

‘ReConnect’: A model for working with persistent pain patients
on improving sexual relationships

Sarah Edwards¹, Anna Mandeville¹, Katrine Petersen¹, Julia Cambitzi¹,
Amanda C de C Williams², Katherine Herron¹

¹ *Pain Management Centre, National Hospital For Neurology and
Neurosurgery, University College London Hospitals, London, UK.*

² *Research Department of Clinical, Educational & Health Psychology,
University College London, London, UK.*

Corresponding Author:

Dr Sarah Edwards

Pain Management Centre, National Hospital of Neurology and Neurosurgery at
Cleveland Street, 25 Cleveland Street, London W1T 4AJ

Phone +44 (0) 20 3448 4776

e-mail: sarah.edwards26@nhs.net

Abstract

Introduction

Many individuals with persistent pain experience difficulties with sexual function which are exacerbated by avoidance and anxiety. Due to embarrassment or shame, sexual activity may not be identified as a goal for pain management programmes (PMPs). In addition, clinicians can feel that they lack skills and confidence in addressing these issues.

Methods

We sought to develop a biopsychosocial model for helping patients return to sexual activity and manage relationships in the context of pain management, known as 'ReConnect'. The model amalgamates well-established methods from pain management and sex therapy to guide multidisciplinary team members. ReConnect comprises three components:

1) 'cognitive and myth-busting', 2) 'sensations and feelings' and 3) 'action-experimentation'.

We collected self-report data from 281 women and 92 men from our specialist PMP for chronic abdomino-pelvic pain, including questions measuring interference with and avoidance of sex due to pain, and the Multi-dimensional Sexuality Questionnaire (MSQ) to measure anxiety about sexual activity.

Results

The results show statistically significant improvements for anxiety, avoidance of sex and sexual interference. By using the ReConnect model to structure clinical work, pain management clinicians reported increased confidence in addressing sexual activity goals.

Conclusion

The ReConnect model is a framework for clinicians to use to support sexual activity goals. It has demonstrated **improvements** in clinical outcomes such as anxiety around sex and interference of pain in sexual activity. We encourage its application in pain management services in both one-to-one and group sessions, as a method for encouraging pain patients to address this important area of life which can be adversely affected by pain.

Introduction

Chronic pelvic pain (**CPP**) describes persistent or recurrent pain in structures related to the pelvis, including the prostate, bladder, urethra, genital and reproductive organs.¹ The global prevalence of **CPP** in men and women ranges from 2.1% to 24% respectively.² Similarly to

other chronic pain conditions, **CPP** leads to behavioral, social, emotional and cognitive changes.³

Difficulties with sexual relationships are twice as common in men and women with chronic pain as in the general population,⁴ and this proportion rises in **CPP**, with a decrease in sexual desire and arousal.⁵ There are frequent reports of problems with marital or romantic relationships,^{6 7} as well as with sexual functioning in particular. Problems with sex understandably lead to anxiety about relationships and future sexual activity, and add to the emotional burden carried by those with **CPP**.^{8 9}

Individuals with persistent pain report that sexual difficulties are challenging to discuss with others,¹⁰ due to embarrassment, shame or stigma. Reluctance in the general population to seek help for sexual difficulties is well-established,¹¹ in part due to the social constraints surrounding the topic.¹² GPs report that sexual dysfunction is often a complex issue which they do not have time to fully discuss.¹³ The taboo around talking about sex may result in both patients and clinicians feeling embarrassed or anxious, and therefore avoiding discussion. Understandably, embarrassment is also a factor inhibiting discussion of this issue by individuals on group pain management programmes (PMPs).

Problems Associated with Intimate Relationships in CPP

The commonly observed fear-avoidance model,^{14 15} is often more pronounced for sexual activity. The experience of regular flare-ups after sex is likely to increase avoidance of sexual contact. Subsequently, on the occasions sex is attempted, anticipatory fear and anxiety plus hypersensitivity in the pelvic area can lead to a significant pain flare-up. Unhelpful thinking patterns in persistent pain, such as catastrophising, mind-reading or magnification of negative events,¹⁶ are highly relevant cognitive components to pain during sex. Individuals may continue to engage with painful sexual contact motivated by beliefs such as ‘If I don’t have sex, my partner will leave me’, or may make strenuous efforts to satisfy their partner,¹⁷ with the anticipation and experience of pain making it something to ‘get over and done with quickly’, reducing any focus on enjoyment as hypervigilance for painful sensations reduces attention to erotic cues and pleasurable sensations.¹⁸ This fear-avoidance pattern mirrors the observation that any general difficulties with sexual contact, independent of pain, are associated with rapid onset of anxiety and reduced confidence,¹⁹ further maintaining avoidance behaviour.

Arousal before and during sexual activity may be compromised by pain, anxiety or side-effects of medication.²⁰ These side-effects are often under-reported in the literature and not warned of or asked about when the drug is prescribed.²¹ This is likely to add to low levels of interest in sex and to exacerbate pain during sexual contact, as the pain-mitigating effects of arousal are not experienced.²²

Avoidance of sex, which may be exacerbated by pain-related low mood, can become an established habit over time,²³ along with loss of sexual interest or libido. Partners of those with **CPP** report feeling tentative about initiating sex for fear of causing pain,⁷ and so reinforce this cycle. Added to this, individuals with **CPP** may have worries about fertility and managing pregnancy and family life, and so may postpone or avoid family planning, feeling that their hoped-for futures have been blocked by pain, and presenting as highly distressed when they attend the pain clinic.²³

For those not in a current relationship, the loss of confidence in ability to have sex may lead to the individual avoiding dating, because of anxiety about future embarrassment or rejection. They may deny themselves any possibility of a relationship, either stating openly that this would be impossible, or adjusting their view of the future so that a partner does not feature.

