PRIMARtY CARE & HEALTH SERVICES SECTION

Review Article
Information About Male Chronic Pelvic and Urogenital Pain on the Internet: An Evaluation of Internet Resources

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Abstract

Objective. The objective of this study was to describe and evaluate the Internet resources available to patients searching for information about chronic urogenital/pelvic pain.

Design. As far as possible, we applied systematic review methods to search, retrieve, sort, and critique Websites, using common search engines and terms in the English language. Evaluation from a patient viewpoint focused particularly on the quality of explanations for chronic urogenital/pelvic pain in men, and on the psychological content of the Websites.

Results. While the 23 Websites reviewed were generally accessible and open, authorial attribution was largely missing and the nomenclature were inconsistent and confusing. Explanations of chronic pain were diverse and often inaccurate or only partially accurate; none represented current neurophysiologic models of chronic pain. Eight described psychological aspects of pain, five in a simple way and three with more complexity, but only one approximated a contemporary biopsychosocial model.

Conclusions. As in other areas of chronic pain, there is a wealth of information available online, but much is of poor quality, and taken together, is likely to confuse more than enlighten patients attempting to understand male urogenital/pelvic pain symptoms or supplement information from health care professionals.

Key Words. Urogenital; Pelvic; Pudendal Neuralgia; Patient Perspective

Introduction

Chronic pelvic pain (CPP), including urogenital pain, is estimated to affect between 5% and 18% of men [1–3] at some time in their lives, causing significant distress and interference with activities. The classification of pelvic pain incorporates pain experienced in the perineum, rectum, prostate, penis, testicles, and abdomen [4], and radiating to the pelvis, lower abdomen, upper legs, and lower back. It is frequently associated with urinary urgency, frequency, hesitancy, and poor or interrupted flow [5]; these and sexual problems significantly reduce quality of life [6].

The classification of pelvic pain is based on recognition of central and peripheral nervous system changes, characteristic of chronic pain conditions [7], rather than on presumed, but often unconfirmed pathology in the end organ. For instance, only around 10% of those originally diagnosed with "prostatitis" show evidence of infection [8], and many of the remainder could be described as having CPP [2]. The European Association of Urology (EAU) guidelines [9] define CPP as “non-malignant pain perceived in structures related to the pelvis of either men or women.” Because of the perception of pain in end organs, there are multiple terms included in the broad term, some implying cause, such as prostatitis (without evidence of infection) [10,11]. The guidelines also describe the psychological and functional difficulties that frequently result from chronic pain.
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The changing taxonomy and terminology reflects changes in the understanding of the pain mechanisms involved, although this is not necessarily shared by specialists for whom pain is regarded as one of several symptoms rather than the primary problem. Additionally, emphasis varies among specialist fields in the focus on any of the multiple factors involved, the particular end organ, and the pain mechanisms [12].

As with any pain for which a clear cause and diagnosis has been pursued without reaching a satisfactory diagnosis, men with CPP are likely to be provided with inadequate, bewildering, or incompatible explanations of their pain. Men tend to be reticent about disclosure of such problems, or of asking questions about them [13,14] and may prefer to seek information anonymously. The World Wide Web provides a huge variety of health Websites much used by people with chronic pain for information [15,16], particularly for pain problems the site of which can make them difficult to discuss [17]. The quality of online information inevitably varies according to factors such as the expertise and affiliation of authors, commercial sponsorship of the Website, and the inclusion of first-person accounts and opinions [18]. A recent study by Corcoran and colleagues [19] found information available to those who searched for information on “chronic pain”, using typical surfer behavior, to be generally poor.

We sought to find what was available to men searching the Internet for information about CPP, including urogenital pain, in particular concerning 1) explanations for pain; and 2) mention of psychological or emotional difficulties [9] associated with any persistent pain. Such information may be important in influencing men’s likelihood of seeking medical help, of consenting to and adhering to particular treatments, and of seeking or agreeing to access psychological support for distress associated with the pain problem.

