Psychological aspects of the management of chronic pelvic pain

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Summary This article outlines the main psychological issues involved in the management of chronic pelvic pain. It argues for an integrated process of care that acknowledges the role of psychological factors in all experiences of pain and attempts to help the patient to understand this from the inception of care. Issues at each level in the process of care, through seeking help and primary and secondary care, are systematically considered, and guidance is provided on when more specific psychological input may be needed. The emphasis is on psychological aspects of management by all staff throughout the process so that women do not feel that their distress is marginalised. The importance of pre-existing beliefs, women’s need for an acknowledgement of the reality of their distress, how to provide information and effective reassurance are discussed. Issues to consider in terms of mood, the role of sexual abuse and the influence of chronic pelvic pain on relationships are included, together with ideas about specific psychological approaches that can be of benefit.

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Psychological factors and the experience of pain

The experience of pain requires perception and is essentially a function of the brain. While asleep, we do not feel pain, and consciousness is therefore a fundamental requirement. It is unsurprising then that the relationship between degrees of pathology and the experience of pain is non-linear. There is no rule of equivalence.

There are clear examples of the experience of tissue damage without pain and pain experienced in the apparent absence of damage or pathology.

One of the most helpful ways of understanding pain is that the physiological patterns are interpreted and themselves influenced by psychological factors. These may be longstanding and a function of the person’s learned responses. We know, for example, that different individuals report different pain thresholds when they are exposed to artificially manipulated pain. Immediate situational factors, such as being able to ignore a mild pain in the company of a friend, also have an impact. Psychological factors are themselves influenced by
social factors so that different societal groups appear to experience illnesses with different responses on a range of stoicism to extreme distress and suffering.

Pain can be thought of as having two dimensions: severity (the actual intensity of the pain) and an affective component, which is how distressing the pain is for that individual. The mechanisms by which psychological factors may influence the experience of pain are thought to operate through descending messages from the brain influencing the patterning of responses from the periphery. There are also likely to be more direct links within the brain.

Of key importance is the meaning that individuals ascribe to their experience of pain, i.e. how they appraise it. Studies have, for example, shown that, after a heart attack, people construing further chest pains as evidence of a further impending attack rated these as more painful than those construing them as evidence of the growth and repair of the blood vessels.

Unfortunately, a common misconception among patients is that pain is caused purely by specific damage or abnormality and that when this is repaired, the pain will cease. For many women with pelvic pain, however, the diagnosis of causation is not a simple matter and acute pain may become chronic.

Impact of living with chronic pelvic pain

In common with other chronic pain patients, women with chronic pelvic pain (CPP) often experience high levels of distress and disruption to their lives, although they have been found to vary substantially with respect to the degree to which they are affected by their symptoms. When the pain is particularly severe, they may have to stop all activities and lie down. Many women find that they are unable to stand or walk for any length of time because of severe pain. In extreme cases, women may end up in a wheelchair as described below (pseudonyms are used in all case studies):

Joanna was a 25-year-old single lady with a 12 year history of pelvic pain. The pain was constant and aggravated by physical activity. Although she could walk, this was very painful, and she attended her appointment with the gynaecologist in a wheelchair. She had suffered extremely traumatic experiences as a child.

Activities which involve stretching, bending and lifting are often particularly troublesome for these women, making many household tasks very difficult. They may have to depend on help with housework, shopping and childcare, and experience significant guilt because they are not able to fulfil their role as partner and mother.

Although some women are able to continue in paid employment, others have repeated pain-related absences from work and may eventually have to give up their job. This can result in a loss of identity and financial hardship. Repeated emergency hospital admissions are not uncommon.

Feelings of frustration, anger and resentment are frequent in women with CPP. They often describe feeling irritable and snappy with others, and this can adversely impact on relationships with partners, children and other family members. Their anger may reflect adverse life experiences that pre-dated the onset of the pain, for example a traumatic childbirth or partner infidelity, or it may be the result of having had chronic pain for many years.

Women may feel angry that conventional treatments have failed to cure their pain and may indeed have made the pain worse. The anger may be directed towards the professional trying to help the woman. This in turn impacts upon doctors who, without a clear understanding of the origins of a patient’s anger, may feel personally attacked, and this may further undermine the outcome of the consultation.

