

Impact of an integrated mindfulness and cognitive behavioural treatment for provoked vestibulodynia (IMPROVED): a qualitative study

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(Received 12 April 2012; final version received 13 April 2012)

Provoked Vestibulodynia (PVD) is a chronic pain condition involving sharp pain to the vulvar vestibule. Because of compelling outcomes using mindfulness-based approaches in the treatment of chronic pain, we developed and tested a four-session mindfulness and cognitive behavioural therapy tailored to women with PVD (called “IMPROVED”). Here we report on the experiences of 14 women (mean age 39.6 years) following IMPROVED using qualitative analysis. Six major themes emerged that captured women’s narrative stories: (1) feelings of normality and community in the group setting, (2) positive psychological outcomes following IMPROVED, (3) impact of relationship – including the beneficial effect of having a supportive partner and the negative impact of having an uncooperative partner, (4) an appreciation for treatment, including gratitude towards group facilitators, (5) barriers impeding ongoing practice of acquired skills following the completion of IMPROVED and (6) self-efficacy, which included a feeling that pain management was much more under women’s own control than they previously believed. Although the precise mechanisms of action are unknown and quantitative analysis of outcomes is still pending, these data are the first to report on the benefits of a mindfulness-based approach for improving quality of life and reducing genital pain among women with PVD.

Keywords: provoked vestibulodynia; mindfulness; group therapy; genital pain

1. Introduction

Provoked Vestibulodynia (PVD) is a major cause of vulvar pain, otherwise known as vulvodynia, which affects up to 16% of women (Bergeron, Binik, Khalife, & Pagidas, 1997; Friedrich, 1987; Harlow & Stewart, 2003). Provoked Vestibulodynia encompasses sensations of burning, stinging, irritation and rawness in the vulvar vestibule – the area delineated by Hart’s Line on the labia minora and containing the urethral opening and the introitus. The pain is provoked by touch (tampon insertion, sexual penetration, gynecologic examination). Genital pain that occurs spontaneously (i.e., not provoked by touch), is known as generalized or dysesthetic vulvodynia. Affecting women of all ages (Bergeron, Binik, Khalife, Pagidas, & Glazer, 2001; Friedrich, 1987; Landry & Bergeron, 2009), PVD is the most common

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cause of dyspareunia, or pain during sexual intercourse, in pre-menopausal women. Primary or “life-long” PVD is present since the first attempts at tampon insertion or intercourse, whereas secondary or “acquired” PVD begins after a period (often many years) of painless intercourse (or other penetration such as fingers, dildo insertion or other means of confirming absence of pain). Because intercourse hurts or may be impossible, PVD has a markedly negative effect on women’s emotional well-being and their sexually intimate relationships (Connor, Robinson, & Wieling, 2008). The diagnosis of PVD is clinical and based on history of the illness and a physical exam. Though the vestibule appears normal, except for variable erythema similar to what is seen in women without PVD, a cotton swab touch to the vestibule reproduces the pain sensations (Bergeron, Bergeron, Binik, Khalife, Pagidas, & Glazer, 2001).

Although much remains unknown regarding pathophysiology, there is increasing evidence that, similar to other chronic pain syndromes, PVD is associated with dysregulation of central pain circuitry (central sensitization) such that the “volume control” on pain is heightened (Bohm-Starke, 2010; van Lankveld et al., 2010). Central sensitization is defined as an amplification of neural signalling within the central nervous system that elicits pain hypersensitivity. Moreover, a number of other medical and chronic pain conditions are frequently co-morbid with PVD, including interstitial cystitis, irritable bowel syndrome, fibromyalgia and muscle tension syndromes (Peters, Girdler, Carrico, Ibrahim, & Diokno, 2008).

Management of PVD is complex and multiple treatment modalities with varying efficacy are currently available (Landry, Bergeron, Dupuis, & Desrochers, 2008). Treatments include biomedical, psychological, physical and surgical options. Very few randomized controlled trials exist and evidence suggests a marked placebo response compared to oral desipramine and topical lidocaine (Foster et al., 2010). The efficacy for topical formulations of estrogen and lidocaine vary widely between 13 and 67% (van Lankveld et al., 2010). Cognitive-behaviour therapy (CBT) carries an efficacy rate of 35–85%, depending on the endpoint (Bergeron, Binik, Khalife, Pagidas, Glazer, Meana, et al., 2001), has very good long-term effects (Bergeron, Khalife, Glazer, & Binik, 2008) and is more efficacious than topical glucocorticoids at follow-up in terms of pain, sexual functioning, treatment satisfaction and reduced catastrophizing (Bergeron, Khalife, & Dupuis, 2008). Although surgery (i.e., vestibulectomy) appears superior to medications (Haefner et al., 2005; Landry et al., 2008), exclusion criteria for this procedure are numerous and, despite moderate pain relief, resumption of intercourse does not always occur (Tommola, Unkila-Kallio, & Paavonen, 2010). There is evidence that baseline levels of pain is a significant predictor of treatment response, even 2.5 years following treatment, and the more pain women experienced during a gynaecological exam at pre-treatment, the less they benefited from treatment (Bergeron et al., 2008). Clinically, there is evidence that most women with genital pain use at least three different treatments before seeing any pain relief (Sadownik, 2000).

