

# Women in pain : the course and diagnostics of chronic pelvic pain

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A cognitive behavioural based assessment of women with chronic pelvic pain





## **ABSTRACT**

From population-based surveys, chronic pelvic pain (CPP) in women is a common condition with a spectrum of associated disability and distress. Those seen by gynaecologists in a referral setting often have substantial impairment of function and mood disturbance. Because in most cases, the aetiology of CPP cannot be explained and the range of effective interventions remains limited, treatment of CPP might easily result in a sense of frustration not only for the patient but also for the gynaecologist. To avoid this situation in clinical practice, a structured assessment of women suffering from CPP using a cognitive behavioural model, is suggested. This type of assessment provides information about the impact of the chronic pelvic pain on a particular patient's daily life. It also facilitates referral for pain management. Future studies are needed to show further evidence of benefit of this approach for women with CPP.

# Introduction

Chronic pelvic pain (CPP) can be defined as a constant or intermittent pain in the lower abdomen or pelvis which is not exclusively related to menstrual period (dysmenorrhoea) or sexual intercourse (dyspareunia) and which lasts for at least 3 months [Merskey 1994; Williams 2004].

Community based studies [Mathias 1996; Zondervan 2001; Grace 2004; Pitts 2008] showed variations in prevalence rates for CPP from 15% to 25%, depending on the definition of chronic pelvic pain, the study design and the measurements used. In primary care an annual prevalence rate of CPP of 3.7% is reported, comparable with figures for asthma (3.8%) and back pain (4.1%) [Zondervan 1999a]. Moreover, in a British setting only 40% of women with CPP were referred to secondary or tertiary care by their general practitioner [Zondervan 1999b]. While this relatively low rate of referral may have reflected specific features of the health care system, it is consistent with study findings from other countries [Grace 2004; Pitts 2008]. This means that gynaecologists are likely to be confronted with a selected group of all women suffering from CPP. In clinical practice, this group is recognised as being difficult to assess and treat [Grace 2000]. At the same time, women with CPP feel dissatisfied with the management of their symptoms. In their opinion, health care professionals have no genuine interest in them, and dismiss or do not believe their complaints [Price 2006].

The pathogenesis of CPP is poorly understood. Although laparoscopy is considered an essential tool to diagnose pathology, in about 40% of the laparoscopies in women with CPP no obvious explanation for the pain complaint can be demonstrated [Howard 1993]. If an abnormality such as endometriosis or adhesions, is observed, the association between the pathology and the site or severity of the pain is poor [Hammoud 2004; Fauconnier 2005; Vercellini 2007]. What is more, the same type of pathology is also noted in pain free women [Howard 1993]. If the pathology is identified, it may be coincidental rather than causal. The attribution of one physical abnormality as the only cause of CPP should therefore be interpreted with caution.

Co-morbid symptoms like dysmenorrhoea and dyspareunia [Zondervan 2001; Grace 2006; Pitts 2008; ter Kuile 2009] as well as co-morbid syndromes like irritable bowel syndrome [Whitehead 2002], interstitial cystitis [Stanford 2007], chronic fatigue syndrome and fibromyalgia [Nimnuan 2001] are frequently observed.

CPP can have a significant impact on the physical and mental health of the affected women and result in an impaired quality of life [Stones 2000]. Patients suffer from higher levels of anxiety and depression and have more sexual problems than pain free controls [McGowan 1998; Zondervan 2001; Grace 2006; ter Kuile 2009] Furthermore, some studies of women with CPP have shown that these women are more likely to have a history of physical and especially sexual abuse than women without CPP [Roelofs 2007]. In other studies this association has been less clear.