Angela was a 28 year married lady who presented with a 7 year history of pain in her left iliac fossa and pain around her scar following a caesarean section. Her section was performed for an undiagnosed breech, and the scar was infected postoperatively and took a long time to heal. She described the birth as very traumatic and did not feel that she had been adequately informed about what was happening.

Angela’s pain was constant and aggravated by any physical activity, driving and sexual intercourse. Standing or walking for more than 10 min resulted in the pain becoming very severe and debilitating. The pain was eased by sitting with her feet up or lying in the fetal position. She had been diagnosed as having postnatal depression after the birth of her daughter and continued taking antidepressants for ongoing depression. She described feeling ‘old and useless’ and fed up with the pain and the restrictions it imposed on her life. She had had to give up her job as a fashion designer because of the pain, and struggled to look after her young daughter.
In addition to feeling angry about the circumstances surrounding the birth of her daughter, Angela felt angry with her mother for pressurising her into having a termination of pregnancy at the age of 17. She sometimes felt that her pain was a punishment for the termination.

Chronic pain is often associated with depressive symptoms. Women whose lives have become severely restricted because of their pain and who do not have supportive partners or families are particularly vulnerable to depression. Higher levels of depression have been reported in women whose partners were perceived to be lower on empathy and positive regard. Punishing responses from partners were associated with greater pain severity, although this association no longer remained when depression was partialled out, suggesting that punishing responses are only indirectly related to pain severity through depression.

Women may present as tearful and fed up, and frequently report feeling isolated and not understood. Some women describe intense feelings of despair and hopelessness, and suicidal ideation is occasionally present. Co-existent psychopathology has been found to correlate with a poorer long-term prognosis.

Relationships often suffer. It is well known that a significant majority of women with CPP report problems with their sexual relationships. Several studies have shown that up to 70% of women with CPP experience sexual dysfunction such as dyspareunia, loss of interest or postcoital pain. Some women's pain is triggered by sexual arousal or sexual intercourse. For other women who are already in pain, intercourse often makes this worse. These women frequently develop anticipatory anxiety and tension with secondary problems of loss of arousal and vaginismus, often leading to an avoidance of sex. This can cause a considerable strain on their relationship. Partners may resent the lack of sex and often become less supportive over time, especially if no diagnosis is found and multiple treatments are ineffective. The impact that CPP is having on a woman's relationship, particularly her sexual relationship, is a common reason for seeking ongoing help for her pain.

Consultation with the general practitioner

In the UK, the general practitioner (GP) is likely to be the first doctor seen, and how he or she responds to this consultation and the possibilities discussed may set the woman's initial ways of understanding her condition. It is well recognised that doctors in primary care find the management of patients with CPP particularly challenging and difficult. It may be that a discussion of pain, at this stage, as a real experience that is influenced by both physiological and psychological factors may be useful in aiding management should the acute become more chronic. A particularly adverse set of circumstances occurs when no clear abnormality is found and the pain is severe and persistent, making the patient feel desperate and helpless.

Given that CPP has such potential to adversely affect the quality of life across several domains, it is important to consider how processes of care can be optimised from the outset.
women begin a repeated and futile cycle of referral to secondary care for investigation. Studies cite examples of women undergoing as many as 14 exploratory operations.

One of the first and perhaps most important task facing the GP is to establish a good therapeutic relationship with the patient. In order for this to happen, a women needs to feel listened to and understood. She needs to be given time to express any particular concerns she might have. She should be asked whether she has any thoughts herself about why she is experiencing the pain. At least two-thirds of women will have some clear beliefs about the cause of their pain, and these need to be explored early on in the presentation. A key area of dissatisfaction reported by women is the extent to which they feel that their problem has been understood and acknowledged.

It can be very helpful to normalise women's problems from the beginning. Letting them know that CPP is almost as common as migraine can help to reduce their anxiety and sense of isolation. It is also important to inform them that, for the majority of women with CPP, investigations do not reveal any disease or pathology. This does not mean that they are imagining the pain, but rather that their pain could be coming from normal structures in their pelvis, such as muscles, nerves and blood vessels. This helps to prepare women for the fact that there may not be a simple diagnosis and cure for their pain. The reality of their pain needs to be clearly acknowledged from the outset and may need to be reiterated because well-meaning but frustrated doctors may have suggested that it is 'all in their head' when repeated investigations prove to be negative.

