

# Perspective - Chronic Pelvic Pain needs an integral approach

BERT MESSELINK

University of Groningen. University Medical Center. Pelvic Pain Center. Groningen, the Netherlands

**Abstract:** Chronic Pelvic Pain needs an integral approach, based on the principles of non-organ based terminology and pain mechanisms, provided by a team of experts with the patient at the best place on the discussion table. Realizing that pelvic pain is quite a private subject and that we are the guest and the patient is the hostess who lets us look into her life. That is what makes caring for patients with pelvic pain, based on an integral approach, so special.

**Key words:** Chronic pelvic pain; Health; Multidisciplinary; Team and Integral.

## INTRODUCTION

Chronic Pelvic Pain is a rather young area of interest in the world of pain. It is an area that is also changing quite rapidly. Pain in the pelvic area is primarily pain and needs to be addressed as pain.

At the same time, we need to realize that pelvic pain patients have to deal with changes in voiding, defecation and sexual functioning. This makes every pelvic pain patient even more unique for the caregiver. An open-minded approach of listening in an atmosphere in which a patient feels heard, is the basis for all that is said and taught and discussed about Chronic Pelvic Pain.

This perspective has 4 different sections:

1. Definitions and guidelines
2. Phenotyping and teamwork
3. New ways to explore
4. Integral approach.

## 1. DEFINITIONS AND GUIDELINES

There can be no guidelines without definitions, and no definitions without understanding the item that is defined. The definitions and terminology we use reflect our present knowledge. When our knowledge improves, our terminology and definitions will change subsequently<sup>1</sup>. Definitions and terms are of utmost importance because they are the basis for the language we use. If terms are spurious or incorrectly used, we will never understand each other and that leads to confusion. Definitions and terms need therefore to be validated by experts based within an independent international organization. Several organizations in the world have been and are working on definitions. The International Association for the Study of Pain (IASP) is the most general oriented organization which has a large set of terms in the field of pain<sup>2</sup>. The subset of terms on pelvic pain has been accepted a few years ago. This subset is made by a group of experts from many different disciplines, thereby guaranteeing an integral approach. Many of these experts are also working for the European Association of Urology (EAU) who made one of the first guidelines on CPP and is still leading in the development of terminology and guidance on this subject<sup>3</sup>.

The definition of chronic pelvic pain that is accepted by the IASP is the one constructed and used by the EAU guideline<sup>4</sup>. The definition goes as follows: “*Chronic Pelvic Pain is chronic or persistent pain perceived in structures related to the pelvis of either men or women. It is often associated with negative cognitive, behavioral, sexual and emotional consequences as well as with symptoms sugges-*

*tive of lower urinary tract, sexual, bowel, pelvic floor or gynecological dysfunction*”<sup>5</sup>.

A few remarks about this definition from within its developmental process.

- The basic idea in the world of chronic pain that has changed our way of thinking and working is that we recognize that pain is a ‘disease in its own rights’, and not necessarily an organ-based problem. Moving away from the one-to-one relation of organ pathology and pain has helped us in better understanding the pain and the pain-patients. And that changed not only the way we talk about pain e.g. in scientific ways but also in the way we treat our CPP-patients.

- The use of the word ‘perceived’ is following this non-organ-based terminology. Patients and caregivers talking and discussing may together come to the conclusion that the pain is perceived in a pelvic organ like the bladder. Perceived is subjective in the way that it is a feeling. It does not mean that something is wrong with the bladder. In taking a pain history this wording might help to start pain education from the beginning. “Where do you perceive your pain?” is a different question than “Where is your pain coming from?” Asking this question might be new but in daily practice one will feel and experience the difference. In easy language, explaining this goes like: ‘the site of your pain is not necessarily the origin’.

- The definition is broad: ‘structures related to the pelvis’. By using this broad description, the unity of the pelvis is accentuated. Remember that we once started with an organ-based idea and now we know that other structures like muscles, tendons, nerves and soft tissue all together play a role in the process of CPP.

A good illustration of these changes, is the name change of the special interest group of IASP. Formerly it was called ‘Pain of Urogenital Origin’ and now its name is ‘Abdominal and pelvic pain’<sup>6</sup>.

In the EAU guideline about CPP the tour starts with this definition. In healthcare practice a patient will come and tell you that she has pain for a longer period and that it doesn’t disappear. She perceives the pain in her bladder and it is often very tough to go on with what she is doing. It affects her bladder- and bowel function as well as her working- and family life.

