Vulvodynia

A talking therapy for women and their partners who are dealing with persistent vulval pain

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3 July 2010 – **Abstract: This article presents a therapeutic response to women and their partners dealing with persistent vulval pain. Developed in the public sexual health service, this response draws on the writer's experience in nursing and pain management, and includes a psychological model for understanding oneself (Transactional Analysis), somatic trauma therapy, and sex therapy. Cultural and relationship factors are shown to be significant in the genesis, maintenance and relief of pain. Particular therapy options are outlined. Achievement of affect regulation and self efficacy underpin these options. One woman's therapy is summarised.**

Introduction

Vulvodynia was an unfamiliar condition when I began working as a counsellor at Wellington Sexual Health Service (WSHS) in 1997. A couple in their late teens were the first of a steady stream of clients whose story became familiar to me –desperation because of the woman's ongoing pain, and frustration with lack of an effective cure. This first couple had been together for three years, and were disappointed with my offer to explore the impact of pain on each to see if we could relieve it with counselling. Rather they desperately wanted to "do something to get rid of [the pain]". This wish is typical of those faced with incomprehensible persistent pain which "seems like the body turning against itself" (Frank, 2005, p. 291). They were referred to counselling by a WSHS doctor who said he had "done all [he] could do for them". Their efforts and those of the health practitioners had achieved no relief, reflecting the fact that issues of diagnosis and treatment of this condition can be very frustrating for both sufferers and health practitioners (Slowinski, 2001; Lamont et al, 2001).

Literature

Vulvodynia is defined as "a chronic pain syndrome of the vulvar area in the absence of an infectious, dermatological, metabolic, autoimmune or neoplastic process" (IASP, 2007). Between 16% (Lotery et al, 2004) and 20% (NVA, 2003) of women experience chronic vulval pain. St Martin (2009) notes that there are many theories about the cause of vulvodynia, and there is no cure. She provides a valuable report of clinical issues, current medical knowledge, and treatments of vulvodynia which are reflected in my own clinical observations, discoveries and reading of the literature. My contribution to the field is to describe cultural and social factors that I consider significant in the genesis, maintenance and relief of pain for many women, and to articulate aspects of two therapies, somatic trauma therapy and sex therapy, for this client group.

Pain

Damasio (2000, p.74) differentiates between "…pain as such and emotion caused by pain" i.e. the sensation and the affect. To Morris (1991), however, it is a myth to entertain the idea of two pains because the whole person experiences pain, both emotionally and physically. For many clients, vulval pain and emotional pain are two different experiences, while for others pain is solely physical. Acknowledging these differing views, I will consider theories about the neuroanatomy of loss and pain, sensory processing sensitivity, and pain traumatically held in the body with autonomic nervous system activation.

Neuroanatomy, Sensitivity and Loss

There is evidence that we experience and regulate pain – whether social, emotional, or physical pain – through

activity in the same parts of our brain (Beutel, 2006; Bean, 2007). Essentially, the anterior cingulate cortex perceives both our physical and emotional hurt – such as rejection – and the amygdala responds with alarm telling the body to prepare for defensive action (Eisenberger et al, 2003).

Cultural messages encourage people to minimise or deny pain. The pain felt by women with vulvodynia can include feeling rejected, ashamed, perceiving oneself as abnormal or different from other women, and feeling a failure, "not a woman" (Ayling and Ussher, 2008). The evolutionary function of social pain is to keep the individual connected with others to ensure survival: because being alone in pain heightens its intensity. Along with unempathic behaviour, such as being called "high maintenance" by family members or their partner, some women receive – directly or indirectly – messages such as "Harden up"; "It's not that bad". One client described herself as 'frozen' during a smear test. She was immobilised by unbearable pain with speculum insertion, unable to communicate and feeling acutely alone. Her situation was not recognised by the smear taker and this was what seemed most hurtful. Because vulvodynia is such a private, embarrassing and sometimes disabling experience, it can also entail a degree of loss of social contact with friends and workmates.