Difficulties in a relationship due to pain during sex, or the inability to feel confident to start a new relationship, mean that pain has disrupted a key and valued area of that individual's life.

Aversive Sexual Experiences

It is often assumed that previous aversive sexual experiences are key risk factors for **CPP**, with possible causality.²⁴ However, most research into this area has been based on retrospective self-report data. The only prospective study of young people who had experienced sexual abuse showed no relationship with **CPP**.²⁵ This suggests a complex relationship between sexual mistreatment or abuse and chronic pain. The possibility therefore needs to be carefully considered on an individual basis when assessing an individual with pain.²⁶

Approaching Difficulties with Sex

Literature on how to work on improving sexual activity for individuals with pain is scarce, and few pain management studies include sexual functioning outcomes. Bergeron in 2008²⁷ compared cognitive-behavioural therapy (CBT) with surgery or biofeedback for women with provoked vestibulodynia,²⁸ and found increased sexual function for all three groups which

was maintained at long-term follow-up. A later study in which women with vulval pain were offered either non-directive supportive psychotherapy without focus on sexual activity or CBT incorporating sex therapy, found greater improvements in sexual function in the CBT group.²⁹ An earlier study by Bergeron and team³⁰ compared a treatment integrating physical therapy and CBT with vestibulectomy for women with sexual pain disorders, and concluded that both approaches are effective.

Considerations For Assessment

Facilitating a biopsychosocial understanding of pain and engagement in self-management approaches, alongside any medical interventions offered, is highly important to initiate at a patient's first pain clinic appointment.³¹ We recognise that shifting away from the medical model can be challenging at times and pain consultants often benefit from the support of a multidisciplinary team (MDT). Many individuals with pain report an impact on sex,⁴ so pain clinicians can be pro-active in openly discussing this area of life from assessment, 'modelling' to the patient that this is a normal issue, which can be discussed as can other impacts of pain, without embarrassment.

Ideally, sexual activity is routinely asked about at initial medical consultation, but as questions about negative sexual experiences are sensitive, they may need to be postponed until trust has been established. Asking gentle, open questions about possible causes or events which may have led to pain, and 'normalising' negative sexual encounters by explaining that these are relatively common and are experienced as extremely distressing, are possible approaches to the subject, whether at first assessment or a subsequent appointment.

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Social factors to consider at assessment include previous relationships and sexual history, and cultural norms and beliefs about both sex and pain. The behaviour, expectations and health of current and previous partners are important, as are general relationship problems such as communication difficulties, anger or resentment. Alternatively, not being in a current relationship brings its own challenges and anxieties. Occasionally, it may become clear that issues around sex are related to something other than pain, such as relationship difficulties or previous unwanted sexual experiences, necessitating referral to another service such as psychosexual counselling or trauma services.³²

To the best of our knowledge, there is no specific framework for reducing pain-related barriers to sexual activity with individuals with persistent **CPP** other than some studies on provoked pain. Over the last five years, our **CPP** team at a large NHS Trust have developed and tested a clinical intervention model to address difficulties with sexual activity, known as ‘ReConnect’.

Methods

The ReConnect Model

The ReConnect model aims to provide a framework to support patients and clinicians from assessment through to treatment through: 1) development of understanding of biological, psychological and social factors,³³ in the processing and experience of pain,³⁴ 2) identification of targets for treatment by a MDT, 3) self-management interventions specifically based on CBT and mindfulness approaches incorporating therapeutic methods from the sexual therapy field,³⁵ and 4) awareness of the context of an individual’s personal history of sexual experiences, health experiences, relationships and cultural beliefs.³⁶

Figure 1 shows the tripartite ReConnect model for clinicians working with persistent pain patients to improve sexual relationships.