Method

Search Strategy and Selection Criteria

We modeled our search strategy on nonexpert browsing choices and strategies, entering single search terms [20], only examining the first 10 Websites retrieved (97% of browsers do not go beyond these 10: [20]); using a widely used browser (Microsoft Internet Explorer) and the four search engines most commonly used in the UK (Google, Yahoo UK & Ireland, MSN/Bing, and Ask) (http://www.websearchworkshop.co.uk; http://www.searchenginespy.co.uk). The search was conducted in September 2010.

To arrive at the search terms, current clinical research literature was sampled and the shortlist of keywords discussed with clinicians working in CPP. The initial search used five key terms (urogenital pain, chronic pelvic pain, chronic prostatitis, penile pain, pudendal neuralgia). They are not terms likely to be used by a completely naive searcher before contact with medical services, but are intended to represent terms used to patients in medical consultations about male CPP. A pilot search using simpler search terms, such as “pain in the testicles,” returned almost entirely acute pain information, and therefore an entirely naive search could not be simulated.

The reviewer (NS) examined the titles of the first 10 URLs (universal resource locators) from each search to determine whether they referred to chronic pelvic and urogenital pain in men. The term urogenital pain failed this test, only producing URLs related to women, or aimed at specialist readers. The term chronic pelvic pain produced a majority of URLs for women; the term chronic pelvic pain syndrome produced results were more relevant to men. Therefore, the terms urogenital pain and chronic pelvic pain were eliminated, and the term chronic pelvic pain syndrome was substituted.

URL titles were subjected to exclusion and inclusion criteria. Inclusion criteria were: URL returned by at least two search engines. Exclusion criteria were: referring only to women; video (e.g., YouTube); and specialist publication such as scientific books and papers. The resulting URLs were reviewed within a 1-week period, following all internal links that were relevant to male CPP.

Evaluating Websites

In the absence of any established protocols for assessing information available on the Internet, Websites were evaluated according to a checklist of qualities drawn from guidelines for evaluating Internet medical and health resources and from criteria used in previous Website reviews on chronic pain [21–23]. The EAU 2010 guidelines [3] were used as a final arbiter for definitions and treatment recommendations. The qualities we sought, in relation to our focus on usefulness for men with pelvic pain, were: accessibility and interactivity; trustworthiness of site; an evidence-based explanation of pain; and an evidence-based psychological content.

Accessibility and Interactivity

We distinguished open-access Websites from those requiring membership or subscription; examined for user feedback or questions; and recorded whether there was a forum for users and if so, whether it was open or required membership.

Trustworthiness of Site

Information regarding the purpose and authorship of the Website was sought, as was information concerning the source of the material presented, and its apparent credibility (i.e., research-based or not); and we searched for links to further information and any disclaimers.

Explanation of Pain

We also recorded any explanations of causes of CPP and related symptoms, and evaluated the accuracy of that content.
Psychological Content

We searched for any mention of psychological problems or emotional reactions frequently experienced and recorded in relation to chronic (persistent) pain in any site. We evaluated psychological content for level of complexity of psychological content: those referring to the influence of stress or mood on pain without detailed explanation were described as simple, and those that provided a more integrated account of pain and of the various interactions of beliefs and mood and pain were described as complex. We also judged whether, on clinical experience, we would expect the information on CPP to reduce or to exacerbate anxiety of a distressed man with CPP.

Qualitative Analysis

Data were sorted using framework analysis [24], a method applicable to exploration of material using a priori questions, and sorting sampled material according to those questions. The first author was responsible for the analysis; and the second author coded and classified several samples, blind to the first author’s decisions, to assess reliability, which was high.

Results

The search yielded 84 URLs, six of which were immediately excluded as duplicates. Exclusion criteria removed 22, more than half of which concerned only women’s pelvic pain, and less than five each were scientific publications, video only, or scientific book details. Of the remaining 73 URLs, 33 met the inclusion criterion of being found by two or more search engines, with the remaining 40 identified only by a single search engine. These 33 URLs referred to 29 Websites, of which two were inaccessible, four related only to acute pain (such as in Peyronie’s disease and priapism), leaving 23 Websites.

