Treatment seeking for vulvodynia and vaginismus: A systematic review

Kathy Bond
Faculty of Health Science
University of Sydney
Australia
kbon3355@uni.sydney.edu.au

Elias Mpofu
Faculty of Health Science
University of Sydney
Australia

Patricia Weerakoon
Faculty of Health Science
University of Sydney
Australia

Russell Shuttleworth
Faculty of Health Science
University of Sydney
Australia

ABSTRACT
This systematic review synthesises the current literature regarding treatment seeking decisions in women with vulvodynia and vaginismus. A database search was conducted to identify literature of interest, including both qualitative and quantitative research. Of the 555 related articles, nine were deemed eligible. Findings suggest that treatment seeking can be a protracted process that has significant implications for women with vulvodynia and vaginismus. The women’s attitudes, perceptions and distress levels impact treatment seeking, with relationship factors and self-concept affecting motivation for treatment seeking. Knowing what motivates treatment seeking could improve the rates of diagnosis and successful treatment, thus improving the quality of life for women with vulvodynia and vaginismus.

Keywords: dyspareunia; health behaviours; sexual dysfunction; treatment seeking; vaginismus; vulvodynia
Healthy sexual functioning is important to well-being (World Association for Sexual Health, 2008) and therefore conditions that interfere with sexual functioning can have a significant negative impact on health and well-being (Gallicchio et al., 2007; Laumann et al., 2006; Laumann, Paik, & Rosen, 1999; Leiblum, Koochaki, Rodenberg, Barton, & Rosen, 2006; Santosa et al., 2011; Santtila et al., 2007). Vulvodynia and vaginismus are genital pain conditions that impact sexual functioning (Haefner, 2007). Vulvodynia is defined as “vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable, neurologic disorder” (Haefner, 2007, p. 49). Vaginismus is defined as recurrent or persistent involuntary spasm of the vagina’s musculature making intercourse painful or even impossible, despite the woman’s expressed wish for penetration. It can be defined as lifelong, where the woman has never been able to experience comfortable intercourse, or acquired, where she has had comfortable intercourse in the past but can no longer do so (American Psychiatric Association, 1994).

Treatment for vulvodynia includes pharmacological treatments to address neuropathic pain and inflammation; surgery to remove the affected vulvar tissue; physiotherapy and biofeedback to address dysfunctional pelvic floor muscles; and cognitive behavioural treatments and psychoeducation to reduce pain and improve sexual/relationship function (Bergeron et al., 2008; Fischer, 2004; Glazer, Rodke, Swencionis, Hertz, & Young, 1995; Weijmar Schultz et al., 2005). Current treatments for vaginismus consist of pelvic floor physiotherapy, pharmacology, general psychotherapy and sex/cognitive behavioural therapy (Lahaie, Boyer, Amsel, Khalife, & Binik, 2010). It is likely that there are a multitude of factors that influence treatment seeking for vulvodynia and vaginismus; however, the literature is largely silent about the topic.

Given the paucity of research regarding treatment seeking for vulvodynia and vaginismus, current health behaviour models may be helpful in understanding treatment seeking for vulvodynia and vaginismus. Health behaviour models are used to organise and understand health related behaviours, including treatment seeking. One such model, the Common Sense Representations of Illness Model (CSM), posits that the perceptions a person holds about the condition and their perceived control over the outcome of the condition influences their health related behaviours (Diefenbach & Leventhal, 1996). Donaldson and Meana’s (2011) research into the experience of dyspareunia supports this model’s use in vulvodynia and vaginismus. They posit that at the onset of pain women attempt to identify the problem and search for causal attributes, which lead to an attempt to control the pain. The impact and consequences of the pain, along with the barriers and incentives, interplay to influence the decision to seek treatment.

Once a woman decides to seek treatment for genital pain, the journey to diagnosis
and treatment for vulvodynia and vaginismus can be complex, complicated, and protracted, which has implications for sexual functioning and general well-being (Basson, 2005; Buchan, Munday, Ravenhill, Wiggs, & Brooks, 2007). It is important to understand the treatment seeking process and to identify the factors that render treatment seeking difficult.