Psychological approaches to pain management have a long history. In the past decade, cognitive-behavioural therapy has been tested in the treatment of chronic pain in a variety of trials (Eccleston, Williams, & Morley, 2009). The use of this approach for PVD is based on the knowledge that chronic genital pain significantly impacts a woman’s psychological, sexual and interpersonal health. Moreover, stress has been found to dysregulate sensitivity to pain (Chapman, Tuckett, & Song, 2008) and to increase one’s vulnerability to developing a pain syndrome (Slade et al., 2007). Cognitive-behaviour therapy is focused on challenging maladaptive pain-related

cognitions, teaching behavioural skills in anxiety reduction and improving affect. Cognitive-behaviour therapy administered in 10 group sessions led to significantly improved psychological adjustment and sexual function and a high rate of treatment satisfaction at 6-months, though only a 30% reduction in pain intensity. Effects were maintained at a 2.5-year assessment (Bergeron et al., 2008). These improvements in pain intensity are mediated by changes in psychological and sexual functioning (ter Kuile & Weijenborg, 2006).

Mindfulness is considered the third wave of cognitive behavioural therapies and is increasingly used together with CBT skills for a variety of psychiatric conditions, especially chronic pain (McCracken, Carson, Eccleston, & Keefe, 2004; Teixeira, 2008; Thompson, & McCracken, 2011). A recent meta-analysis found that mindfulness-based therapies are a good alternative to CBT in the treatment of pain, particularly for those who do not respond to CBT (Veehof, Oskam, Schreurs, & Bohlmeijer, 2011). Mindfulness promotes a state of awareness in which thoughts are allowed to enter consciousness and then are let go without any emotional attachment. It has been described as “uncoupling” of the physical sensation from the emotional and cognitive experience of pain (Kabat-Zinn, 1982). Research suggests that meditation primarily reduces the negative appraisal of pain during its anticipation (Brown & Jones, 2010). Given the documented hypervigilance to pain shown by women with PVD (Granot & Lavee, 2005), mindfulness may be of particular benefit. As well, there is evidence that mindlessness might be a precursor to pain catastrophizing – also characteristic of women with PVD (Schütze, Rees, Preece, & Schutze, 2010; Sutton, Pukall, & Chamberlain, 2009). Moreover, acceptance, a significant component of mindfulness defined as the “willingness to continue to actively experience pain along with related thoughts and feelings” (Thompson & McCracken, 2011) may allow women to accept their emotional response to PVD in a compassionate manner.

Despite strong speculation that mindfulness-based approaches may be especially useful for women with PVD, there are not yet any published data. Here we report on the qualitative experiences of women taking part in group treatment program that integrates mindfulness-principles along with cognitive behavioural therapy. We named this treatment IMPROVED (Integrated Mindfulness for Provoked Vestibulodynia). Although participants were part of a larger randomized trial with primary quantitative endpoints, the goal here was to capture women’s narratives of the impact of this intervention on their life and their genital pain.

2. Materials and methods

2.1. Participants

All women who took part in IMPROVED between November 2008 and June 2009 were eligible to participate in the current study. They were referred to the program by specialists and primary care physicians with a diagnosis of PVD and all were treated in a large metropolitan west coast city. Participation was voluntary and no remuneration was provided. As a result of 22 letters of invitation, 14 women consented to the study and completed the interview (63.6% response rate). We achieved saturation of themes with these 14 participants.

The mean age of the participants was 39.6 years (SD 13.6, range 21–68 years of age) and the mean relationship duration was 7.2 years (SD 8.71) for the nine women who were partnered. Of the 14 women, 9 were of European ancestry and the

remaining women were East Asian. All women had received post-secondary education with two having graduate degrees. Six women had lifelong PVD and eight women had acquired PVD, they ranged in the number of years they had PVD from 2 to 26 years.