Four of the 23 had identical content, a single paper. Of these 23, 17 (74%) of the Websites stated when they were last updated: 9 within the last year, with a range of 2003 to September 2010, the month of the search (see Table 1). The number of pages specifically related to CPP varied from one to 80, with a mean of 16 pages per Website. Eleven of the Websites presented the information in text only: 10 included some graphics, mostly diagrammatic, photographs (1), X-rays (1), and micrographs (1); and two Websites featured video clips to convey information.

Accessibility and Interactivity

All 23 Websites contained information that was free for anyone to view (see Table 3). Only six provided information on volume of access, all around several thousand hits per month. The majority of the Websites evaluated (N = 20, 87%) had a feedback mechanism whereby users could comment, give feedback or ask questions. Six (26%) of the Websites provided a forum for users to share experiences and information and to provide mutual support, one of which required membership (but no fee) to join (http://www.chronicprostatitis.com).

Trustworthiness of Site

Authorship and Sources

Eleven Websites claimed to have been written by doctors (see Table 1) from a variety of specialist fields: pain management, family medicine, sexual dysfunction, emergency medicine, and urology. Three of the Websites were authored by groups of researchers with a special interest in CPP; four of the Websites were run or partly run by people with CPP. Three did not give any information on the author, and three were unattributed Wikipedia contributors who may or may not have expertise in the subject matter. More sections of material were anonymous than attributed to one or more of the authors.

Fourteen Websites (61%) referenced credible information sources (see Table 1) either in the text or at the end of papers: scientific publications, government guidelines, and quotations from respected professionals. These appeared to be used appropriately. The remaining nine (39%) Websites did not state the source of the information presented.

Purpose and Disclaimers

All Websites clearly disclosed their purpose: 19 aimed to provide information to help people understand their symptoms, five to provide advice on how to cope with them, three to provide a forum for support, two to raise awareness of the condition, two to promote research, two to promote a specific treatment, and one to share experience (see Table 1). Nineteen (83%) Websites contained disclaimers (see Table 1), often at the end of a page or a paper, typically stating that the information was not a substitute for medical advice, and that users were encouraged to consult a physician for accurate information regarding their symptoms.

Two of the Websites carried prominent advertisements for CPP-related products, such as nutritional supplements, treatments, and books, few of which have been rigorously tested for efficacy. One of these (http://www.chronicprostatitis.com) advertised books via a widely used online shop and stated that “we accept sponsors who produce products we know to be helpful to CP/CPPS patients.” The Website authors’ opinions were generally substituted for data on effectiveness.

Explanation of Pain

Most of the Websites contained descriptions of symptoms, causes, how to obtain a diagnosis, common treatments, and related topics. Some also provided links to papers and presentations about various kinds of CPP, and/or diagrams and photos of pelvic anatomy, frequently asked questions, and testimonials from patients with CPP.
## Table 1  Features of Websites evaluated