This systematic review synthesises the current literature regarding treatment seeking decisions/behaviours in women with vulvodynia and vaginismus. It explores the rates of and the influences on treatment seeking, as well as exploring the experience of treatment seeking.

**METHODS**

This article forms part of a larger qualitative research study investigating treatment seeking for vulvodynia and vaginismus. It utilises constructivist grounded theory methodology. The choice of methods for this systematic literature review reflects the purpose of the review (Petticrew & Roberts, 2008c). This literature review was interested in answering the question, “What is known, to date, about professional treatment seeking for vulvodynia and vaginismus?”, and therefore the following methods were employed.

**Selection criteria**

Both qualitative and quantitative studies were included in this systematic review to increase the variety of information gathered. Studies were included if they explored treatment seeking for vulvodynia and/or vaginismus or if they presented specific data about vulvodynia and/or vaginismus, in addition to other sexual dysfunctions. Articles were excluded if they were not in English or did not gather data on formal treatment seeking, that is treatment/information from a health professional (i.e., doctor, nurse, allied health professional).

**Literature search and search period**

Medical Subject Heading (MeSH) terms and text words for genital pain, vulvodynia, vaginismus, dyspareunia and female sexual dysfunction were combined with MeSH terms and text words for treatment seeking, health care seeking behaviour, help seeking behaviour, treatment barriers, primary health care and patient acceptance of health care. Searches were carried out in the Cumulative Index to Nursing and Allied Health Literature (CINAHL), (1981-3rd week November 2011), Psychological Information Database (PsychINFO), (1806-3rd week November 2011) and Medical Literature Analysis and Retrieval System on Line (Medline) (1950-3rd week November 2011). Additionally, a Boolean search was conducted using the website boolify.org (11 October 2010). The reference lists of included articles were also
reviewed for additional studies; however, this yielded no new articles. The titles and abstracts were screened and then excluded if they did not fit the selection criteria. Studies that appeared to include relevant data or information were retrieved and their full text versions were analysed for eligibility.

**Data extraction and synthesis of findings**

Each article was read at least three times by the first author to ensure no important data was overlooked. Data extraction was performed using a data extraction form developed by the first author utilising information from several sources (National Health Service Centre for Reviews and Dissemination 2001; Petticrew & Roberts, 2008b). Appendices A and B contain copies of the data extraction tools and can be visited on the New Voices website at http://www.newvoicesinpsychology.co.za/. Study findings were tabulated, study quality was assessed and the information was synthesised by the first author. The remaining authors provided editorial assistance and guidance. Although great care was taken to reduce bias, the fact that all data extraction and synthesis was carried out by one author is a limitation of this review.

**RESULTS**

The initial database search yielded a total of 555 citations (see Table 1). Of these 504 were deemed ineligible after review of the title and abstract. Of the remaining 51 articles, 42 were excluded after full text analysis because they focused on diagnosis and treatment of vulvodynia and/or vaginismus (n=15), treatment efficacy (n=2), prevalence (n=2), treatment compliance (n=1), the experience of having vulvodynia and/or vaginismus (n=1), did not include data on vulvodynia and/or vaginismus (n=3), did not include formal treatment seeking (n=1), and included vulvodynia and/or vaginismus but did not differentiate from other female sexual dysfunctions when reporting the results (n=17). This process yielded nine studies; four were qualitative (Buchan et al., 2007; Connor, Robinson, & Wieling, 2008; Donaldson & Meana, 2011; Marriott & Thompson, 2008) and five quantitative (Danielsson, Sjöberg, Stenlund, & Wikman, 2003; Evangelia et al., 2010; Harlow & Stewart, 2003; Ogden & Ward, 1995; Reissing, 2012). See Appendix A for a summary of the included articles (The appendix is available on the New Voices website).
Table 1: Search results and identification of relevant literature