2.2. Procedure

The IMPROVED program consisted of four, two-hour sessions, spaced two weeks apart. It consisted of basic education on PVD and pain neurophysiology, CBT skills in identifying problematic thoughts and progressive muscle relaxation and mindfulness exercises including eating meditation, mindfulness of breath, body scan and mindfulness of thoughts. These mindfulness exercises were adapted from those that form part of the mindfulness-based cognitive therapy (MBCT) program for depression developed by Segal, Williams and Teasdale (2002). Although mindfulness skills formed the basis of IMPROVED, it was not a traditional MBCT program given that, in IMPROVED, facilitators discussed the possibility of challenging problematic thoughts as well as described instances in which thoughts might simply be accepted as they are. Thus, IMPROVED was not strictly an “acceptance-based” treatment program but, rather, facilitators discussed instances in which acceptance might be preferable and others in which challenging thoughts might be preferred. IMPROVED also included elements of sex therapy, including a discussion of non-penetrative pleasuring and a description of the circular sexual response cycle as it relates to PVD (Basson, in press). A comprehensive treatment manual that included facilitator and participant handouts was developed by the authors.¹

Interviews were conducted by telephone or in person in a confidential setting, 12–18 months following completion of the 4-session IMPROVED by a trained interviewer not involved in the treatment sessions. Participants were told that the purpose of the interview was to explore how different aspects of their lives – physically, sexually, emotionally and psychologically – have progressed since their participation in IMPROVED. A list of pre-established guideline questions was prepared for the interviews and relevant follow-up questions were asked (Table 1). Opening questions focused on inviting participants to provide narratives of how their lives had been in regards to their PVD. Subsequent open-ended questions then probed attitudes towards themselves and their pain, mood and behaviours. The interview also explored women’s feelings about their sexuality, their pain, their relationships or relationship prospects if they were currently single and feedback on the IMPROVED intervention itself.

The interviews ranged from 18 to 60 minutes in length. Both telephone and in-person interviews were digitally recorded and then manually transcribed. All participants provided written consent and procedures were approved by the University’s Behavioural Research Ethics Board.

2.3. Data analyses

We used the typical analytic framework for qualitative studies described by Marshall and Rossman (1999). Content analyses were used to explore the transcripts by a team of three investigators, two of whom had no contact with the women during the interview process and a third who conducted the interviews but was not involved in any aspect of their treatment. The investigators initially read the interviews

Table 1. Key questions asked during qualitative interviews.

Categories	Sample questions
General questions	Please share your story since you participated in the mindfulness group sessions.
Women's feelings about themselves	How have you been feeling about yourself lately? Have your attitudes or feelings towards yourself changed since your participation in the four sessions? Describe your mood on a day-to-day basis since completing the sessions.
Women's feelings about themselves as a sexual person	Describe your thoughts of yourself as a sexual person. How would you describe your confidence with regards to being sexual?
Women's sexual desire and response	Has your own level of sexual desire changed from the beginning of the sessions until now? Have any of your sexual practices changed?
Women's feelings about their pain now	Has the experience of your pain changed since the beginning of the sessions up until now? What are your attitudes or thoughts about the pain now?
Women's feelings about their sexual relationships (or potential thereof)	(If they mentioned that they were currently sexually active) How do you feel about your current relationship? Emotionally? Sexually? Has the experience of the relationship changed since beginning the sessions? (If they mentioned that they were not currently sexually active) How do you feel about the prospect of engaging in a sexual relationship?
Women's current relationship/partner reactions	How has your partner responded since you participated in the sessions? What was his/her reaction to your therapy?
Women's feelings about the IMPROVED sessions	In general, what was your experience of the group sessions? How did you find the experience of the PVD sessions? Are there skills you learned in group that you have adapted in your own life in some way?

independently and made general impression notes in the margins of the transcript copies. A first meeting of the investigators then took place via teleconference, where they discussed initial reactions and formulated a tentative list of seven themes. With these broad themes in mind, the investigators then divided the transcripts equally, re-read the transcripts and meticulously coded all passages of text that directly corresponded to these themes. Investigators also continued to be attentive to themes that were not apparent upon the first read-through and made note of these additional themes for more exploration. A second meeting allowed investigators to consolidate their work and resolve any discrepancies and resulted in a list of six specific themes with a separate list of subthemes. The investigators then performed a third read-through of the transcripts, selecting specific quotes that exemplified each major theme.