Figure 1: The ReConnect Model

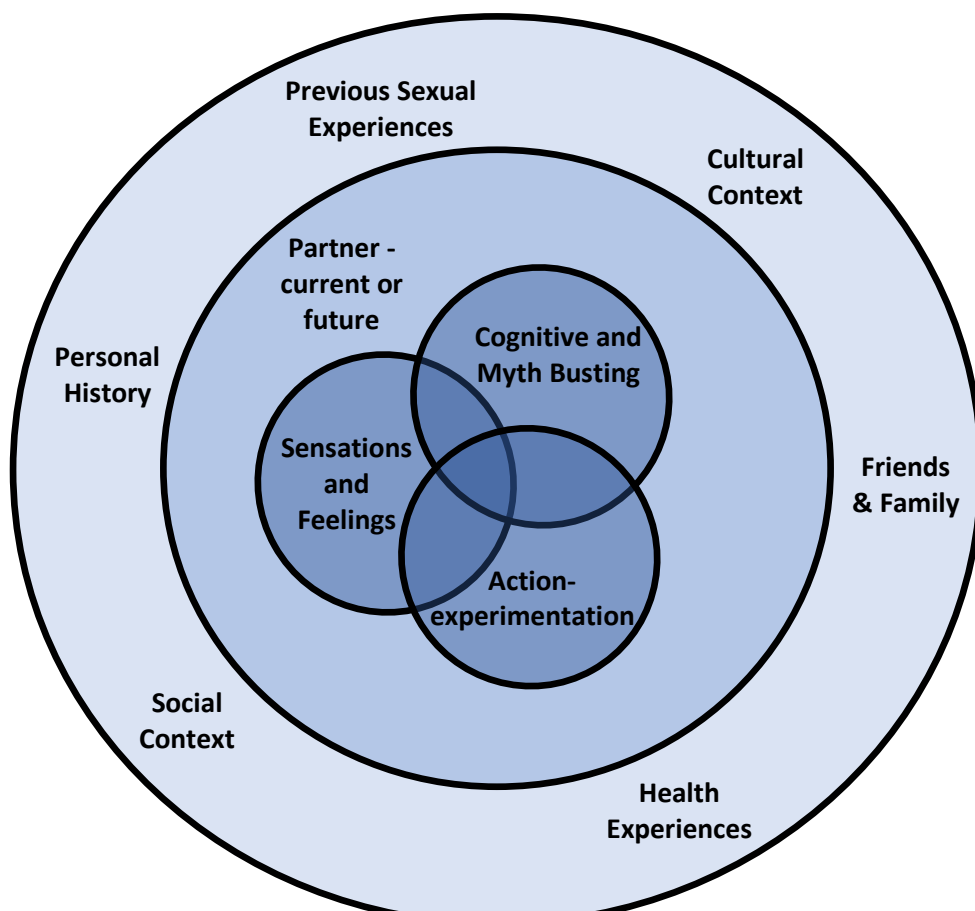


Table 1 shows the treatment components within the ReConnect model. These strategies can be delivered via PMPs or individual sessions as provided by a MDT. The theory behind the components in the table is further elaborated below.

Table 1: Treatment Components of the Reconnect Model.

	Components	Application (Adapt To Psychosocial Context)
Myth Busting and Pain Education	<ul style="list-style-type: none"> • Exploration of common ‘myths’ • Pain Education • Communication 	<ul style="list-style-type: none"> ✓ Invite patients identify and discuss myths about sex reinforced by the media, e.g. people with health problems do not have sex. ✓ Question the accuracy of myths. Provide explanations of pain mechanisms in the context of re-building sexual activity. ✓ Share this information with partners.
Sensations and Feelings	<ul style="list-style-type: none"> • Attentional focus and mindfulness • Sensate Focus 	<ul style="list-style-type: none"> ✓ Develop mindfulness skills help cultivate the ability to refocus the mind purposefully. Encourage patients to practice regularly, not just in intimate contexts. ✓ Support patients to develop awareness of pleasurable sensations and refocus on them when thoughts drift to pain. ✓ Also encourage refocus on pleasurable sensations when patients notices unhelpful thoughts such as concerns that the pain will get worse, worry about what their partner thinks or that intimacy is causing damage. ✓ Educate patients on the steps involved in the sensate focus approach. Emphasise the importance of setting a mutually agreed boundary that defines the extent to which intimacy is comfortable.
Action Experimentation	<ul style="list-style-type: none"> • Avoidance reduction • Desensitisation • Flare up 	<ul style="list-style-type: none"> ✓ Reduce avoidance of intimacy by encouraging patients to plan and prioritise. ✓ Helping patients to transfer previously learned desensitisation skills into an intimacy context. This may involve desensitising painful areas through self-touch prior to being intimate with partner. ✓ Encourage patients to develop a flare-up plan

	management	which contains a range of strategies to help calm the nervous system following a painful activity. This is best used as soon as possible after intimacy.
	• Communication	✓ Support patients who find it difficult to talk about intimacy with their partner to develop communication skills such as talking in a contained space, being assertive, managing emotions, ‘mind-reading’ during communication, and sharing resources.
	• Medication management	✓ For patients who use medication, consider use prior to intimacy and/or included in flare up plan as appropriate.

1. Myth Busting and Pain Education

Hawton’s key text on sex therapy³⁷ highlights societal ‘myths’ about sexual behaviour and how it ‘should’ be approached, such as “sex is for the young and beautiful”, “it should always be spontaneous” or “it is not ‘proper sex’ unless it involves penetration”. Such myths put pressure on those with sexual difficulties and can drive unhelpful cognitions and behaviours. By questioning these myths, the individual is encouraged to explore and develop the conclusion that ‘perfect sex’ does not exist, and increase their awareness of the negative effect which such expectations can have on anxiety and confidence. Such beliefs can be examined to help reduce the feelings of guilt towards a partner, which are prevalent among those with sexual dysfunction due to CPP,¹⁷ and to identify unhelpful thinking styles,³⁸ such as ‘mind-reading’ of the current or future partner. This can then be challenged by open communication within the relationship.

Studies have shown that individualised neurophysiological pain education can help to reduce fear and avoidance and catastrophic thoughts.³⁹ Understanding that pain does not equal harm, and introducing the concept of neural plasticity, can form the basis for introducing a new model of pain management,^{40 13} reducing anxiety about returning to sexual activity, regardless of any underlying pathology or structural problems. This new understanding should then be shared with partners.

2. Sensations and Feelings

It is known that pain, anxiety and focus on unhelpful thoughts about intimacy, diverts attention away from erotic cues, inhibiting arousal.^{41 42} Intervening in this negative feedback

loop involves helping the individual to re-focus attention towards somatic sensations and erotic cues, and to develop more accurate perceptions of arousal. The therapeutic goal is not to reduce anxiety per se but to reinterpret physiological cues such as increasing heart rate as healthy arousal, thus reducing their threat value.⁴³ A purposeful focus on pleasurable sensations, which often compete unsuccessfully for attention with pain, also helps the person to ‘remember’ that sexual activity is a pleasurable experience, something which may have been lost over time. Mindfulness skills are particularly useful in this context and are increasingly used to help rebuild intimacy.^{44 45}

Most patients benefit from noticing and addressing anxiety, hypervigilance and fear, which are known to influence muscle tension.⁴⁶ This is often done in combination with re-training of the pelvic floor’s response to urinary urgency, stress and sexual activity. It could include hands-on intervention from a pelvic floor physiotherapist focusing on self-management strategies, movement with awareness, pelvic floor relaxation and desensitization. The focus shifts from specifically changing the function of the muscle to addressing the way the nervous system responds in situations of perceived threat such as the prospect of penetrative intercourse.