<table>
<thead>
<tr>
<th>Name of Database</th>
<th>CINAHL</th>
<th>PsychINFO</th>
<th>Medline</th>
<th>Boolean search via boolify.org</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of articles</td>
<td>37</td>
<td>19</td>
<td>412</td>
<td>87</td>
</tr>
<tr>
<td>Total Number of articles yielded from database search</td>
<td>555</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of articles exclude after review of title and abstract</td>
<td>504</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reason for exclusion
- About etiology and symptoms \( (n=32) \)
- About diagnosis and treatment \( (n=55) \)
- Investigating partners of women with vulvodynia and/or vaginismus \( (n=1) \)
- Prevalence study \( (n=2) \)
- Related to male sexual dysfunction or illness related sexual problem \( (n=334) \)
- Explores Barriers for health professionals \( (n=3) \)
- Not a study \( (n=23) \)
- Duplicate articles \( (n=54) \)

Total number of articles remaining after title and abstract review | 51 |

Number of articles excluded after full text analysis | 42 |

Reason for exclusion
- About Diagnosis and treatment \( (n= 15) \)
- Investigating Treatment efficacy \( (n=2) \)
- Prevalence study \( (n= 2) \)
- Investigating Treatment compliance \( (n=1) \)
- Not vulvodynia and/or vaginismus \( (n= 3) \)
- About experience of having vulvodynia and/or vaginismus \( (n=1) \)
- Does not include information about professional treatment seeking \( (n= 1) \)
- Does not differentiate between vulvodynia and/or vaginismus and other sexual dysfunctions \( (n=17) \)

Total number of articles included in this review | 9 |
Qualitative studies

Four studies investigated genital pain and treatment seeking qualitatively (Buchan et al., 2007; Connor et al., 2008; Donaldson & Meana, 2011; Marriott & Thompson, 2008). All four studies utilised in-depth, semi-structured interviews. Sampling in all of these studies constituted a limitation. Three studies recruited from very specific populations – vulvar pain clinics/private practitioners (Buchan et al., 2007; Marriott & Thompson, 2008), and the fourth, from a university (Donaldson & Meana, 2011). All four study populations were homogenous, being educated, mostly white and middle class. Furthermore, Donaldson and Meana’s (2011) participants were all young, with a mean age of 19.

Buchan et al. (2007) aimed to evaluate the women’s experience of accessing treatment for vulvodynia. They recruited patients (past or present) from a vulvodynia treatment programme. Twenty-nine women agreed to participate and they ranged in age from 22 to 58. The data indicated that the journey to diagnosis took a mean time of 24 months and women consulted up to 15 physicians prior to diagnosis. The delay to diagnosis led to distress, low self-esteem, altered self-image and emotional problems including low mood, stress and clinical depression requiring medication. Many had not talked about their pain with anyone, including their partner, and this lead to feelings of abnormality, isolation, failure, shame and embarrassment. When women finally received a diagnosis, the majority felt relief and a sense of validation. Furthermore, most felt the diagnosis was the first step towards acceptance and commitment to managing the condition.

The study conducted by Connor et al. (2008) explored women’s experience of vulvodynia, which included the process of treatment seeking. Thirteen heterosexual couples and three heterosexual women (29 respondents in total) were recruited through medical clinics, and the National Vulvodynia Association (NVA) website and member list. The women reported having to be strong advocates for themselves in their search for diagnosis and effective treatment. They saw multiple practitioners before receiving a diagnosis and effective treatment and many reported exasperation at the lack of medical consensus about vulvodynia. They spoke of long lists of medication/treatments and five women experienced serious side effects, which affected their willingness to try new treatments. All but two participants were satisfied with their level of care.

Donaldson and Meana (2011) studied the experience of treatment seeking and coping strategies for dyspareunia, and the impact on self-concept and the sexual relationship. They recruited 14 university students. In addition to in-depth, semi-structured interviews they also utilised the Female Sexual Function Index (FSFI), a validated screening tool for sexual dysfunctions that solicits information about sexual problems experienced during the last four weeks. Only five of fourteen (36%) of the participants reported seeking treatment for their pain. Reasons cited for not
seeking treatment included a belief that the pain might spontaneously disappear, doubt that medical assistance will help, belief that there is not a cure, fear of the severity of the condition, not wanting to admit to having had sex, fear of stigma of having a sexual problem, or belief that it is not a medical problem. Inability to identify the cause of the pain and embarrassment also prevented them from seeking treatment. When the pain worsened, was unrelenting, or when it began to impact their relationships, the women were more likely to seek treatment.

