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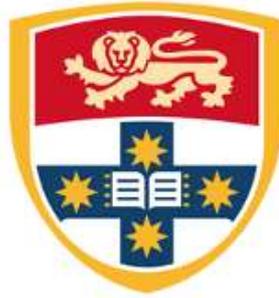
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THE UNIVERSITY OF
SYDNEY

Living with genital pain: Women's experience of treatment seeking

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A thesis submitted in fulfilment of the requirements
for the degree of Doctor of Philosophy

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2015

Author's Certification

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16 January 2015

Abstract

Healthy sexual expression is important to well-being and sexual dysfunctions like female genital pain (FGP) negatively impact quality of life. FGP is a sexual dysfunction that is difficult to diagnose and treat which can make treatment seeking a distressing experience. In the present study I explored the lived experience of women with genital pain in order to develop an evidence based grounded model of treatment seeking for FGP. I was interested in identifying the perceived motivators and barriers to treatment seeking for genital pain. I also sought to ascertain the personal agendas that influenced treatment seeking for FGP, specifically the influential self-beliefs and perceived illness contestations. I investigated the salient intra- and interpersonal survivorship resources and the personal narrative that influenced treatment seeking.

A constructivist lived experience perspective underpinned this research, in which multiple and emergent realities around FGP were co-created by interacting with the participants on their own terms and in their own language. Although constructivist grounded theory and phenomenology differ in philosophy and methodology, this study shows how they can be used in a complementary fashion to investigate a very private matter such as FGP. Participants were 26 women with genital pain, specifically vaginismus (n=4) and provoked and generalised vulvodynia (n=13 and n=9, respectively). The average age of the participants was 27, with a range of 19-43.

Women were motivated to seek treatment for their pain when they thought they might have an infection, held optimistic views about their health or when they expected their relationship to include intercourse. The women

experienced barriers when they normalised or discounted their symptoms or held negative treatment beliefs. Unsurprisingly, the identified barriers were associated with delayed treatment seeking. The women described three significant personal agendas for their treatment consultation with a health care professional (HCP) – validation of their symptoms, an informed HCP, and a strong HCP–patient alliance. Agendas that were met played a significant role in decreasing the distress the women experienced during treatment seeking.

Identified salient survivorship resources were a supportive HCP and support network, and personal agency. A supportive relationship with an HCP was characterised by solution-focused treatment, empathy, and understanding, which led to a less distressing treatment seeking experience. Support from a partner, family member or friend was characterised as selfless, non-judgemental, practical and providing advice and perspective. These resources encouraged consistent treatment seeking. The women who demonstrated personal agency were more likely to have sought treatment immediately and continuously. The personal narratives that contributed to more consistent treatment seeking were personal agency, communion, redemption, creating meaning of suffering, positive sexual identity and positive resolution. Identities that were characterised by contamination and negative sexual self-schema were associated with no treatment seeking or delayed treatment seeking. The findings of this study also indicate that gender and power are salient influencers on the experience of treatment seeking for FGP.

This study provides significant and important support and extension to previous research that applied a cognitive behavioural model to treatment seeking for early dyspareunia by identifying the intra- and interpersonal factors that influence treatment seeking. It also elucidates a unique lived experience insight into the entire treatment seeking trajectory from onset of symptoms to successful management of genital pain.

The findings of this study allow HCPs and researchers to better understand the needs of women with genital pain. Furthermore, this research will help guide future research and the development of future initiatives to improve the treatment of genital pain conditions, thus improving the outcomes and quality of life for women with genital pain.

Dedication

This thesis is dedicated to the women who generously shared their stories with me (and you).

Acknowledgments

They say it takes a village to raise a child. At times this thesis has felt like a child of mine (never my favourite though) and true to form, this thesis has required a village. If I were to thank every person for the particular ways in which they helped me I would have to write another entire thesis-length document and I don't intend writing another for a while! There are a few other people who require special mention. First and foremost, I want to thank my family who supported me on a daily basis. Mike, my partner in crime and in life, phew, what a journey. What doesn't kill us makes us stronger – this has truly been a strengthening experience. Thank you for your support and love along the way. Roma, I could not have done this without your continued interest in my progress, offers of help and your encouraging words. If I could be a teenager again, I would want to be just like you. Luke, your single-minded passion and gentle determination inspires me to do what it takes to follow my dreams. I would also like to thank the women who participated in this research, your generosity and openness overwhelms me. I would also like to thank those who assisted with recruitment, with gratitude I am in your debt – this research would not be without you.

I wish to express gratitude to Prof. Elias Mpofu – you have taught and guided me, and I am a much better researcher for it. I would also like to thank Drs. Michael Millington, Patricia Weerakoon and Russel Shuttleworth. You have each left your unique mark on this thesis. The following people have also provided me with much support and love along the way: Christopher Fox, Lynda Carlyle, Renee O'Donnell, Carolyn Bowen, my PhD buddies Heather and Deb, my friends and colleagues at MHFA and the University of

Melbourne, Ferri Bond, Peter and Fay Bond, Matt and Anne Bond, Chris and Paul Atkins, Kelly and Mitch Klein, Jan Bond and Roger Hocking and last but not least, Bart and Tabby.

Finally, I wish to thank and acknowledge my parents, Gail, Lindy, Helene, and Jack. You started me on my higher education journey many years ago. Thank you for the many ways you inspired me to become the person I want to be.

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Chapter One: Introduction

Healthy sexual functioning is important to well-being (World Association for Sexual Health, 2008) and is positively linked to relationship satisfaction (Leiblum, Koochaki, Rodenberg, Barton, & Rosen, 2006; Santtila et al., 2007), quality of life, (Santosa et al., 2011), overall happiness (Laumann et al., 2006), general well-being (Laumann, Paik, & Rosen, 1999), better mental health (Leiblum et al., 2006), and self-reported general health (Gallicchio et al., 2007). Conversely, sexual dysfunction negatively impacts quality of life, emotional health and general happiness (Laumann et al., 1999; Lewis et al., 2010; Sadovsky & Nusbaum, 2006). There is an interactive association between sexual dysfunction and other health conditions, including diabetes, cardiovascular disease, psychological disorders and other chronic diseases (Basson, Rees, Wang, Montejo, & Incrocci, 2010). Female genital pain (FGP) is a sexual dysfunction that has negative consequences for health and well-being. This research aims to explore the experiences of women with FGP.

This chapter introduces the concept of FGP and posits the rationale for this research investigating the treatment seeking behaviours of women with FGP. The introduction is presented in the following sections: (1) FGP, (2) treatment seeking for FGP, (3) distress about FGP, (4) pain, distress and treatment seeking, (5) interpersonal processes that influence treatment seeking, (6) intrapersonal processes that influence treatment seeking, (7) scaffolding treatment seeking for FGP, (8) statement of the problem, (9) research objectives, (10) research questions, (11) significance, (12)

assumptions, (13) limitations and strengths, and (14) definition of key concepts and terms.

Female Genital Pain

FGP is a sexual dysfunction that involves the experience of chronic¹ genital pain and can have negative consequences for women and their well-being (Arnold, Bachmann, Rosen, Kelly, & Rhoads, 2006). FGP can negatively impact a woman's quality of life (Arnold et al., 2006), mood (Brauer et al., 2009b; Gates & Galask, 2001), other areas of sexual functioning (Graziottin, Brotto, Graziottin, & Brotto, 2004; Pitts et al., 2008) and sexual satisfaction (Gates & Galask, 2001), leading to significant personal and relational distress (Arnold et al., 2006; Ayling & Ussher, 2008; Dennerstein, Guthrie, Hayes, DeRogatis, & Lehert, 2008; Elmerstig et al., 2008; Graziottin, 2008; Hayes et al., 2008a). The impact of FGP is a chronic condition where the symptoms of pain are rarely cured (Danielsson, Sjöberg, Stenlund, & Wikman, 2003).

In this study, FGP encompasses two vulvovaginal/pelvic pain syndromes – vulvodynia and vaginismus² (Amarraj, Kelly, & Bachmann, 2009, pp 2-3; Binik, Bergeron, & Khalife, 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

¹ The use of the word 'chronic' in this thesis is used to indicate the acute chronic pain of provoked vulvodynia and the truly chronic pain of generalised vulvodynia.

² For simplicity and literary flow, the term FGP and genital pain conditions will be used to describe both vulvodynia and vaginismus. When discussing either vulvodynia or vaginismus specifically the appropriate term will be used.

making intercourse painful or even impossible, despite the woman's expressed wish for penetration" (Binik et al., 2007, p127).

More recently vulvodynia and vaginismus have been subsumed into one diagnosis Genito-Pelvic Pain/Penetration Disorder (GPPPD). GPPPD diagnosis requires a six month history of at least one of four symptoms (see DSM-5): 1. difficulty with vaginal penetration, 2. marked genital or pelvic pain during attempted or actual intercourse, 3. significant fear of pain as a result of vaginal penetration, and 4. tensing or tightening of the pelvic floor muscles during attempted vaginal penetration (American Psychiatric Association, 2013). GPPPD is a new diagnosis that subsumes a number of diagnoses, including vulvodynia and vaginismus (Binik et al., 2007, Amaralraj et al., 2009, pp. 2-3). It can be further classified as (Haefner, 2007):

- Generalised (affecting the entire vulva),
- Localised (affecting only an area of the vulva),
- Provoked (where direct pressure on the vulva causes pain),
- Unprovoked (where the pain appears spontaneously and can be unrelenting),
- Primary (where the pain has always been present), or
- Secondary (where the pain has developed after a period of time without pain).

Because the 'spasm' of vaginismus could not be reliably measured, the diagnosis of vaginismus was removed from the DSM-5 (Reissing, Binik, Khalifee, Cohen, & Amsel, 2004). The omission of the diagnosis of vaginismus occurred after the data collection phase of this study, therefore the diagnosis of vaginismus will be maintained.

Given the newness of the diagnosis, it is impossible to know the prevalence of GPPPD (Meana, & Maykut, 2015). However, prevalence studies for vulvodynia and vaginismus can give some guidance. Prevalence studies for vulvodynia vary from 3-18 % of the general population reporting vulvodynia, and up to 46% in a clinical population (Graziottin, 2008; Harlow & Stewart, 2003; Laumann et al., 1999; Nguyen, Turner, Rydell, MacLehose, & Harlow, 2013; Pitts et al., 2008). Researchers estimate that 1-6% of women worldwide have vaginismus (Binik et al., 2007; Kadri, Mchichi Alami, & Mchakra Tahiri, 2002; Lahaie, Boyer, Amsel, Khalifee, & Binik, 2010; Weijmar Schultz et al., 2005) with prevalence in clinical settings being between five and 17% (Crowley, Richardson, & Goldmeier, 2006; Lahaie et al., 2010).

Treatment Seeking for FGP

Research suggests that between 6 and 54 per cent of women with FGP seek treatment (Danielsson et al., 2003; Donaldson & Meana, 2011; Harlow & Stewart, 2003; Nguyen et al., 2013; Ogden & Ward, 1995). This large range in treatment seeking rates is likely due to varied definitions of FGP being used, e.g., Donaldson and Meana (2011) investigated early experience of pain with intercourse, and Danielsson et al. (2003) prolonged and severe pain. Donaldson and Meana (2011) explored why young women with early genital pain delay treatment seeking for genital pain. They found women cited a belief that the pain was normal, doubt that medical assistance would help and fear of the stigma of having a sexual problem. The findings of this study may not be generalisable to chronic genital pain because the researcher asked about pain within the last 4 weeks. Women's motivations

for treatment seeking for vaginismus are a desire for vaginal penetration for themselves or their partner, wanting to be like other women, wanting to conceive, and a concern for the impact on their current or future relationships (Reissing, 2012). In addition, research suggests that seeking effective treatment for FGP can lead to significant distress (Buchan, Munday, Ravenhill, Wiggs, & Brooks, 2007; Connor, Robinson, & Wieling, 2008).

Although these studies give some indication of the factors that impact treatment seeking for FGP, questions remain about the intrapersonal, interpersonal and environmental motivations for and barriers to treatment seeking for genital pain conditions. This research aims to explore the influences on treatment seeking for FGP.

Distress about FGP

Distress about FGP has implications for treatment seeking, motivation for therapy and prognosis (Basson et al., 2004; Basson et al., 2003). A woman who is not distressed may be less likely to seek treatment, or if she does seek treatment for other reasons, such as pressure from a partner, she may be less likely to follow through with treatment recommendation, leading to a poorer prognosis. Three types of distress have been investigated regarding female sexual problems: psychological distress, sexually related personal distress, and relationship distress. Table 1.1 is a summary of distress related to FGP as evidenced in the literature.

Psychological Distress

The research investigating distress and FGP has tended to focus on the psychological symptoms of distress by measuring the concepts of depression, anxiety, paranoia etc. (Arnold et al., 2006; Brauer et al., 2009b;

Gates & Galask, 2001; Granot, Friedman, Yarnitsky, & Zimmer, 2002; Jantos & White, 1997; Nunns & Mandal, 1997; Payne et al., 2007; Reed et al., 2000; Reissing, Binik, Khalife, Cohen, & Amsel, 2003; Stewart, Reicher, Gerulath, & Boydell, 1994; van Lankveld, Weijnenborg, & ter Kuile, 1996; Wylie, Hallam-Jones, & Harrington, 2004). However, there is a range of manifestations of distress in women with genital pain and psychological distress is only present in some women with FGP (Bond, Weerakoon, & Shuttleworth, 2012b). Including personal and relationship distress is therefore important when researching distress related to FGP.

Relational and Sexually Related Personal Distress

Sexually related personal distress is defined as “negative and distressing feelings that a woman may experience about her level of sexual function” (Hayes, 2008, p.216), while relationship distress is usually associated with communication, emotional closeness and sexual attraction to a partner (Bancroft, Loftus, & Long, 2003; Hayes et al., 2008a). Research investigating personally related sexual distress in women with genital pain is scarce and often explores all female sexual dysfunction without presenting distress data specific to FGP. When specific genital pain distress data is presented it indicates that women with genital pain are more likely to experience sexually related personal distress compared to women with other forms of sexual dysfunction (Elmerstig et al., 2009; Hayes, Dennerstein, Bennett, & Fairley, 2008b). The meanings women with genital pain assign to sexual activity may also impact sexually related distress. Stephenson and Meston (Stephenson & Meston, 2010) found that women who strongly

associate intimacy with sexual activity experience more distress about their genital pain than women who have a broader definition of intimacy.

Both quantitative and qualitative research have explored the relational and sexually related personal distress associated with genital pain conditions (Ayling & Ussher, 2008; Bancroft et al., 2003; Dennerstein et al., 2008; Elmerstig et al., 2008; Hayes et al., 2008a; Oberg & Fugl-Meyer, 2005; Rosen et al., 2009; Shifren, Monz, Russo, Segreti, & Johannes, 2008; Stephenson & Meston, 2010). The quantitative studies that included a control group found no significant increase in relationship distress for women with FGP (Smith & Pukall, 2011). The qualitative research clearly identified significant relational distress in women with genital pain conditions (Ayling & Ussher, 2008; Elmerstig et al., 2008). This may indicate that the measures used to identify relational distress are not sensitive enough or do not target the constructs that are most meaningful to women who are experiencing relational distress associated with FGP (Bond et al., 2012b).