Sensate Focus

Sensate Focus is a well-established step-by-step approach in psychosexual therapy which helps couples or individuals to build up confidence in intimacy.⁴¹

The six stages of intimate contact are the ‘stepping stones’ to regaining a more spontaneous sexual relationship. The initial stages involve touching in non-sexual areas, building up the physical affection which often falters when sexual contact reduces. Further stages gradually build up towards penetrative sex, but this is not necessarily the end goal. Individuals can work through the stages by themselves, using sex aids if they choose, and can involve a partner at any point. Moving on to the next stage can only occur when the individual feels comfortable and relaxed, helping to desensitise the nervous system and increase confidence.

Education about medication is provided so that patients can make sensible medication choices. Group feedback within the PMP is helpful to challenge overuse of medication and the limited utility of opioids for CPP. Whilst side-effects of medications are problematic for all patients, there are certain effects which can specifically exacerbate CPP symptoms. Neuropathic pain medications and opioids will affect desire, arousal and orgasm. Reports of

effects of sexual dysfunction caused by medications range from 25% to 75%²¹ and effects vary between and within drug classes.^{47 48} It can be hard to ascertain whether medication or another factor, such as depression, is affecting sexual function^{49 50} whereas if the patient's mood is lifted by the psychopharmacological agents then their libido may improve. During the medication discussions and throughout the patient journey, patients are made aware that opioid consumption of higher than 120 mg oral equivalent per day⁵¹ can cause amenorrhoea in women, reduced libido in both sexes, erectile dysfunction in men, depression and hyperalgesia.^{52 53 54}

3. Action-Experimentation

Most individuals in MDT pain management settings will already have been exposed to general pain management principles such as gradually building up activity, flare-up plans^{55 56} and clear communication. Furthermore, clinicians can model talking about sexual activity without embarrassment and be frank about sexual activity as part of goal-setting. Therefore, committing to action-experimentation is essential for building up sexual activity.⁵⁷

Desensitisation can be challenging in a sexual context because sex is often viewed as an 'all or nothing' activity. Pain education can assist patient's understanding and choices in the response to the sensation, learning that the nervous system is capable of adaptation. As with other activities, the individual is encouraged to establish their baseline by asking themselves what they are prepared to experiment with as the first step towards their goals. They can start by exploring sensations to touch and notice their response with lubrication, in the shower, using relaxation, using vibrators etc., and/or involving the partner. Each individual will build up at their own pace. Desensitisation can remain a 'physiotherapy exercise' until confidence has reached a point where they can communicate their needs to the partner. Penetration may not be the aim but for many people, re-engaging with their sexuality and physically exploring intimacy can have a big impact on quality of life.

Once individuals are sexually active, helpful practical considerations to aid with building or maintaining intercourse include: experimenting with sexual positions; incorporating heat during or after sex (e.g. electric blanket); planning around the best time of day; and using lubrication (experimentation with more than one brand may be helpful).

Clinical Outcomes

Our team has applied the ReConnect model on our specialist PMP for men and women with CPP known as 'Link'. All patients on the PMP experience persistent pelvic pain, and some also experience persistent abdominal pain. Link is based on the general principles of CBT-based PMP work for individual with chronic pain,⁵⁸ and includes additional sessions on issues particularly pertinent to this group, such as difficulties with sex, bladder and bowel urgency and frequency, managing feelings of embarrassment and shame, and fertility.

Design

Data is from UK patients treated between 2008 and 2017, who attended seven weekly sessions of Link that comprised at least two hours on rebuilding sexual activity using the ReConnect model. The programme also comprised composite sessions on subjects such as Pain Mechanisms, Desensitisation, Medication, Communication and Flare-up Management (see Table 1), which are transferable pain management skills. Self-report questionnaires were completed at the beginning and end of the programme, and at 9-12 month follow-up.

Measures

Sexual functioning was assessed through:

- (1) The Anxiety subscale of the Multi-Dimensional Sexuality Questionnaire⁵⁹. The MSQ comprises five items concerning anxiety about sexual activity rated from 0 ('not at all characteristic of me') to 4 ('very characteristic of me'). Greater anxiety is therefore represented by higher scores
- (2) Questions about the degree of interference of pain during sex, embarrassment, and discomfort during sex, from 0 ('does not interfere at all') to 10 ('completely interferes')
- (3) Questions about avoidance of touch and avoidance of sex, because of embarrassment and discomfort during sex, from 0 ('do not avoid at all') to 10 ('completely avoid').

Analysis

Effect sizes of change during treatment and between baseline and follow-up were calculated as Cohen's *d* separately for men and women. We also compared the MSQ data with that of other clinical and non-clinical populations^{60 61} Data distribution supported the use of a paired samples t-tests for statistical significance of difference for men and women combined, across treatment and between pre-, post- and follow-up. Analysis involved only cases with complete data sets at post-treatment and follow up, so group sizes differ across time.

Results

Participants (Table 2)

92 men and 281 women, mean age 45, attended 37 single-sex programmes. The most common diagnoses were chronic pelvic pain, endometriosis and pudendal neuralgia, with median pain duration of 10 years. 69% based their answers on a current relationship, 20% on a past relationship, and 11% on an imagined relationship.

Table 2: Demographic information of CPP PMP patients ; SD=standard deviation.