Marriott and Thompson (2008) explored the meaning women make of their vulvar pain, of being treated for vulvar pain, and the impact of pain on their relationships. The authors recruited eight Caucasian women, between the ages of 18 and 41 (mean age 27), through a vulvar pain clinic. Many of the participants felt uncertainty surrounding the diagnosis and felt that their symptoms had been minimised and misunderstood. Many of the participants expressed disappointment that no organic cause for their pain could be found. This lack of an organic diagnosis suggested to them that a psychological cause may be behind the pain, which led to feelings of distress and shame.

Quantitative studies

Five studies explored treatment seeking for vulvodynia and/or vaginismus quantitatively (Danielsson et al., 2003; Evangelia et al., 2010; Harlow & Stewart, 2003; Ogden & Ward, 1995; Reissing, 2012). Specifically, they examined aspects of sexual concerns, pain experiences and satisfaction of health care. Danielsson et al. (2003) investigated the prevalence and incidence of prolonged dyspareunia (defined as greater than six months), the rate of recovery and the inclination to seek medical care. The authors surveyed 3150 Swedish women from a national cervical cancer screening programme. They found that only 39 % of the women with prolonged dyspareunia had consulted a physician and/or a midwife and that only 4 % had consulted another health professional such as a psychologist or counsellor. Although recruited from the general population, women with dyspareunia who had sought treatment for their pain may have had their cervical screen through their treating doctor; thus, they may not have participated in the national cervical screening programme.

Evangelia et al. (2010) assessed the influence of bother about sexual concerns on treatment seeking. The study participants were men and women between the ages of 18 and 80 who were hospital inpatients. Of the 415 participants, 52 % were women and of those women 21.5 % experienced pain during intercourse. Following stepwise backward regression, pain was positively associated with willingness to seek treatment, not actual treatment seeking in women with pain. Several limitations exist, treatment seeking for vulvodynia and/or vaginismus was not the researchers’ main aim. Furthermore, because they recruited from a hospital population the results may not represent the general population. Participants in hospital treatment are
likely to be less healthy than the general population and may be more likely to seek treatment for sexual problems.

Harlow and Stewart (2003) estimated the prevalence of unexplained chronic vulvar pain and explored treatment seeking and diagnosis. Participants consisted of 3358 women from an ethnically diverse population. Women with vulvar pain were asked if they had sought treatment, whether they had received a diagnosis and, if so, what it was. Fifty-four percent of the women who reported a history of vulvar pain had sought treatment. For those women with pain who limited intercourse, the percentage rose to 64%. More than 60% of those who sought treatment consulted three or more clinicians, with 30% of the women whose pain limited intercourse seeking care from five or more clinicians. Sixty-one percent of the women with pain obtained a diagnosis. It is not clear what percentage of these women had vulvodynia and vaginismus. Furthermore, the data included women with other diagnoses such as ovarian cysts, endometriosis, and pelvic infections; therefore applying these findings to the vulvodynia and/or vaginismus population must be carried out cautiously.

Ogden and Ward (1995) examined diagnosis, help-seeking behaviour and satisfaction with care. The authors surveyed 89 women with vaginismus, or a history of vaginismus, and found that 94.4% of the women sought treatment and that they consulted an average of three professionals. The professionals they consulted were General Practitioners (GPs), sex therapists, psychotherapists, counsellors, gynaecologists, and family planning health professionals. The women perceived the consultations with their GPs to be least helpful and the psychotherapy to be most helpful.