3. Results

Six major themes emerged after in-depth immersion in the transcripts: (1) feelings of normality and community, (2) positive psychological outcomes, (3) impact of relationship, (4) an appreciation for treatment, (5) barriers and (6) self-efficacy.

3.1. *Feelings of normality and community*

A consistent theme emerging across all interviews was women's reports of feeling more normal and less isolated. They recalled feeling they were a part of a community of women with similar if not identical experiences:

I think I derived much benefit from the group sessions. Really just feeling inclusive, valued, not feeling alone, the fact that there are other women who can identify with a similar problem that I've got. (Maya, age 51)

Women shared stories reflecting that the IMPROVED sessions broadened their view of PVD as a condition that can be manifested in manifold ways. They expressed appreciation for the variable course of PVD and its complexity. Interacting with other women who were at different stages of life, of varying ages and who suffered in different ways provided a source of personal healing for them:

I found it...like comforting that I wasn't alone. And it's like...I felt bad because I don't want anybody else to be going through it either, but it was nice to know I wasn't the only one. Because I really felt like I was the only person going through this until the group therapy. So that was...that was helpful. Although I did notice too that...the people in the group, everyone sort of had different levels of it or different...so that was kind of interesting because oh ok, this is how it manifests itself in a lot of different ways...(Patricia, age 30)

Women also noted that improvements they experienced after IMPROVED were not solely focused on reduced genital pain intensity:

So having the sessions and meeting other women – that was the biggest thing. I mean, the training and the information is phenomenal – I mean it's changed my life. But also meeting other women with the same problem – is just huge. Just knowing that there are other women out there all different types of women, and we're all dealing with the same thing. Suddenly you don't feel like "OK, I'm just some freak of nature"...I don't feel damaged anymore, but I do feel complicated. (Irene, age 25)

3.2. *Positive psychological outcomes*

Every participant remarked on some degree of psychological benefit following IMPROVED. Decreased fear and anxiety over PVD was a recurrent theme, allowing women to experience excitement, optimism and hope for the future. A positive outlook for the future was expressed by many:

Extremely positive. It's, I mean, my life two years ago to now is, I mean, almost unrecognizable. I was in such crisis two years ago, and now you know I'm so happy with my life and don't want changes...I don't have any need for change the way I did two years ago. Very very satisfied with the life that I have. (Jessica, age 58)

Further probing revealed certain distinct categories of improvement. Many described improvements in recognizing problematic or irrational thoughts about themselves following IMPROVED, regardless of their degree of pain resolution. Specifically, they noted improvements in self-esteem, self-confidence and an increased sense of optimism:

I don't have the negative tapes going on in my head that I'm a bad person as much anymore. So I think that has helped my positive outlook on myself. So yeah. My self-esteem, my self-awareness I think is better. (Jackie, age 26)

Several also described an improved ability for positive thinking. They were better able to identify and challenge negative thinking and, as a result, reduce their anxiety, moving on to less self-critical thinking and an acceptance that thoughts are just thoughts. Women attributed these improvements directly to the skills practiced during session, including a combination of identifying thoughts as just thoughts, as well as other more change-oriented exercises that involved identifying and gently challenging problematic thoughts. Many also provided stories of improved social and sexual confidence:

So now I haven't seen anybody seriously enough yet to contemplate a sexual relationship, but I think I have more confidence in terms of going out and meeting people and dating, whereas I didn't even have that before. I guess in the last... year-and-half or so... (Claire, age 58)

3.3. *Impact of relationship status*

Women described an influence of their relationships on their benefits with IMPROVED. Those women who self-reported having a supportive, positive relationship at the time of treatment reported a more pronounced improvement in their psychological well-being:

... those were good just for really the purpose of them was to just be really expressive with your partner and um... they were really helpful, and I think provided a lot of help to my husband as well, seeing things progress and having that kind of outlet too... you know... to speak and talk and get intimate in other ways. So that's been really helpful... yeah! (Megan, age 29)

Women who were single at the time, however, generally felt isolated from the women in relationships. As well, they remarked that although they had gained some self-confidence, they still had difficulty embracing new friendships and relationships:

It's a little bit more difficult because I didn't have a partner, and I don't have a partner, and I didn't have one at the time. I think there was maybe one other lady who didn't, so... they talked about more coping mechanisms with their partners and how to overcome that, and it... it would have been nice to have... the other part of it too. If you don't have a partner then... you know... helping us cope with, you know... because these ladies have partners and their partners were aware of their... or have worked with them so are aware of the condition they have. But for us women who don't have partners and are dating somebody or something like that... you know there's a whole other coping thing in that how do you even bring this up and discuss this with somebody. (Claire, age 58)