<table>
<thead>
<tr>
<th>URL</th>
<th>Number of Hits</th>
<th>Feedback</th>
<th>Forum</th>
<th>Number of Pages</th>
<th>Text/ Picture</th>
<th>Disclaimers</th>
<th>Last Updated</th>
<th>Author</th>
<th>Statement of Purpose</th>
<th>Sources of Information Stated</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://spuninfo.org">http://spuninfo.org</a></td>
<td>138,575</td>
<td>✓</td>
<td>✕</td>
<td>22</td>
<td>Text</td>
<td>✓</td>
<td>May 2008</td>
<td>Research physicians</td>
<td>Info to patients and clinicians</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://pudendal.com">http://pudendal.com</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✕</td>
<td>1</td>
<td>Text, photos, diagrams</td>
<td>✕</td>
<td>Sep 2010</td>
<td>GEP</td>
<td>Info and advice</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.painclinic.org/nervepain-pudendalnergi.htm">http://www.painclinic.org/nervepain-pudendalnergi.htm</a></td>
<td>7,000–10,000 views per day</td>
<td>✓</td>
<td>✕</td>
<td>80</td>
<td>Text</td>
<td>✓</td>
<td>Sep 2010</td>
<td>retired Pain Management Consultant</td>
<td>HOPE, veterans of PN</td>
<td>Info and support</td>
</tr>
<tr>
<td><a href="http://www.pudendalhope.org">http://www.pudendalhope.org</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✓ open</td>
<td>50</td>
<td>Text, diagram</td>
<td>✓</td>
<td>Jul 2008</td>
<td>Doctor</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.painclinic.org/nervepain-pudendalneuralgia.htm">http://www.painclinic.org/nervepain-pudendalneuralgia.htm</a></td>
<td>7,000–10,000 views per day</td>
<td>✓</td>
<td>✕</td>
<td>80</td>
<td>Text</td>
<td>✓</td>
<td>Sep 2010</td>
<td>Retired Pain Management Consultant</td>
<td>HOPE, veterans of PN</td>
<td>Info and support</td>
</tr>
<tr>
<td><a href="http://www.painclinic.org/nervepain-pudendalnergi.htm">http://www.painclinic.org/nervepain-pudendalnergi.htm</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✕</td>
<td>50</td>
<td>Text, diagram</td>
<td>✓</td>
<td>Sep 2010</td>
<td>Retired Pain Management Consultant</td>
<td>HOPE, veterans of PN</td>
<td>Info and support</td>
</tr>
<tr>
<td><a href="http://www.pudendalhope.org">http://www.pudendalhope.org</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✓ open</td>
<td>1</td>
<td>Text</td>
<td>✓</td>
<td>Sep 2010</td>
<td>Doctor</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.pevicpainhelp.com">http://www.pevicpainhelp.com</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✕</td>
<td>14</td>
<td>Text, videos</td>
<td>✕</td>
<td>July 2008</td>
<td>Doctor</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.patient.co.uk/health/Prostatitis-Chronic.htm">http://www.patient.co.uk/health/Prostatitis-Chronic.htm</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✓ sister site (open)</td>
<td>4</td>
<td>Text, diagram</td>
<td>✓</td>
<td>Jan 2010</td>
<td>No author given</td>
<td>Info and advice</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.medicinenet.com/prostatitis/article.htm">http://www.medicinenet.com/prostatitis/article.htm</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✕</td>
<td>4</td>
<td>Text, diagram</td>
<td>✓</td>
<td>Sep 2009</td>
<td>Professor of Medicine and Urologist</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.chronicprostatitis.com">http://www.chronicprostatitis.com</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✕</td>
<td>69</td>
<td>Text, videos, ads</td>
<td>✓</td>
<td>Mar 2010</td>
<td>Doctors and patients</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.cks.nhs.uk/prostatitis_chronic">http://www.cks.nhs.uk/prostatitis_chronic</a></td>
<td>7,342 in the last year</td>
<td>✓</td>
<td>✕</td>
<td>36</td>
<td>Text, micrograph</td>
<td>✓</td>
<td>Sep 2010</td>
<td>No author given</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.ckstc.nhs.uk/prostatitis_chronic">http://www.ckstc.nhs.uk/prostatitis_chronic</a></td>
<td>7,342 in the last year</td>
<td>✓</td>
<td>✕</td>
<td>36</td>
<td>Text, micrograph</td>
<td>✓</td>
<td>Sep 2010</td>
<td>No author given</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.netdoctor.co.uk/menshealth/facts/prostatitis.htm">http://www.netdoctor.co.uk/menshealth/facts/prostatitis.htm</a></td>
<td>Unknown</td>
<td>✓</td>
<td>open</td>
<td>1</td>
<td>Text</td>
<td>✓</td>
<td>Feb 2002</td>
<td>Doctor specializing in Family Medicine</td>
<td>Person with UCPPS</td>
<td>Info and advice</td>
</tr>
<tr>
<td><a href="http://www.parsec.it/summit/p0.htm">http://www.parsec.it/summit/p0.htm</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✕</td>
<td>10</td>
<td>Text, diagram</td>
<td>✓</td>
<td>Sep 2009</td>
<td>Doctor specializing in Urology</td>
<td>Info</td>
<td>✓</td>
</tr>
<tr>
<td><a href="http://www.bps-assoc.org.uk">http://www.bps-assoc.org.uk</a></td>
<td>Unknown</td>
<td>✓</td>
<td>✕</td>
<td>18</td>
<td>Text and ads</td>
<td>✓</td>
<td>Jul 2006</td>
<td>Consultant in Pain Medicine and Anaesthesia</td>
<td>UCPPS patients</td>
<td>Info, support, raise awareness; encourage research</td>
</tr>
</tbody>
</table>