Table 1.2 Summary of the Concept of Distress Relating to Genital Pain

	Definition	Measures	Conclusions
Psychological Distress (Arnold et al., 2006; Brauer et al., 2009b; Gates & Galask, 2001; Granot et al., 2002; Jantos & White, 1997; Nunns & Mandal, 1997; Payne et al., 2007; Reed et al., 2000; Reissing et al., 2003; Stewart et al., 1994; van Lankveld et al., 1996; Wylie et al., 2004)	A unique emotional state, with attributes including perceived inability to cope, change in emotional status, discomfort and harm (Ridner, 2004).	<i>Concepts measured:</i> Depression, anxiety, paranoia, perfectionism, somatisation, hypochondriasis etc. <i>Validated scales:</i> Becks Depression Inventory, Brief Symptom Inventory, Epidemiologic Studies Depressed Mood Scale, The Barsky Somatosensory Amplification Scale, The Whitely Index, STAI <i>Non-validated scales:</i> History of medication use, self-report	There are a range of manifestations of distress in women with genital pain. Some women experience psychological distress as a result of their genital pain. Some women never experience psychological distress as a result of their genital pain.
Relationship Distress (Ayling & Ussher, 2008; Bancroft et al., 2003; Dennerstein et al., 2008; Elmerstig et al., 2008; Oberg & Fugl-Meyer, 2005; Stephenson & Meston, 2010)	Distress related to various relational attributes including emotional closeness, communication etc. (Bancroft et al., 2003; Hayes et al., 2008b)	<i>Concepts measured:</i> Decision-making, the sexual relationship, values, relationship stability, conflict, communication and interests <i>Validated scales:</i> Dyadic Adjustment Scale (DAS) <i>Non-validated scales:</i> Self-report	Literature is inconclusive and contradictory. Quantitative research that includes a control group finds no significant increase in relationship distress for women with genital pain. Qualitative research finds women report significant relationship distress.
Sexually Related Personal Distress (Dennerstein et al., 2008; Hayes et al., 2008a; Rosen et al., 2009; Shifren et al., 2008)	Negative and distressing feelings that a woman may experience about her level of sexual function (Hayes, 2008).	<i>Concepts measured:</i> Embarrassment, frustration, guilt, anger about the sexual problem <i>Validated scales:</i> Female Sexual Distress Scale <i>Non-validated scales:</i> None noted in the literature	Women with genital pain are more likely to experience sexually related personal distress than women with other forms of female sexual dysfunction.

Pain, Distress and Treatment Seeking

Treatment seeking for pain is not merely a response to physical or psychological symptoms, but is a social encounter influenced by individual meanings, experiences and the social context of the encounter (Maxwell, Streetly, & Bevan, 1999). Pain intensity and pain-related disability appear to influence treatment seeking for chronic pain. The longer someone has had pain, the more intense the pain is, and the amount of disability experienced, the more likely it is that that person will seek treatment for their pain (Andersson, Ejlertsson, Leden, & Schersten, 1999; Hagen, Bjørndal, Uhlig, & Kvien, 2000; Jacob, Zeev, & Epstein, 2003; Molano, Burdorf, & Elders, 2001; Mortimer, group, & Ahlberg, 2003; von Korff, Wagner, Dworkin, & Saunders, 1991; Walker, Muller, & Grant, 2004).

Distress does not have a clear relationship to treatment seeking for chronic pain conditions, with some studies finding higher levels of distress increases the likelihood of treatment seeking (Andersson et al., 1999; Drossman et al., 1988; Whitehead, Bosmajian, Zonderman, Costa, & Schuster, 1988) and others finding no relationship (von Korff et al., 1991; Welch, Hillman, & Pomare, 1985). There are likely to be several reasons for this discrepancy. Methodological differences in the research design of these studies may be responsible for the discrepancy or the complexity of the human response to pain and treatment seeking may be implicated.

The relationship of distress to treatment seeking for FGP has not been fully explored in the literature, but is likely to be a complex biopsychosocial interaction. Although not all women with genital pain are distressed by it, or seek treatment (Danielsson et al., 2003), genital pain coupled with distress

increases the likelihood of treatment seeking (Evangelia et al., 2010).

Distress plays a role in the experience of and treatment seeking for FGP, however, other interpersonal processes influence treatment seeking.

Interpersonal Processes that Influence Treatment Seeking

The interaction between the HCP and the patient influences treatment outcomes, which is particularly true in complex and long-term medical conditions, such as genital pain conditions (Arora, Street Jr, Epstein, & Butow, 2009). High quality HCP–patient interaction involves a continuous process of addressing patient agendas and fostering a healing relationship that promotes self-management and patient empowerment (Arora et al., 2009; Epstein & Street, 2007; Masalla, De Waal, & Friedrich-Nel, 2010; Roter, 2000). Illness contestation is often the result of an HCP–patient relationship where empowerment is not fostered (Asbring & Narvanen, 2004; Moss & Teghtsoonian, 2008).

Addressing Patient Agendas

Understanding patient agendas is central to fostering good HCP–patient interaction (Chewning & Wiederholt, 2003). Patient agendas are the implicit or explicit problems that people bring to the medical consultation, including the patient's expectations, feelings and fears about their health status. HCPs who are able to listen to and empathise with their patients are more likely to uncover and effectively address patient agendas (Butler, Champion, & Cox, 1992).

HCPs also have agendas and Thorne and colleagues (2006), in their study investigating the communication of cancer risk, recognised that the HCP's and patient's agendas sometimes appear to be at cross purposes.

They found that the HCP's felt the need to fully disclose prognosis, rather than give 'false hope', which led to significant distress for their patients. The patients described the HCP's communication as 'being brutal' and 'catastrophising' and felt the HCP could fully disclose while still communicating hope. This research will help HCPs understand the agendas of their patients with FGP.

Promoting Self-management and Patient Empowerment

HCPs who promote patient self-management and empowerment positively influence patients and their well-being. Empowerment is a process whereby the HCP enables the patient to understand and cope with their illness (Skuladottir, 2008). It is achieved through relationship-centred health care (Roter, 2000), rather than either an HCP focus or a patient focus. In a relationship-centred model, HCP and patient interaction is characterised as being medically functional, educational, responsive, facilitative and participatory. Carlsson, Segesten, Nelbert, and Nilsson (2007) found that when both the HCP's knowledge and the patient's perspective contributed to health care outcomes improved. If HCPs are to improve the outcomes for women with genital pain, a relationship-centred approach that promotes self-management and empowerment is essential (Mercer & Reynolds, 2002; Reynolds & Scott, 1996).

FGP as a Contested Illness

Due to the difficulty of diagnosing and treating vulvodynia and vaginismus (Petersen et al., 2008), these conditions could be considered contested illnesses. A contested illness is one that is rejected because it is considered illegitimate by researchers, health professionals and policy

makers, with the symptoms being framed as psychosomatic or even non-existent (Brown, Morello-Frosch, Zavestoski, & The Contested Illnesses Research Group, 2012; Conrad & Barker, 2010; Moss & Teghtsoonian, 2008). Contested illnesses also extend to illnesses that are well defined, however, treatment protocol may be contested. The person with a contested illness can often feel powerless and unable to control and influence their state of health (Asbring & Narvanen, 2004; Moss & Teghtsoonian, 2008).

Contestation occurs because illness is positioned within multiple power relationships and various social processes (Conrad & Barker, 2010; Moss & Teghtsoonian, 2008). Diagnosis and treatment can be influenced by the HCP–patient relationship, the gender, social and economic status of the patient, and the country or community the patient lives in. Pain is unable to be seen or measured and for this reason HCPs have often contested pain conditions (Conrad & Barker, 2010). Furthermore, pain behaviours and their associated emotions, such as depression, can also be ambiguous, again leading to contestation (Jackson, 2005). On the other hand, diagnosis serves to legitimise the experience of pain, countering the negative effects of contestation (Ballard, Lowton, & Wright, 2006; Clarke & James, 2003; Connor et al., 2008; Cox, Henderson, Andersen, Cagliarini, & Ski, 2003; Glenton, 2003; Hyden & Sachs, 1998; Lillrank, 2003; Milliken & Northcott, 1996; Moss, 2008; Oldfield, 2013).

The experiences of women with genital pain are invaluable HCPs because their treatment needs can be understood and more easily met, and the negative impact of having a contested illness can be avoided, which can help to improve the subjective quality of life of the women they treat

(Gallicchio et al., 2007). Intrapersonal processes also influence treatment seeking for FGP.

Intrapersonal Processes that Influence Treatment Seeking

Pain is a subjective experience and therefore it is influenced by the intrapersonal processes of avoidance and acceptance (Clarke & Iphofen, 2007; Endler, Corace, Summerfeldt, Johnson, & Rothbart, 2003; Jensen & Karoly, 1992; Munton, Silvester, Stratton, & Hanks, 1999; Rathmell, Simopoulos, Bajwa, & Ahmed, 2006). The stories or narratives people construct about their pain also positively and negatively influence the experience of chronic pain.

Avoidance, Acceptance and Chronic Pain

Avoidance and acceptance are intrapersonal processes that influence the experience of chronic pain. Avoidance is an emotion-focused behaviour that is motivated by fear of pain and is associated with greater distress and disability in people with chronic pain (Endler et al., 2003; Gil, Williams, Keefe, & Beckham, 1990). Conversely, acceptance (defined as engagement in normal daily activities despite pain) is associated with lower levels of distress, disability and pain intensity (Endler et al., 2003; McCracken & Eccleston, 2003; Viane et al., 2003).

Research investigating the processes that influence the subjective experience of genital pain is conflicting. Some research indicates that women with genital pain tend to demonstrate higher levels of avoidant, emotion-focused cognitions, as compared to healthy controls, which influences sexual functioning (Brauer, Laan, & ter Kuile, 2006; Brauer, ter Kuile, Janssen, & Laan, 2007; Brauer et al., 2009b; Gates & Galask, 2001; Granot & Lavee,

2005; Meana, Binik, Khalifee, & Cohen, 1997; Nunns & Mandal, 1997; Reissing et al., 2003). However, a systematic literature review points out that other research indicates that there is a sub-group of women who do not display these unhelpful processes (Bond et al., 2012b) suggesting that the psychosocial profile of women with FGP is varied.

Narratives about Pain

Personal narratives are the stories people construct in order to make sense of their experiences (Anderson, 2008; White & Epston, 1990). Narratives shape one's sense of identity, thereby influencing actions and attitudes (White & Epston, 1990) making the narratives of women with genital pain invaluable to HCPs. The experience of chronic pain has a significant impact on a person's life and people will attempt to make meaning of their pain through narratives (Charmaz, 2002, 2006b; Conrad & Barker, 2010; Frank, 1993). Pain narratives communicate (to oneself and to others) the process of reconstruction of the self after the destructive effects of chronic pain (Hydén, 1997). This research explored women's stories and experiences related to FGP and its treatment. It will therefore help health professionals better understand and meet the treatment needs of women with genital pain, thereby improving their quality of life (Gallicchio et al., 2007).

Scaffolding Treatment Seeking for FGP

Within the context of this research, treatment seeking is defined as seeking assistance from a HCP. It is contoured by previous experiences of health, illness and treatment seeking and the current context and narratives that the individual constructs around their treatment seeking experience

(Finfgeld, Wongvatunyu, Conn, Grando, & Russell, 2003; Schwarzer, 2008a). The concepts of lived experience, survivorship and trajectory are useful in understanding the impact of previous experiences, current context and personal narratives on treatment seeking.

The Lived Experience of FGP

The term 'lived experience' is used to describe the first-hand accounts and impressions of living as a member of a group, in this case women with genital pain conditions. The lived experience expresses the personal and unique perspective of a person, and explores how their experiences are shaped by subjective factors. The lived experience acknowledges the integrity of an individual's life and creates a space for storytelling, interpretation, and meaning-making (Boylorn, 2008).

One way to capture and understand the lived experiences of women with genital pain is through narrative identity (McAdams & McLean, 2013). People organise their lived experiences into stories and the stories they construct about their lives evolve and integrate into a narrative identity. Narrative identity reconstructs the autobiographical past and the imagined future to provide a person with purpose and meaning. Through narrative identity people express who they are and where they hope to be in the future (McAdams & McLean, 2013). This lived experience research, utilising the concept of narrative identity, will add to the understanding of the experience of treatment seeking for genital pain conditions by elucidating the meanings women make of their genital pain.

Survivorship of FGP

Survivorship is a way of conceptualising the overall course of an illness and is most often associated with cancer (Naus, Ishler, Parrott, & Kovacs, 2009). It encompasses the physical, psychosocial and economic aspects of an illness trajectory and goes beyond diagnosis and treatment to include quality of life³. Family members, friends and caregivers are a part of the survivorship experience (National Cancer Institute, n.d.). The concept of survivorship involves three components: personal context, adaptation processes and quality of life outcomes (Naus et al., 2009) making it a useful way to understand the variety of ways people may experience chronic conditions. Women vary considerably in the way they adapt to genital pain, with personal context, adaptation and quality of life playing a role (Antoni, 2013; Borg, Peters, Schultz, & de Jong, 2012; Brauer et al., 2007; Stephenson & Meston, 2010). The framework of survivorship allows for exploration of the complexity of living with a chronic condition, making it an ideal framework for understanding the treatment seeking for FGP.

Trajectory of Treatment Seeking for FGP

A trajectory is a pathway or sequence of linked situations or circumstances within a conceptually defined experience (Benson, 2001) and can be characterised as having both duration and shape, terms derived by the seminal work of Glaser and Strauss (1968). Classic examples of trajectories are Glaser and Strauss's work on dying trajectories (Glaser & Strauss, 1968), in which they describe the experiences of people with

³ Survivorship is a concept that can be applied to all who experience a particular illness (e.g., cancer or FGP). It could be argued that because survivorship applies to everyone, it is a meaningless construct. We argue that while it may apply to all participants, the individual woman's quality of life gives meaning to her survivorship.

terminal illnesses from diagnosis to death; and the chronic illness trajectories described by Corbin (1998) and Strauss (1975), that describes the illness's course, as well as the actions taken by those affected by the illness. An example of a treatment seeking trajectory for FGP based on the model by Donaldson and Meana (2011) involves the onset of symptoms, experienced through intra- and interpersonal factors, i.e., agendas, narrative identities and relationships. There is an attempt to manage symptoms without seeking professional help. As the impact of the symptoms on the woman and her relationship increases she may then seek professional help. The effectiveness of the treatment sought, the accumulating impact and consequences of the pain, and intra- and interpersonal factors impact on the experience of survivorship.

The FGP treatment seeking trajectory duration or timing can be characterised as immediate treatment seeking (treatment seeking at the onset of symptoms), delayed treatment seeking (delay of treatment seeking for a period of time after onset of symptoms), discontinuous treatment seeking, or no treatment seeking at all. The shape of the trajectory can be characterised as continuous treatment seeking (treatment seeking is pursued without any disruptions) or episodic treatment seeking (treatment seeking is marked by interruptions and delays). See Figure 1.1 for a preliminary model of the treatment seeking trajectory for FGP. This model is partially based on a cognitive behavioural model developed by Donaldson and Meana (2001) that posits that at the onset of pain women attempt to identify the causal attributes⁴ of the pain, which leads to an attempt to self-manage the pain. As

⁴ This finding confirms an earlier study about causal attributes of FGP (Meana, Binik, Khalife, & Cohen, 1999).

the consequences of the pain increase, the likelihood of seeking treatment increases. The consequences along with the barriers and incentives to treatment seeking interplay to impact the decision to seek treatment.

It would be beneficial to understand the experiences of women who have sought treatment and explore their motivations for doing so. Evidence is also needed on what aspects of the preliminary model are salient to women with the lived experience of genital pain, including how intra- and interpersonal factors such as patient agendas, survivorship and narrative identities influence the treatment seeking trajectory.

Statement of the Problem

Living with chronic pain, and treatment seeking, are subjective experiences. Little is known about the personal framing of the lived experience of FGP. Pain itself is primarily a subjective experience and research is needed to understand FGP in the context of lived experiences. Extant research has not fully conceptualised the subjective experience of treatment seeking for FGP drawing on the personal narratives of the pain survivors, including their personal agendas in treatment seeking. The ways in which treatment seeking for genital pain conditions is influenced by interpersonal processes, such as patient agendas, illness contestation and HCP communication are incompletely understood. Furthermore, the treatment seeking trajectory is influenced by the intrapersonal meanings and cognitions that comprise and feed into the personal narratives of women with FGP. These personal narratives likely colour the distress associated with the pain and treatment seeking, and the women's identities as survivors. There is scarcity of research evidence on how women living with FGP interpret their

treatment seeking behaviour and the related contexts and processes for and survivorship of FGP.