Using an on-line survey developed by researchers, Reissing (2012) explored which health care professionals women with vaginismus typically consult, what treatments were received, and which were rated as helpful. They recruited 75 women with life-long vaginismus (LLV) and 93 women with acquired vaginismus (AQV) through advertisements on various websites related to vaginismus. The reasons cited for wanting to seek treatment were similar between the two groups and included wanting vaginal penetration to be part of sexual activity, wanting to please their partner, wanting to be like other women, wanting to conceive, fearing the loss of their partner, being afraid of not being able to have a long term relationship, and other reasons such as wanting to use tampons or having a pelvic examination without anxiety. Women in both groups were most likely to consult a gynaecologist or family doctor, followed by a psychologist. The LLV group was also likely to consult a sex therapist. The most helpful consultations for both groups were physiotherapy, then for the LLV group it was a psychologist and a sex therapist, and for the AQV group, a gynaecologist, and a sex therapist. An average of four different interventions were tried by the participants; however, the women with LLV had tried a range of 0-14 interventions, while the women with AQV had tried a range of 0-21 interventions. Because recruitment was mostly through websites dedicated to vaginismus, these
results may not be representative of all women with vaginismus, because the participants may have been knowledgeable about vaginismus and its treatments. Furthermore, the survey, a non-validated tool, was developed by North American researchers which may have introduced cultural bias.

SYNTHESIS OF DATA AND DISCUSSION

The information gleaned from the review gives a picture, although somewhat limited, of the treatment seeking journey, the rates of treatment seeking and the influences on and experience of treatment seeking. There are a number of limitations evident in the presented research that contribute to the incomplete picture of treatment seeking for vulvodynia and vaginismus. First, sampling varied, with Danielsson et al. (2003), Harlow and Stewart (2003) and to some degree Ogden and Ward (1995) recruiting from the general population; Donaldson and Meana (2011) recruiting from a university campus; Buchan et al. (2007) and Marriott and Thompson (2008), from a vulvodynia treatment clinic; Connor et al. (2008), from a clinic and the NVA website/member list; Reissing (2012) from vaginismus websites, and Evangelia et al. (2010), from a hospital population.

Second, several definitions of genital pain were used. Buchan et al. (2007), Connor et al. (2008), Ogden and Ward (1995) and Marriott and Thompson (2008) recruited women with a diagnosis of vulvodynia or vaginismus or both, whereas Donaldson and Meana (2011), Danielsson et al. (2003) and Evangelia et al. (2010) inquired about pain with intercourse, Harlow and Stewart (2003) investigated women with chronic vulvar pain that is not necessarily associated with intercourse, and Reissing (2012) inquired about penetration and thrusting. The studies that used participant self-report (Danielsson et al., 2003; Donaldson & Meana, 2011; Evangelia et al., 2010; Harlow & Stewart, 2003; Ogden & Ward, 1995; Reissing, 2012) to determine the presence of pain with intercourse may have included women with infection or lack of lubrication rather than women with vulvodynia or vaginismus. Furthermore, each study used a different time frame for reporting pain with intercourse. One study asked for symptoms experienced in the last four weeks (Donaldson & Meana, 2011); another, for three or more months (Harlow & Stewart, 2003); and another, for six or more months (Danielsson et al., 2003). The remaining studies did not report on the time frame. While the various time frames suit the purposes of the particular studies it causes problems in being able to generalise to women with vulvodynia and vaginismus. For example, someone who has only just started experiencing symptoms may have different reasons and barriers to seeking treatment from someone who has had the symptoms for 6 to 12 months.

One further limitation is that only two of the quantitative studies used validated scales, the Brief Sexual Symptom Checklist (Evangelia et al., 2010), and Female Sexual Function Index (Donaldson & Meana, 2011). The remaining quantitative
studies utilised tools developed by the researcher (Danielsson et al., 2003; Ogden & Ward, 1995; Reissing, 2012) and could have issues with validity and reliability.

The literature can be organised into several themes: the journey from onset of symptoms to effective treatment, rates of treatment seeking, influences on treatment seeking rates and experience of treatment seeking. Each of these themes are presented, followed by a discussion on two health behavior models that may be helpful in understanding the treatment seeking process for vulvodynia and vaginismus.