Women who had unsupportive or indifferent partners at the time of treatment reported negative outcomes. They claimed that they were hurt by their partners' indifferent attitude. They also had ongoing difficulty with intimacy, which added to the burden of their PVD:

It's not our problem together. It's not something we have to work through – it's something I have to work through. And I don't think he means to make it seem like that, but yeah so I think with him always pushing me a little bit, I just kind of close off. So I know that that has affected me, and we've talked about it a little bit, and he really hasn't come to a lot of appointments with me – he hasn't really come with me because it's my issue... my husband didn't engage that process, and I don't know how that would have worked better. (Jackie, age 26)

In addition to relationship factors interacting with outcome, many women noted a positive effect of IMPROVED on their relationships. Those women in relationships appreciated the way that IMPROVED provided for them tools to enhance communication and sexual intimacy with their partners. They expressed that the sessions allowed them to have ways to explain PVD better to their partners, promoting increased understanding from them and increased relationship cohesiveness. The mindfulness skills also allowed them to address the challenges in their relationship, as a result of their PVD, in a more accepting manner:

Participating in the sessions and learning ways of defining what I have and understanding what I have but also dealing with it...was just huge, and feeling comfortable and then being able to bring that information home to my partner and discuss it with him so he has a bigger understanding. So he's not feeling that he's doing something wrong. And just really opening up dialogue – it was just a really invaluable experience. And so since then, things have changed a lot for me. Overall it's been really beneficial and definitely has improved my life but also improved my marriage. (Irene, age 25)

3.4. *Appreciation for therapy*

Many participants expressed, sometimes even out of context, how much they appreciated having the IMPROVED program available to them. The women were not only grateful for the program's existence, they also placed a high value on these group sessions in their lives:

I'm very thankful that the opportunity was even there, because nobody else in my life had answers for me on this one. (Jessica, age 58)

As well as appreciation, there was a subtheme of therapy value. Participants expressed the wish that other women with PVD might access IMPROVED and experience some benefit. They emphasized group processing as being a valuable and necessary component of addressing PVD and they encouraged more widespread marketing of IMPROVED:

You know I think this whole process is really important. And really valuable. And I hope that they continue it. I mean the whole – the whole organization...the whole institute, if you like, of the sexual medicine centre is just so valuable. And there's just so many people that don't know anything about it. (Emma, age 58)

Like women generally receiving treatment for PVD (Sadownik, 2000), many of these women had previously tried a number of treatment modalities that resulted in little or no improvement in their genital pain (and in some cases, it worsened their symptoms). For some women, IMPROVED resulted in a reduction of their pain symptoms, anxiety and an improvement in their quality of life:

I cannot imagine where I would be right now if I hadn't had this training. I was terrified all these years dealing with this that it was going to cost me my marriage. Because I didn't know what was wrong, and I didn't know how to fix it, and it was a major deal, and nothing positive was happening. So I basically looked to this program and the centre as really changing my life for the better, changing my marriage for the better, and giving me all the tools that I need to really move forward. And after 11 years of bouncing around in the health care system, this has just been amazing. (Irene, age 25)

3.5. *Barriers to therapy efficacy*

Despite noted improvements in pain and psychological well-being, several women expressed regret for not maintaining regular practice of the learned skills once the groups had ended. An observed trend throughout the interviews was that, for most participants, practicing the cognitive behavioural and mindfulness exercises peaked during and just after the sessions ended and then waned over time. A small group of participants continued on with regular practice of their learned skills.

Two of the most powerful and prominent barriers that emerged following the end of IMPROVED, which impeded ongoing benefit, were stress and inability to make skill practice a priority:

Well, I've been trying to do the mindfulness practice, and was pretty good with it at the beginning of the time just after I finished the education sessions, but it's kind of deteriorated over time. And I was trying to do some meditation just before I went to bed as well. That was sort of less successful, but sometimes that worked and sometimes it didn't. Sometimes I would do it, and I would still be wide awake and couldn't relax. And other I'd find it really hard to concentrate. So I have to say at this stage that it's completely off the rails. I'm finding it really hard to do the mindfulness practice. There's just been a lot of stress lately, and I think that's just thrown me off course. But I did find it, I think, a valuable strategy to use to try and stop my mind from thinking about things all the time. But the struggle was always there to try and maintain the practice. (Allison, age 51)

Participants described their lives as busy and full of stressors (e.g. moving, relationship stress, pregnancy, other medical co-morbidities) that made finding the time to practice their acquired skills very difficult. These women shared stories of prioritizing items on their to-do lists in place of continued skill practice, as a means of alleviating their anxiety. Because the perception of improvement is not immediately apparent following practice of new skills, and many women desired a “quick fix”, this led to impatience. Mindfulness, however, emphasizes letting go of need for change and posits that it is through self-acceptance, opportunities for change emerge. During the IMPROVED sessions we emphasized the importance of accepting where one is at.