GEP = Groupement European de Perineologie; NCPPR = National Center for Public Policy Research; PN = pudendal neuralgia; UCPPS = urogenital chronic pelvic pain syndrome.
Five Websites provided a list of five or more causes, whereas three Websites offered no explanation or stated only that the causes are poorly understood. As shown in Table 2, a range of explanations for CPP is given by these Websites. These include infection (7 Websites); pudendal neuropathy from specific local injury, such as from bicycle saddles or surgery (6); pelvic floor muscle dysfunction and resulting referred pain (5); life stresses, emotions, and beliefs as contributors (6); and neurophysiological explanations consisting of gate control theory, neural wind-up, and central sensitization (5). All but the last, based on the neurophysiology of chronic pain, are likely to have limited applicability to CPP on the basis of current evidence [9].

Fifteen (65%) of the URLs provided links to further information: from external organizations, such as patient support and lobbying groups (http://www.ucpps.org/; http://www.ic-network.com/; including The British Prostatitis Support Association); and internal links to other parts of the Website with more detailed information or related topics.

### Psychological Content

Only eight (35%) of the Websites evaluated made any reference to the emotional and/or psychological effects of experiencing chronic pain. Of these, five referred to emotional or psychological factors in a simple way, in that mechanisms were not explained and/or a linear model of cause and effect was stated (see Table 3), while three provided more complex models. These are all discussed later.

#### Simple Psychological Models

All five Websites propounding a simple model of psychological aspects of pain mentioned stress or psychological factors as contributing to or causing the pain, two providing the further suggestion that pelvic floor muscles overcontracted in response to particular thoughts and emotions. There was some acknowledgment of the effects of CPP on people's emotional well-being and one Website even stated that “pain causes emotional and behavioural changes.” Two of the Websites suggested some kind of psychological therapy under the treatment section, but this was not described in terms of what it would involve and how it might help. There was surprisingly little on sexual problems in relation to pain, but because this was not a specific target of our search, it was not quantified.

The attribution of pain to “psychological factors” in this simple way is unlikely to be helpful to men seeking information, particularly because the Websites did not normalize the experiences of anxiety and pain, nor explain adequately by what mechanism psychological factors might lead to CPP. By contrast, the acknowledgment of emotional and behavioral changes as a consequence of CPP normalizes those experiences and is likely to be somewhat reassuring.

### Table 2  Explanations of cause of pain given for 23 Websites evaluated

<table>
<thead>
<tr>
<th>Explanation</th>
<th>Website</th>
</tr>
</thead>
</table>
| Multiple (including infection, injury, pelvic floor dysfunction, psychological causation, pain mechanisms) | http://www.painclinic.org/nervepain-pudendalneuralgia.htm  
http://www.pudendalhope.org  
http://www.wrongdiagnosis.com/sym/penis_pain.htm  
http://www.netdoctor.co.uk/menshealth/facts/prostatitis.htm  
| Infection | http://www.medhelp.org/posts/Family-Medicine/Penile-pain/show/227424  
http://www.patient.co.uk/health/Prostatitis-Chronic.htm  
http://www.parsec.it/summit/p0.htm |
| Injury | http://spuninfo.org  
http://pudendal.com  
http://en.wikipedia.org/wiki/Pudendal_nerve_entrapment  
http://www.malehealth.co.uk/penis-and-testicles/18755-penis-problems-erections-and-pain |
| Pelvic floor dysfunction | http://www.penilepain.org  
http://www.pelvicpainhelp.com  
http://www.chronicprostatitis.com |
| None | http://www.cks.nhs.uk/prostatitis_chronic  
http://www.medicinenet.com/prostatitis/article.htm  
http://www.bps-assoc.org.uk |
Complex Psychological Models

Three Websites provide what we considered to be complex psychological models. However, two specified pudendal neuralgia as the focus of the explanation (http://www.painclinic.org; http://www.pudendalhope.org), possibly deterring those without that diagnosis (self- or clinician-determined) from reading further, although some of the information is more broadly applicable. The third provides an explanation of pain as the rationale for the treatment that it promoted (http://www.pelvicpainhelp.com).