The influence of psychological factors such as mood, beliefs and behaviour on the experience of pain needs to be explained early on in the consultation process. This is likely to be more acceptable to the patient if it comes from her doctor rather than a psychologist at a later date. This can form the grounding for a later discussion of how the patient can influence her symptoms and help her to gain a sense of control over her pain and her life. Encouraging her to take an active role in managing her pain early on in the consultation process reinforces the message that there is often not a simple cure for CPP.

Consultation with the gynaecologist

The second stage typically involves referral to a gynaecologist, and an exploratory operation is almost inevitably recommended as a result of this. Again, the integrated perspective is crucial, and this can be achieved in several different ways of providing the service. It has long been recognised that a multidisciplinary approach is the most effective way of managing CPP. Such an approach involves a team of health care professionals working in close proximity. This emphasises to the patient and the family the importance of all aspects of the pain experience. A psychologist should be a core member of this team.

Given that we know that the meaning individuals attach to their pain is important in how it is experienced, it is important, as in primary care, for the doctor to ask about the woman's own explanations of why she has the pain. We know that women have their own theories and that these often relate to damage through previous gynaecological surgery such as sterilisation, caesarean section or hysterectomy, to some sort of reproductive loss such as a termination, miscarriage or stillbirth, or indeed to some form of stress. They may often think of their internal organs in a very negative and emotive way, for example "I'm sure my insides are like a mangled mess." In asking about these ideas, the gynaecologist sets up an opportunity to discuss and influence some of the assumptions and beliefs that the woman may have. At a later stage in the process, it may also be possible to address any negative imagery. Given that changes in beliefs about the pain have been shown to be the best predictors of an improvement in pain ratings from consultation to after laparoscopy (above and beyond whether pathology was found and removed), such aspects have received little consideration.

Women's expectations of the consultation with the gynaecologist are typically focused on gaining a solution to the pain, i.e. finding a cure. Again, it may be important to discuss the fact that this is not always the case and that the pain is not always evidence of pathology. It is, however, crucial that the reality of the experience is endorsed and that there is recognition of the level of distress and disruption to life. As with the GP, key elements of the process concern the doctor really listening, taking time to explain and showing concern and sympathy.

When taking a history, it is important to identify any events that may have occurred at the time the patient first became aware of her pain. Where women associate the onset of their pain with a traumatic experience, they may still have unresolved conflicts relating to this that need addressing, as demonstrated in the following two examples:

Sarah was a 24-year-old single woman with a 6-year history of central pelvic pain and dyspareunia.
Her pain began after she had a termination of pregnancy following a rape. She had never spoken about the rape and felt very angry about what had happened.

Diane was a 26-year-old married woman who presented with a 12-year history of pelvic pain. A careful history revealed that she was raped at the age of 14 by a group of boys and subsequently developed herpes. She had a very disturbed and abusive childhood and married a man who also abused her emotionally and physically.

Both of these women responded well to psychotherapy, and their pain symptoms improved significantly.

In view of the high prevalence of lifetime abuse in women with CPP, it has been argued that such women should be routinely asked about any abuse history as part of their initial assessment. A number of studies have shown that women with CPP are rarely asked whether they have had any negative sexual experiences, and only a small minority of women volunteer this information to a doctor. When women were asked whether they thought they should be asked, 90% responded in the affirmative.

It is generally acceptable to women to be asked whether they have ever had any unwanted and upsetting sexual experiences at the same time as enquiring about the possible impact of the pain on their sexual relationship. Such questions may elicit a strong emotional response from the patient and should be responded to empathetically. Some women will find their experience too distressing to talk about in any detail. If they have not spoken to anyone about their experience and would like an opportunity to do so, a possible referral to a mental health specialist should be offered. In addition to asking about any past abuse history, it is important to enquire whether the woman is involved in any ongoing abuse. Concerns about trust in the doctor–patient relationship are common in women with a history of child sexual abuse. Such women report more anxiety, embarrassment and vulnerability associated with a gynaecological examination than other women.

The woman’s mood should also be assessed at initial presentation, and any evidence of clinical depression needs to be addressed. Depression may increase their isolation and perception of pain, as well as their motivation and ability to adopt a self-management approach. Antidepressants have been used with a variety of chronic pain syndromes, although there has been little study of their use in women with CPP.

The reasons for carrying out particular tests and investigations should be carefully explained to the patient, if possible in the presence of a significant other. Very few studies have reported attempts to include the current partners of women with CPP in assessment, but partners can often benefit from being present early on in the process. If tests are repeated, the rationale for this needs to be explained as the more diagnostic procedures offered or performed, the more this magnifies the seriousness of the complaint in the patient’s eyes. This is likely to result in heightened anxiety and firmly entrenched beliefs that there must be something seriously wrong. This will then aggravate the problem and its management.