Another barrier to ongoing improvements related to the reported need for ongoing assistance from a professional. Some women depended on this face-to-face reassurance and requested additional “booster sessions” following program completion to enhance accountability to practicing skills. Some women described a sense of guilt for not continuing with their practice and this guilt served to further impede their practice:

There just hasn't been a place where I can find the time or the energy to be healed or to work on it... It feels like one thing after another, so I just have not found, after the sessions, that I've been able to come to a place where there is no stress or I can deal with it. There's always just that one more thing you know? I think my biggest hurdle has been the guilt of not sticking with it, like it's probably my own fault I'm not going to get better. (Jackie, age 26)

3.6. *Self-efficacy*

Despite noted barriers to ongoing practice, all women described an improved sense of self-efficacy, defined here as feelings of empowerment, ability to manage pain and enhanced self-esteem. The women recalled that IMPROVED gave them a sense that

they were able to gain control of their condition as well as other aspects of their lives. The analgesia afforded from the belief that pain can be managed has been recently studied (Wiech et al., 2006). They reported feeling better able to open their lives to new experiences and prospects now, whereas they had no such desire previous to treatment:

Mindfulness strategies and the meditation and all those . . . the relaxation strategies . . . I think those are really practical tools that I could use. So I think in terms of being able to face a future relationship where there is sex then I would have more tools, so that way I feel positive about it. And yeah I guess I'm not as afraid of getting into a relationship as I was before doing the course. Because that was always a big worry – you know, how am I going to talk about this with people and have them understand that it is painful? And so I feel better equipped now. (Allison, age 51)

Self-efficacy also came in the form of self-acceptance – that pain can exist and one can still remain open to intimacy and sex without intercourse. Such self-efficacy then served to lessen the emotional and psychological burden of their disease:

I guess it's almost like accepting that this pain is a part of my life, and now it's not so much as trying to get rid of the pain because I don't think that's ever going to be possible, but sort of learning coping strategy on how to deal with the pain and how to still have a fulfilling sexual life with the pain. (Claire, age 58)

Women described a strong sense of empowerment following the IMPROVED sessions that was cultivated by both the session leaders and other participants around them. They described feeling like they were part of a team and that the sessions enabled them to find strength within themselves to move on with their lives:

I don't feel in the dark as much anymore, again because there are more people who I know share this condition. And I feel definitely more empowered, like I can do this, like I can cope with this. There was a lot of despair I think, initially, where I had been actually crying a bit and just not knowing how to deal with this, and the future looked quite bleak. And I didn't think, you know there was going to be much happiness because I was dealing with this pain, and now it's – I can see that there are tools that I can use to cope with it, that I can move on. (Kate, age 30)

4. Discussion

Provoked Vestibulodynia continues to be a pervasive disease that affects women of all ages and backgrounds and our open-ended interviews allowed them to share their thoughts on its physical, psychosocial and sexual impact. This is also the first report of qualitative outcomes following a treatment that integrated mindfulness along with CBT skills for women with PVD. The theme of normalization was evident: women described a sense of relief in learning that they were not alone in their suffering and they directly credited this normalization to some of their subsequent improvements. Past research has shown a similar normalizing effect when women with PVD attended group psycho-educational sessions (Sadownik, Seal, & Brotto, 2012). The IMPROVED group became a solution for these women after sometimes months of frustration due to misdiagnosis, misunderstanding, unsuccessful medical treatments or, worse, disbelief of their symptoms on the part of care providers. Because the sessions allowed women to meet others with the same stresses, symptoms and consequences, it encouraged them to explore together ways of coping. When they

were informed that PVD is a real, highly prevalent but complex condition involving mind and body they were able to be open to psychological approaches, including acceptance, without succumbing to the insinuation that their pain symptoms were somehow a result of their psychological make-up.