The effectiveness of medical as well as surgical treatment modalities has been investigated in randomised controlled trials and systematic review findings have been presented [Stones 2005]. Fourteen studies with satisfactory methodological quality could be identified. From these studies the conclusion could be drawn that the range of effective interventions remained limited and that recommendations for treatment were based on single studies. Results showed that progestogens (medroxyprogesterone acetate) were associated with a reduction of pain during treatment while gonadotropin-releasing hormone analogues gave a longer duration of benefit. Counselling supported by ultrasound scanning was associated with reduced pain and improvement in mood. A multidisciplinary approach was beneficial for some outcome measures. No benefits were demonstrated for adhesiolysis (unless adhesions were severe), uterine nerve ablation, sertraline or photographic reinforcement after laparoscopy. Writing about the stress of pelvic pain and the use of magnets applied to abdominal trigger points showed some evidence of short-term benefit.

A recent study [Weijenborg 2009b] demonstrated that abdominal pain persists in one out of three women two years after an acute episode of abdominal pain. It also showed that a low education level and an abuse history at a younger age (< 16 years) related to the risk of chronicity. Furthermore, no more than one out of four to five women with CPP recovered from pain at a mean follow-up period of 3 years after a variety of treatments like physiotherapeutic, psychological, medication and/or surgical treatment or expectant management between baseline and follow-up [Weijenborg 2007; Weijenborg 2009a]. None of the sociodemographic variables, pain related characteristics and/or clinical factors predicted recovery. Only a decrease in catastrophizing thoughts about pain was associated with an improvement from baseline in pain and adjustment to pain [Weijenborg 2009a]. These results were compared with findings from other studies of women with CPP and from studies of populations suffering from other chronic pain conditions like back pain or neck pain. It was concluded that CPP in women should be considered a chronic pain condition. Such a perspective could have far-reaching consequences for the assessment and management of women with CPP in clinical practice. Attention would have to be paid not only to the somatic factors associated with CPP, but also to pain adjustment (i.e., anxiety and depression and health related quality of life) and to pain appraisals (i.e., attributions and expectancies about pain) and pain coping strategies [Keefe 2004]. A so-called cognitive behavioural (CB) model for the assessment and treatment of chronic pain conditions in general [Turk 2004; Vlaeyen 2005] focuses on thoughts and feelings that are a problem for patients with persistent pain. It also comprises behaviour that makes pain, disability and distress worse [Eccleston 2009].

In this paper, we present a structured model for the assessment of women with CPP based on cognitive behavioural (CB) principles. A case history of a CPP patient is used as an example to give a step-by-step explanation. This model may facilitate referral for pain management for two categories of women. First, for those women with CPP for whom after

gynaecological examination, ultrasound investigation and/or laparoscopy, no diagnosis or somatic explanation for their pelvic pain is found. Second, for CPP patients whose complaints persist despite adequate treatment of the initial diagnosis. The model is adapted from a strategy successfully used to motivate patients for CB-treatment. These patients visited a general medicine outpatient clinic because of medically unexplained physical symptoms [Speckens 1995].

# Assessment of women with CPP

# Step 1. History taking about pain

History taking starts with an account of patient's pain. As in other pain conditions, the characteristics, location and description of current pain and the pattern of pain severity during the day need full attention and can be recorded using a Visual Analogue Scale (VAS) score on a scale from 0 to 10 (0 = no pain at all, 10 = worst pain imaginable). In addition, co-morbid symptoms like dyspareunia and/or dysmenorrhoea, associated bowel and urinary problems as well as other chronic (pain) conditions are assessed. Apart form the pain history, all diagnostics and treatments by previous medical specialists as well as complementary or alternative care providers, are recapitulated. The effects of these interventions on pain and on other complaints are addressed.

# Case-history

35-year-old S., married with 3 children (aged 11, 7 and 5) had been suffering from pain in her pelvis and lower abdomen for 4 years. The pain first started after the birth of her youngest child. She described the pain as a nagging pain, which typically increased during the day and coincided with a bloating of the abdomen. At unexpected moments, the pain would grow worse, about 3 times a week for 1 to 5 hours, sometimes for a whole day. On average, S. would be without pain for only 2 days a month. Changes in the severity of the pain were not related to her uncomplicated micturition, defecation, menstrual period or sexual intercourse. For years, S. had also been suffering from back pain. Sometimes it was difficult to distinguish between pelvic and back pain, because the pelvic pain would radiate to the back on both sides. Especially over the weekend S. could have severe migraines lasting at least 3 days, despite medication.