Intra- and interpersonal processes likely mediate the trajectory. The interpersonal influences include the woman's relationships with the HCP and her partner, family and friends; the intrapersonal influences include her experience of symptoms and distress, and the meanings she makes of her experiences.

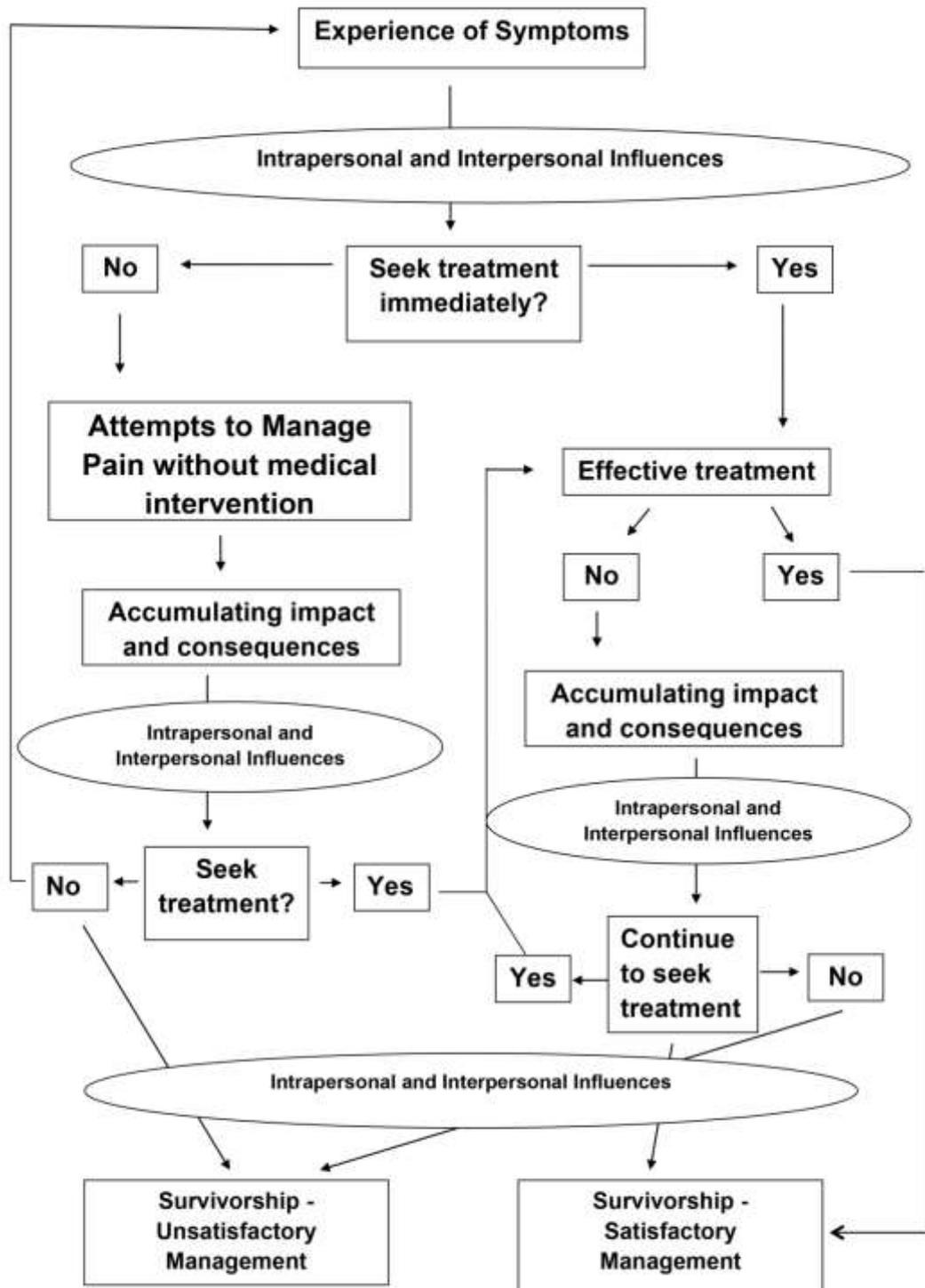


Figure 1.1 Preliminary Model of the Treatment Seeking Trajectory

Research Objectives

The goal of this research is to utilise a lived experience approach (Grbich, 2004) to explore the intra- and interpersonal influences on the treatment seeking of women with genital pain conditions, and to profile their treatment seeking trajectories. Specifically, the study will:

1. Investigate the perceived barriers to and motivations for treatment seeking.

1.1 Explore the nature of the facilitators of treatment seeking for FGP.

1.2 Examine the hindrances to treatment seeking.

2. Characterise the personal agendas that influence the treatment seeking trajectory.

2.1 Explore the ways in which personal (or patient) agendas moderate treatment seeking trajectory experiences of the woman with genital pain.

2.2 Examine the illness contestation processes that moderate the treatment seeking trajectory of the woman with genital pain.

3. Characterise the salient survivorship resources of women seeking treatment for FGP across treatment seeking trajectories, including:

3.1 The intra- and interpersonal processes, and

3.2 The environmental and contextual resources.

4. Characterise the survivorship identities from the treatment seeking histories of women with genital pain conditions.

4.1 Examine the personal narratives that influence survivorship.

4.2 Explore how survivorship narratives align to statuses in treatment seeking trajectories.

Research Questions

The following questions guided the research. From the perspective of the woman with genital pain:

1. What are the perceived motivators and barriers to treatment seeking for FGP?

1.1 What are the facilitators of treatment seeking for genital pain that explain the treatment seeking trajectory?

1.2 What are the hindrances to treatment seeking for genital pain that explain the treatment seeking trajectory?

2. What personal agendas influence the treatment seeking trajectory with genital pain?

2.1 How do self-beliefs moderate the treatment seeking experiences of the woman with genital pain?

2.2 How do perceived illness contestations influence the treatment seeking trajectory of the woman with genital pain?

3. What are the salient survivorship resources of women seeking treatment for FGP across treatment seeking trajectories?

3.1 What are the intrapersonal processes which are resources for treatment seeking for FGP?

3.2 What are the interpersonal processes which are resources for treatment seeking for FGP?

3.3 What environmental and contextual factors influence survivorship, e.g., accessibility of resources?

4. How do women with genital pain construct survivorship identities from their treatment seeking histories?

4.1 What personal narratives are survivorship identities constructed on?

4.2 How do survivorship narratives align to statuses in treatment seeking trajectories?

Significance

This research has practical, methodological and theoretical significance. From a practical standpoint, the research methods used (i.e., lived experience and grounded theory) will lead to a better understanding of the inter- and intrapersonal influences on the treatment seeking trajectory, as well as the barriers to and motivations for treatment seeking. This improved understanding may lead to practical changes that will reduce the environmental and personal barriers that women experience when seeking treatment for FGP, e.g., public education campaigns that reduce the stigma associated with FGP or increase knowledge about services for women with genital pain. This research will also lead to improved health professional understanding about how interactions with women with genital pain influence patient outcomes and the woman's subjective experience of treatment.

Methodologically, this research will showcase and advocate the use of grounded theory and lived experience methods for understanding treatment seeking for contested illnesses. It will demonstrate the importance of using this method for understanding the experience of genital pain conditions and treatment seeking for them.

Current theoretical knowledge about the intra- and interpersonal influences on the treatment seeking for FGP is limited. A cognitive behavioural model proposed by Donaldson and Meana (2011) addresses early genital pain, specifically the period of time before a woman chooses to

seek treatment. This research will build on this knowledge to allow for a theoretical model that will address the entire treatment seeking trajectory from onset of symptoms to effective management or cure. It will also provide insight about the experience of women seeking treatment for genital pain conditions, specifically focusing on the intra- and interpersonal aspects of their experience. It will provide insight into how a health professional can work with a woman with genital pain to assist in achieving better outcomes.

Assumptions

This research is shaped by several assumptions. First, sexuality, health and illness, genital pain and treatment seeking for genital pain are subjective experiences. The meanings the participants assign to these subjective experiences are created by their past and present experiences, as well as by their thoughts, hopes and fears for the future. Second, meaning is co-constructed through the interactions the participants have with others, specifically family members, partners, and HCPs. Finally, it assumes that individuals sharing a common experience may have both common and unique thoughts, behaviours and perceptions to report.

Limitations and Strengths

There are several limitations worth mentioning. First, the study cannot be considered representative of the FGP population because it was a self-selecting sample (Liamputtong, 2009). Furthermore, women at either extreme of the distress continuum (either extremely distressed or low to no distress) may have avoided participation. Highly distressed women may have wanted to avoid talking about an exceedingly distressing experience, or women who were not distressed may have not felt enough motivation to

participate. Another limitation of this research is that the interview schedule was researcher-developed and therefore may be limited in the topics covered. Finally, the interview schedule was not piloted.

There are also a number of strengths associated with this lived experience research. First, lived experience research can guide researchers to pertinent areas for future research. Second, it provides a multidimensional understanding of treatment seeking for FGP which may lead to a more nuanced and empathic approach to women who are seeking treatment for genital pain (Kearney, 2001). As researchers and clinicians gain a more complete understanding of the experiences of the woman with genital pain and her encounters with treatment seeking, the clinical outcomes for women will be improved.

Definition of Key Concepts and Terms

Vital to this thesis are key concepts and terms that help to inform the foundation of this research. The definitions of the terms included here are informed by the literature.

Contested Illness. An illness that is considered illegitimate, with the symptoms being framed as psychosomatic or even non-existent. It may also be an illness that is well defined, however, treatment protocol may be contested (Brown et al., 2012; Conrad & Barker, 2010; Moss & Teghtsoonian, 2008).

Distress. In this study this term refers to any form of distress (i.e., psychological, personally related sexual or relationship distress) that results from the experience of the FGP or treatment seeking for it.

Dyspareunia. This term literally means pain with intercourse (Binik et al., 2007). Dyspareunia can be a symptom of infection, lack of lubrication, cancer, neurologic damage, vaginismus or vulvodynia (Haefner, 2007).

Female Genital Pain (FGP) and Genital Pain Conditions. Generally refers to several vulvovaginal/pelvic pain syndromes including vulvodynia, vaginismus, lichen sclerosis, vulvar dermatose and hidradenitis suppurativa (Amarlraj et al., 2009, pp 2-3; Binik et al., 2007). In this research it refers to vulvodynia and vaginismus.

Health Care Professional (HCP). Any person who is professionally trained to treat women with sexually related problems, e.g., GP and specialist doctors, psychologists, counsellors, occupational therapists, physiotherapists, nurses.

Survivorship. A way of conceptualising the overall course of an illness, encompassing the physical, psychosocial and economic aspects of an illness trajectory (National Cancer Institute, n.d.; Naus et al., 2009).

Trajectory. A pathway or sequence of linked situations or circumstances within a conceptually defined experience (Benson, 2001).

Treatment Seeking. Although this concept can be a broad concept that includes professional help seeking; informal help seeking from the internet, friends and family; treatment seeking decisions; or treatment seeking behaviours, this study focuses on professional treatment seeking. It includes treatment seeking from any HCP and includes treatment seeking decisions and behaviours.

Vaginismus. Previously defined as involuntary vaginal muscle spasm interfering with sexual intercourse (Reissing et al., 2004).

Vulvodynia. "Vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible finding or a specific, clinically identifiable, neurologic disorder" (Haefner, 2007, p. 49).

Summary and Conclusion

Sex and sexual expression is important to a healthy and satisfying life. There are a number of sexual problems, including genital pain conditions, that can interfere with sexual expression. Diagnosis of FGP conditions can be complicated and complex making it difficult for the woman with genital pain to receive a timely diagnosis and effective treatment. The reasons for the difficulty in diagnosing and treating genital pain conditions are likely to be a combination of factors including unclear aetiology, stigma and beliefs about both the cause of the pain and the efficacy of treatment, and the interactions the woman has with HCPs.

There is little research investigating treatment seeking for FGP, particularly research focused on the woman's experience of the entire treatment seeking trajectory. Using grounded theory methods, this qualitative study provides a theory on treatment seeking for FGP that includes the intra- and interpersonal factors that impact treatment seeking for FGP. It also explores the impact of treatment seeking on the woman's quality of life and the interactive nature of treatment seeking and quality of life.

Chapter Two: Literature Review

Healthy sexual expression is important to well-being, and sexual dysfunctions like FGP negatively impact quality of life (World Association for Sexual Health, 2008). The experience of female sexuality and female sexual problems is influenced by societal views of sexuality and sexual problems. This chapter will present a broad overview of the construction of female sexuality, sexual problems and FGP throughout recent history. The current understanding of the aetiology and diagnosis of FGP will also be presented.

FGP is a sexual dysfunction that is difficult to diagnose and treat which can make treatment seeking a distressing experience (Buchan et al., 2007; Nelson et al., 2012). Applying pain coping models to FGP may be helpful in understanding the experience of treatment seeking for FGP. This chapter will present an overview of the literature about treatment seeking for chronic pain and genital pain, and proposes two frameworks, trajectory and survivorship, that are helpful to understanding the experience of FGP. Finally, the literature on the intra- and interpersonal influences on treatment seeking and coping with chronic pain and FGP will be presented.

The Construction of Female Sexuality, Sexual Problems and Genital Pain

Sexuality and sexual problems are understood through the lens of current and historical socio-cultural influences (Morrow, 1994; Tiefer, 2001). The constructs of female sexuality, sexual problems and genital pain have transformed significantly in the last century from being viewed through a moralistic lens in the late 19th and early 20th century, a psycho-physiological lens in the 1930s to the 1950s, a feministic lens in the 1960s and 1970s, a

biological lens in the 1980s, a medical lens in the 1990s, to a contextual lens from the 2000s to now. Table 2.1 presents a summary of the historical construction of female sexuality, sexual problems and genital pain and the ways in which societal influences altered the view of sexuality and sexual problems over time. The approach to sexual dysfunctions has evolved from being viewed as a barrier to fertility, to deviant behaviour, and later as being accepted as worthy of treatment that was predominantly medically focussed. The current approach is more nuanced, incorporating medical and contextual approaches to treatment.

Moralistic Lens

A moralistic lens refers to viewing the world through a system of values and morals that distinguish right from wrong, and judging people's actions according to those criteria. Morality played a significant role in the way the world was viewed in the late 19th century because this time period was influenced by strict Christian religious standards; the result was sexual repression and narrow mindedness (Baldick, 2008; Rosenberg, 1973). While predominant Christian thought viewed female sexuality primarily as a means of procreation, the scientific community recognised female sexual pleasure as important, albeit constructed within narrow boundaries – too little pleasure (frigidity) or too much (nymphomania) was considered pathological (Angel, 2010; Rosenberg, 1973).

Genital pain was acknowledged in the scientific literature during this time period (Binik et al., 2007; Haefner, 2007). The term 'dyspareunia' was coined by a 19th century physician who attributed the aetiology to physical causes, but also emphasised its impact on sexual functioning (Binik et al.,

2007). Dyspareunia was described as "excessive sensibility of the nerves" (Haefner, 2007, p. 48). Physicians referred to vaginismus as "...spasmodic contraction of the sphincter vaginae, resulting from an irritable condition of the nerves..." (Binik et al., 2007, pp. 126-127). It is possible that interference with sexual intercourse and, therefore with fertility, was the major motivation in the treatment of FGP during this time period.