The journey from onset of symptoms to effective treatment

The literature suggests that the journey to diagnosis and effective treatment can be complex, protracted and difficult. As previously noted, one study found it took a mean time of 24 months to receive a diagnosis (Buchan et al., 2007). For many it took time to decide to seek treatment for pain believing the pain was normal, might disappear, that there was no cure, they doubted that medical assistance would help, or feared the severity of the condition. Some did not want to admit to having had sex, or feared the stigma of having a sexual problem. When the pain began to impact on them significantly, the women decided to seek treatment (Donaldson & Meana, 2011). Women often saw multiple medical practitioners in an attempt to get a diagnosis and effective treatment (Harlow & Stewart, 2003), with one study reporting their participants had consulted between 3 and 15 different doctors (Buchan et al., 2007). Finding effective treatment was also elusive, with one study finding their participants tried between 0 and 21 different treatments (Reissing, 2012). Women often endured months of incorrect treatment (usually being treated for candidal infections) and experienced exacerbation of their symptoms which lead to significant personal and relationship distress (Buchan et al., 2007; Connor et al., 2008; Marriott & Thompson, 2008).

Several implications follow from the delay in receiving effective treatment, including mental health issues and a poor prognosis. For instance, chronic pain develops when, over time, hyperactivity of the sensory pain receptors triggers nerves in the central nervous system. This can lead to pain in the absence of the original pain stimuli. This secondary pain (chronic pain) is very difficult to treat (Graziottin & Rovei, 2006; Treede et al., 2008). The secondary effects of delayed treatment multiply the personal and social cost of the experience of vulvodynia and vaginismus.

Rates of treatment seeking

We know that only a portion of women with genital pain seek treatment. We have some indication as to why women do not seek treatment and also what type of health professional women consult. Four of the reviewed studies reported between 5.6 % (Ogden & Ward, 1995) and 54 % (Harlow & Stewart, 2003) had sought treatment,
with two studies finding 39% had sought treatment (Danielsson et al., 2003; Donaldson & Meana, 2011). The discrepancies in the rates are likely to be due to methodological differences in the studies. As has been highlighted in this review, women often delay treatment seeking for a number of reasons and therefore it is not surprising that the Harlow and Stewart study (2003) reported a higher prevalence of women seeking treatment as they included women with pain for more than three months, as compared to the Donaldson and Meana (2011)* study, which included women experiencing pain in the last four weeks. It is not clear why the Danielsson et al. (2003) data, which included women with pain for more than six months, is lower than that reported in the Harlow and Stewart (2003) data. One possible explanation is that they may have under-represented women with genital pain. As was stated earlier their sample was obtained from a cervical screening programme and may have not included women with genital pain who had their cervical screen organised through their gynaecologist (rather than the national screening programme). The high rate of treatment seeking for the Ogden and Ward (1995) study is likely to be due to recruitment strategies with 75% of their participants being recruited from a clinical population.

**Influences on treatment seeking rates**

A number of factors have been identified as having an influence on treatment seeking rates. Evangelia et al. (2010) found that pain coupled with distress about the pain increased the odds of willingness to seek treatment; however, it did not increase the odds of actual treatment seeking. It may be that a woman who is distressed about her genital pain would like to seek treatment; however, cultural, personal and environmental factors prevent her from doing this. As stated earlier, women have a number of reasons for not seeking treatment for their pain including beliefs about the pain, the severity of the condition or the efficacy of treatment. Personal and cultural values also influence rates of treatment seeking (i.e., views on sex outside of marriage or stigma of sexual problems) (Donaldson & Meana, 2011). Conversely, the reasons cited for seeking treatment were wanting vaginal penetration for themselves or their partner, wanting to be like other women, wanting to conceive, and worrying about the impact on their current or future relationships (Reissing, 2012).