Other cultural messages about pain are contradictory and exploit pain: "No pain, no gain", "If it doesn't break you it'll make you". Those who endure pain, such as athletes, explorers and individuals who conquer illnesses and physical limitations are admired (Morris, 1991). Contrary to these messages, the important function of pain is to prevent serious injury and help us learn how to keep safe: its function is to "set limits on activity and enforce inactivity and rest" (Melzack and Wall, 1996, p.11) when there is ongoing damage to tissues.

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Unlike St Martin (2009, p.40), I notice characteristics which are typical of many clients. They are often busy, capable, creative and successful in activities they undertake. Since sexual relationships can mirror wider social, cultural and power relations, and are in line with culturally sanctioned values and sex roles, another characteristic of many clients is to prioritise the needs of others. These clients often do not know their own needs, particularly needs for inactivity and rest. My thesis is that these characteristics contribute to an individual's vulnerability to "the genesis of pain through stress-related mechanisms" (Plante and Kamm, 2008, p.513).

Women with vulvodynia have overall increased pain sensitivity (Reed et al, 2004), are hypersensitive to being touched (Pukall et al, 2003; Granot and Lavee, 2005), and many identify that they are highly sensitive in the way they process sensory stimuli (Aron, 1998). Briere (2009) suggests the possibility of a hypersensitive limbic system response, which predisposes individuals to reacting with a traumatic response. For some, a traumatic genital experience has occurred while growing up. The experience has been overwhelming, exceeding the individual's capacity to cope. It has involved being alone, emotionally isolated, and with no opportunity to process the experience with a significant other for the distressing affect to be regulated.

Traumatic pain experience, which includes fear as if the individual's survival is threatened, is stored in implicit memory. The autonomic nervous system's preparation to fight, flee or freeze is triggered by implicit memories of threats to one's safety. The amygdala in the limbic system records intense experiences and hurts as implicit memory. These memories are non-verbal, building a store of learned procedures and behaviours which are triggered and acted on at a pre-conscious level with fear. Autonomic preparation occurs 50 milliseconds after exposure to a stimulus as compared to conscious processing by the cerebral cortex which occurs 500-600 milliseconds after a stimulus (Cozolino, 2007). Traumatic experiences appear to be recorded in implicit memory because the amygdala remains fully functioning under extreme stress – unlike the explicit, verbalised memory system which shuts down (Rothschild, 2000). Under extreme stress the individual's capacity to relate, reason and to learn new material is inhibited. Social engagement fails, and the individual's focus is automatically on self-protection and safety, according to Porges (Dykema, 2006).

These are primary considerations in therapy with individuals who are readily activated, and whose pain persists. When given feedback about their state of activation, clients are initially bewildered. Activating at the prospect of sexual activity with someone they love, a necessary smear test, or social messages from friends or the media encouraging sexual activity, is perplexing.

In summary, vulvodynia can be seen as a complex confluence of sensory processing sensitivity, historical genital or urinary infection or injury, and both historical and contemporary experience of self in relationship with others. These clients' experiences include painful social exclusion and loss of important engagement with another or others. Social pain functions to ensure contact, which is evolutionarily necessary for survival. Furthermore

pain is experienced and expressed in a cultural context. The individual's neuroanatomical sensitivity records persisting vulval pain as a trauma. Accordingly, many clients find themselves caught in autonomic responses to pain in their genital function and sexual issues.

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Therapy options

Some clients arrive at counselling thinking they are "going mad", because successive health practitioners have examined them and assessed them as having nothing wrong. Many have had treatment which "disavows the role of subjectivity in pain" (Grace, 2003, p.45). Some question how their subjective experience could affect the physical problem, and how a physical problem could be resolved or improved in counselling – which they perceive as a treatment for mental or behavioural problems.