Demographics	
Female (n)	281
Male (n)	92
Mean Age (SD)	44.33 (13.21)
Mean Pain Duration (SD)	9.65 (8.41)
Clinical Diagnosis (n):	
Endometriosis	52
Bladder Pain Syndrome	20
Chronic Pelvic Pain	89
Pudendal Neuralgia	34
Prostatitis	7
Vulval Pain Syndrome	11
Miscellaneous	54

Multidimensional Sexuality Questionnaire (MSQ)

Table 3 presents the MSQ results. Overall, all patients ratings of anxiety about sexual activity continued to improve after treatment as shown by lower scores at follow up.

Table 3: Mean MSQ total scores (and standard deviation) with Cohen's *d*.

MSQ	Pre	Post	<i>d</i>	Follow Up	<i>d</i>
Female (n=126)	12.5 (6.3)	10.4 (6.5)	0.34	9.8 (6.8)	0.44
Male (n=55)	10.8 (6.6)	9.51 (6.3)	0.19	8.84 (6.7)	0.30

Questions on Interference and Avoidance

Table 4 shows the mean scores (M) for the questions on interference (embarrassment and sex) and avoidance (touch and sex) for males and females at pre, post- and follow up. In order to correct for multiple tests, the p-value is $p=0.0063$ using the Bonferroni correction.

Table 4: Self-reported scores for interference and avoidance drawn from in-house designed questionnaire.

	<i>Pre</i>		<i>Post</i>		<i>FU</i>		<i>Pre to Post</i>		<i>Pre to FU</i>	
	M	SD	M	SD	M	SD	t	df	t	df
<i>Embarrassment</i>	5.5	3.4	4.3	2.8	4.2	2.8	7.1**	274	7.9**	229
<i>Sex</i>	7.7	2.7	6.8	3	6.4	3.2	6.0**	264	7.1**	217
<i>Interference</i>										
<i>Avoid Touch</i>	3	3.3	2.7	3.1	2.2	3	2.9*	274	4.9**	228
<i>Avoid Sex</i>	7.5	0.2	6.6	3.2	6.1	3.4	6.7**	261	7.2**	214

* $p \leq 0.01$

** $p \leq 0.001$

Clinical Observations

Our experience of using ReConnect revealed benefits for clinicians, who agreed that the model is a highly useful framework for pain management goals about sexual activity.

Increased confidence in treating issues with sex and better awareness of how existing clinical skills can be adapted in this context were reported.

Discussion

We aimed to develop guidance and structure for clinicians working with persistent pain patients on rebuilding sexual activity. Reviews of the literature and the specialist CPP team’s clinical experience produced a multi-dimensional approach, similar to when working with a patient to return to any other valued activity. The results show a significant improvement in patients who have undergone pain management approaches for sexual activity using the ReConnect principles. Men and women report a significant reduction in anxiety about sex at post-treatment, and this continues to improve at follow-up. It is also encouraging that self-reported scores in other related domains such as embarrassment, avoidance of touch or sex and interference significantly reduced.

Clinical Implications

- The ReConnect Model provides a useful framework for a biopsychosocial approach facilitated by multidisciplinary roles which support a holistic assessment, psychological formulation of difficulties, including cognitive and behavioural patterns which may contribute to maintenance of the problem, and identification of treatment targets.
- The framework supports clinicians working in CPP to feel more confident in having conversations around sex with patients, and to apply their existing pain management skill-set to rebuilding sexual activity, just like any therapeutic goal.
- The development of the model was driven by the high prevalence of difficulties with sexual activity in **CPP**. The model is underpinned by theory and evidence in pain management and sexual health with encouraging outcomes. Overall, this highlights a clear need for clinical training, research and application of this model in practice.
- The model can be used with all genders, either within groups or in 1:1 sessions. It can also be applied with individuals of any sexual orientation, with appropriate adjustments.

Intimate relationships as a valued area of life

Having successful close relationships with others is commonly cited by patients as being a key value in life. Difficulties in a romantic relationship due to pain during sexual activity, or the inability to feel confident to start a new relationship, mean that pain has disrupted an important and valued area of that individual's life. This impact is felt by a partner as well as by the individual with pain, for example partners of those with **CPP** report decreased relationship and sexual satisfaction.⁶²

As intimacy in some form is often part of a romantic relationship, working on returning to sexual activity in some form is an important goal for pain management interventions. This work can be done individually, with the clinician modeling and normalising the discussion of sexual activity, paving the way for the patient to have conversations with current or future partners. These conversations can also be rehearsed, role-played and problem-solved in 1:1 or group sessions. Facilitating communication and helping the patient to open up a conversation is a key first step to rebuilding sexual connection, and to reassuring a partner that this is an important issue which is not being ignored. Alternatively, 1:1 sessions can be broadened to include the partner from the outset. Partners as well as individuals with pain are

susceptible to ‘myths’ about sex, to anxiety about why sex has become difficult, and to unhelpful patterns of thinking about their relationship, and these may be helpfully explored.

Limitations

For some individuals, rebuilding sexual activity can be a lengthy task, especially if communication skills, self-confidence and general pain management skills are low initially. This can be problematic when services have clinic constraints. Therefore it is important to consider time between sessions to give the patient time to practice whilst maintaining momentum. Our clinic provides a follow-up at nine months post-PMP which also supports these long-term goals; however this length of follow-up may not fit with clinical practice in some centres.

Additionally, in clinic, there are instances where an individual does not wish to discuss issues of a sexual matter or work on them. Motivational interviewing⁶³ techniques may be helpful in ‘nudging’ the individual towards contemplating change. Even when there is strong indication to offer this approach and sensitively broach the subject, clinicians should use clinical judgement and awareness to be respectful of an individual’s wishes, culture and beliefs.

Alongside this, as with any self-management-based intervention for persistent pain, progress may be hampered or reversed by other health issues, or by ongoing medical interventions such as surgery. Such additional barriers can reduce the individual’s ability to implement changes and to focus on sexual activity as a priority.