Previous studies have alluded to the frustration of the women with PVD because physical examination of the vulva reveals no signs of abnormality (Friedrich, 1987; Connor et al., 2008). Often seeing many different physician specialists (Eccleston et al., 2009), women report having to advocate for themselves that their pain condition is real and significant: most then receive three or more marginally effective treatment modalities. This sense of frustration and anxiety was highly evident in our interviews and women noted a reduction in these symptoms as a function of receiving information based on recent neuroscientific studies. In this way, it is likely that the purely educational components of IMPROVED led to some improvement in symptoms for these women. This mirrors what has been found previously, in that education alone can improve aspects of sexual functioning for women with PVD (Brotto, Sadownik, & Thomson, 2010).

Previous studies comparing PVD treatments have shown that CBT is 35–85% efficacious for reducing vestibular pain, depending on the endpoint measured (Bergeron, Binik, Khalife, Pagidas, Glazer, Meana, et al., 2001). Our participants receiving IMPROVED noted a meaningful reduction in genital pain as well as lessening of the associated distress, although quantification of these improvements is yet to be undertaken. In analyzing women's qualitative stories, it is evident that for some women, benefit may have been a direct result of their addressing negative thoughts and attempting to gently challenge these thoughts and replace them with more rationale ways of thinking. However, it is also important to note that for some women, their narratives focused more on the mindfulness skills they developed and it is possible that cultivating acceptance of their pain symptoms, viewing their maladaptive thoughts simply as “mental events” and “lessening the grip” on their negative affect may have contributed to their improvements in pain and quality of life. The latter explanation corresponds with other studies showing that practicing mindfulness allows for actual pain relief as well as benefit on emotional and functional aspects of pain conditions (Grant & Rainville, 2009). Provoked Vestibulodynia has a deleterious impact on a woman's physical quality of life, but also on her psychological well-being, which interacts with her physical health to influence overall quality of life. Women diagnosed with PVD, in general experience high degrees of general anxiety and are more prone to negative self-image (Basson & Weijmar Schultz, 2007; Brotto, Basson, & Gehring, 2003; van Lankveld et al., 2010). The experience of living with PVD only compounds these difficulties. It is known that women with PVD may be more anxious, emotional and analytical than their non-PVD counterparts (Sutton et al., 2009). Psychological factors including personality profiles are currently acknowledged to be potential stressors (Diatchenko, Nackley, Slade, Fillingim, & Maixner, 2006). One mechanism by which the mindfulness skills practiced within IMPROVED may have benefited women is by reducing stress – a common outcome of mindfulness with other chronic conditions, including anxiety and chronic pain from fibromyalgia or cancer (Grossman, Niemann, Schmidt, & Walach, 2004). Because of their negatively-skewed psychological profile, women's positive response to IMPROVED on so many levels highlights its importance to their care. Following their treatment, women regained a significant level of confidence and mental

well-being and many attributed this directly to the sessions as opposed to simply being due to the passage of time.

Somewhat independent of their pain relief, all participants noted the marked benefits from experiencing a sense of community and support with other PVD sufferers. It is possible that these non-specific therapeutic factors (i.e., experiencing support and community) may have also contributed to improvements in symptoms found in previous studies that found benefits from education alone (Brotto et al., 2010). Indeed, there is also evidence that providing support can be efficacious for chronic genital pain (Davis & Hutchison, 1999).

Despite improvements, women also described barriers to continued skill practice, namely time-constraints, confounding social factors and misgivings about less-than-perfect practice. This feedback is important to potentially improve treatment – increased discussion of barriers to continued practice during the sessions or post-sessions may be the key to improving compliance. The duration of treatment needed for continued benefit is also unclear. While there is evidence that improved mindfulness can take place even after only three 20-minute mindfulness training sessions (Zeidan, Gordon, Merchant, & Goolkasian, 2010), other research suggests that thousands of hours of mindfulness practice are required to produce and maintain changes in brain processing (Grant & Rainville, 2009). Our IMPROVED involved four, two-hour sessions and approximately 3–4 hours of weekly at-home practice. It is important to note that this is considerably less than established MBCT treatments and mindfulness-based stress reduction (Kabat-Zinn, 1982), which is built upon eight sessions and at least 45 minutes of daily mindfulness practice. Because women expressed guilt over their compliance with ongoing home practice, it is important that therapists encouraging the practice of mindfulness balance messages about the importance of practice along with validating women's tendency to experience guilt over insufficient practice, because such guilt engenders further negative affect and avoidance of practice. Because mindfulness deliberately cultivates acceptance, avoidance and/or struggles with practice are accepted non-judgmentally and there is an opportunity for curiously exploring what the resistance involves.