The views of the 19th century that were predicated on a moralistic view of sexual expression were rejected in the late 19th and early 20th century allowing for exploration of sexuality outside the confines of procreation and religious morality (Baldick, 2008). This led to changes in the way female sexuality, sexual problems and genital pain were perceived.

Psycho-physiological Lens

Towards the end of the 19th century concentrated scientific attention to sexuality resulted in the birth of the field of sexology (Hall, 2004; The Kinsey Institute, 2014) and sexuality began to be viewed through a psycho-physiological lens. A psycho-physiological lens refers to viewing sexuality and sexual problems as psychological and physiological in nature, rather than as morally based actions.

During this time period sexology came to be seen as a legitimate scientific field of study, with the first sexology journal being published in 1908 (Moddelmog, 2014; The Kinsey Institute, 2014). The scientific fields of psychiatry and criminology were also gaining prominence and influenced the field of sexology. As a result sexual problems were seen as deviant, and therefore some were forensically classified, i.e., homosexuality, sadism, masochism, fetishism and nymphomania (Angel, 2010; Leiblum, 2007;

Tiefer, 2006a). This view of sexual problems possibly led to a significant under-reporting of sexual problems.

The 1950s saw significant changes to the classification and treatment of sexual dysfunction, with the first Diagnostic and Statistical Manual (DSM) being published in 1952 (American Psychiatric Association, 1952). Sexual problems were considered either sexual deviations or psychophysiological autonomic and visceral disorders. Sexual deviation was included under the section of personality disorders and comprised the diagnoses homosexuality, transvestism, paedophilia, fetishism and sexual sadism. Psychophysiological autonomic and visceral disorders comprised impotence and frigidity (Angel, 2010). Genital pain was not mentioned in the DSM (Binik et al., 2007).

During this time period the field of psychology was psychodynamically focused (Moddelmog, 2014; The Kinsey Institute, n.d.), resulting in the sexological discourse being dominated by the concept of frigidity (Angel, 2010). The discourse of frigidity served to define female sexuality with regards to what was missing or lacking, further perpetuating the narrow confines of 19th century female sexuality (Moore, 2009). With the growth of the field of psychology during this time frame, psychological explanations for genital pain emerged (i.e. the pain was psychological in origin) (Meana & Binik, 1994), although there was less interest in this sexual dysfunction compared to other dysfunctions. Etiological explanations of genital pain tended to emphasise conscious and unconscious motivations, linked genital pain with female hysteria and dismissed the sensory experience of pain.

Views on female sexuality drastically changed with the publication of Kinsey's *Sexual Behavior in the Human Female*, proposing that women were

sexually active beings, widening the narrow view of female sexuality (Moore, 2009; Roof, 2007). Kinsey's body of work along with the feminist movement led to a shift from a psychophysiological lens to a feministic lens.

Feministic Lens

The 1960s and 1970s were a watershed for female sexuality in that Feminism, Women's Rights, the Sexual Revolution and the introduction of the birth control pill challenged the traditional patriarchal views of sexuality, allowing for an expanded acceptance of female sexuality and sexual pleasure (Angel, 2010; Tiefer, 2006a). The feministic lens refers to viewing sexuality through the use of women's voices and a female-centric approach.

During this time period there were two influential voices in the field of sexuality and female sexuality in particular – Shere Hite and Masters and Johnson⁵ (Angel, 2010; Nolan, 2007). In 1976, Shere Hite, a sex educator and feminist, released her report on female sexuality, *The Hite Report* (Nolan, 2007), which challenged the popular notion that women should be able to orgasm through vaginal penetration. Hite's report concluded that women were not sexually satisfied and that society's views on female sexuality must change so that women could lead sexually satisfying lives. Hite's emphasis on sexual satisfaction for women possibly led to a greater willingness of women to seek help for sexual problems.

Masters and Johnson were sex researchers who pioneered research that defined the nature of sexual response (Masters & Johnson, 1966) and the diagnosis and treatment of sexual dysfunction (Masters & Johnson,

⁵ The use of the concept of a lens is somewhat problematic, particularly in the case of Masters and Johnson. Their work spanned three decades from the 50's to the 70's and was bio-physiologically focused. They are included in this lens because this time period is when their work was most influential and because their work likely contributed to the shift towards the medical lens.

1970). Masters and Johnson defined sexual response based on biological urges and outlined three forms of female sexual dysfunction - dyspareunia, vaginismus and orgasmic dysfunction (Angel, 2010; Basson, 2000). The biological framework for sexual problems emphasised by Masters and Johnson possibly led to a shift to the medical lens of the 1980s and 1990s.

In 1976, the International Society for the Study of Vulvovaginal Diseases (ISSVD) recognised "idiopathic vulvar pain as a unique entity and termed it burning vulva syndrome" (Haefner, 2007, p. 48). This condition would later be called vulvodynia.

Medical Lens

Female sexuality continued to be influenced by feminism and the sexual revolution during the 1980s and 1990s further strengthening the notion that female sexual pleasure is important (Boyle, Dunne, Purdie, Najman, & Cook, 2003). Another significant influence during this time period was the trend towards biological explanations in the fields of medicine and psychiatry, with the on-flow effect being the medicalisation of sexuality, (Conrad, 2005; Hartley, 2006; Tiefer, 2006b) or viewing sexuality through a medical lens. This trend towards biology is evidenced in the publication of DSM-III and DSM-III-R in the 1980s and the release of Viagra in the 1990s.

The DSM-III and III-R were published in 1980 and 1987, respectively, and represented a huge shift from psychoanalytic to biological psychiatry. Explicit diagnostic criteria were introduced and the two chapters of sexual problems (sexual deviation and psychophysiological autonomic and visceral disorders) were subsumed into one, entitled *Sexual Dysfunctions*. Female sexual dysfunctions were defined as sexual desire disorder, sexual aversion,

female sexual arousal disorder, inhibited female orgasm, dyspareunia, vaginismus and sexual dysfunction not otherwise specified (American Psychiatric Association, 1980, 1987).

Another significant impact on sexology was the introduction of Viagra in 1998. Viagra was viewed as a pill that could solve men's sexual problems and there was hope that many sexual problems, including female sexual problems, could be treated as medical problems that could be 'fixed' with a pill (Angel, 2010; Tiefer, 2006a). These factors likely led to an increased openness to discussing sexual problems and increased research into sexual problems, including FGP.

As sexology became more medically focused, the definition of vulvodynia, a condition with biological aetiology, continued to be developed, whereas the term vaginismus, a psychosomatic condition, remained largely unchanged in the literature (Lahaie et al., 2010). In 1987 Friedrich (1987) used the term "vulvar vestibulitis syndrome" in the literature (which later became vulvodynia). In 1999, the classification of vulvodynia was further specified as either generalised or localised (Haefner, 2007).

The medicalisation of sexual problems has led to significant gains in treating female sexual problems, including the menopausal symptoms of vaginal dryness and dyspareunia with hormone replacement therapy (Altman, 2009), and neuropathic vulvar pain with anti-depressants (Fischer, 2004; Weijmar Schultz et al., 2005). However, an over-reliance on medical approaches to sexual problems ignores the relational, emotional and psychological aspects of sexual problems (Hart & Wellings, 2002) and

recently researchers and therapists have called for female sexuality and sexual problems to be viewed contextually (Basson, 2000; Tiefer, 2010).

Contextual Lens

A contextual lens refers to the view that context and individuality is integral to female sexuality. The influence of postmodernism, which challenges the belief in universal truth, likely contributed to the shift from a medical to a contextual lens (Scott & Marshall, 2005). The continued influence of feminism (Boyle et al., 2003) and the contextual view of sexuality has resulted in a paradigm shift in the field of sexology – male and female sexuality are different. By the end of the 1990s the Masters and Johnson's biological view of sexual response and the medicalisation of female sexual problems were being questioned because they ignored some of the key components of women's sexual satisfaction - trust, intimacy, respect, communication, affection, and pleasure from non-penetrative sexual activities (Basson, 2000; Leiblum, 1998; Tiefer, 1991). Sexologists now believe an intelligent approach to female sexuality must include the biological, social and emotional context (Angel, 2010; Leiblum, 2007; Tiefer, 2001). This has led to the use of combination therapy, meaning medication (when available), plus therapy to address the psychosocial aspects of sexual problems (Althof, 2012; Angel, 2010).

This contextual focus has also influenced the treatment of complex pain conditions (including vulvodynia and vaginismus) with multidisciplinary treatment, including the services of medicine, pharmacy, anaesthesia, physiotherapy, occupational therapy, social work and psychology (Fishman, 2012). With this broadened approach to female sexuality and sexual

problems in mind, the focus of this chapter will now be the diagnosis and treatment of FGP.

Table 2.1 Summary of the Influences on Female Sexuality, Sexual Dysfunction and Genital Pain

Societal Approach to Sexuality	Societal Influences	Female Sexuality	Female Sexual Dysfunction	Female Genital Pain
Moralistic Lens (Late 19th Century)	Religiously based sexuality, sexually repressed (Baldick, 2008)	Narrowly defined and focused on procreation (Angel, 2010)	Scientific thought beginning to be applied to sexual problems (Leiblum, 2007; Tiefer, 2006a)	Term 'dyspareunia' coined by Victorian physicians and described as "excessive sensitivity of the vulva" (Haefner, 2007, p. 48) Vaginismus referred to as "spasmodic contraction of the sphincter vaginae..." (Binik et al., 2007, p. 127)
Psycho-physiological Lens (Turn of the 20th Century to 1950s)	Rejection of previous eras moralistic approach, scientific approach to sexuality (Baldick, 2008)	Psychoanalytic influence on sexuality (Moddelmog, 2014) Concept of frigidity dominated scientific discourse (Angel, 2010)	Sexual problems entangled with criminology (Angel, 2010) First sexology journal published (Moddelmog, 2014) DSM published - sexual deviance and psychophysiological disorders (American Psychiatric Association, 1952) Kinsey report released broadening the understanding of female sexuality (Roof, 2007)	Etiological explanations emphasised conscious and unconscious motivations, linked genital pain with female hysteria and dismissed sensory experience of pain (Meana & Binik, 1994) Genital pain not included in the DSM (American Psychiatric Association 1952)

Table 2.1 Summary of the Influences on Female Sexuality, Sexual Dysfunction and Genital Pain (cont.)

Societal Approach to Sexuality	Societal Influences	Female Sexuality	Female Sexual Dysfunction	Female Genital Pain
Feministic Lens (1960s and 1970s)	Feminism, women's rights, sexual revolution and 'The Pill' (Angel, 2010)	Hite report released (Nolan, 2007) Greater acceptance of female sexuality and female sexual pleasure (Tiefer, 2006a) Masters and Johnson defined sexual response based on biological urges (Basson, 2000)	Masters and Johnson outlined three forms of dysfunction - dyspareunia, vaginismus and orgasmic dysfunction (Angel, 2010).	Vaginismus defined as "recurrent or persistent involuntary spasm of the ...vagina that interferes with sexual intercourse." (Binik et al., 2007, p. 127) ISSVD recognised idiopathic vulvar pain as a unique entity – "burning vulva syndrome." (Haefner, 2007, p. 48)
Medical Lens (1980s and 1990s)	Continued influence of feminism, sexual revolution (Boyle et al., 2003) Medicalisation of health and illness (Conrad, 2005) Sociobiological influence on psychology (Tiefer, 2006b)	Medicalisation of sexuality (Hartley, 2006; Tiefer, 2006b)	DSM III and DSM IIIR published, introducing dyspareunia as a sexual dysfunction (American Psychiatric Association, 1980, 1987) Viagra released (Angel, 2010; Tiefer, 2006a) Medical focus led to significant changes in the way female sexual problems are treated (Altman, 2009; Fischer, 2004; Weijmar Schultz et al., 2005)	Attempts to further define and classify vulvodynia (Haefner, 2007) The term "vulvar vestibulitis syndrome" came into use (Friedrich, 1987) and was further classified as generalised or localised (Haefner, 2007)
2000s to current	Influence of post modernism (Scott & Marshall, 2005)	Paradigm shift recognising the difference between male and female sexuality (Leiblum, 2007; Tiefer, 2006a)	Pharmacology and recognition of contextual factors leads to focus on combination therapy (Leiblum, 2007; Tiefer, 2006a)	Multidisciplinary approach to genital pain (Fishman, 2012).

The Diagnosis and Classification of Genital Pain Disorders

In light of the changing views of female sexuality and sexual problems, the diagnosis of FGP has been imprecise, which can result in women consulting numerous physicians over a significant period of time before receiving a diagnosis and appropriate treatment (Buchan et al., 2007; Harlow, Wise, & Stewart, 2001). Buchan et al. (2007) found that their participants visited up to 15 physicians and it took a mean time of 24 months to receive a diagnosis of vulvodynia. The participants reported that the journey to diagnosis was distressing and that the process exacerbated their genital pain. Another study (Harlow et al., 2001) found that 40% of participants who sought treatment for pelvic pain did not receive a diagnosis. In this study all participants were screened for vulvodynia via a self-report questionnaire. Of the women who had received a diagnosis from a health professional none of them had been given a diagnosis of vulvodynia. The authors stated that (Harlow et al., 2001, p. 448) “on the basis of our screening questionnaire...traditional diagnoses associated with other forms of pelvic pain disorders (e.g., endometriosis, pelvic adhesions, and myofascial disorders) comprised only a small percentage of women who reported chronic genital pain.” This may indicate that women with vulvodynia and vaginismus are often misdiagnosed.

Until recently vaginismus was defined as “recurrent or persistent involuntary spasm of the musculature of the outer third of the vagina that interferes with sexual intercourse” (American Psychiatric Association, 2000). It is a clinical syndrome that consists of overlapping elements including hypertonic pelvic floor muscles, anxiety, pain, fear and difficulty with

penetration (Crowley, Goldmeier, & Hiller, 2009). Reissing et al. (2004) published the first empirical study of the spasm of vaginismus, finding that spasm was an unreliable diagnostic criterion and recommended that fear of pain should be the differential diagnostic criterion for vaginismus (Reissing et al., 2004). The current diagnostic criteria for vaginismus are “persistent difficulties to allow vaginal entry of a penis, a finger, and/or any object, despite the woman's expressed wish to do so. There is variable involuntary pelvic muscle contraction, phobic avoidance and anticipation/fear/experience of pain” (Basson et al., 2003, p. 226). Vaginismus can be further classified as primary (lifelong) or secondary (acquired), can be situational or global, and partial (uncomfortable or painful penetration) or total (no penetration) (Binik, 2010a). There is some suggestion that total vaginismus may be associated with penetration phobia, whereas partial vaginismus is more likely to be vulvodynia (Engman, Wijma, & Wijma, 2010; Reissing, 2012).

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). It can be classified generalised (affecting the entire vulva), localised (affecting only an area of the vulva, such as vestibulodynia or clitorodynia), provoked (where direct pressure on the vulva causes pain), unprovoked (where the pain appears spontaneously and can be unrelenting), primary or secondary (Haefner, 2007). Vulvodynia is considered a clinical syndrome that involves the overlapping elements of dysfunctional pelvic floor muscles, inflammatory responses and neuropathic pain (Zolnoun et al., 2006).

The DSM-5 (American Psychiatric Association, 2013) subsumed dyspareunia and vaginismus into a new disorder: Genito-Pelvic Pain/Penetration Disorder (GPPPD) – a condition defined by the experience of the inability to have vaginal penetration without marked pain, fear, anxiety and/or tensing or tightening of the pelvic floor muscles. This new diagnosis has some clear strengths. First, it is descriptive and provides a framework for clinical diagnosis and assessment that more widely includes women suffering from pain and penetration difficulties. Additionally, it makes no assumption of cause and reflects the dimensional nature of genital pain, i.e., the inconsistency of genital pain, the co-morbidity of other sexual dysfunctions and the elements of fear of pain and pelvic floor dysfunction. The new diagnosis is not without limitations. Including women with vulvodynia and vaginismus into one category may unnecessarily confuse and complicate treatment and research (Binik, 2010b). Table 2.2 compares the diagnostic criteria for vaginismus, vulvodynia and genito-pelvic pain/penetration disorder.

