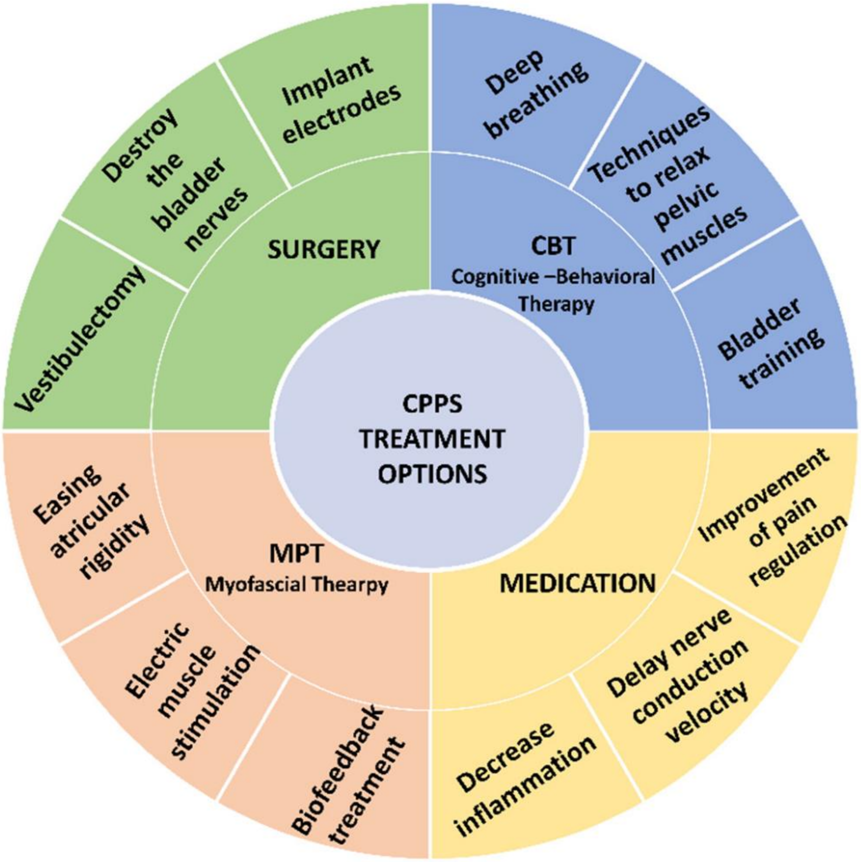

Figure 1. Diagram depicting the multidisciplinary treatment options for CPPS.

From Grinberg K, Sela Y, Nissanholtz-Gannot R. New Insights about Chronic Pelvic Pain Syndrome (CPPS). *Int J Environ Res Public Health*. 2020;17(9):3005. Published 2020 Apr 26. doi:10.3390/ijerph17093005

Conclusion:

Chronic pelvic pain syndrome is a very common condition among women that affects various aspects in life from disrupting daily activities to causing interpersonal and sexual difficulties. In addition to the financial burden caused by CPPS on both the individual and society, these patients receive insufficient relief from the condition necessitating consults from multiple doctors. One of the major barriers for diagnosis of these patients is a widespread lack of awareness, lack of understanding of the condition, and bias within healthcare. While treatments exist for these conditions and many of those patients experience relief, many undiagnosed patients continue to suffer.

Future Directions:

The future of CPPS must be focused on increasing awareness among providers and decreasing the number of patients who remain undiagnosed. The underlying cause behind the lack of awareness is likely due to the various clinical presentations of patients and the lack of evidence for the pathophysiology of CPPS. Therefore, advocacy among providers who regularly deal with this patient population is crucial. It is also particularly important to increase awareness among primary care providers who are often the first health care providers that these patients encounter. Accurate diagnosis at the first encounter would significantly decrease the time to treatment and therefore decrease the morbidity that patients experience.

One related issue is the impact of the use of inappropriate or unclear coding in medical records. Inappropriate coding hinders diagnosis and also affects the patient's ability to obtain treatment as well as reimbursement and social benefits.[2] Inappropriate coding is a syndrome of a lack of awareness and also a lack of consensus in coding for CPPS amongst the medical community. The use of proper coding decreases the time to treatment and ensures that they will receive disability support if needed. Obtaining social benefits is also important for financial support and increases access to treatments through insurance that would otherwise be out of reach.

While educating clinicians is crucial, it is also important to educate the general public. Public awareness of CPPS could provide relief for many of the fears that patients experience when they see a provider for their symptoms. Many of the symptoms experienced by CPPS patients involve sensitive areas and therefore create apprehension to seeking treatment. Widespread acknowledgement could reduce the by normalizing CPPS as a common condition experienced by many. Awareness in the general public also empowers patients to be able to advocate for themselves.

Another method to improve awareness begins with improvement of the medical residency curriculum. In order to create new generations of physicians who are comfortable with diagnosing and treating CPPS, the education and exposure would need to begin in residency. This condition is complex and the more that residents are exposed to these patients, the more likely they are to view this condition as manageable and rewarding. In addition, a curriculum change should also be done for other health care professionals who would encounter these patients, such as physician assistants and nurse practitioners. Finally, the data and information for CPPS is still lacking and therefore requires more multidisciplinary studies. More studies would allow for phenotyping which could aid in both research and in providing targeted treatments for certain CPPS patient populations. More research is also needed to develop new treatments for CPPS as many of the treatment options are slow and may not adequately relieve patients’ symptoms, resulting in increased use of opiates.

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