Endometriosis can have a major and devastating impact on all aspects of women’s lives and those of their male partners. The data highlight two key dilemmas relating to pain management: pain and intimacy in couples and pain management and parenthood.

1. Pain and Intimacy

For women, dyspareunia results in a difficult choice between abstaining from sex, with resultant feelings of guilt, loss, frustration, disappointment, and/or concerns about risks to relationships, and enduring painful sex to experience desired intimacy and closeness. Pain is sometimes actively selected as other factors — such as desires for intimacy and avoidance of pain - take priority.

"It was the one thing I felt I could do for [partner], do you know what I mean? It was really difficult. And I'd kind of like put on a brave face, but he'd, oh god am I hurting you, am I hurting you? And I was like, no, it wasn't how it should be, you know, it was, oh, oh. And then for two days later I'd be walking around clutching my stomach in agony... it's not fair, it is, you know, for him to go without." (Trisha)

For men, abstention from sex results in feelings of loss, frustration and disappointment, alongside working to understand and accept the situation, whereas engaging in sex frequently results in feelings of guilt. For both women and men, pain can become a learnt, repetitive behaviour, reducing options for action. Pain is, therefore, a problem for both women and men, through its gendered impacts on pain and intimacy in couples, and its contribution to contextual pain management decisions.

Despite the significant impact of dyspareunia on couples’ relationships, few reported discussing their feelings about dyspareunia, sex and intimacy with one another. Furthermore, as other studies (e.g. Butt and Cheila, 2007; Denny, 2004a; Denny, 2004b) have found, few received input from healthcare practitioners or other people outside the relationship, to help them navigate these dilemmas and address symptoms of dyspareunia.

2. Pain Management and Parenthood

Treatments that alleviate pain often prohibit conception: hormonal treatments for endometriosis include contraceptive medication (e.g. oral contraceptive pill, minirea coil and progesteragen) and GnRH analogues; surgical treatments can also pose risks to fertility.

For Yasmin, her endometriosis symptoms had a huge impact on her life, and that of her partner, Zak. In order to cure her pain symptoms, Zak, along with his family and friends, used to try to persuade Yasmin to have a hysterectomy. However, Yasmin knew the hysterectomy might not cure the physical pain and that it would definitely cause her significant ‘emotional pain’ of not being able to have a child. This caused tensions: ‘he wanted me to have a hysterectomy, he’s been begging me for a hysterectomy, he’s been really bad, and I just refused…. we’ve had tense arguments’.

For some couples, endometriosis pain is intrinsically linked with biographical disruption and couples are required to continually re-assess their priorities. This decision making takes place within a context of risk and uncertainty.

References

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