The broadest of the three (http://www.painclinic.org), in a section describing all chronic pain, uses gate control theory as the basis of an account of beliefs and emotions influencing pain transmission and experience. Anxiety, depression, and anger are all mentioned as influences on descending inhibition. Early adverse experience and other emotions are described as “emotional baggage,” which can impair the individual’s capacity to cope with difficulties, including chronic pain. The CPP-specific content concerns pudendal neuralgia as a specific nerve pain, with clear and concise information on the definition, anatomy, causes, differential diagnoses, investigations, and types of treatment, but no mention of psychological components. There is a reasonably accurate and empathic description of cognitive behavioral therapy as a way to address unhelpful beliefs about pain as part of rehabilitation.

A second Website (http://www.pudendalhope.org) written by patients with pudendal neuralgia includes a section on “emotional aspects”, normalizing various emotions, some linked to particular experiences in the journey of the person with chronic pain. However, the model outlined is a “cycle of acceptance” which the authors claim to be based on the Kübler–Ross model of bereavement [25], a stage model that has not stood up to scrutiny [26] and that can generate unhelpful expectations of correct and incorrect ways to adjust to loss. Emotions such as anger, depression, and strategies such as avoidance and substance use are validated as normal, if unhelpful, ways to handle difficulties with pain; patient testimonials illustrate these points. The authors recommend working toward acceptance, maintenance of self-esteem, emotional expression, and finding positive meaning. A brief description of what each of these entail is provided, but guidance

Table 3  Examples of simple psychological content of Website

<table>
<thead>
<tr>
<th>URL</th>
<th>Psychological Content</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.penilepain.org">http://www.penilepain.org</a></td>
<td>“In every day life, your pelvic muscles contract and release with every thought. These muscles are extremely connected with your brains thoughts and emotions. As your brain processes thoughts, your pelvic muscles either relaxes or contracts. Even in your sleep.”</td>
</tr>
<tr>
<td><a href="http://www.nlm.nih.gov/medlineplus/ency/article/000524.htm">http://www.nlm.nih.gov/medlineplus/ency/article/000524.htm</a></td>
<td>“Life stresses and some psychological factors may also contribute.”</td>
</tr>
<tr>
<td><a href="http://en.wikipedia.org/wiki/Chronic_prostatitis/chronic_pelvic_pain_syndrome">http://en.wikipedia.org/wiki/Chronic_prostatitis/chronic_pelvic_pain_syndrome</a></td>
<td>“Category III prostatitis may have no initial trigger other than anxiety, often with an element of OCD, panic disorder, or other anxiety-spectrum problem. This is theorized to leave the pelvic area in a sensitized condition resulting in a loop of muscle tension and heightened neurological feedback (neural pain wind-up). Current protocols largely focus on stretches to release overtensed muscles in the pelvic or anal area (commonly referred to as trigger points), physical therapy to the area, and progressive relaxation therapy to reduce causative stress.”</td>
</tr>
<tr>
<td><a href="http://www.netdoctor.co.uk/menshealth/facts/prostatitis.htm">http://www.netdoctor.co.uk/menshealth/facts/prostatitis.htm</a></td>
<td>“A recent study suggests that in the majority of patients the condition is a consequence of modern living. Psychological tests have demonstrated higher than average scores for anxiety, depression and hypochondriasis in men with CPPS.”</td>
</tr>
<tr>
<td><a href="http://www.londonpainconsultants.com/articles/2006/10/28/chronic_pelvic_pain_syndrome">http://www.londonpainconsultants.com/articles/2006/10/28/chronic_pelvic_pain_syndrome</a></td>
<td>“The term CPPS is also used to refer to the group of emotional and behavioral changes that occur due to the duration of the pain and stress produced by the discomfort.” Under characteristics of pain section: “Signs of depression exist (sleep disturbances, constipation, slow body movements)” and “Altered family roles” “Psychological factors” mentioned as a cause Under treatment section: “Psychological support, Counselling, Stress management, Relaxation techniques”</td>
</tr>
</tbody>
</table>
Male Pelvic/Urogenital Pain on Internet