Giving information after the exploratory operation is a crucial element in the care process, and how this is achieved may influence a woman’s subsequent adaptation. As already acknowledged, there will be many women for whom there is no clear pathology, and often the woman is said then to be provided with ‘reassurance’. For many, however, this is unfortunately not reassuring.

Some of this may relate to the context in which the information is given. In many services, this has been while the woman is still recovering from an anaesthetic by a doctor or nurse she has not met before. It is perhaps unsurprising that she may, in these circumstances, still have queries unanswered and a feeling of being ‘fobbed off’. It is important that any postoperative information is provided by someone who knows about her case, in circumstances in which the woman is fully coherent and has an opportunity to ask questions. A follow-up appointment to cover these issues should be arranged. Studies have shown that many women felt that when they were given a diagnosis, the meaning of this was not explained adequately, and those who had had surgery stated that they had not been informed of alternatives to surgery.

Some services have introduced videoing of the actual exploratory operation, with women having an opportunity to view excerpts from this with the gynaecologist. This can either enable the woman to see the pathology and its removal or give her an opportunity to view her normal uterus. This may hold the benefit of creating more positive visual imagery but still requires more systematic evaluation. There is also a need for some potential understanding of continuing pain to be given, and this is where the initial emphasis upon the interaction of psychological factors is so useful.

Helen was a 21-year-old woman with a 12 month history of stabbing pain in her right iliac fossa that was present most days. The pain was
exacerbated by any activity, had become increasingly severe, was significantly affecting her quality of life and was interfering with her ability to work. Intercourse had become impossible. She had had a number of emergency hospital admissions and a diagnostic laparoscopy that showed no obvious pathology.

At examination, Helen was exquisitely tender over one specific area on the right iliac fossa and showed increased levator tone on pelvic examination. She walked with a slight limp, and flexion of her thigh reproduced the pain. On the basis of these findings, it was felt that this was a musculoskeletal pain, which was explained to her. She found this explanation very reassuring and left the consultation accepting that there was not a simple cure for her pain but that she could learn positive ways of managing it with the help of a physiotherapist and relaxation techniques. Psychosexual therapy was also offered.

Before being discharged back to the care of their GPs, there needs to be attention to what input can be given in terms of helping women to cope with any ongoing pain. As already stated, the potential impact of CPP on a woman’s quality of life across many dimensions is quite considerable, and attention to management rather than cure is crucial.

Facilitating coping with chronic pelvic pain

As part of the process of trying to understand the patient’s pain, it can be very helpful to ask her to keep a monthly pain diary. This will record the severity of her symptoms on a scale of 0 to 10 where 0 indicates no pain and 10 indicates the worst pain she has experienced. She will also be asked to indicate the times and heaviness of her periods, as well as any events preceding exacerbations of her pain. It is important to help the patient to become aware of factors in her environment that may be influencing her pain symptoms, for example family arguments or conflict at work. This enables a woman to see that her experience is affected by situational or emotional factors and enhances the view of this as a response that can be influenced rather than just experienced and suffered. It starts to help a woman to see herself as an active agent in coping with and influencing her experience rather than a passive and helpless victim. Some women acknowledge that their pain is worse when they are feeling stressed, and stress may precipitate pain for some women. A psychosocial history will help to understand the environment and context of a woman’s pain.

Jane was a 26-year-old lady referred to the gynaecologist with a 10 month history of intermittent pelvic pain and dyspareunia. Repeated investigations for pelvic inflammatory disease were all negative, and a course of antibiotics made no difference. She had had a termination of pregnancy 4 years previously and was concerned that this had caused her some damage and might be responsible for her pain. Jane’s pain was causing her to have time off work and was putting a strain on her 3 year relationship with her partner.

Following examination, Jane was told that her pelvic organs seemed completely normal and that it was extremely unlikely that the termination had caused any damage. She presented as quite tense and anxious, and when the relationship between stress and pain was explained, she acknowledged that she had a problem with stress, particularly at work. She was being bullied by colleagues and found it very difficult to manage interpersonal conflict. She was keen to learn how to relax and how to be more assertive, and after three sessions with the clinical psychologist Jane was feeling much better and her pain and dypareunia had almost disappeared.