Further research investigating the experience of symptoms of genital pain could clarify some of the issues surrounding diagnosis and reduce the time it takes a woman to receive a diagnosis and treatment. Quicker and more effective treatment may reduce the long-term impact of genital pain on quality of life and relationships.

Table 2.2 Diagnostic Criteria of Genital Pain

	Vaginismus (Basson et al., 2003)	Vulvodynia (Haefner, 2007)	Genito-Pelvic Pain/Penetration Disorder (American Psychiatric Association, 2013)
Diagnostic Criteria	Persistent difficulties to allow vaginal entry of a penis, a finger, and/or any object, despite the woman's expressed wish to do so. There is variable involuntary pelvic muscle contraction, phobic avoidance and anticipation/fear/experience of pain.	Vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable, neurologic disorder.	Persistent or recurrent difficulties towards vaginal penetration manifested as at least one of the following: <ul style="list-style-type: none"> - Intense fear/anxiety in anticipation of, during, or as a result of vaginal intercourse - Actual pain experienced in pelvis or vulvovaginal area during attempted or as a result of vaginal penetration - Marked tensing or tightening of the lower pelvic/inner-abdominal muscles during attempted vaginal penetration Symptoms cause significant distress
Time Frame	None stated	None stated	Symptoms present for six months
Further Classification	Primary or secondary Situational or global Partial or total	Generalised or localised Provoked or unprovoked Primary or secondary	Lifelong or acquired Mild, moderate, or severe

The Aetiology of Genital Pain Conditions

The aetiological picture for vaginismus and vulvodynia is far from clear (Petersen et al., 2008; Zolnoun et al., 2006). Vaginismus is thought to be psychological in its aetiology with a variety of contributing factors (Reissing, Binik, & Khalifee, 1999). It is likely a conditioned response to factors including negative sexual attitudes, strict religious beliefs, poor sexual education, sexual trauma and dyspareunia. In vaginismus a cycle evolves whereby fear and anticipation of pain increases muscle tone of the pelvic floor, thereby increasing painful or impossible penetration, which then re-enforces the anticipatory fear of painful penetration (Engman et al., 2010).

Vulvodynia is most likely a chronic pain condition with various aetiological factors (infection, inflammation, genetics, hormones, neurological changes and muscle dysfunction). It is thought that any of these factors can lead to physiological changes in three interdependent systems, namely (1) the nervous system in the vestibular mucosa and spinal cord leading to neuropathic pain, (2) the pelvic floor musculature leading to dysfunctional pelvic floor muscles and (3) psychosexual function leading to problems with arousal, desire and orgasm (Bohm-Starke, 2010; Petersen et al., 2008; Zolnoun et al., 2006). Given the aetiological complexity of vulvodynia and vaginismus there are some aspects of these conditions that remain unclear – are they single conditions or a variety of genital pain syndromes, the overlapping of symptoms of vulvodynia and vaginismus and the spasm of vaginismus.

Vulvodynia and Vaginismus: Single Entities or a Variety of Genital Pain Syndromes

Because vulvodynia and vaginismus do not have a single aetiology, it has been argued that they represent a variety of conditions (Binik et al., 2007). Furthermore, Zolnoun et al. (2006) point out that some women respond better to treatments that address the organic factors (e.g., inflammation, neuropathic pain), while others respond positively when the functional factors are addressed through biofeedback and CBT, indicating that there may be multiple syndromes that present as vulvodynia and vaginismus.

The Overlap of Vulvodynia and Vaginismus

Clinically, total vaginismus presents with phobic components, whereas women with partial vaginismus tend not to exhibit phobic reactions to penetration and other sexual activity (Reissing et al., 1999). Partial vaginismus has many common symptoms with vulvodynia, with between 42 and 100% of women with vaginismus also meeting the diagnostic criteria for vulvodynia (Basson, 1996; De Kruiff, Kuile, Weijenborg, & van Larikveld, 2000; Reissing et al., 2004; Ter Kuile, Van Lankveld, Vliet Vlieland, Willekes, & Weijenborg, 2005). Another study found that electromyography readings of women with vaginismus and vulvodynia were not significantly different (Reissing, Brown, Lord, Binik, & Khalifee, 2005).

The Spasm of Vaginismus

The muscle spasm of vaginismus has not been clearly operationalized. It has been defined as an involuntary muscle cramp, hyper-tonicity of the pelvic floor or a defensive reaction of the muscles (Reissing et al., 1999).

There is also a lack of consensus about the muscles involved in vaginismus with some researchers and clinicians referring to a broad group of muscles, while others specify the individual muscles of the levator ani, pubococcygeus and the bulbocavernosus (Lahaie et al., 2010; Reissing, 2002). Furthermore, there is no empirical evidence that a spasm is consistently present in women with vaginismus. Reissing et al. (2004) found that only 28% of women diagnosed with vaginismus displayed vaginal muscle spasm on exam. Other studies that measured the electromyography reading of women with vaginismus have been contradictory with some finding spasm (Frasson et al., 2009; Shafik & El-Sibai, 2002) and others not (Engman, Lindehammar, & Wijma, 2004; van der Velde & Everaerd, 2001; van der Velde, Laan, & Everaerd, 2001). It has been suggested that the presence of phobia and not muscle spasm be the differential diagnostic criteria for vaginismus (Graziottin & Rovei, 2006; Lahaie et al., 2010).

The current uncertainty that surrounds the aetiology and diagnosis of vulvodynia and vaginismus make them difficult conditions to treat (Nelson et al., 2012). Research that compares the experience of women with the various symptoms (e.g., the experience of fear, the experience of pelvic floor dysfunction) could provide some clarity about the diagnostic criteria that differentiates genital pain conditions.

Treatment for Genital Pain

Treatment for genital pain typically includes medical interventions, dermatological and muscular treatments, psychological and sexual therapy and alternative therapies (Fugl-Meyer et al., 2013; Nelson et al., 2012). This

section highlights the most common treatments for vulvodynia and vaginismus and reviews the literature on the efficacy of treatment.

Treatment Options and Treatment Efficacy for Vulvodynia

Effective treatment for vulvodynia should be multimodal and multidisciplinary due to its complex aetiology (Bergeron et al., 2008; Binik et al., 2007; Danielsson, Eisemann, Sjöberg, & Wikman, 2001; Edwards, 2005; Fugl-Meyer et al., 2013; Goldstein & Burrows, 2008; Graziottin, 2001; Kellogg-Spadt, Fariello, & Safaeian, 2008; Nelson et al., 2012; Stockdale & Lawson, 2014; Weijmar Schultz et al., 2005). There are very few randomised clinical trials (RCT) evaluating the efficacy of the usual treatments for vulvodynia and therefore most treatment guidelines are based on clinical observation (Andrews, 2011; Bergeron et al., 2008; Davis, Bergeron, Binik, & Lambert, 2013; Groysman, 2010). The most commonly cited treatments for vulvodynia are pharmacology, vestibulectomy, psychological intervention, skin care, botulinum toxin, dietary changes and acupuncture.

Pharmacology.

Low dose tricyclic anti-depressants or anti-convulsants are used to address neuropathic pain, while anti-thrush and steroidal creams can be used to address infection and inflammation (Fischer, 2004; Weijmar Schultz et al., 2005) which in theory reduce the pain associated with pressure to the vulva. Anecdotal evidence based on clinical experience and a small number of non-RCT studies suggest that oral medications such as tricyclic anti-depressants and anti-convulsants are effective in reducing pain adequately (Groysman, 2010; Harris, Horowitz, & Brogida, 2007), however, given the

methodological limitations (lack of RCTs) it is difficult to draw reliable conclusions about efficacy of these treatments (Andrews, 2011).

Vestibulectomy.

Vestibulectomy is a surgical intervention that removes painful vestibular tissue. One study explored the efficacy of vestibulectomy finding it provided significant pain reduction and increased sexual functioning; both at post-treatment and at 18-month follow-up (Bergeron et al., 2008). This study was the only RCT, however, other studies have shown vestibulectomy to be between 43 and 100% effective, with the majority of participants surpassing 60% efficacy (Andrews, 2011; Bergeron et al., 2001; Bergeron et al., 2008). Although vestibulectomy appears to be the most effective treatment, it is not considered first line treatment given the invasive nature of surgery (Curran, Brotto, Fisher, Knudson, & Cohen, 2010).

Physiotherapy and biofeedback.

Physiotherapy and biofeedback are used to return the dysfunctional pelvic floor muscles to a more normal state (Bergeron et al., 2001). There are few randomised trials, however, one study indicated that 79% of their sample had a significant reduction in pain, with 52% able to have pain free intercourse (Glazer, Rodke, Swencionis, Hertz, & Young, 1995). Another study by Bergeron et al. (2008) found biofeedback provided significant pain reduction and increased sexual functioning post treatment and at 18-month follow-up.

Psychological treatments.

Psychological treatments include cognitive behavioural therapy (CBT) and psychoeducation to reduce pain and improve sexual and relationship

function by addressing negative cognitions, and sexual and relationship behaviours that perpetuate pain (Basson & Smith, 2013; Bergeron et al., 2001; Binik et al., 2007; Brotto, Basson, Carlson, & Zhu, 2013; Groysman, 2010; Rosenbaum, 2013). In a previously mentioned study, the efficacy of vestibulectomy, CBT and biofeedback were compared and it was found that all three treatments provided significant pain reduction and increased sexual functioning, both at post treatment and at 18-month follow-up (Bergeron et al., 2001; Bergeron et al., 2008). Other studies support the efficacy of CBT, finding 43-68% of the participants experiencing significant improvement or complete relief of their pain (Abramov, Woman, & David, 1994; Ter Kuile & Weijnenborg, 2006; Weijmar Schultz et al., 1996). A qualitative study, found that mindfulness, a cognitive behavioural treatment, improved symptoms and decreased stress associated with vulvodynia allowing the women to feel more 'normal' and have a greater sense of control over pain management (Brotto et al., 2013).

Skin care.

Measures to reduce skin irritation and manage pain are often suggested by HCPs and include using soap substitutes and products without dyes, fragrances and preservatives. Although this treatment has anecdotal evidence from clinical experience, no studies were found to support the efficacy of this treatment (Groysman, 2010).

Botulinum toxin.

It is hypothesised that the use of botulinum toxin to treat vulvodynia and vaginismus works in two ways, first, it helps to relax the muscles that are in constant contraction thus reducing the mechanical pain of penetration.

Second, it is thought that botulinum toxin has an effect on the release of neuropeptides that are involved in pain and inflammation thus reducing pain at a neurological level as well (El-Khawand, Wehbe, & Whitmore, 2013).

There have not been any large scale studies, however, smaller studies have found that women experience significant pain reduction with the use of botulinum toxin suggesting further research is needed (Abbott, Jarvis, Lyons, Thomson, & Vancaille, 2006; Dykstra & Presthus, 2007; El-Khawand et al., 2013; Groysman, 2010).

Acupuncture.

Acupuncture operates on the premise that pain is due to an imbalance or block of meridians. Acupuncture reduces pain by rebalancing or unblocking the meridians. There have been three small studies (n = 8 to 13 participants) exploring the efficacy of acupuncture. Powell and Wojnarowska (1999) found that 9 of 12 participants reported reduced pain after acupuncture, while 7 of 8 participants of another study described reduced pain with intercourse after acupuncture treatment (Curran, Brotto et al. 2010). The third study found that 10 of their 13 participants reported less pain at three-month follow-up (Danielsson, Sjoberg et al. 2001). These results indicate further study of acupuncture is needed.

Treatment Options and Treatment Efficacy for Vaginismus

Current treatments for vaginismus are designed to address both the phobic and muscular components of the condition. Typical treatment consists of pelvic floor physiotherapy, pharmacology, general psychotherapy, CBT and sex therapy with first line treatment for vaginismus being CBT (Lahaie et al., 2010).

CBT.

CBT for vaginismus generally includes exposure therapy to extinguish the conditioned reflex and pain avoidance response, and training to identify and gain control over the pelvic floor muscles involved in the vaginistic reflex (ter Kuile et al., 2009; Van Lankveld et al., 2006). It also involves the elimination of fear of penetration by building trust with the partner and allowing the woman control over all attempts at penetration, through the use of relaxation techniques, psychoeducation, and sensate focus activities (Engman et al., 2010; Rosenbaum, 2013; Wijma & Wijma, 1997). Although RCTs are scant, studies indicate that CBT is between 21 and 61% effective in allowing women to participate in and enjoy intercourse at greater than one year post-treatment (Engman et al., 2010; van Lankveld et al., 2006).

Pelvic floor rehabilitation.

Pelvic floor rehabilitation is a program that combines behaviour modification and pelvic floor exercises. It aids in developing awareness and control of the pelvic floor musculature, thereby restoring muscle function and reducing pain. Relaxation techniques, local tissue desensitisation, vaginal dilation, biofeedback and manual therapy may all be used in the rehabilitation process (Lahaie et al., 2010). Although current research indicates pelvic floor rehabilitation may be helpful in the treatment of vaginismus (Reissing, Armstrong, & Allen, 2013), there are no RCTs to date that demonstrate the efficacy of this treatment (Lahaie et al., 2010). Two studies report 100% efficacy of the use of biofeedback immediately following treatment, however, in another study that looked at six-month follow-up the

success rate was 60% (Barnes, Bowman, & Cullen, 1984; cited in: Lahaie et al., 2010; Seo, Choe, Lee, & Kim, 2005).

Pharmacology.

Three pharmacological treatments have been used for the treatment of vaginismus. Local anaesthetics are proposed to work based on the assumption that the muscle tightness is a result of pain. The efficacy of this treatment is unknown as only two case studies have been reported in the literature (Lahaie et al., 2010; Peleg, Press, & Ben-Zion, 2001). Another pharmacological treatment for vaginismus is the use of anxiolytics in conjunction with psychotherapy, which is based on the belief that vaginismus is the result of trauma, anxiety and phobia. This treatment has limited support in the literature with no RCTs reported (Lahaie et al., 2010).

Botulinum toxin injections for vaginismus are believed to work by relaxing the muscles and reducing neurological pain (El-Khawand et al., 2013). One small study used a control group, who received an injection of saline, found that the women treated with botulinum toxin were able to engage in satisfactory intercourse compared to the control group. The successful outcome persisted for an average of 10 months (Ghazizadeh & Nikzad, 2004). Other uncontrolled clinical studies report between 63 and 100% success rate, however, there are methodological limitations with all of these studies (Bertolasi et al., 2009; Shafik & El-Sibai, 2000). Pacik (2010; 2009; 2011) suggests injecting botulinum toxin and inserting vaginal dilators while the patient is under anaesthesia, however, there are no published studies to date regarding the efficacy of this combination of treatments.

Further research is needed to determine the efficacy of botulinum toxin in the treatment of vaginismus.

General psychotherapy.

The premise behind general psychotherapy to treat vaginismus is that it addresses the negative sexual attitudes, lack of sexual education and/or childhood trauma (Long, Burnett, & Thomas, 2005). Marital therapy, individual psychotherapy and hypnosis have all been investigated as treatments for vaginismus with all but two studies being case reports (Ben-Zion, Rothschild, Chudakov, & Aloni, 2007; Delmonte, 1988; Elkins, Johnson, Ling, & Stovall, 1986; Gottesfeld, 1978; Harman, Waldo, & Johnson, 1994; Hawton & Catalan, 1990; Kennedy, Doherty, & Barnes, 1995; Kleinplatz, 1998). Of the two studies that were not case reports, the interventions included not only psychotherapy but also other interventions, including biofeedback and behavioural treatments, therefore the efficacy of general psychotherapy is difficult to assess (Ben-Zion et al., 2007; Kennedy et al., 1995). These studies reported a 78 to 100% success rate, e.g., pain-free intercourse in one study (Ben-Zion et al., 2007) and reduced psychological distress in the other (Kennedy et al., 1995). Both studies had significant methodological limitations, including small sample sizes, no control groups and no follow-up data (Lahaie et al., 2010). Further methodologically sound research about the efficacy of psychotherapy as a treatment of vaginismus is needed.