**Experience of treatment seeking**

Danielsson et al. (2003) found that those who sought treatment were more likely to consult a physician or midwife rather than another health professional, such as a psychologist or counsellor. GPs were most often consulted, followed by a sex therapist and psychologist (Ogden & Ward, 1995; Reissing, 2012). The specific statistics on how many women consulted the specific health professional varied between the studies; this is likely to be due to cultural norms given that the participants stemmed
from Sweden (Danielsson et al., 2003), North America and Europe (Ogden & Ward, 1995; Reissing, 2012). Additionally, the design of the surveys could have biased the results. They were primarily quantitative surveys and it is not clear if the participants were limited by having to choose from a list of health professionals.

Many women felt judged, not listened to and not believed in their quest for diagnosis. Often they were told that the symptoms were “in their head” which led to feelings of shame (Marriott & Thompson, 2008). When they finally received a diagnosis, the majority felt relief at being believed, and most felt it was the first step towards acceptance and commitment to managing the condition (Buchan et al., 2007). Some, however, felt despair and disappointment when they were told there was no cure (Buchan et al., 2007) or no organic cause could be found, or both (Marriott & Thompson, 2008).

In seeking effective treatment, many also felt exasperation at the lack of medical consensus. Women participated in between 0 and 21 different types of treatments (Reissing, 2012) and up to 60+ sessions of therapy with their health professional (Ogden & Ward, 1995). Some women experienced significant side effects to treatments and felt angry at what they perceived as insensitivity to these side effects. These side effects affected the women’s willingness to try new treatments (Connor et al., 2008). One early study with women experiencing vaginismus found the GP to be the least helpful and psychotherapy to be the most helpful (Ogden & Ward, 1995), while a more recent, but similar study, found physiotherapy to be the most helpful for women with both LLV and AQV. Interestingly, the most helpful treatment, physiotherapy, was not as frequently used as an intervention (Reissing, 2012). This would suggest that doctors, sex therapists and psychotherapists should be educated regarding the benefits of pelvic floor physiotherapy so that more women are referred for pelvic floor assessment and rehabilitation. Although the data from both the Ogden and Ward (1995) and Reissing (2012) studies only include women with vaginismus, there is some suggestion that AQV may in fact be vulvodynia (Graziottin & Rovei, 2006; Lahaie et al., 2010; Reissing, 2012) and therefore these findings may also be generalisable to women with vulvodynia.

### Treatment seeking models

There are a multitude of factors that can influence a person’s health related decisions and a theoretical framework, or model, could assist in organising and understanding these factors. Health behaviour models offer explanations about the manner in which people understand health and illness as well as explain the way people behave in response to their understanding. Therefore, health behaviour models can have implications for understanding health related decisions (Finfgeld, Wongvatunyu, Conn, Grando, & Russell, 2003). As stated earlier, only one model, the CSM, has been applied to treatment seeking for dyspareunia (Donaldson & Meana, 2011).

Another model that may be helpful in understanding treatment seeking for
vulvodynia and vaginismus is the Health Action Process Approach (HAPA). It proposes that motivation, behavioural intention, and self-efficacy, as well as outcome expectations and perceptions of the illness influence health behaviour. This model expands previous models by including strategic planning for and the maintenance of the health behaviour (Schwarzer, 2008). This model has been applied to a number of health related behaviours including physical exercise, breast self-examination, seat belt use, dietary behaviours, dental flossing, cervical cancer screening (Luszczynska, Goc, Scholz, Kowalska, & Knoll, 2011; Schwarzer, 2008), and condom use (Teng & Mak, 2011). To our knowledge it has not been applied to treatment seeking for vulvodynia or vaginismus. Given what we know from the literature, that the treatment seeking process can be protracted (Buchan et al., 2007) and characterised as emotionally difficult (Marriott & Thompson, 2008), a model, such as the HAPA, that addresses the motivation to persist in finding correct diagnosis and effective treatment may be helpful.