It is somewhat concerning that Websites present out-of-date evidence, nor was it the case that those that declared medical authorship were also the most consistent with current pain science. The most widely described model of pain was that of stress/anxiety and pelvic floor muscle tension, both of which are more likely to be contributory, or consequential, than causal. There was considerably less on changes in the central nervous system [7,9]. Processes of central and peripheral sensitization affecting the urogenital and pelvic areas appear to be difficult concepts to convey, despite the possibilities for animated explanations. There was undue reliance on the more easily described phenomena of hyperalgesia and allodynia, although these are far from universal in pelvic and urogenital pain in men [9], and so can leave men feeling that their problem does not “match” that described.

Only one-third of Websites described psychological factors in pain, either as contributory, consequential, or both. Five of these eight we considered to oversimplify the associations in a potentially unhelpful way, so that the recommendation of psychological therapy without integrating therapeutic aims or process into the explanation of pain is unlikely to be persuasive [28]. Psychological interventions most commonly aim to reduce the distress and disability, which are more closely associated with the individual’s beliefs and way of understanding pain than are diagnosis or pain characteristics [3,12,29]. The three more complex descriptions of psychological aspects of pain were rather narrow in their focus, either on a diagnostic group or on a causal model of pain and associated treatment. Those Websites without any mention of the distress consequent upon chronic pain, and upon the search for diagnosis and relief, or even patient testimonials that allude to this, can be experienced as invalidating of those emotional difficulties, and discouraging of their expression in medical settings.

A quarter of Websites provided advice on what to do next and information about specific treatments, which would be useful for men who now have some idea about their diagnosis and are searching for solutions. Arguably, however, Websites could offer much broader explanations and reassurance about the unlikelihood of an exact match between the searcher’s own experience and what he reads. They could introduce a more integrated model of pain involving beliefs, emotions, muscle tension, and neuropsychophysiological and behavioral change, and encourage men to monitor for particular associations while they pursue expert medical consultation. Illness beliefs draw on any available source of information [29], but for men with urogenital and pelvic pain, little such information may be available from the usual formal (medical) or informal sources, making Websites potentially very influential.

The study has several shortcomings. Websites reviewed may have already been updated, rendering specific aspects of the review inaccurate. It is not inevitable, however, that change always implies greater accuracy and consistency with evidence. We also limited our searches to Websites available in the English language, and cannot

Discussion

Taking a qualitative approach focusing on the likely information needs of men with urogenital/pelvic pain, this Website review shows that relevant and helpful information is hard to find. There are many reasons for this.

Overall, accessibility of sites was good other than many pelvic pain sites dealing exclusively with female pelvic pain, distinctly unhelpful to men who have been given the diagnosis of pelvic pain. Nomenclature of the problems varies between sites describing similar problems, but with different causal statements. While this is an authentic reflection of differences in the medical community about etiology and mechanism [9], from the patients’ viewpoint, it is not helpful. Most Websites provided a clear statement of purpose, but authorship was more obscure, with only half stating that they were written by medical professionals. Given that these credentials are reported by lay searchers to be important for the credibility of the health care information [20], it is surprising to see so many pages unattributed. Variability in accuracy (for instance, in statements concerning cause [Table 3] and on psychological aspects) and balance was expected and was found, although some of the variability is likely to be attributable to the choice of search terms. All those Websites that allowed interaction did so free of barriers, but responses to questions posted were of variable accuracy.