Advice on relaxation and breathing exercises can be very helpful for many women with CPP as it can help to break the pain–tension–pain cycle. Women can be encouraged to join yoga classes or purchase relaxation tapes. If the anxiety is particularly severe or entrenched, a referral to a mental health professional may be appropriate. As in the case of Jane, learning to be assertive can be very important for women with CPP. Assertiveness training can help a woman to set limits on demands from others, improve communication in her relationships and deal more directly with people or situations that may exacerbate her pain.

Many patients may benefit from advice on activity management and goal-setting. CPP patients, in common with other chronic pain patients, often base what they do on how they feel. When they are having a better day, they try to catch up on tasks and often end up overdoing it. The pain is then worse the following day, and they are able to do very little. This is called activity cycling, and women are encouraged to pace themselves to break the cycle, i.e. to keep to a regular amount of activity each day and base what they do on a
plan and not how they feel. Women also typically avoid doing things that they think will make the pain worse. They need to be helped to understand that hurt does not necessarily mean harm. Avoidance is not helpful in the long term and can make life increasingly negative, as well as undermine confidence. Goal-setting is a process that helps a patient to identify long- and short-term goals and break these down into achievable steps using the principle of pacing.

Where CPP has had an adverse effect on sexual relationships, women and their partners may benefit from specific interventions such as Kegel exercises, the use of graded vaginal dilators and advice on lubrication and sensate focus exercises. Advice can also be offered on positions that limit the depth of penetration (e.g. the lateral position) in cases where the women complains of deep dyspareunia, or that give the woman a greater sense of control (e.g. female astride). If there are significant relationship problems, a referral to a specialist may be appropriate. Similarly, where the initial assessment by the gynaecologist suggests the importance of a traumatic event, specific psychological input is probably required.

Group therapy using a combination of cognitive-behavioural techniques and physical exercises has been shown to be effective in treating chronic pain patients. This may well be appropriate for women with CPP, although there are few reports in the literature of such groups.

The emphasis is on individual analysis of need and thinking through the most appropriate care for the particular woman, care that incorporates both physical and psychological aspects. If such provision is not put in place, the outcomes are not very favourable and many women may continue to experience significant pain in the longer term, which this will impact on many aspects of their life, mood and relationships in a negative way. The types of theme encapsulating the experiences of women in these circumstances were that the emotional impact was intensified by a sense of not being believed, and fuelled by the sense of uncertainty generated by the lack of information. These women felt a sense of helplessness, isolation and coping alone, feeling that they did not know where to turn. Through the provision of psychological care, integrated by all staff at all levels of the process, such outcomes can be avoided. This would be a positive development not just for the patients themselves, but also for the doctors caring for them and indeed the economics of services since the common and costly process of ‘a futile cycle of referral and investigation’ would be avoided.

Summary and conclusions

Women with CPP are likely to suffer considerable distress not just from the experience of pain, but also in terms of adverse effects on many aspects of their lives.

It is crucial that, in the initial discussions about the woman’s pain, psychological and physical strands are considered together. This avoids the all too common scenario of a woman being referred to a psychologist after multiple investigations have enhanced her belief in severity and pathology, leading to feelings of being ‘fobbed off’, with her distress invalidated and disbelieved. This can be avoided by working closely with psychological ideas in initial stages of assessment. In particular, recognising the importance of the personal meanings of experienced symptoms and how these appraisals dramatically influence suffering and distress is crucial.

There are obvious general implications relating to the process of care in the initial gynaecological consultation in terms of the importance of professionals taking time to listen, validating the experience of pain and exploring and responding to the woman’s own beliefs about causation. It may also be helpful to provide educational materials indicating the fact that CPP is common and that it is often the case that clear explanations are unavailable. The clinician also needs to be alert to issues of problems of mood, sexual difficulties and physical and sexual abuse.

Practice points

- Listen and validate the woman’s pain experience and distress.
- Explore and respond to her beliefs about causation.
- Provide written information.
- Ask about sex, including any history of abuse.
- Set up a multidisciplinary team and include a psychologist in the woman’s care.

Research directions

- To identify processes in the gynaecological consultation that facilitate adjustment and produce longlasting reassurance.
- To test ways of facilitating changes in beliefs about pain and their impact.
- To evaluate systematically ways of coping with CPP incorporating both physical and psychological aspects of care.
Further Reading