RECOMMENDATIONS

Clearly more research is needed to improve the outcomes of treatment seeking for vulvodynia and vaginismus, including both increasing the rates of treatment seeking and decreasing the distress associated with it. It would be helpful to explore treatment seeking for vulvodynia and vaginismus in order to answer some of the questions that have not been fully answered in the existing literature. Areas of interest include health process factors (Schwarzer & Luszczynska, 2008) that influence treatment seeking, taking into account specific personal, social, environmental and cultural factors that are implicated in the delay women experience in the diagnosis of vulvodynia and vaginismus. Research could also investigate the role of distress as a mediator of treatment seeking. It would also be beneficial to understand the experiences of women who have sought treatment and to explore their motivations for doing so. Research that attempts to apply current models of health behaviour, such as the HAPA model, may elucidate the treatment seeking process further.

Public health and community education could target some of the beliefs women hold about sexual problems and genital pain; these programmes could address specific faulty beliefs, such as the belief that genital pain is not a medical problem, that there is no cure, fear of severity of the problem, and so forth. Programmes that normalise sexual problems could be helpful in reducing the stigma associated with sexual problems. Given that some of the barriers are directly related to health professionals, training for doctors, sex therapists, psychologists and counsellors would be helpful. Finally, screening for vulvodynia and vaginismus during routine cervical cancer screening or wellness checks could increase numbers of women being diagnosed and treated for vulvodynia and vaginismus.
CONCLUSION

This review has highlighted the complexities and complications inherent in the journey of treatment seeking for vulvodynia and vaginismus or both. Barriers to treatment seeking include lack of knowledge about genital pain (both the woman and the health professionals she consults), fear of social stigma and treatment side effects. Research indicates that the treatment seeking process for vulvodynia and vaginismus can be protracted and difficult, with some women indicating that they feel judged, not listened to and ashamed after consulting health professionals for genital pain.

Theory led research is likely to better explain treatment seeking for vulvodynia and vaginismus and increase our understanding around what motivates women to seek treatment. A model of treatment seeking for vulvodynia and vaginismus would be helpful in organising the information already elucidated in the literature and for guiding future research. The follow on effect of such a model would be more timely diagnosis and increased efficacy of treatment for vulvodynia and vaginismus, which in turn would lead to better prognosis and improved quality of life for women with these conditions.

NOTE

1. Dyspareunia literally means pain with intercourse. It is a symptom rather than a diagnosis. Dyspareunia can be a symptom of infection, lack of lubrication, cancer, neurologic damage, vaginismus or vulvodynia (Binik, Bergeron, & Khalif, 2007; Haefner, 2007).

BIOGRAPHICAL NOTES

Kathy Bond is a Melbourne, Australia based Sex Therapist and a PhD candidate at the University of Sydney. Her research is investigating the lived experience of treatment seeking for vulvodynia and vaginismus. She holds a Bachelor’s of Science in Occupational Therapy, a Graduate Diploma in Counselling and a Master’s in Sexual Health. In addition to her research, she works with men and women with a wide range of sexual difficulties and provides educational seminars to allied health professionals.
Elias Mpofu, Ph.D., DEd, CRC is a qualified rehabilitation counsellor and recipient of three international research awards in rehabilitation. He holds an honorary doctoral degree in education by the University of Pretoria (2010). He is Editor of the *Australian Journal of Rehabilitation Counselling* and the *Journal of Psychology in Africa*. He also serves on the editorial boards of several rehabilitation counselling related journals, including Journal of Rehabilitation Administration, Rehabilitation Education, Rehabilitation Counseling Bulletin, Psychological Assessment, and the International Journal of Disability, Development and Education.

Patricia Weerakoon (MBBS (Sri Lanka); MS (Hawaii); MHPEd (UNSW)) is a medical doctor turned sexologist and is an honorary senior lecturer with the school of medical sciences, University of Sydney. In addition to teaching and research, she works within the community to develop and deliver sexuality education to people of all ages.

Russell Shuttleworth, a medical anthropologist, is currently a senior lecturer in social work at the School of Health and Social Development, Deakin University Geelong, Australia. His primary research interests are in sociocultural aspects of sexuality and disability, sexuality and ageing, and gender and disability. He has also conducted disability research on other issues including leadership, communication, communication technology, and aged care.
REFERENCES


with relationship satisfaction. *Journal of Sex & Marital Therapy, 34*(1), 31–44. doi: 10.1080/00926230701620548