Initially, the complaint was thought to be caused by a descent of the uterus. However, after an abdominal fixation of the uterus to the sacrum (sacropexy), pelvic pain persisted. Further investigations by a gastroenterologist (ultrasound, barium enema, colonoscopy), a surgeon (MRI) and urologist (cystoscopy) yielded no abnormalities. Recently, a laparoscopy was performed by her gynaecologist. After adhesiolysis of some thin adhesions the pelvic pain complaint did not change.

## Table 1 Assessment questions in case of Chronic Pelvic Pain

#### Pain complaint

Amount of pain at this moment on a scale of 10 (0= no pain at all, 10=most heavy pain)

Location of pain, with radiation

Description of pain, kind of pain

Course of pain during the day

Character of pain (continuous, intermittent, exact period of time)

#### History of pain

Since when have you had pain complaints?

Previous diagnostics by medical doctor? If so, what were the results?

Previous treatment? If so, what were the results?

#### Ideas about pain

What is in your opinion the cause of your pelvic pain?

#### Pain coping strategies

What do you do when the pain increases?

What do you do to prevent increase of pain (medication, taking rest)?

What do you do when the pain has decreased, when you are improving?

## Consequences

#### Cognitive:

What are your thoughts when pain exacerbates; do you worry about (the (consequences of) your pain; to what extent do you feel able to influence pain; do you feel helpless regarding your pain?

#### Emotional:

Do you feel anxious, depressive, irritated, annoyed, distressed, unhappy?

## Behavioural:

Do you go on with your activities despite pain or do you stop because of pain; how many prescribed and nonprescribed drugs do you use and what is the effect on pain; current or past alcohol abuse and use of other psychoactive drugs; do you visit complementary health care providers?

#### Physical:

Do you experience accompanying symptoms such as sweating, nausea, a high heart rate; do you feel tired or exhausted, do you experience muscle tension, is your participation in physical exercise and/or sexual functioning affected by pain experience; can you fulfil your household duties?

#### Social:

Do you experience problems in your relationship with your partner, relatives or friends and/or in your job; does pain affect your participation in pleasurable activities, going on vacation?

## Step 2. Ideas about pain and coping

The patient is explicitly asked about her views on the factors causing the chronic pelvic pain complaint. The patient's usual way of dealing with an increase or decrease in symptoms needs explicit attention. It is determined by pain appraisals and pain coping strategies. The term "pain appraisals" [Gatchel 2007] refers to a patient's opinions and beliefs about pain. Examples are "pain can cause damage", "activity should be avoided", "pain leads to disability" and/or "pain is uncontrollable". Catastrophizing is an important maladaptive belief often seen in chronic pain patients [Sullivan 2001; Gatchel 2007]. It comprises an exaggerated, negative mental set towards actual or anticipated pain experiences. An example is: "I cannot bear this pain any longer". The term "pain coping" covers intended behaviour or cognitions for dealing with pain, such as pain medication use, diverting attention from the pain, increasing or decreasing activity, relaxation or prayer.

## Case history (continued)

Although S. had received surgical treatment for the intra-abdominal adhesions, she was still convinced that (new) adhesions were the cause of her pain. She kept wondering whether another operation would result in a solution to her chronic pain condition. An exacerbation of pain repeatedly strengthened her fears that the mesh used for the sacropexy would break down.

At this particular moment, she did not take any analgesics, because she was afraid to become addicted. Only when the pain got worse and she started sweating, felt feverish and nearly fainted as well, did she take an opioid three times a day. After such episodes, she felt exhausted and had to recuperate for days. S. was feeling powerless, because she did not know which factors contributed to an improvement or deterioration of the pain complaints.

# Step 3. Consequences

A variety of sequelae of "living in pain" are uncovered if the cognitive, emotional, behavioural, physical and social consequences are addressed. Examples of the questions that should be asked are shown in table 1. The consequences of living in pain might prolong and even worsen the complaint and become linked in self-perpetuating vicious circles. Specific patterns can be recognized in each woman suffering from CPP, even though these patterns might be subject to fluctuation within one person.