It is important to note that the authors of the MSQ have not advised on a clinical cut-off score for the anxiety subscale. The MSQ validation study shows that student populations score five and six for females and males respectively⁵⁹. We can conclude that reductions in MSQ, as well as other scores on our in-house questionnaires, may still remain above a clinical level which is problematic for patients, and therefore show the need to continue working in this way on these issues. It is not uncommon for further significant changes to occur over at least a year.^{64 65} We also acknowledge the statistical bias towards those who attended the full programme and follow-ups, where the completion rate from pre-scores to follow-up was 40% for males and 55% for females. We are aware that some patients who did not find the PMPs beneficial, are seeking treatment elsewhere or have worsened, are less likely to attend

therefore we were less able to represent their scores in the data. The data warrants further exploration alongside analysis of additional domains which is beyond the scope of this article.

Future Directions

To the best of our knowledge, most PMPs do not include any sessions on sexual activity, with the British Pain Society's 2013 guidelines for PMPs for adults not referencing this subject.⁵⁸ However, having sexual activity as a goal for treatment has been shown to lead to greater relationship satisfaction for both members of a couple, for example women with **CPP** who have goals around sex report greater sexual and relationship satisfaction.⁶⁶ A high number of individuals with all types of pain, not just those with **CPP**, experience difficulties with sexual activity.⁴ We suggest that rebuilding sexual activity should be considered as a standard topic for PMPs for all types of pain, rather than only being included in specialist pelvic PMPs such as Link and others.⁶⁷ We also encourage clinicians to explore this as a goal for 1:1 pain psychology and physiotherapy sessions.

Pain measures are routinely used in clinical practice however the literature suggests that sexual activity outcomes are lacking. We encourage the use of sexual activity measurement instruments and further research into such outcomes. Research on which areas of the model individuals find most helpful, so that the model can be refined according to what the key active ingredients are, is a future direction.

Conclusion

In conclusion, this article presents strong clinical reasoning for addressing sexual activity as part of pain management. Many clinicians from multidisciplinary pain teams possess the skills to treat issues with sex due to pain, and we would like to encourage the expansion of such work in all pain services and across pain conditions. This **review** attempts to make progress in building clinician skills in a relatively under-researched area. Helping individuals with persistent pain to move towards rebuilding or maintaining what is a key value in life for many people, that of having an intimate relationship with a partner, is an important goal for pain management work. Initial outcome analysis of the data from application of our clinical skills model on this area, ReConnect, shows that an integrated cognitive, sensory-affective and behavioural model can have a beneficial impact in this area. We hope that using the

model as a basis for interventions will help to build clinician confidence in working with individuals on this area of life.

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References

- ¹ Fall M, Baranowski AP, Elneil S, Engeler D, Hughes J, Messelink EJ, Oberpenning F, Williams ACdeC. EAU guidelines, Chronic Pelvic Pain. *Online referencing* <https://uroweb.org/guideline/chronic-pelvic-pain/> (2016, accessed 10 March 2019)
- ² Latthe P, Latthe M, Say L, et al. WHO systematic review of prevalence of chronic pelvic pain: neglected reproductive health morbidity. *BMC Public Health* 2006; 6: 177.
- ³ Stones RW, Selfe SA, Fransman S, et al. Psychosocial and economic impact of chronic pelvic pain. *Best Pract Res Clin Obstet Gynaecol* 2000; 14(3): 415–431.
- ⁴ Ambler N, Williams AC, Hill P, et al. Sexual difficulties of chronic pain patients. *Clin J Pain* 2001; 17: 138–145.
- ⁵ Aubin S, Berger RE, Heiman JR, et al. The association between sexual function, pain and psychological adaptation of men diagnosed with chronic pelvic pain syndrome type III. *J Sex Med* 2008; 5(3): 657-667.
- ⁶ Savidge C, Slade P, Stewart P, TL. Women’s perspectives on their experiences of chronic pelvic pain and medical care. *J Health Psychol* 1998; 3:103–16.
- ⁷ Hudson N, Culley L, Law C, et al. 'We need to change the mission statement of marriage': biographical disruptions, appraisals and revisions among couples living with endometriosis. *Sociol Health Illn* 2016; 38(5): 721-735.
- ⁸ Zondervan KT, Yudkin PL, Vessey MP et al. The community prevalence of chronic pelvic pain in women and associated illness behaviour. *Br J Gen Pract* 2001; 51: 541–547.
- ⁹ Tripp DA, Nickel JC, Wang Y, Litwin et al. National Institutes of Health Chronic Prostatitis Collaborative Research Networks (NIH-CPCRN) Study Group. Catastrophizing and pain-contingent rest predict patient adjustment in men with chronic prostatitis/chronic pelvic pain syndrome. *J Pain* 2006; 7: 697-708.
- ¹⁰ Wood N, Qureshi A, Mughal F. Positioning, telling and performing a male illness: Chronic prostatitis/ chronic pelvic pain syndrome. *Br J Health Psychol* 2017; 22(4): 904-919.
- ¹¹ Mercer CH., Fenton KA, Johnson, AM, et al. Sexual function problems and help-seeking behaviour in Britain: National Probability Sample Survey. *BMJ* 2003 ; 327 : 426-427.