The diversity of explanations of pain, both within and between Websites, is likely to cause confusion and potentially to distress readers who observe that the treatments associated with these explanations are also divergent. Although the term prostatitis was on some Websites accompanied by a statement that infection was not necessarily implied, others implied infection by directing the reader toward antibiotics as treatment. Yet, the same symptoms on other sites were attributed to pelvic floor tension, with various physical and psychological treatments recommended.

The third Website (http://www.pelvicpainhelp.com) is the work of The National Centre for Pelvic Pain Research and promotes the “Wise-Anderson Protocol” as a treatment for pelvic pain syndromes. The authors describe the theory of pelvic floor muscle dysfunction as the cause of CPP in both men and women, also described in their book [27]. Anxiety and catastrophic thinking are listed as symptoms, while anxiety and depression are referred to as exacerbating and resulting from pelvic pain, with reference to the impact of pain on self-esteem and quality of life. Much of the description of treatment uses emotional terms, but in fairly technical language, which may present difficulties for some readers; there is encouragement to buy the book and attend the courses to master the techniques, and references are provided to studies of effectiveness.

as to how to achieve these things is lacking, as is any reference to psychological therapies.

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assume that Websites available in other languages necessarily share either the strengths or weaknesses of those reviewed here. Nor did we assess literacy level—an important consideration for the utility of the Website. We conducted the review using search strategies based on behavior in the health field [20], but not on the basis of concern about symptoms, which is one of the commonest reasons for searching [15,17]. We know little about the impact of the information found, both in the authored material and in the patient forums and testimonials (see [17,30]), and a study both of the process of patient use of these Websites, and of the outcome, would be of considerable interest. We also made subjective judgments, as clinicians, about what might be helpful or unhelpful for relatively naive male patients, and ideally, this would be tested empirically.

Concern is expressed in clinical circles about patients arriving with Internet-generated information, and about using it to self-diagnose [31], but from this review, we would expect little certainty and much confusion. Several studies suggest that it is more common for patients to search after their initial discussion with a doctor [15,30], and to ask for help from a doctor in evaluating the quality of the information found [15,17]. While we would not expect Websites to encourage self-diagnosis, they have a clear role—not realized by the sites we reviewed—in legitimating problems arising from the pain and describing likely pathways to find appropriate help. The role of the expert explanation of pain, in the context of the men’s preconceptions, confusions, and particularly symptoms and history, appears more important than ever rather than made redundant by the Internet.

A recent survey of European urologists [32] on the information given to patients found that most used printed information from a variety of sources, but just less than half the respondents referred patients to online sources. Those who did not refer patients to Websites expressed a lack of confidence in the availability and/or the reliability of such information. The online sources used were diverse, very possibly reflecting the large number of different European languages and the few sites available in multiple languages. Nearly three quarters of respondents endorsed the need for independent information available across European countries and languages for patients with urological symptoms, including pain. The need appears to be for accurate and consistent information to complement and reinforce that offered in personal medical care, rather than to replace it. This review found no Websites that would meet these requirements, and the development of such a resource would be of considerable value. It would, however, need to build on considerations outlined here by iterative testing with current patients with urogenital and pelvic pain, and interested parties who are not in the health care system. For the present, clinicians might wish to provide a shortlist of possible Websites to patients, with caveats about applicability, and to encourage them to return to resolve uncertainties. Additionally, the possibility of combining pain-relevant psychological help via the Internet alongside direct medical care for urogenital/pelvic pain is increasing: Internet-based psychological interventions for pain problems on the Internet appear promising for improving function and even reducing health care costs [33], although it remains unclear for whom they are suitable and effective.

In summary, we had hoped to find one or more easily accessible Websites with an accurate and authoritative description of CPP in the many sites in which it is experienced [3]; which provided a model of chronic pain that integrated psychology within the neurophysiological mechanisms; which described some of the common psychological and social consequences of chronic pain; and which made clear the source of information, in terms of origin, authorship and of the current status of evidence. We were unable to do so, and only accessibility satisfied our criteria, of little value when the content is largely of poor quality to the lay searcher.

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References


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