*First step* is to confirm the fact that she has pain. She has pain when she says so and it is there any time she states it is. For pain patients, this unconditional acceptance of their pain message is the basis for any further discussion, diagnostic and treatment. Be aware that you, as caregiver cannot objectify her pain. We still do not have a dolorimeter.

Second step is to rule out well-known-diseases. And here we must take notice of the fact that moving away from an organ based pain theory does not mean that we put the organ completely away. We need to know if there is a pathological process in the organ going on that needs treatment. Another way to say it: is there nociception going on based on a well-known disease process. This is an illustration of the important role of pain-mechanisms in dealing with CPP.

The EAU guideline says: “Chronic pelvic pain may be subdivided into conditions with well-defined classical pathology (such as infection or cancer) and those with no obvious pathology. For the purpose of this classification, the term “specific disease-associated pelvic pain” is proposed for the former, and “chronic pelvic pain syndrome (CPPS)” for the latter.” [Figure 1] In the definition of CPPS we also read: “... CPP is often associated with negative cognitive, behavioral, sexual or emotional consequences”. This sentence indicates that we might need to look even further than the patient itself. Attention must be paid to cognitions, (pain) behavior, sexual (and relational) consequences and the emotions that we often can feel and hear during the first talk with the patient.

## 2. PHENOTYPING AND TEAMWORK

Moving away from the organ-based pain construct, means that we need other ways to characterize patients with CPP. Phenotyping is the method used in the guideline and in many other advices about classifying CPP patients. A useful figure is the snowflake which illustrates that every patient is special and has its own features which need to be recognized to build the snowflake<sup>7</sup>. Phenotyping means looking at all the aspects of the pain and of the patient. In daily practice, it often helps to do a good history, a good physical examination and tailored diagnostics to rule out well-known diseases. Attention should be paid to already know psychological items in the past or presented during taking history. Attention also for the social surrounding: partner, kids, family, working place. By reading this, one might realize that it is time consuming to do a thorough investigation. True, so be honest and explain this to the patient by saying that it takes time to listen carefully and that

a second talk might be necessary. When you are working in a clinical setting you should consider forming a team that constitutes of specialist in the different areas.

Phenotyping helps to get a clear picture of the pain patient and it avoids doing procedures over and over again. Drawing a good picture of the phenotype supports you in doing all the investigations that are recommended by the guideline(s). Patient organizations often ask attention for one of the main problems with pain-care, which is that doctors keep on doing things like endoscopy, MRI, functional tests etcetera. The same is heard about seeing many different doctors, one after another. Patient call this the ‘revolving door’. An approach based on phenotyping before starting with treatment, makes it transparent, easier to discuss and more helpful for the patient. It also helps the caregiver to guide him in the assessment, treatment and follow up of these patients.

Treatment of CPPS is seldom a mono-therapy thing. It always needs more than one approach. A combination of two or three of the most offered forms of therapy is a good start. By these three forms we mean: organ- and nerve-based, musculoskeletal and psychological. Providing patient tailored treatment means that the patient is included as a member of the team and that the whole team discusses the situation and constructs the best applicable snow-flake. The conclusion of the team discussion can be a plan to do more diagnostic (organ or pain based) or to start the therapeutic route. Making a plan as a team is helpful for both the caregiver and the patient. It is a joined effort to start dealing with the pain. Patients will feel the support from the whole team and realize that they do not stand alone with their pain. Presence of an important relative during the presentation of the plan may be helpful and gives the patient the opportunity to talk it over with that relative when they are back home after a session with the team that is often felt as impressive.

Pain education is a kind of common thread in the communication with CPP patients. For many patients, the idea that pain is made by the brain and not by the organ can be an eye-opener. Some patients will be enlightened by this, others might feel disappointed because an organ based problem is easier to understand. Listen, observe and discuss the reaction. Pain education is successful when patients understand that this is the mechanism nature uses, instead that they end up with the feeling that it is a way of explaining the doctor’s inability or, even worse, saying that ‘it is all in your head’. Explaining processes like central sensitization, using drawings and pictures, is often very much appreciated. The Australian Neuro Orthopedic Institute has done a lot in this field by publishing their “Explain pain” books<sup>8</sup>. The content of these books is valuable for both caregiver and patient and the illustrations and metaphors might help the patient understand the saying “no brain, no pain”. Using patient based language, taking into account the education level of the patient, is always a principle in talking to patients.