There is a significant body of work indicates there are efficacious treatments available, however, with the relatively small number of randomised controlled trials there remains a lack of knowledge about the

efficacy of treatments (see Tables 2.3 and 2.4 for a summary). Therefore, HCPs are often forced to guess about what treatments may alleviate the individual woman's symptoms. Making unsuccessful suggestions may lead to frustration for both the woman and the HCP. The HCP may believe the woman is experiencing psychosomatic symptoms and the woman may feel she needs to find another HCP or to discontinue treatment. For women with the phobic component of vaginismus, repeated exams may exacerbate symptoms of fear and lead to a discontinuation of treatment. For these reasons rigorous research is needed to test new treatment options.

Furthermore, understanding the experience of genital pain and receiving ineffective treatment for it, may help HCPs to better support women as they go through the process of finding effective treatment. Applying a framework to the experience of FGP can help researchers and clinicians to organise the experiences of genital pain in a way that can shape future research and treatment. Two frameworks that can help organise the experience of FGP are trajectory and survivorship.

Table 2.3 Summary of gold standard studies of treatment approaches for vulvodynia

<i>Vulvodynia</i>		
Treatment approach	Supporting research	Conclusions about treatment approach
Pharmacology		
Systemic medication	Foster et al., 2010 (RCT)	Systemic medication failed to reduce pain >placebo
Topical medication	Danielsson et al., 2006 (RT)	Topical Lidocaine as effective as biofeedback, however, there was no control group
Vestibulectomy	Bergeron et al., 2001 (RT) and 2008 (2.5 yr follow-up)	Vestibulectomy resulted in about twice the pain reduction compared to the two other treatments At follow-up pain reduction was maintained
Biofeedback/physiotherapy	Bergeron et al., 2001 (RT) and 2008 (2.5 yr follow-up)	Approximately 30% reduction in pain, which was maintained at 2.5 yr follow-up
Cognitive behavioural therapy	Bergeron et al., 2001 (RT) and 2008 (2.5 yr follow-up)	Approximately 30% reduction in pain, which was maintained at 2.5 yr follow-up
Skin care, Botulinum toxin injections, acupuncture	No RTs or RCTs	

Table 2.4 Summary of gold standard studies of treatment approaches for vaginismus

<i>Vaginismus</i>		
Treatment approach	Supporting research	Conclusions about treatment approach
Pharmacology	No RTs or RCTs	
Biofeedback/physiotherapy	No RTs or RCTs	
Cognitive behavioural therapy	Van Lankveld et al., 2006 (RCT)	21% of the CBT participants reported successful intercourse at the 12-month follow-up. Small effect size of the treatment warrants further research.
General psychotherapy	No RTs or RCTs	

Trajectory and Survivorship: Underpinning Concepts

The concepts of trajectory and survivorship refer to frameworks for conceptualising the overall course of a chronic illness or condition (Henly, Wyman, & Gaugler, 2011; Naus et al., 2009). A trajectory framework has been applied to a number of illnesses and conditions, including illness in older adults (Godfrey & Townsend, 2008), traumatic injury (Halcomb & Davidson, 2005), multiple sclerosis (Miller, 1993), kidney disease (Schell & O'Hare, 2013), stroke (Burton, 2000), muscular dystrophy (Boström & Ahlström, 2004) and dying (Glaser & Strauss, 1968), while most of the survivorship literature focuses on living with cancer (Blows, Bird, Seymour, & Cox, 2012; Doyle, 2008; Gao & Dizon, 2013; Miller, Merry, & Miller, 2008).

Trajectory Defined

A trajectory begins with onset of symptoms, however, pre-trajectory factors influence the trajectory. The trajectory continues until the symptoms are resolved, or in the case of chronic illnesses the trajectory continues until death (Burton, 2000; Corbin & Strauss, 1992; Miller, 1993). Although an illness trajectory has a general course, for example full remission of symptoms, chronicity or death, the individual path is variable depending on the actions and interactions of individual factors (Halcomb & Davidson, 2005). Wiener, Dodd, and Oberst (1993) liken a trajectory to a projectile travelling through space, in that the projectile's speed and path can be altered by external forces. In other words, the illness trajectory is influenced by the complex interplay of environmental, contextual, intra- and interpersonal factors. Trajectories are multi-dimensional and complex (Corbin, 1999) and are helpful in elucidating the influences on treatment seeking for chronic conditions, and are therefore an ideal framework for understanding treatment seeking for FGP.

Trajectories are phased. Corbin and Strauss (1992) characterised the trajectories of chronic illnesses to comprise phasing, projection, management, and scheming. Another concept that influences trajectories is biography (Corbin & Strauss, 1992; Corbin & Strauss, 1991). Trajectory phasing represents the course of, and the changes that occur in, a chronic condition (Corbin & Strauss, 1992). Trajectory phasing is often dynamic and fluctuating, even in a phase characterised by stability or an upward course (Corbin & Strauss, 1992; Halcomb & Davidson, 2005). Phasing begins with the pre-trajectory phase followed by the trajectory onset. The trajectory then

moves into and often fluctuates between, an acute, stable or unstable phase (Halcomb & Davidson, 2005). The trajectory of chronic illnesses inevitably deteriorates, labelled by Corbin and Strauss (1992) as the 'downward' phase, culminating in death.

The trajectory projection is the meaning that the person and others (e.g., family, HCP) assign to the illness course. For example, a woman with vulvodynia may wonder, "Will I ever be able to have a pleasurable sexual relationship?" (Corbin & Strauss, 1992; Corbin & Strauss, 1991).

Trajectory management is the process of shaping the condition's course through its phases (Corbin & Strauss, 1992). It includes managing symptoms, side effects of treatment and disability, as well as preventing complications. Management includes procuring the needed resources, finances and services (Corbin & Strauss, 1992). Management strategies may change over time in response to the evolving illness, technological and medical advances, and political and societal trends (Corbin, 1998). The trajectory scheme is related to management and refers to the plan for managing the condition and its symptoms. It includes the medical treatment plan and the plan for any alternative treatments. It also includes strategies for managing the impact on the person and their life course, or biography (Corbin & Strauss, 1992; Corbin, 1998; Corbin & Strauss, 1991).

Biography refers to the many facets of the self that make up the person's life course (Corbin & Strauss, 1992; Corbin & Strauss, 1991). Corbin and Strauss (1992, p. 18) define it as "the temporal dimension of identity" and assert that the self and biography constitute identity. Biography can be altered by the course of a condition, just as one's biography can

influence the course of the condition (Charmaz, 2002). This mutual influence is known as reciprocal impact (Corbin & Strauss, 1992).

The trajectory framework is helpful in understanding the impact of symptoms on the person and their life (Corbin, 1998). The application of this framework could also identify influential pre-trajectory factors and explain the way various biographical factors influence treatment seeking and pain management. Survivorship is another framework that conceptualises the course of an illness.

Survivorship Framework Defined

Survivorship is a framework for understanding what it means to “live with, through and beyond” an illness (Naus et al., 2009, p 1358). It is most often defined as the period from diagnosis to death (Doyle, 2008).

Survivorship encompasses the physical, psychosocial and economic aspects of an illness, including quality of life, and the influence of family members, friends and caregivers (National Cancer Institute, n.d.). Doyle (2008) developed a model of cancer survivorship, asserting that cancer survivorship has an antecedent, attributes and consequences. The antecedent is the diagnosis of cancer, while the attributes are that it is a process that begins on diagnosis, and is an uncertain life changing event that has both positive and negative aspects. Finally, cancer survivorship leads to consequences for physical, psychological, social and spiritual health. Chronic pain is an uncertain, life changing event that requires personal adaptation, and it influences quality of life outcomes, making survivorship an ideal framework for understanding how women conceptualise living with and seeking treatment for genital pain.

As with the trajectory framework, survivorship (Miller et al., 2008) has been conceptualised into phases – acute, transitional, extended and permanent. The acute survivorship phase is identified as the medical stage, with the focus being testing and treatment. After treatment is complete, the transition phase focuses on transitioning back into a more normal lifestyle. Extended survivorship represents a time in which the person may be celebrating living through the diagnosis and treatment. It may also be a time of watchful waiting, or even fear about the outcome of treatment. Permanent survivorship is characterised as a gradual sense that survival is possible and by a return to normal life activities. In both the extended and permanent survivorship phases the person may be living with the significant side effects of the condition and its treatment.

Influences on survivorship include personal context, adaptation and quality of life outcomes (Naus et al., 2009). Personal context, adaptation and quality of life are inter-related concepts central to the survivorship framework (Naus et al., 2009). Personal context, not unlike biography, includes the intra- and interpersonal characteristics of the survivor and provides background to the experience of diagnosis, treatment and survival. Some examples of these characteristics are the personality, life stage and physical and mental health of the person, the spiritual or philosophical beliefs of the person, their social and medical supports, and the type and nature of their condition (Naus et al., 2009).

Adaptation involves the appraisal of intra- and interpersonal conflict that is causing a fractured sense of self and adjusting personal goals, beliefs and values (personal context) to allow the fractured self to be unified

(adaptation) (Naus et al., 2009). This includes adapting to the news of the diagnosis, the uncertainty of prognosis, and the short- and long-term effects of the illness and treatment (Alfano & Rowland, 2006; Corbin & Strauss, 1992; Doyle, 2008; Naus et al., 2009).

Quality of life, another key concept in survivorship, is multidimensional, comprising biological, psychological, social and spiritual domains (Bellizzi et al., 2009; Gao & Dizon, 2013; Naus et al., 2009). Quality of life after diagnosis fluctuates through the phases of survivorship and is influenced by the person-specific factors (i.e., personal context) of age, disease factors, and personal values and goals, which may change over time, i.e., adaptation (Gao & Dizon, 2013; Naus et al., 2009). Naus et al. (2009) asserts that quality of life exists on a continuum of positive and negative adjustment and that it is continually changing as the person adapts to their circumstances.

Applying a survivorship framework to the experience of FGP will bring insight into how women adapt to and live with genital pain. This framework may help HCPs understand the characteristics of women with genital pain and how they influence positive and negative adjustment. Research investigating the potential different characteristics of women with the specific types of genital pain may help HCPs tailor their treatment more effectively.

Treatment Seeking for Chronic Pain and Chronic Genital Pain

A significant number of people with chronic pain do not seek treatment for their pain, with international studies indicating that between 25 and 83% do not seek medical treatment for chronic pain due to a number of personal and pain related-factors (Mitchell, Carr, & Scott, 2006b; National

Collaborating Centre for Chronic Conditions, 2008; Peat, McCarney, & Croft, 2001; Veale, Woolf, & Carr, 2008). Treatment seeking for genital pain is not dissimilar, with between 5.6% and 54% of women with genital pain conditions seeking treatment (Danielsson et al., 2003; Donaldson & Meana, 2011; Harlow & Stewart, 2003; Nguyen et al., 2013; Ogden & Ward, 1995).

Treatment seeking is influenced by recognising, interpreting and responding to bodily changes or symptoms (Mojtabai R, 2002). Interpretation of symptoms involves first recognising that something has changed and then making meaning of this change, which is influenced by personal, social and cultural factors (Helman, 2001). One of the reasons cited for delaying treatment for genital pain is the belief that the pain is normal (Donaldson & Meana, 2011). Another cited barrier to treatment seeking is patient and doctor hesitancy to talk about sexual problems, for both male and female patients and doctors (Couldrick, 1999, 2008; Moreira et al., 2005; Nazareth, Boynton, & King, 2003; Nicolosi et al., 2005; Rubin, 2005).

Once the symptoms are interpreted as an illness the person may respond in a variety of ways (e.g., wait and see, self-medicate, see a doctor), again influenced by personal, social and cultural factors (Helman, 2001; Zola, 1973). Zola (1973) proposed five triggers to treatment seeking: 1) interpersonal crisis; 2) interference with social or personal relations; 3) sanctioning of treatment seeking by family or friends; 4) interference with vocational or physical activity; and 5) temporalising of symptoms, i.e., 'I will go if my symptoms have not resolved by tomorrow.' Specific triggers for seeking treatment for genital pain conditions have been identified and include wanting vaginal penetration, wanting to be like other women, wanting

to conceive, and worrying about the impact of the pain on their current or future relationships (Reissing, 2012).

Others have identified reasons for delaying treatment for chronic pain, including fear of the diagnosis (Smith, Pope, & Botha, 2005), severity of symptoms (Safer, Tharps, Jackson, & Leventhal, 1979), cultural factors (Fischer & Farina, 1995), cost of care (Safer et al., 1979), and stigma associated with the illness or health problems (Cooper, Corrigan, & Watson, 2003a). Similar reasons have been cited for delaying treatment for genital pain, as well as believing the symptoms might disappear or that there is no cure, or doubting that medical assistance will help (Donaldson & Meana, 2011).

Once a person decides to seek treatment for a health problem there may be other barriers that prevent diagnosis and effective treatment, such as availability of services (Bicknell & Cohen, 2008), the doctor minimising symptoms (Ballard et al., 2006), discordant patient and doctor agendas (Gross et al., 2013), and poor HCP communication (Bicknell & Cohen, 2008). Similar barriers have been identified in women with genital pain (Marriott & Thompson, 2008), however, a recent systematic literature review highlighted methodological shortcoming in the genital pain research and recommended further research to identify “specific personal, social, environmental and cultural factors that are implicated in the delay women experience in the diagnosis of vulvodynia and vaginismus” (Bond, Mpofu, Weerakoon, & Shuttleworth, 2012a, p 65).

Pain intensity and level of disability are other factors that increase the chances someone will seek treatment; in other words, the longer someone

has had pain, the more intense the pain is and the amount of disability experienced as a result of the pain, the more likely it is that the person will seek treatment (Bedson, Mottram, Thomas, & Peat, 2007; Cornally & McCarthy, 2011; Cote, Baldwin, & Johnson, 2005; Cote, Cassidy, & Carroll, 2001; Dominick, Ahern, Gold, & Heller, 2004; Hagen et al., 2000; Jacob et al., 2003; Leung, McMillan, & Wong, 2008; Ljzelenberg & Burdorf, 2004; Miro et al., 2007; Mitchell, Carr, & Scott, 2006a; Molano et al., 2001; Mortimer et al., 2003; Smith, Penny, Elliott, Chambers, & W, 2001; Thorstensson, Gooberman-Hill, Adamson, Williams, & Dieppe, 2009; Walker et al., 2004). Similarly, Donaldson and Meana (2011) found that when genital pain significantly interferes in the woman's life she will seek treatment for her pain.

There are a multitude of factors that can influence a person's health-related decisions. Applying a theoretical framework, or model, helps to organise and understand these factors.

Health Behaviour Models

Health behaviour models offer explanations about the way people understand health and illness, as well as, explain the way people behave in response to their understanding (Finfgeld et al., 2003). The Health Belief Model (Finfgeld et al., 2003), the Health Action Approach Model (Schwarzer & Luszczynska, 2008) and The Common Sense Representations of Illness Model (Diefenbach & Leventhal, 1996) are examples. However, only the Common Sense Representations of Illness Model has been applied to genital pain (Donaldson & Meana, 2011). Donaldson and Meana (2011) posit that at the onset of pain women attempt to identify the problem and search

for causal attributes, which leads 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. See Table 2.5 for a summary of the models considered here.