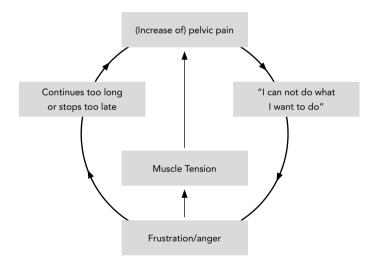
## Case history (continued)

When asked, S. mentioned some of the consequences of her pain, which in turn led to more pain. This vicious circle is illustrated in Figure 1. This pattern emerges when patients have "non accepting thoughts about pain" and is frequently observed in women with CPP.

When S. experienced more severe pain, she felt burdened by her pain. She did not accept that the pain influenced her everyday life to such an extent and as a result was angry. In its turn, this anger caused tension everywhere in her body and had a negative effect on the level of experienced pain. With great effort, she succeeded in fulfilling her regular household duties but still she was convinced that she failed as a partner and mother. When the pain obliged her to rest, she blamed herself for her inactivity. As soon as the symptoms improved, she would resume her activities and would try to catch up on lost time. Subsequently, the pain might increase as a result of over-exertion.

Figure 1 "Non accepting thoughts about pain"

An example of a vicious circle between cognitive, emotional, behavioural, physical and social consequences and Chronic Pelvic Pain



## Case history (continued)

The next example of a vicious circle is shown in figure 2. Now the focus is on "anxious thoughts about pain and associated avoidance behaviour". This circle is easily activated when pain exacerbates. The fear that something might be seriously wrong can result in a renewed search for medical help.

S. was convinced that she could no longer do anything because of the pain. She was anxious and over-concerned and was convinced that serious damage to her abdomen caused the increase of pain. S. tried to avoid all activities in order to prevent this expected intensification. She even gave up s her job as a secretary and withdrew from social events. No longer distracted from her pain, S. concentrated her attention on all

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bodily sensations (in other words manifested hypervigilance) and this affected her pain experience in a negative way. Consequently, in the long term, disuse resulted in a loss of physical fitness and disability, weight gain and depressive symptoms.

## Step 4. Reorientation

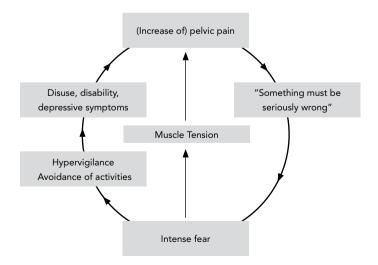
Where appropriate, the findings of the consultation and further examinations are summarized. Thereafter, specific points are communicated to the patient.

First, an explanation of current views on chronic (pelvic) pain is given. "Being in pain" is an unpleasant sensory and emotional, thus subjective experience [Merskey 1994]. An objective quantification of the severity of pain experienced by the patient is impossible, but the consequences of CPP for everyday life illustrate the impact and burden of these complaints. Moreover, the patient is informed that only a minority of patients suffering from CPP will recover over time, taking a narrow definition of recovery as complete relief of pain.

Second, further examinations are considered to be of minor value because each imaging investigation or invasive technique evaluates only the shape or size of the internal organs. If an abnormality is diagnosed, it is judged coincidental rather than causal. That the cause of CPP cannot be explained properly is "bad news" and might lead to deterioration of the patient's condition because her expectations of a specific diagnosis and subsequent medical solution for her pain are not met.

Figure 2 "Anxious thoughts and avoidance behaviour".

An example of a vicious circle between cognitive, emotional, behavioural, physical and social consequences and Chronic Pelvic Pain



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Third, by recapitulating the medical aspects and psychosocial consequences of the patient's complaint, the gynaecologist expresses and demonstrates his or her genuine interest in and acknowledgment of the patient and her pain. Using one of the vicious circles as an example, the gynaecologist can explain how the consequences of pain in every day life can prolong and even worsen her pain.