Trauma psychotherapy responds to the client who is anxious, fearful and hypervigilant. These responses to factors which might cause pain are themselves important factors in maintaining persistent pain (Payne et al, 2004). This therapy brings implicit memory to explicit conscious memory, making sense of the remembered emotion or sensation (Rothschild, 2000). In this process, the client learns to "apply the brakes" on autonomic responsiveness to calm her frightened self (ibid). It helps her to experience that today's situation is safe and manageable, and that yesterday's harm is not happening now. Once calm, the client can learn new information, new ways of behaving.

Therapy to increase pleasure in the couple's relationship is important. Like Binik et al (2007), I question the validity of using penile-vaginal penetration as a criterion for ultimate treatment success. Many couples have a range of sexual activities – of which sexual intercourse may be one. If penetrative sexual activity is not part of the couple's sexual relationship, this may become a goal. Some want intercourse for the purpose of conceiving. An overall criterion of treatment success could be that provided by Nott (1994), who asserts that women who achieve a greater sense of control over the condition, manage their symptoms more effectively and cope better overall. Learning to manage symptoms such as fearfulness requires curiosity about oneself, and motivation to try new behaviours. Curiosity and motivation can be fostered in the therapy relationship.

De Charms et al (2005) devised research with chronic cancer pain patients in which subjects were able to train themselves to reduce the pain they perceived. Using feedback from images of their anterior cingulate cortex activation, subjects could reduce both activation and pain. I notice that clients who methodically gather data about vulval sensations, or regularly practise a breathing strategy as though "training" themselves, make progress towards achieving goals. Another form of training utilises a vibrator. Zolnoun et al (2008) found that 73% of subjects reported less painful sex with vulval vibration therapy applied to sore spots three days weekly over five months. I recommend that clients systematically try vibration therapy for a period.

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Hypotheses underpinning therapy include:

- Cultural beliefs, including lack of understanding that psychological states can affect pain, contribute to the persistence of vulval pain
- These clients have patterns of unhelpful internal communication and self-experience which contribute to pain
- They have a highly sensitive sensory neuroanatomy
- Trauma psychotherapy can access the body's capacity to regulate pain by working with activated implicit memory of both physical and emotional pain
- A body-oriented therapy relationship can assist development of a client's sense of control over the pain, bring relief, and help the couple develop an intimate sexual relationship

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This therapy involves:

- Building a therapeutic relationship
- "Applying the brakes" on body activation, to learn control of this through self-observation and self-management strategies.
- Utilising a psychological model to understand oneself and relationships with others; to challenge unhelpful feelings, beliefs and actions; to make narrative sense of pain.
- Working with the couple to increase pleasure and develop positive intimacy.

1. Building a therapeutic relationship

Three considerations here are: the effects of empathy; client scepticism about therapy; and the principles underpinning the goals that we negotiate, when pain may not be able to be eliminated.

Bean (2009, p.23) concludes that "when experiencing empathy for another's pain, one's own pain matrix is activated in the brain". This raises the issue of the impact on carers and partners when empathising with someone in pain. However, an empathic therapeutic relationship can provide a sense in the client of her feelings and experiences being shared. This reduces painful loneliness. The helper who attempts to tune in to the sufferer and succeeds well enough engenders soothing. As Lewis et al (2000, p.172) say "People who need regulation often leave therapy sessions feeling calmer, stronger, safer, more able to handle the world. Often they don't know why."

When there is scepticism and curiosity about the usefulness of talking therapy, the issue of the physical and emotional components of pain can be discussed. Some clients would rather deal with *either* physical pain *or* anxiety – as if these are separate parts of the self. The woman and her partner can be invited to reflect about mind and body connectedness. I may encourage each to recall an experience of self-protective responses when they were extremely frightened, to illustrate the body's implicit functioning. Invariably the woman identifies these responses regarding contact with her vulva. Her partner has an opportunity to empathise through the experience of his own split-second responses during an alarming event.

Feeling the client's pressure to get rid of the pain, I may explain that I have no magic wand. Principles that underpin the goals we negotiate are: with self-care experimentation – for example, applying a cold flannel – it is possible to impact positively on sensations in the vulva; through development of an observing self it becomes possible to learn strategies to take charge of body responsiveness; and through effective self-management it is possible to down-regulate fear and pain. The therapeutic relationship provides self-regulating experiences, which the client gradually becomes able to perform for themselves.