Table 2.5 Summary of Health Behaviour Models

Model	Explanation	Strengths	Weaknesses
Health Belief Model (Finfgeld et al., 2003; Janz & Becker, 1984)	Health behaviours are influenced by: <ul style="list-style-type: none"> - Perception of susceptibility to illness - Perception of illness's severity - Perception of the benefits and costs of treatment - Perception of barriers to health behaviour or treatment 	Widely used and studied to understand health behaviours	Poor operationalisation of core concept leads to questions of reliability when applying to health behaviours such as genital pain (Strecher, Champion, & Rosenstock, 1997) Does not address health maintenance behaviours (Diefenbach & Leventhal, 1996) Does not address affective components of health behaviours (Hamilton & Chou, 2014)
Health Action Process Approach (Schwarzer, 2008a)	Health behaviours are influence by: <ul style="list-style-type: none"> - Motivation - Behavioural intention - Self-efficacy - Outcome expectations - Perceptions of the illness - Competencies - Supports 	Expands previous models by including strategic planning for and the maintenance of the health behaviour Applied to a number of health-related behaviours	Does not address the role of environmental factors (Ogden, 2012) Addresses social factors in a limited way, i.e., supports (Ogden, 2012)

Table 2.5 Summary of Health Behaviour Models (cont.)

Model	Explanation	Strengths	Weaknesses
Common Sense Representation of Illness Model (Diefenbach & Leventhal, 1996)	<p>Five dimensions that prompt treatment seeking:</p> <ul style="list-style-type: none"> - Ability to identify the disease or disorder - Perceived severity and impact of the disorder - Perceptions about the illness's development and course - Attributions about the causes of the illness - Perceived level of control to help the symptoms or cure the illness 	<p>This model includes cognitive and emotional factors as well as the individual, social and cultural context (Diefenbach & Leventhal, 1996)</p> <p>Preliminary research suggests this model may apply to early dyspareunia (see Cognitive-behavioural model below)</p>	<p>It is unclear if the interactions between emotional and cognitive factors within the model are individual features or if they are interactive (Diefenbach & Leventhal, 1996)</p>
Cognitive–Behavioural Model of Early Dyspareunia (Donaldson & Meana, 2011)	<p>At the onset of pain women:</p> <ul style="list-style-type: none"> - Attempt to identify the problem - Search for causal attributes - Attempt to control the pain <p>The impact and consequences of the pain, plus the barriers and incentives to treatment seeking influence the decision to seek treatment</p>	<p>A model developed specifically for dyspareunia</p> <p>Addresses affective and cognitive aspects</p>	<p>Only applied to early onset of dyspareunia and young women</p> <p>Only applies to the initial decision to seek treatment and does not explore the entire treatment seeking process</p>

The Health Belief Model

The Health Belief Model (HBM) (Finfgeld et al., 2003; Janz & Becker, 1984) postulates that health behaviour has four factors: (1) perception of susceptibility to illness; (2) the perception of its severity; (3) the perception of the benefits and costs; and (4) the perception of barriers to health behaviour or treatment. These factors interact, leading to the likelihood of a particular health behaviour. Within the sexual health literature the HBM has primarily been applied to safer sexual practices and sexual risk behaviours (Asare, 2012; Croff, 2010; Downing-Matibag & Geisinger, 2009; Hill, 2009; McDonough, 2013; Parks, 2014; Pollack, Boyer, & Weinstein, 2013; Wirtz et al., 2014; Wright, Randall, & Hayes, 2012), and contraceptive use (Herold, 1983; Hester & Macrina, 1985; Katatsky, 1977).

The HBM has not been applied to genital pain conditions; however, several of the factors included in this model could apply to genital pain. For instance, when a woman experiences pain she may seek treatment immediately for her pain if she perceives herself as being susceptible to a sexual transmitted infection (STI). Another woman may choose not to seek treatment due to her perceived stigma associated with an STI. Yet another woman may not feel she can afford the treatment that may be recommended for genital pain, such as physiotherapy. One limitation of this model is that it does not address maintenance of health behaviours, an important factor in chronic conditions that may require long-term treatment, such as genital pain (Diefenbach & Leventhal, 1996). One model that does address maintenance of health behaviours is the Health Action Process Approach.

The Health Action Process Approach

The Health Action Process Approach (HAPA) (Schwarzer, 2008a), is a social-cognitive model that proposes motivation, behavioural intention and self-efficacy, as well as outcome expectations and perceptions of the illness influence health behaviour. The model distinguishes between two phases: the motivation phase and volition phase. Risk perception, consequences, competencies and outcome expectancies influence the motivational phase, which leads to the formation of an intention to behave. It is at this point the volition phase is entered. Planning, action, control, social support and recovery self-efficacy influence the maintenance of health behaviours in the volition stage.

The model has been applied to a number of health-related behaviours including physical exercise, breast self-examination, seat belt use, dietary behaviours, dental flossing (Schwarzer, 2008b), cervical cancer screening (Luszczynska, Goc, Scholz, Kowalska, & Knoll, 2011), and condom use (Teng & Mak, 2011). It has not been applied to genital pain. Research indicates that outcome expectations and perception of sexual problems affect treatment seeking for sexual dysfunctions (Moreira, Glasser, & Gingell, 2005), therefore this model may be usefully applied to genital pain conditions. Its application to genital pain could help HCPs tailor health messages to the particular phase (i.e., motivation or volition) that the woman is in with regards to treatment seeking. Research investigating outcome expectations and perceptions of FGP may also help HCPs tailor messages and treatment strategies that will encourage women to stay motivated to manage their pain.

The Common Sense Representations of Illness Model

The Common Sense Representations of Illness Model (CSM) (Diefenbach & Leventhal, 1996) proposes five dimensions of the experience of illness and factors that prompt treatment seeking: (1) the ability to identify the disease or disorder; (2) the perceived severity and impact of the disorder; (3) perceptions about the illness's development and course; and whether its acute or chronic, (4) the attributions about the causes of the illness and (5) the perceived level of control the person has to help the symptoms or cure the illness. Cognitive and emotional factors are considered in this model, as well as the individual, social and cultural context. These key dimensions interact with existing beliefs enabling the person to make sense of their symptoms and guide actions. As the person obtains new information about their condition and attempts to cope with it, new perceptions are formed, which impact upon coping actions (Hale, Treharne, & Kitas, 2007).

This model has been shown to apply to treatment seeking for early dyspareunia. Donaldson and Meana (2011) found that at the onset of pain women attempt to identify the problem and search for causal attributes, which leads to an attempt to control the pain. When these attempts fail, the impact and consequences of the pain, along with the barriers and incentives to treatment seeking, interplay to impact the decision to seek treatment. While this research gives some insight into initial help-seeking decisions, further research into subsequent health behaviours could provide insight into what keeps women motivated to manage genital pain and could be applied to women who appear less motivated to seek effective management.

Health behaviour models can help researchers and clinicians to understand the processes that influence decisions about treatment, from the initial decision to seek treatment, to decisions about maintaining behaviours that help with managing pain, or the decision to discontinue treatment.

Interpersonal and Intrapersonal Influences on Treatment Seeking

Intra- and interpersonal processes are central to health behaviour models. Interpersonal factors are the processes that occur between two people that influence the outcome of the relationship; in the case of this research the processes that occur during a health care consultation that influence patient outcomes (Carlsson et al., 2007; Emanuel & Emanuel, 1992). Intrapersonal factors, or the thoughts and beliefs a person constructs also influence the treatment seeking trajectory (Rosenfeld, 2004). The intra- and interpersonal factors that influence the treatment seeking trajectory for chronic conditions are: (1) health care professional qualities; (2) patient agendas; (3) illness contestation; and; (4) personal narratives. (Table 2.6 summarises the state of the research of these influences.)

Table 2.6 Research investigating the inter- and intra-personal processes that influence treatment seeking for FGP

Interpersonal process	Current research and results	What further research is needed
HCP Qualities		
Use of power	None	Identify HCP qualities that are most influential on the treatment seeking trajectory*
Empowerment-focused care	Buchan et al., 2007 and Connor et al., 2008 found that empowerment in the form of knowledge improved outcomes	Understand the appropriate use of power in health care interactions Identify HCP–patient alliances and their influence on outcomes*
Patient centred communication	None	Identify agendas of women with genital pain*
Patient Agendas		
	None	Identify HCP agendas Exploration of the interplay between HCP and patient agendas
Illness contestation		
	Buchan et al., 2007 emphasised the importance of diagnosis to reducing contestation	Explore the influence of illness contestation on the treatment seeking trajectory*
	Connor et al., 2008 demonstrated the link between practitioner knowledge and contestation	Identify the HCP factors that influence contestation Identify the woman factors that influence contestation*
Personal narratives		
	None	Identify common narratives* Understand how narratives influence treatment seeking* Understand how narratives influence coping*

Note: *Indicates this is investigated in the current study.

Health Care Professional Qualities

The qualities of the HCP that influence the trajectory of and survivorship with chronic illnesses include the use of power, empowerment-focused care and patient centred communication.

Appropriate use of power.

Power (Asbring & Narvanen, 2004; Goodyear-Smith & Buetow, 2001) is inherent in relationships, including the HCP–patient relationship. Power is neither good nor bad, but can be properly used or misused. Power has three key sources: force, material resources and knowledge. In the HCP–patient relationship power is mainly sourced from knowledge. Power, and particularly when it is sourced from knowledge, is an infinite resource and therefore both the HCP and the patient can have power (Goodyear-Smith & Buetow, 2001). Traditional models of HCP–patient relationships are based on the doctor being all-powerful, all-knowing and making the decisions regarding the patient's healthcare. At the other extreme, the patient is the lone decision-maker with the doctor providing information. Somewhere between these two models is the notion of shared decision making (Charles, Gafni, & Whelan, 1997, 1999; Emanuel & Emanuel, 1992; Mead & Bower, 2000). Roter (2000) identified the optimal model for positive patient outcomes to be 'relationship-centred medicine', rather than either an HCP focus or a patient focus. In this model, HCP and patient interaction is characterised as being medically functional, educational, responsive, facilitative and participatory.

It has been recognised that the interaction between the HCP and the patient is influential in treatment outcomes, which is particularly true in

complex and long-term medical conditions, such as genital pain conditions (Arora et al., 2009). High quality HCP–patient relationships are centred around empowerment of the patient, which involves a continuous process of fostering a healing relationship, addressing patient concerns and anxieties, and promoting self-management (Arora et al., 2009; Epstein & Street, 2007; Masalla et al., 2010; Roter, 2000).

Fostering patient empowerment.

Empowerment (Skuladottir, 2008), a concept important to the relationship-centred model of health care, is a process whereby the HCP bestows power to their patient. This is achieved through genuine concern and respect, and enables the patient to understand and cope with their illness. HCPs who are able to empower their patients help improve patient outcomes (Barry, Bradley, Britten, Stevenson, & Barber, 2000; Becker & Maiman, 1980; Brody et al., 1989; Butler et al., 1992; Chewing & Wiederholt, 2003; Kravitz, Callahan, Azari, Antonius, & Lewis, 1997; Kravitz, Cope, Bhrany, & Leake, 1994; Marquis, Davies, & Ware Jr, 1983; Rao, Weinberger, & Kroenke, 2000; Ware Jr & Davis, 1983; Williams, Weinman, Dale, & Newman, 1995). When empowerment is not a central component of the HCP–patient relationship negative outcomes may ensue, including delay in diagnosis, increased symptomology, iatrogenic mood disorders and significant biographical disruption, e.g., infertility, loss of career and relationships (Buchan et al., 2007; Cox et al., 2003; Lillrank, 2003).

Empowerment, particularly in the form of knowledge, has been shown to improve healthcare outcomes for women considering hysterectomy (Uskul, Ahmad, Leyland, & Stewart, 2003) and women with endometriosis

(Cox et al., 2003), back pain (Lillrank, 2003), chronic fatigue syndrome (Asbring & Narvanen, 2004; Bulow, 2008), chronic muscular pain (Steihaug, 2001), fibromyalgia (Asbring & Narvanen, 2004) and vulvodynia (Buchan et al., 2007; Connor et al., 2008). Patient-focused communication skills promote patient empowerment.

Patient-focused communication.

Patient-focused communication involves information exchange related to the patient's agendas for the consultation (Beck, Daughtridge, & Sloane, 2002; Pawlikowska, Zhang, Griffiths, van Dalen, & van der Vleuten, 2012), positive and supportive talk (Little et al., 2001; Pawlikowska et al., 2012), and a friendly, warm and sympathetic approach (Cooper et al., 2003b; Eide et al., 2004; Mercer & Reynolds, 2002; Paasche-Orlow & Roter, 2003; Pawlikowska et al., 2012; Price, Mercer, & MacPherson, 2006). Although not conclusive, relaxed non-verbal communication appears to promote empowerment as well (Mead & Bower, 2000; Mead & Bower, 2002; Paasche-Orlow & Roter, 2003; Pawlikowska et al., 2012).

Research investigating the HCP qualities that are most influential on the treatment seeking trajectory of women with genital pain is needed to ensure that HCP training is appropriate. Understanding the appropriate use of power in health care interactions with women with genital pain will lead to better HCP–patient alliances and improved outcomes for women with genital pain. Three other processes that can either strengthen or weaken the HCP–patient alliance are understanding patient agendas, personal narratives and illness contestation.

Patient Agendas

Patient agendas are central to understanding patient responses to illness and treatment seeking (Chewning & Wiederholt, 2003), but eliciting patient agendas is often neglected by HCPs (Marvel, Epstein, Flowers, & Beckman, 1999). Patient agendas are the implicit or explicit problems that people bring to the medical consultation, including the patient's expectations, feelings and fears about their health status (Butler et al., 1992). Unmet patient agendas are associated with poorer health outcomes (Barry et al., 2000) and lower patient satisfaction (Brody et al., 1989; Kravitz et al., 1997; Kravitz et al., 1994; Rao et al., 2000; Williams et al., 1995), which is in turn associated with doctor switching and poor adherence to medical recommendations (Becker & Maiman, 1980; Chewning & Wiederholt, 2003; Marquis et al., 1983; Ware Jr & Davis, 1983). The HCP is also affected by the unmet expectations of their patients, with one study finding that unmet patient expectations lead to more demanding consultations (Bell, Kravitz, Thom, Krupat, & Azari, 2002).

Patients often have multiple agendas for their interaction with their HCP, with some of these agendas unvoiced (Rao et al., 2000). HCPs may believe that patients come to them for a specific action (e.g., prescription, test or referral) (Rao et al., 2000), however, the literature suggests there may be other agendas. Patients expect HCPs to provide information and clinical expertise (Guise, McVittie, & McKinlay, 2010; Kravitz et al., 1994; Sanchez-Menegay & Stalder, 1994), explore psychosocial needs (Gross et al., 2013; Newell, Sanson-Fisher, Girgis, & Bonaventura, 1998), take physical

symptoms seriously (Newell et al., 1998), and to listen to and empathise with them (Connor et al., 2008; Cox et al., 2003; Guise et al., 2010).

HCPs also have agendas, and they are not always in line with patient agendas (Butler et al., 1992; Thorne et al., 2006). Thorne et al. (2006), in their study investigating the communication of cancer risk, recognised that the HCPs' and patients' agendas sometimes appear to be at cross purposes. They found that the HCPs need to fully disclose prognosis, rather than give 'false hope', led to significant distress for their patients. The patients described the HCP's communication as "being brutal" and "catastrophising" and they felt the HCP could fully disclose while still communicating hope. Research investigating the agendas of women with genital pain will help HCPs understand and address the agendas of their patients. Research identifying the agendas of HCPs who treat women with genital pain may help individual HCPs recognise their own agendas and help them to balance their professional needs with those of the women they treat. A clearer understanding of conflicting HCP and patient agendas may also enhance empowerment even when there is disagreement about the nature of genital pain.