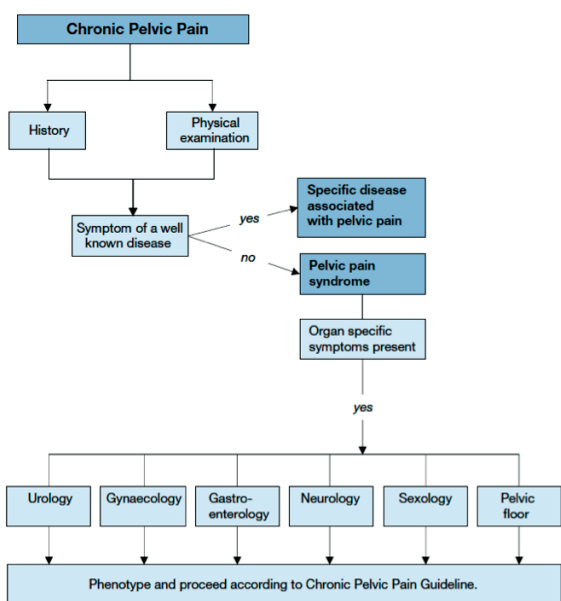


Figure 1. – EAU Guideline Chronic Pelvic Pain, 2016. Figure 1 page 32

## 3. NEW WAYS TO EXPLORE

As said before, definitions reflect the modern ideas and ways of thinking. As a consequence of developments in the way we think about pain and health, new definitions were proposed and discussed.

### IASP

The first new definition, proposed in 2016, is that of pain in general. The prevailing IASP definition, dating from 1979 goes as follows.

- Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage<sup>9</sup>.

The leading word in this definition is 'experience'. Pain is defined as an emotional or sensory experience. This wording is comparable to the word that is used in the EAU guideline: 'perceived' (as in experience in the first line).

The use of this word reflects the basic idea about what pain is. And it can help both pain patients and those who care for pain patients. Stressing the character of pain being an experience of a feeling perceived in a certain part of the body, helps patients in understanding both the pain itself and the treatment options offered. Only by speaking in a clear and understandable language we can build up a conversation and a care-relation.

The *potential tissue damage* is another term that should be highlighted. Patients will often describe their pain using words that reflect this idea of damage: stabbing, burning, cutting. Caregivers should just listen and notice the words used and realize that this is how the patient thinks about it. Cognition comes into play at this moment and gives the caregiver an opportunity to address this as part of pain education. Because patients speak and think in terms of damage, it is not surprising that they are in a hurry to get good treatment for this damaging and thereby threatening pain. At the same time, it will affect their family members and friends. They also might get worried about this pain that is damaging their relative. And subsequently they might re-inforce the ideas of the patient and their need for ongoing searches for causes. In case the doctor does not address this way of thinking and this reaction, patients will not only be disappointed but they may become scared or even angry. The doctor must explain that chronic pain does not necessarily mean there is danger, and that cognitions interfere with our experience of pain. The idea "I do not get the treatment that repairs the danger" can otherwise introduce a feeling of perceived injustice and that in itself may strongly effect the pain in a negative way.

Last year a new definition was proposed to get a discussion on how we will implicate modern scientific developments into our terminology.

- Pain is a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive and social components<sup>10</sup>.

Two items have changed: unpleasant has become distressing and cognitive and social have been added. Looking at the addition it becomes clear that cognitions have been recognized as a valuable factor in the field of chronic pain. The authors of the new definition tried to illustrate this in their article by mentioning some models used in pain research and pain treatment. They say that models based on fear and avoidance and on catastrophic thinking "... have identified important pain-associated beliefs and cognitive biases, with emotional and behavioral consequences ..."

The strong message that hopefully comes from this article and the new definition, is that pain is not just about nociception. Cognitions are not only a psychological phenomenon, cognitions are a human feature. We all have our cognitions and they are often based on what we have experienced in life and how we were trained in the jobs we do.

Pain is seen as an illness and therefore placed within the healthcare systems. The nature and structure of our healthcare system is dependent on the definition of health that is used. In this field, new definitions have also been proposed and discussed and partly accepted. The difference between old and new definitions can be a good illustration for the daily practice of healthcare providers, also for those dealing with pain patients.

World Health Organization (WHO) 1948

- a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity<sup>11</sup>.