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2. "Applying the brakes" on body activation, to learn control of this through self-observation and self-management strategies.

It can be adaptive to focus our attention on the pain (Fuhrmann and Johnson, 2008). However, many clients' unconscious adaptations involve the use of opposite psychological protective mechanisms: denial, avoidance, suppression, dissociation. Cutting pain off from awareness seems to work to a degree. Frustration or desperation when pain breaks through into consciousness with, for example, another attempt at sexual intercourse, can activate the fight, flight or freeze response. Such mechanisms can only provide brief relief.

The role of the therapist is to assist the client to recognise her experience of alarm such as chest constriction, shallow breathing, dissociation. The client's capacity to observe her sensations, feelings, thoughts and actions increases. Using this awareness, the client can undertake home exercises by touching her vulva to locate and scale the intensity of sore spots, noticing their characteristics and duration. Data about pain is gathered over a period. Touching her vulva triggers the implicit memory and affect associated with sensations, but with the woman in control. She is encouraged to use grounding or breathing to stay present in her body, aware of her surroundings. She is invited into mindful dialogue with herself about what she experiences, in an intricate process of learning and integration which creates disparity between past circumstances and experience, and contemporary circumstances and experience. Exercises are concluded with self-care and self-soothing strategies. Many clients find that they have been magnifying the pain, and in fact it is not there all the time.

Some clients are willing to review their stressful busy lives, and consider doing less, to prioritise their needs for self-care and relaxation.

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3. Utilising a psychological model to understand oneself and relationships with others; to challenge unhelpful feelings, beliefs and actions; to make narrative sense of pain.

A psychological model provides language for therapist and client to analyse the individual's self-talk and communication with others. I formulate a hypothesis with the client about her problematic experiences, such as beliefs that she is helpless, is unable to act in a manner to achieve certain goals, or unable to influence her situation. Self-efficacy increases when these beliefs change. Self-efficacy builds on personal competence in other areas of the individual's life. Some clients find that recording details of their emotions, their sense of coping and their stressors, helps to identify if a daily pattern is impacting negatively. Some are challenged to become compassionate towards themselves or their partner.

Many clients want to make sense of their various experiences of pain and relationships. In some cases, clients' mothers have described similar difficulties. They seek to understand "why me?"; "why this (painful condition)?", and what the pain might represent in light of previous life events and decisions made. Broom (1997) supports the provision of psychotherapy for clients who are aware that their emotional life affects their physical condition.

4. Working with the couple to increase pleasure and develop positive intimacy.

Women with vulvodynia have a high incidence of adverse life experiences, including relationship conflict (Plante and Kamm, 2008). I notice that many couples seem to be at a relationship developmental stage of dispute in which challenging differences have emerged (Roughan & Jenkins, 1990). These may be differing needs, with one seeking to be closer emotionally, the other to be independent. The couple's goals may include addressing conflict created by differing desire for sexual contact, and differing preferences for sexual activities.

I teach many couples strategies for gaining or regaining comfort in physical proximity. Strategies may include how to use breathing, grounding or a visualisation. The principle here is to increase the resources that each one has to call on for affect regulation. Some partners are able to take the role of coach, helping the woman to stay in the here-and-now, as she takes charge of activation and as she experiments or practises new skills.

It is important to encourage these couples to pursue pleasurable sensations and activities together. Pleasure and positive emotional bonding increases a sense of wellbeing, and generates the body's endogenous pain regulating capacity. Orgasm increases oxytocin in the blood, which also assists wound healing and helps relieve pain (Park, 2004). Many of these clients find that conflict has distanced them from accessing pleasure in their loving.

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Limitations

In respect of vulvodynia, expectations of quick change are unrealistic. Gaining new experience might take a woman from twelve sessions over one year to many sessions over three or more years. It takes time, not only because vulvodynia has been a persistent problem which requires persistent efforts, but also because the woman might have a busy life, and not make therapy a priority.