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- ¹² Bahouq H, Allali HR, Rkain H. Discussing sexual concerns with chronic low back pain patients: barriers and patients expectations. *Clin Rheumatol* 2013; 10: 1487-1492.
- ¹³ Gott M, Galena E, Hinchliff S, et al. 'Opening a can of worms'. GP and practice nurse barriers to talking about sexual health in primary care. *Fam Pract* 2004; 21(5): 528–536.
- ¹⁴ Crombez G, Eccleston C, Van Damme S, et al. Fear-avoidance model of chronic pain: the next generation. *Clin J Pain* 2012; 28: 475-483.
- ¹⁵ Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. 2000 *Pain*; 85(3): 317–332.
- ¹⁶ Sullivan MJL, Bishop SR, Pivik J. The Pain Catastrophizing Scale: Development and validation. *Psychol Assess* 1995; 7: 524–32.
- ¹⁷ Fritzer et al 2013. More than just bad sex: Sexual dysfunction and distress in patients with endometriosis. *Eur J Obstet Gynecol Reprod Biol* 2013; 169(2): 392-6.
- ¹⁸ Payne KA, Binik YM, Amsel R, et al. When sex hurts, anxiety and fear orientation towards pain. *Eur J Pain* 2005; 9: 427-436.
- ¹⁹ Hawton K. Sexual dysfunctions. In: Hawton K, Salkovskis P, Kirk J Clark D. (Eds): *Cognitive Behaviour Therapy for Psychiatric Problems: A practical Guide (Oxford Medical Publications) Paperback*. Oxford: Oxford University Press, 1989, pp 370-405.
- ²⁰ Serretti A, Chiesa A. Treatment-emergent sexual dysfunction related to antidepressants: A meta-analysis. *Jr Clin Psychopharmacol* 2009; 29(3): 259-66.
- ²¹ Higgins, A. Nash, N. Aileen, L. (2010) Antidepressants-associated sexual dysfunction: impact, effects and treatment. *Drug Healthc Patient Saf* 2010; 2: 141-50.
- ²² Komisaruk BR, Whipple B. Functional MRI of the brain during orgasm in women. *Annu Rev Sex Res* 2005; 16: 62–86.
- ²³ Cambitzi, J, Nagaratnam, M. Endometriosis-associated pain syndrome: A nurse-led approach. *Br J Pain* 2013; 7(1): 31-38.
- ²⁴ Daniels JP, Khan KS. Clinical review: Chronic pelvic pain in women. *BMJ* 2010; 341: 772-5.
- ²⁵ Raphael KG, Widom CS, Lange G. Childhood victimization and pain in adulthood: a prospective investigation. *Pain* 2001; 92:283-293.
- ²⁶ Edwards S, Herron KA, Williams De C A. Psychology in Assessment and Management of Pain. In: Messelink B, Baranowski AP, Hughes J (Eds) *Abdominal and Pelvic Pain: From Definition to Best Practice*. Philadelphia: Wolters Kluwer & IASP, 2014, pp 237-245.
- ²⁷ Bergeron S, Khalife S, Glazer HI. Surgical and behavioural treatments for vestibulodynia: Two and one-half year follow-up and predictors of outcome. *Obstet Gynecol* 2008; 111(1): 159-66.
- ²⁸ Bergeron S, Binik YM, Khalife S. A randomized comparison of group cognitive behavioral therapy, surface electromyographic biofeedback, and vestibulectomy in the treatment of dyspareunia resulting from vulvar vestibulitis. *Pain* 2001; 91(3): 297-306.

-
- ²⁹ Masheb RM, Kerns R, Lozano C. A RCT for women with vulvodynia: CBT versus supportive therapy. *Pain* 2009; 141: 31-40.
- ³⁰ Bergeron S, Lord MJ. The integration of pelvi-perineal re-education and cognitive-behavioural therapy in the multidisciplinary treatment of the sexual pain disorders. *Sex Relation Ther* 2003; 18(2): 135-141.
- ³¹ Baranowski AP, Mandeville AL, Edwards S, et al. Male chronic -pelvic pain syndrome and the role of interdisciplinary pain management. *World J Urol* 2013; 31: 779-84.
- ³² Bergeron S, Likes WM, Steben M. Psychosexual aspects of vulvovaginal pain. *Best Pract Res Clin Obstet and Gynaecol* 2014; 28: 991-999.
- ³³ Edwards, Mandeville, Petersen, Herron, Keeling, Merali, McLoughlin. ReConnect: A model for working with persistent pain patients on returning to sexual activity. Poster presented at British Pain Society Annual Scientific Meeting. Glasgow, UK, April 21st – 23rd 2015.
- ³⁴ Bushnell MC, Ceko M, Low LA. Cognitive and emotional control of pain and its disruption in chronic pain. *Nat Rev Neurosci* 2013; 14: 502-11.
- ³⁵ Fruhauf S, Gerger H, Schmidt HM, et al. Efficacy of psychological interventions for sexual dysfunction: A systematic review and meta-analysis. *Arch Sexl Behavr* 2013; 42(6): 915-933.
- ³⁶ Rosenbaum T. An Integrated Mindfulness-based Approach to the Treatment of Women with Sexual Pain and Anxiety: Promoting Autonomy and Mind/Body Connection. *Sex Relation Ther* 2014; 28: 1-2, 20-28.
- ³⁷ Hawton, K. *Sex Therapy: A Practical Guide*. Oxford Medical Publications 1985.
- ³⁸ Beck JS. *Cognitive behavior therapy: Basics and beyond*. 4th ed. NY: Guilford Press, 2011.
- ³⁹ Robinson V, King R, Ryan CG, ‘Pain Neurophysiology Education’ as Part of a Pain Management service Decreases Fear Avoidance and Improves Patient’s Understanding of the Neurophysiology of Chronic Pain at Four Months Follow Up. *Pain Rehab* 2013; 34: 30-33.
- ⁴⁰ Petersen K. A Review of the Physiotherapy Pain Management Strategies in the Management of Chronic Pelvic Pain. *Pain Rehab* 2015; 39: 21-19.
- ⁴¹ Masters WH, Johnson VE. *Human Sexual Inadequacy*. NY: Little, Brown and Company, 1970.
- ⁴² van den Hout JH, Vlaeyen JW, Peters ML, et al. Does failure hurt? The effects of failure feedback on pain report, pain tolerance and pain avoidance. *Eur J Pain*. 2000; 4(4): 335-46.
- ⁴³ Mandeville A. Psychological Intervention in Persistent Pelvic Pain. In Baranowski AP, Abrams P, Fall M. *Urogenital Pain in Clinical Practice*. 1st ed. NY: Informa, 2008, pp 415-425.
- ⁴⁴ Brotto LA, Goldmeier D. Mindfulness interventions for treating sexual dysfunctions: The gentle science of finding focus in a multitask world. *J Sex Med* 2015; 12: 1687-1689.
- ⁴⁵ Dunkley CR, Brotto LA. Psychological Treatments for Provoked Vestibulodynia: Integration of Mindfulness-Based and Cognitive Behavioral Therapies. *J Clin Psychol* 2016; 72(7): 637-650.
- ⁴⁶ Rosenbaum, T. Addressing anxiety in vivo in physiotherapy treatment of women with severe vulvodynia, a clinical approach. *J Sex Marital Ther* 2011; 37: 89-93.