A major goal of IMPROVED was to identify women's beliefs that they had no control over their genital pain and to instill hope that they could play an active role in coping with and eventually reducing their pain. This is otherwise known as "self-efficacy". We identified increased self-efficacy about pain as a major theme in women's narratives and this variable has previously been found to be a strong predictor of improved outcomes following treatment of PVD (Desrochers, Bergeron, Khalife, Dupuis, & Jodoin, 2009) and correlates with increased pain tolerance and reduced pain-avoiding behaviour. Stories of improved self-efficacy were evident in our sample, suggesting that this may have played a role in mediating the other self-reported improvements in mood, relationship and, ultimately, pain.

IMPROVED involved an integration of mindfulness skills along with aspects of CBT. Although the primary focus during groups was on the acknowledgement and observation of problematic thoughts (e.g. "when my partner touches my back, this means he wants sex and I need to avoid this at all cost") and the practice of mindfully accepting such thoughts as mental events, the IMPROVED group also discussed situations in which it may be useful for the woman to attempt to challenge problematic thoughts. For example, using the above example, the group would have allowed the woman to recognize this simply as a thought, and then either accept it as

a “mental event” or to challenge the thought as being irrational. While the change-oriented nature of CBT and the acceptance of current reality-based nature of mindfulness practice may appear to be at odds with one another (Fennell & Segal, 2011), mindfulness and CBT actually complement one another as they provide options for women for how to cope with problematic and distressing PVD-related thoughts. Importantly, it may be that only once one is able to identify a thought as being problematic (through mindfulness) that one is then able to challenge it (through CBT).

Although IMPROVED was delivered to women alone, the nature of the condition and the contents of our sessions inevitably involved women’s partners. Those women who had supportive partners reported better relationship outcomes than participants with less involved partners. Participants expressed their wish for partners to have better understood their situation and to have been more involved and interested in their sessions. Thus, sharing some of the session material and practices with their partners may have heightened partners’ understanding of PVD. Some un-partnered women in our sample expressed that they felt divided from the women in relationships. Although they were grateful for the acquisition of new skills, they still felt isolated from some of the relationship-directed education. They also expressed ongoing fears about starting a new relationship in light of their PVD and concerns about how to tell a new partner. In individual sessions, a mindfulness-based approach may have encouraged women to view these concerns as “mental events” and to non-judgmentally remain in the present moment. The potential danger in worrying about future relationships and the impact of this stress on pain and psychological well-being is an important aspect of mindfulness-based guidance in individual therapy.

Our use of qualitative methodology to explore women’s lived experiences after participating in a mindfulness and CBT group offers a richness not typically afforded by traditional quantitative methodologies. Questionnaires may not have captured the subtle themes identified, including the importance of the women meeting other women with the same symptoms, or the importance of the reassurance that she is not suffering alone, or the importance of learning with other women that she is not responsible for the creation of her pain and is not fabricating or exaggerating her pain. Feedback about IMPROVED that was gathered qualitatively may then be used to directly improve the program to enhance its usefulness for future PVD sufferers. Indeed, there is evidence of the importance of qualitative methods in other domains of sexuality research given that quantitative methods often offer only a narrow perspective on one’s experience (Tolman & Szalacha, 1999).

There are limitations to this study that must be acknowledged. IMPROVED involved only four sessions and it is possible that effects may have been different with a longer treatment program, such as MBCT for depression, which involved eight weekly sessions (Segal et al. 2002). However, there is evidence for the acquisition of mindfulness skills after even only three brief sessions (Zeidan et al., 2010) and other evidence showing the significant improvement in sexual symptoms after a similar four-session intervention (Brotto et al., 2012). Our sample size was also limited to the 14 of 22 women who participated in interviews, thus our themes may not necessarily be generalizable to the larger population of women with PVD. Finally, despite all of the advantages afforded with qualitative methods, it must be recognized that it provides only a retrospective snapshot of a relatively dynamic experience of recovery in the context of genital pain.

Conclusion

Overall, this qualitative analysis supported the utility and benefits of a mindfulness-based CBT intervention for women with PVD. The strong endorsement of the group setting may guide other clinicians to create similar programs. Recognition that in this study relationship status impacted overall treatment satisfaction as well as pain relief highlights the need for initial relationship counselling for some women prior to beginning group therapy for pain. Future modifications to our IMPROVED protocol will increase the focus on single women with PVD as well as on barriers to continued practice. As well, we will continue to encourage the woman's sense of self-efficacy, her understanding of her condition and the dialogue between the women telling of their own unique experience of PVD. The need to persist with mindfulness practice was evident and suggests that future treatments might emphasize the importance of ongoing practice in order to sustain benefits.

Note

1. The treatment manual is available from the first author upon request.

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