Talking therapy does not suit all people. Therapeutic assumptions and proposed interventions are dissonant for some clients. Studies show that there are several factors which contribute to the success or otherwise of therapy. The largest component, 40%, is client-related factors e.g. hope and motivation (Miller et al, 2000). Some women openly dislike the idea of looking at and touching their vulva for tracking and scaling work, or dislike the idea of experimenting with self-care and self-soothing. For some, these ideas raise too much anxiety, difficult feelings such as shame, and are contrary to their need for privacy. A shared belief that the woman "is/has the problem" precludes working with some couples. For others, to think for and about themselves raises anxiety, and seems irrelevant to physical pain. Some keep hoping for medical science to establish a cure.

It can be hard to build trust and a working alliance with some WSHS clients whom I see, because our counselling service has limited resources and sessions may be infrequent. This resource scarcity was one of my reasons for offering a support and education group for women and their partners (Wade, 2000). Participants continued to meet and support each other informally for some time after the group had ended. They established an informative free website which numerous women found helpful, until it expired in 2009. Women who seek therapy in the private sector are able to bypass such limitations.

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"Julie's" therapy

"Julie", a 38 year old heterosexual European New Zealander, manages a business. She complained that when she thought about her genitals or sex she was reminded of pain. She felt "hopeless the pain would ever change", helpless to do anything "against the pain", and frustrated about her situation. She said "having a child is an issue now", and she was not currently in a relationship. She identified herself as "extremely shy", and described a settled, nurtured early family life.

Julie reported two long-term sexual relationships in which she had numerous bladder and vaginal thrush infections accompanied by "hot, burning, taut, tender" pain. She had not had thrush in the last five years. In her first relationship at 23 years, Julie had a termination of pregnancy because her partner refused to support its continuation. Sexual intercourse had become painful following the termination. She felt renewed grief, and thought that the pain might be connected somehow.

Over the years she felt "passed from one doctor to another", until ten years ago a gynaecologist performed a biopsy and a "Fenton's operation to cut out the sore area". She was relieved to hear that she had "non-specific inflammation" of her vulva, and therefore a physical condition. The specialist encouraged her to use a glass dilator. She understood this was to help the skin heal, and prepare her vaginal opening should she want to have sexual intercourse. She found, however, that the burning pain persisted.

Five years ago her second long-term relationship ended around which time she experienced several stressful life events. Two years ago she found herself "crying a lot", and experienced "frightening panic attacks." Her GP prescribed an antidepressant "to help manage the anxiety". During this time Julie visited a dermatologist, who prescribed a low dose tricyclic antidepressant for the vulval nerve pain which she stopped after a year because of "bad side effects," deciding "it didn't work". When she visited the WSHS doctor, she had the spasm in her pelvic floor muscle explained, and was relieved to understand "the psychological aspect of my problem". She was referred to counselling which "…was to be the turning point, although I didn't realise it at the time".

I noted her motivation: she had bought a dildo to see if she could have pain-free penetration; was aware of her emotional life, and curious about herself. I concluded that she had strengths for therapy, that she could persevere with the necessary self-experiments, and sustain herself within the therapeutic contact available at WSHS.

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The therapeutic process

Julie's goal was to have "help to keep on track" with experiments she would undertake to see if she could reduce or relieve pain. Other goals were to "be confident with [using her] pelvic floor muscles"; "to understand [her] experiences [of herself] sexually". She had 21 sessions over two years.

Despite wanting a sexual partner she was avoiding attractive men, ashamed about "having to explain that I can't have sex". We used Transactional Analysis (Berne, 1961) to understand her self-talk, how she felt and behaved when in pain, and how she held back from challenges because of helplessness and hopelessness. Julie expressed appropriate sadness for herself.