This definition is old but was quite modern when it was first suggested and it has been proven useful in the past decades. Some have tried to rewrite the definition, with extra attention for the environment for instance, including natural, built and social environment. But the need for a change remained. One of the best, although not fully accepted new approaches, is the one made by the people who talk about 'positive health'.

Institute for Positive Health (IPH) 2011

- Health as the ability to adapt and self-manage, in light of the physical, emotional and social challenges of life.

In her article about this definition Machteld Huber<sup>12</sup> says that the most direct reason for change is the fact that the old definition is static and the newly proposed one is dynamic. In the positive health view, health is seen as an ability. Not something you are, but something you can. Not about how much the environment gives you a state of social well-being but about how well you can adapt to the environment you live in. Not about what limitations the pain has brought you but about how to adapt your life and develop new options with what is still possible. Note that *social challenges* have been introduced into the definition and compare this with the adding of *social components* to the definition of pain.

Apart from adaptation, this definition talks about self-management: "manage one's own well-being". Here we find a good similarity with what is seen as important in treating chronic pain. In the EAU guideline on CPP, management of one's own pain is described in the management section. All patients with pain and maybe especially those who did not react on diverse treatment options, will need to find out how to live with their pain. Incorporating self-management is best done from the start of the therapeutic relation in patients with chronic pain. It should not be seen as a kind of "last resort" therapy. Patients should be aware that caregivers often cannot explain their pain, neither in a physical way nor in a psychological or social way. Self-managing their pain is what is at hand every day of the week and is therefore of basic importance. Knowing this, the definition based on positive health fits well in the ideas about chronic pain. Patients need to adapt to their pain and need to manage their pain and all its consequences by themselves. However, let us not forget the social components that are not only challenges but also opportunities. Patients can go and search for others to join and support their self-management. When they find a caregiver who wants to support them, we call it shared care. But, not only doctors or psychologist can support the self-management, also lay people can (and maybe even better). By talking with other pain patient-companions they can interchange ideas on how to manage. They can form groups on social media or whatever medium that suits them. Many questions will be practical or about experiences and both type of questions can be answered by companions. For healthcare institutes, it is necessary to provide information on chronic pain and on self-management of that pain. Health care institutes should consider to invest in developing these programs for patients and relatives.

This new approach to health and healthcare is characterized by a positive view on health and also by a patient centered approach. The patient in the center, not as someone to be looked at by many different healthcare workers, but as the main participant at the round table where the team is listening to what the patient wants, where the sit-

uation, the plan and the support is constructed and discussed. Would be great if this will be daily practice in pain-centers.

#### 4. INTEGRAL APPROACH

The patient with chronic pelvic pain deserves an integral approach. And, although it sounds complicated, that is quite easy. If we succeed in building our care system with the patient in the lead, we might all benefit.

An integral approach is based on the biopsychosocial model.

– Bio: we need to be aware of the fact that biological or somatic aspects play a role. Nociception is not obligatory but it can play a role in CPP. Understanding pain mechanisms is important to educate the patient and to help guiding the management program. A well-defined and balanced diagnostic protocol must be followed to rule out and treat well-known diseases and to get insight in pain mechanisms like peripheral and central sensitization.

– Psycho: psychological diagnostics and management should be part of the program from the very beginning. Whether or not there's a somatic origin found, it will be helpful to elucidate what pain does with a person and how you can learn to implement it into your life. Even if the pain can be cured it might help to reinforce the human system and thereby lower the risks to get a recurrence or another chronic pain problem. History has its influence on how the brain deals with your pain. Chronic or acute pain episodes will leave memories in the brain and the way they were dealt with can influence the chronification of pain. Fear and anxiety, as well as catastrophizing and perceived injustice are well-known aspects influencing the way our brain deals with pain.

– Social: the social environment plays a special and recently better understood role in chronic pain. Pain patients can easily become isolated because of their limitations but also because of their thinking: 'they don't understand my problem, it is invisible'. The way the environment reacts will influence the process of self-management either in a positive or a negative way. Remember the new proposed definition of pain talking about social components. Society can be helpful in so many ways that it is very important that we look at his aspects more and better than we have done in the past. Social media, patient organizations, positive health, they are all focused on this aspect.

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*Correspondence to:*

Bert Messelink  
Urologist-Sexologist, University Medical Center Groningen.  
Pelvic Pain Center. Groningen, the Netherlands. Email:  
[e.j.messelink@umcg.nl](mailto:e.j.messelink@umcg.nl)