-
- ⁴⁷ Khazaie H, Rezaie L, Payam N, et al. Antidepressant induced sexual dysfunction during treatment with fluoxetine, sertraline and trazodone; a randomized controlled trial. *Gen Hosp Psychiatry* 2015; 37: 40-5.
- ⁴⁸ Rothschild A. (2000) Sexual side effects of antidepressants. *J Clin Psychiatry* 2000; 61(11): 28-36.
- ⁴⁹ Balon R. SSRI- associated sexual dysfunction. *Am J Psychiatry* 2006; 163(9): 1504-9.
- ⁵⁰ Makhoulf A, Kparker A, Niederberger C.(2007) Depression and Erectile Dysfunction. *Urol Clin North Am* 2007; 34: 565-74
- ⁵¹ Royal College of Anaesthetists (2017) Opioids Aware: A resource for patients and healthcare professionals to support prescribing of opioid medicines for pain. Accessed on 4/12/17 <https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware>
- ⁵² Daniell HW: Hypogonadism in men consuming sustained-action oral opioids. *J Pain* 2002; 3: 377-384.
- ⁵³ Daniell HW. Opioid endocrinopathy in women consuming prescribed sustained-action opioids for control of non-malignant pain. *J Pain* 2008; 9: 28-36.
- ⁵⁴ Seyfried O, Hester J. Opioids and the Immune system. *Br J Pain* 2012; 6: 17-24.
- ⁵⁵ McLoughlin R, Brooks S, Petersen K. In: Messelink B, Baranowski AP, Hughes J (eds) *Abdominal and Pelvic Pain: From Definition to Best Practice*. Philadelphia: Wolters Kluwer & IASP, 2014, pp 229.
- ⁵⁶ Herron K. A simple plan for complexity: managing chronic pain patients who regularly attend accident and emergency. *Pain News* 2018; 6(1): 42-43 (C) The British Pain Society.
- ⁵⁷ Behavioural experiments: historical and conceptual underpinnings, Bennett-Levy J, Westbrook D, Fennell M. et al. In: Bennett-Levy J, Butler G, Fennell M et al (eds) *Oxford Guide to Behavioural Experiments in Cognitive Therapy*. NY: Oxford University Press, 2004, pp. 1-20
- ⁵⁸ Guidelines for Pain Management Programmes for Adults. British Pain Society, November 2013. Guidelines for Pain Management Programmes for Adults. British Pain Society, November 2013
- ⁵⁹ Snell W, Fisher T, Waters AS.. The multidimensional sexuality questionnaire: An objective self-report measure of psychological tendencies associated with human sexuality. *Ann Sex Research* 1998; 6(1): 27-55.
- ⁶⁰ Snell, W. E., Jr. (Ed.). (2001). New directions in the psychology of human sexuality: Research and theory. Cape Girardeau, MO: Snell Publications. <http://cstl-cla.semo.edu/snell/books/sexuality/sexuality.htm>.
- ⁶¹ Liao LM, Conway GS, Ismail-Pratt I, et al. Emotional and sexual wellness and quality of life in women with Rokitansky syndrome. *Am J Obstet Gynecol* 2011; 205(2): 117.
- ⁶² Smith KB, Pukall CF, Tripp DA et al. Sexual and Relationship Functioning in Men with Chronic Prostatitis/Chronic Pelvic Pain Syndrome and Their Partners. *Arch Sex Behav* 2007; 36: 301-311.
- ⁶³ Miller WR, Rollnick S. *Motivational Interviewing: Preparing People to Change*. 2nd ed. New York: Guilford press, 2002

⁶⁴ Herron KA, Ferguson A, Edwards, S, et al. The evidence for specialist pain management programs (PMPs): Benchmarking outcomes against meta-analyses. 15th World Congress on Pain, International Association for The Study of Pain (IASP), 6th – 11th October 2014, Buenos Aires, Argentina.

⁶⁵ Edwards S, Williams A. C de C, Brook S, et al. Pelvic pain patients: Outcomes for men and women on multidisciplinary pain management programmes. Annual Scientific Meeting of the British Pain Society, April 2012, Liverpool, UK

⁶⁶ Rosen NO, Dewitte M, Merwin K, et al. Interpersonal goals and well-being in couples coping with genito-pelvic pain. *Arch Sex Behav* 2017; 46(7): 2007-2019

⁶⁷ Twiddy H, Lane N, Chawla R et al. The development and delivery of a female chronic pelvic pain management programme: a specialised interdisciplinary approach. *Br J Pain* 2015; 9(4): 223-240.