We identified that when Julie tensed her torso while talking, she was trying to stop anxiety, feeling "near a threshold" for panic sometimes. She experimented with different breathing and grounding exercises to find a strategy to apply the brakes on this experience and help her relax. A breathing strategy helped her to stay in charge in the here-and-now. She decided to gather data about her vulval sensations, and experimented with self-care and self-soothing. She discovered that intense pain was present for a week after menstruating and that mid-cycle she had no sensations of vulval discomfort.

Unable to stop urinating mid-stream, she wondered if her pelvic floor muscles might be weak. She declined referral to physiotherapy for assessment of this. We worked with a visualisation to increase her internal sensing and control of these muscles in action. She took home reading and exercises to practice conscious control of them.

After reading Aron's (1998) writing about the highly sensitive person, Julie was relieved that "other people are like me". Appreciating her sensitivity, she realised that she needed to take better care of herself, and assertively made changes so her stressful work load became manageable. She made sense of her two previous relationships, realising that these partners "weren't right" for her. She realised she had been too alone during the termination, and in a new relationship she would want someone who would try and understand what she felt: "someone supportive".

With a self-help kit of vaginal trainers (dilators) that she bought on the internet, and a non-irritating lubricant, she worked her way up to the largest trainer. We devised steps for her to reduce fear of the pain by integrating skills in managing body activation, noting vulval sensations, using her pelvic floor muscle awareness, and taking in a vaginal trainer. The trainer increased from digital to erect penis size as she gained confidence. Over time the pain she felt was reduced. She talked about the importance of "patience and persistence", putting the trainers in daily, and ensuring that she felt "ready and relaxed" beforehand. She bought "love balls" (vaginal), and practised wearing these during the day. The pleasure she experienced increased her sexual desire. She voiced satisfaction about these developments, and began to have sex within a trusted and comfortable casual relationship. She was still taking the antidepressant, "scared the anxiety might come back" if she stopped, but after examining her fears about this anxiety she decided to try managing without. She consulted her general practitioner and stopped the medication gradually.

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Unhelpful experiments

Julie bought a dildo early on, which hurt her because it was too big. On reflection she recognised this, and that she had been "slightly ambitious" due to insufficient self-awareness and knowledge. She gained this over time with experiments, coming to understand the importance of sexual arousal. Trying out balms for her vulval skin was of "no help". The lubricant she later discovered prevented friction, and assisted with comfort.

Outcomes

Julie became knowledgeable about the pain she experienced, and gained a sense of control from being able to obtain relief. She became confident about herself sexually. She started a relationship. She described effective communication with her partner, and gave a balanced appraisal of him and the developing relationship. She felt positive about his supportive responses to her. She had pain-free, pleasurable sexual intercourse, and on follow-up a year later said the pain had not returned.

Summary

Earlier recognition of Julie's persistent pain, and an offer of referral to a specialist counsellor or psychotherapist, would have shortened the period of her suffering.

This therapy helped Julie to learn about herself and her relationships, to cope with and relieve persistent vulval pain, and to develop skills in self-efficacy evident in other areas of her life. The outcome was successful because, as the therapeutic relationship developed, she learned to speak about difficult things like the termination, and she could grieve. We were able to instigate some practical measures such as learning a breathing strategy to calm herself when activated. Julie gained psychological understanding of herself. She learned to articulate links between her emotions and her body's responses.

Accompanying the client as she integrated new self-awareness and abilities in self-management provided its own reward. This was both challenging and complex therapy across the disciplines of medical and allied health sciences, dealing with the whole person, her body, pain, trauma, sexuality and relationships.

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Conclusion

This article has outlined an integrated approach utilising sex therapy and somatic trauma therapy, and illustrated its effectiveness with one client. When referring such clients for psychological assistance, health practitioners could consider counsellors and psychotherapists who are trained in working with pain – both physical and emotional. Early referral to psychological therapy is recommended. Also recommended is for this to occur in conjunction with medical interventions. Knowledge of vulvodynia and its treatment continues to develop. The complex nature of this condition requires ongoing research in order to provide women and their partners with timely and effective therapeutic options.

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