Fourth, at this stage the patient is given the opportunity to re-orientate her thinking about chronic pain. She is encouraged to change her view from the former dualistic biomedical way of thinking which she has previously internalised, towards a multidimensional biopsychosocial perspective.

## Case history (continued)

S. recognized herself in the summary of her pelvic pain history, current pain experience and the impact of the pain on every day life. She realized that her thinking about her complaints and her management of the pain might influence her pain experience. However, she was really disappointed to hear that further surgical treatment for her adhesions would not be provided although other specialists had already informed her similarly. It was difficult for her to give up her quest for this supposed cure. It became clear that S. needed time to reconsider her former beliefs and to internalise the new perspective.

## Step 5. Pain management

If the patient is willing to identify with and accept the cognitive behavioural model as presented above, the gynaecologist is in a position to explain what can be achieved with pain management approaches based on this broad model. Referral to a cognitive behavioural psychologist with special chronic pain expertise is recommended for evaluation of the condition. This evaluation should include identification of psychological co-morbidity such as anxiety and depressive disorders or other psychopathology as well. In this way, it is possible to tailor pain management to the needs of a particular patient. This approach aims to alleviate the impact of pain on daily life. A combination of medical (pain medication), physical (functional restoration; graded activity) and psychological modalities can be offered (such as goal setting, problem solving, relaxation training, development of effective coping strategies, changing maladaptive beliefs about pain and graded exposure to stimuli that may generate pain). Medical consultation has to continue on a regular basis during treatment to provide support for the pain management programme and to preempt any perception of feeling dismissed. If complaints should increase at a given point in time, a thorough medical examination remains mandatory, as some underlying conditions such as endometriosis can manifest new symptoms

## Case history (continued)

After repeated consultations, S. accepted the offer to visit a CPP team and to be assessed by a psychologist. The results of self-report measures on pain, adjustment to pain and pain appraisals and coping strategies endorsed the burden of her chronic pelvic pain condition. They indicated high scores for depressive symptoms and impaired physical health. She also coped ineffectively with pain with a tendency to catastrophize pain. S. started pain management and received psychological treatment. Gradually, she realized that it would take time to get a better life despite her chronic pelvic pain. At a follow-up, 2 years thereafter, S. still suffered from pelvic pain complaints, but the impact of pain on her life had decreased substantially. She had found a new balance between rest and activity. She no longer felt depressed and had started a new job on a part-time basis.

## Discussion

In clinical practice, the use of a model based on cognitive behavioural principles for the assessment of chronic pelvic pain patients as presented here, has great advantages for the gynaecologist as well as the patient. The model provides the gynaecologist with an elegant and sufficiently inclusive method of understanding patients' symptoms and their impact on everyday life. Furthermore, the patient feels that her pain is taken seriously because not only the physical aspects are addressed but also her concerns, her thoughts and her ways of coping with pain. In addition, by labelling the pain related sequelae as consequences rather than as potential etiological agents, the gynaecologist can avoid fruitless discussions about the causality of diverse somatic or psychological factors. This CB-based assessment is one of the strategies [Jensen 2002] to motivate the patient for pain management referral and can be applied by each gynaecologist dealing with CPP patients.

Additionally, other specific questions are of interest and need further study. For instance, the health service issues arising from the need to devote more time than is allotted to a normal consultation when using this model. What should be the appropriate management pathway for patients who insist on further medical treatment to the exclusion of psychological intervention? How to cope with patients' stated or unstated inappropriate ideation about chronic pain based on the traditional biomedical view, for example that extreme pain indicates pathology? And how can practitioners best be equipped to handle the emotional challenges arising from interactions with patients?

## Conclusion

The step-by-step assessment proposed, based on cognitive behavioural principles as presented in this paper, provides information about the impact of the chronic pelvic pain on the daily life of women with CPP. It takes time to help the patient change her perspec-

tive on chronic pain. Simultaneously, the use of a structured CB model facilitates referral for pain management. Further research is needed to study the benefits of this model for women suffering from CPP.

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