Illness Contestation

Contestation is a process that occurs when an illness is rejected as illegitimate by researchers, HCPs and policy makers, with the symptoms being framed as psychosomatic or even non-existent (Brown et al., 2012; Conrad & Barker, 2010; Moss & Teghtsoonian, 2008). Contested illnesses do not conform to known or accepted definitions of illness, which leads to disagreements about the existence and aetiology of an illness (Moss &

Teghtsoonian, 2008). The symptoms of contested illnesses are often difficult to recognise and understand, which can lead to tension between medical and lay knowledge (Bulow, 2008; Conrad & Barker, 2010). Even well-defined illnesses can be contested if treatment protocols are poorly understood (Moss & Teghtsoonian, 2008). Given the lack of clarity about aetiology and treatment, FGP can be classified as a contested illness.

Chronic pain is also a highly contested experience. Despite technical advances in pain management, pain is unable to be seen or measured and for this reason HCPs have often contested pain conditions (Conrad & Barker, 2010). Pain behaviours and their associated emotions, such as depression, can also be ambiguous, again leading to doubts about the legitimacy of pain (Jackson, 2005). At the centre of contestation is the notion that illness cannot exist outside of social context or subjective experience (Conrad & Barker, 2010; Moss & Dyck, 1999).

Illness and Pain: Socially Constructed and Subjectively Experienced.

People attribute meaning to their illness within the context of their personal and social relationships, and in this way illness becomes socially constructed (Burr, 2003; Conrad & Barker, 2010; Engebretson, 2003). In some cultures illness may be seen as a spiritual rather than a biomedical problem. In Australia, infertility, although considered a biomedical problem, is not usually seen as an illness (Burr, 2003). Chronic pain is also a socially constructed and subjective experience (Clarke & Iphofen, 2007; Jackson, 2005; Jensen & Karoly, 1992). Being subjective, pain is difficult to verbally describe and objectively measure (Jackson, 2005).

Genital pain has biomedical origins (e.g., pelvic floor and nerve dysfunction), however, the experience of genital pain and its treatment is socially constructed (Farrell & Cacchioni, 2012). For example, heteronormativity, a social process that leads to the view that real sex is 'penis in vagina' sex, often defines what constitutes 'successful' treatment of genital pain (Ayling & Ussher, 2008; Elmerstig et al., 2008; Farrell & Cacchioni, 2012). A woman who is managing her pain in all areas of her life but is unable to participate in pain-free intercourse may assess the results of treatment as unsuccessful because of the value society places on intercourse. Taking a social constructionist approach to chronic pain and illness gives voice to the personal experience of chronic conditions and allows for an intimate view of the embodied, social and contextual experience of chronic genital pain (Conrad & Barker, 2010; Moss & Teghtsoonian, 2008).

Embodied, Social and Contextual Experience of Illness.

Embodied knowledge, or knowledge that comes from the body, is derived from the cognitions, sensations, emotions and biology of the individual's experiences of illness and pain (Moss, 2008). Understanding the embodied experience provides insight into the meaning of illnesses (Plach, Stevens, & Moss, 2004), and in particular the meaning of contested illnesses (Moss, 2008).

Embodied knowledge (Moss & Dyck, 2002) is both discursive and material. Discursive knowledge is derived from ideas, notions, images, and written and spoken words, therefore it is profoundly influenced by the political, social and cultural context, what Moss and Dyck (2002) call a "body

in context". Material knowledge is derived from the physiological, sensual and biological experience (Moss & Dyck, 2002).

Inscription (Moss & Dyck, 2002) involves imprinting an interpretation, derived from discursive and material experiences, on to the body (both the ideal and fleshed body). Morality and values about health and illness are inscribed on the body through social practices and medical processes. For example, the person with chronic pain, a subjective experience, can be inscribed as a 'drama queen', faker, liar etc. Jackson (2005) cites several reasons why chronic pain is problematic for society. First, pain is seen to be a symptom of tissue damage, whereas chronic pain is no longer a symptom but is the problem itself, which can lead to doubts about the pain and its intensity. Furthermore, pain behaviours (e.g., avoidance) and associated emotional states (e.g., distress, depression) can be highly ambiguous. Finally, chronicity (i.e., the pain never ends) and notions of secondary gain can bring moral judgements to those who have chronic pain. Jackson (2005) argues that these features of chronic pain lead the sufferer to be seen to contravene the division between mind and body (dualism) and thwart the codes of morality that surround health and sickness.

Dualism is a philosophical view that considers the mind and the body to be two separate and distinct entities (Mehta, 2011). This view permeates Western culture and research related to genital pain conditions (Farrell & Cacchioni, 2012). Dualism extends beyond mind and body, for example the ideas that one is sick or healthy, disabled or able-bodied, normal or deviant. Chronic illness and chronic pain challenges dualism – a person with chronic

pain is both healthy and sick at the same time, or perhaps neither healthy or sick (Moss & Dyck, 2002; Moss & Teghtsoonian, 2008; Ware, 1992).

Embodied knowledge is constantly in a state of tension. This tension is derived from the ongoing need for the negotiation of power between the person with the embodied knowledge and the HCP (Moss & Dyck, 2002). For instance, it is often the HCP, with the power bestowed upon them by society (and their education), who diagnoses, decides treatment and measures the outcomes of treatment (Werner, Steihaug, & Malterud, 2003). Diagnosis is one of the more salient examples of the power a doctor holds because with diagnosis comes legitimation, social acceptance of symptoms and access to treatment (Dumit, 2006; Hyden & Sachs, 1998; Lillrank, 2003; Moss & Dyck, 2002; Ware, 1992).

Diagnosis: legitimacy, acceptance and treatment.

Diagnosis serves to affirm, legitimise and integrate the experience of pain (Glenton, 2003; Lillrank, 2003). Without diagnosis, HCPs, family and friends, society and even the sufferer themselves may question the authenticity of the symptoms and the character of the sufferer. The questioning of the authenticity of symptoms may become a central characteristic of the illness and can lead to treatment barriers (Conrad & Barker, 2010; Glenton, 2003).

Research indicates that people with chronic back pain feel that diagnosis provides proof to others that their pain and suffering is legitimate (Glenton, 2003; Lillrank, 2003). Diagnosis has been shown to provide similar relief to women with endometriosis (Ballard et al., 2006; Cox et al., 2003), hypothyroidism (Milliken & Northcott, 1996), chronic fatigue syndrome

(Clarke & James, 2003; Hyden & Sachs, 1998), fibromyalgia (Oldfield, 2013), myalgic encephalomyelitis (Moss, 2008) and vulvodynia (Connor et al., 2008).

The experience of chronic pain can destabilise identity, and diagnosis can help integrate the subjective experience of pain into identity, which re-establishes social status as a normal or ordinary person (Lillrank, 2003). The pain is no longer seen as the result of a character flaw and therefore the person is seen to deserve treatment and support (Ballard et al., 2006; Glenton, 2003; Milliken & Northcott, 1996).

Research investigating the experience of illness contestation by women with genital pain will help HCPs to understand the many factors that contribute to illness contestation. This will help HCPs address these factors, decreasing the impact of illness contestation and increasing patient health outcomes and satisfaction with health care consultations. Research investigating illness contestation of genital pain may also help define the woman-related factors that may contribute to contestation. One such factor may be personal narratives.

Personal Narratives

Personal narratives are the stories people construct in order to make sense of their experiences, their life and the world around them (Anderson, 2008; White & Epston, 1990). Personal narratives shape one's sense of identity, thereby influencing the person's actions and attitudes (White & Epston, 1990). They are used to communicate who the person is now, "how they came to be, and where they think their lives may be going in the future" (McAdams & McLean, 2013, p. 233).

The experience of chronic conditions, including chronic pain, has a significant impact on body, biography and self (Clarke & James, 2003; Conrad & Barker, 2010), and as a result the self becomes destabilised (Conrad, 1987; Hydén, 1997) and biography is disrupted (Bury, 1982; Clarke & James, 2003). Illness narratives are used to reconstruct the self after the destructive effects of illness, and to communicate (to oneself and to others) this process of reconstruction (Charmaz, 2002, 2006b; Conrad & Barker, 2010; Frank, 1993; Hydén, 1997). A number of typologies have been used to analyse narratives and are presented in Table 2.7.

Table 2.7 Narrative Typologies

Author	Organising themes	Description
Frank (1993)	Rediscovery of the self who has always been	The discovery of the fundamental self that was not fully realised prior to illness.
	The radical new self	Creation of a self that could never have been imagined before illness.
	There is no new self	Illness is assimilated within the life the person has always led.
Frank (1992, 1993)	Restitution	Desire for health to be restored.
	Chaos	Loss and pain are overpowering.
	Quest	The journey of working out the changes brought about by illness.
Robinson (1990)	Stable	Impact of illness on life goals is stable.
	Progressive	Impact of illness on life goals decreases.
	Regressive	Impact of illness on life goals increases.
Hydén (1997)	Illness as narrative	Illness is expressed in and through narrative. Narrative is central to the occurrence of the illness and the impact of the illness on the person's life. Narrative is a way of integrating or solving the problem of illness.
	Narrative about illness	Symptoms and consequences of the illness are integrated. Narrative is primarily about illness and they helps the person communicate with HCPs.
	Narrative as illness	Narrative generates the illness, for example: A brain injury that interferes with the ability to communicate about the illness. Psychological issues such as repressed memories or events that took place before conscious memories. Inability to understand events such as phobias. Future being bereft of possibilities and choices (depression).

Table 2.7 Narrative Typologies (cont.)

Author	Organising themes	Description
Bulow (2008)	Pilgrimage	The process of recognising oneself as ill and in need of medical assistance.
	Diagnosis	Endows legitimacy.
	Genesis of illness	Questioning the meaning of being ill.
McAdams and McLean (2013)	Psychological adaption and development	Making sense of suffering in a way that strengthens the self.

With its focus on psychological adaptation, McAdams and Mclean's (2013) typology is particularly salient for this research. McAdams and McLean (2013) identified specific narratives that are associated with higher levels of adaptation and those that are not. Table 2.8 summarises these narratives.

Table 2.8 Narratives Associated with Health, Well-being and Maturity

Narrative	Description
Agency	Self-mastery, empowerment and achievement are evident and the author of the narrative is able to affect change.
Communion	Interpersonal connection, intimacy, belonging and care are evident in the narrative.
Redemption	Negative events lead to positive outcomes.
Meaning making	Narrative exposes learning and meaning of suffering.
Exploratory narrative processing	Self-exploration and self-understanding are evident in the narrative.
Coherent positive resolution	Tensions and suffering are resolved to produce resolution and a positive ending.
Contamination	Positives are interpreted as bad or negative, negativity overwhelms or destroys any positivity.

Applying a narrative framework to the experiences of women with genital pain will help HCPs to tailor treatment for and interactions with women with genital pain. For instance, as an HCP comes to recognise contamination narratives in a woman with genital pain they can work with the woman to reframe her experiences to more helpful narratives. Women with genital pain may also benefit from hearing about other women's narratives as a way of examining and reframing their own narratives.

Coping with Chronic Pain and Chronic Genital Pain

Coping with chronic pain is the purposeful attempt to adapt to pain, or manage negative responses to pain (Jensen, Turner, Romano, & Karoly, 1991; Keefe, Salley Jr, & Lefebvre, 1992; Lazarus & Folkman, 1984; McCracken & Eccleston, 2003). The notion of coping has been operationalised several ways in the chronic pain literature, including behaviours that are in response to pain regardless of their impact on the experience of pain, and as behaviours that reduce pain or its impact (McCracken & Eccleston, 2003). Learning, affect, cognition and behaviour have been implicated in coping with chronic pain (Ogden, 2012). These processes are interrelated and interact to influence the experience of pain. For instance, a person may learn to associate increased pain with movement and therefore limit activity, leading to a sedentary life. A sedentary lifestyle may, in turn, lead to the person having more time to focus on (hypervigilance) and catastrophise about the pain, both being cognitions that are associated with higher pain levels and poorer health outcomes (Block & Brock, 2008; Richardson et al., 2009; Turner, Jensen, & Romano, 2000). The concepts of learning, affect, cognitions and behaviours are presented here

separately, however, they are interrelated, which will be discussed in relationship to various pain models.

Learning

Learning, or changes in behaviour that are a result of one's environment (Goubert, Vlaeyen, Crombez, & Craig, 2011), influences the predisposition, development and maintenance of chronic pain and pain behaviours (Flor, 2007; Hermann, 2007). Learning has been shown to influence beliefs about pain and pain treatment, behavioural responses to pain, and pain-related fear (Craig & Prkachin, 1978; Evans, Seidman, Lung, Zeltzer, & Tsao, 2013; Goodman & McGrath, 2003; Olsson, Nearing, & Phelps, 2007; Trost, France, Vervoort, Lange, & Goubert, 2014).

According to operant learning theory, pain behaviours can be reinforced or discouraged through consequences, i.e., rewards and punishments (Gatzounis, Schrooten, Crombez, & Vlaeyen, 2012). Decreased intensity of pain, reduced pain-related fear, the pleasant feeling of rest and the attention of others have been shown to reinforce pain behaviours (Fordyce, 1988; Goubert, Crombez, & Peters, 2004; Jensen, Nielson, & Kerns, 2003; Sullivan, 2008). An example of operant learning in chronic pain is partner solicitousness (partner responses that reinforce pain behaviours, such as doing activities for the person with chronic pain). These partner responses have been associated with increased pain intensity (Flor, Kerns, & Turk, 1987; Turk, Kerns, & Rosenberg, 1992; Weiss & Kerns, 1995), increased disability (Campbell, Jordan, & Dunn, 2012; Raichle, Romano, & Jensen, 2011; Turk et al., 1992), increased pain behaviours (Paulsen & Altmaier, 1995; Romano et al., 1992; Romano et al., 1995; Turk et al., 1992),

decreased levels of activity (Flor et al., 1987), and decreased use of coping statements (Flor, Breitenstein, Birbaumer, & Fürst, 1995; Kerns, Haythornthwaite, Southwick, & Giller Jr, 1990). Similar findings are evident in women with vulvodynia (Desrosiers et al., 2008; Rosen, Bergeron, Glowacka, Delisle, & Baxter, 2012; Rosen, Bergeron, Leclerc, Lambert, & Steben, 2010), however, depression and relationship satisfaction mediate the effects of solicitousness in people with chronic pain and in women with vulvodynia (Flor et al., 1987; Kerns et al., 1990; Kerns & Turk, 1984; Kremer, Sieber, & Atkinson, 1985; Rosen et al., 2014; Toby, 2002; Turk et al., 1992).

Affect

Affective reactions to pain include anger, guilt, frustration, anxiety, depression and fear, and how these emotions are regulated has a direct impact on the experience of pain (Bruehl, Chung, & Burns, 2006; Lethem, Slade, Troup, & Bentley, 1983; Linton & Shaw, 2011; Vlaeyen, Kole-Snijders, Rotteveel, Ruesink, & Heuts, 1995c). Depression, anxiety and fear are associated with poorer outcomes for people with chronic pain (Main, Sullivan, & Watson, 2008; Scott et al., 2007; Tsang et al., 2008) and are important factors in understanding the experience of chronic pain (Ogden, 2012).

A literature review by Bair, Robinson, Katon, and Kroenke (2003) found that depression and chronic pain co-occur in between 13% and 85% of study participants. A more recent multinational, population based study found depression and chronic pain co-occurred in 5% of participants (Tsang et al., 2008). This comorbidity is associated with greater pain intensity, increased disability and poorer treatment outcomes (Bair et al., 2003; Linton &

Bergbom, 2011; Nicholas, 2007; Pincus, Burton, Vogel, & Field, 2002; Sullivan, Adams, Thibault, Corbière, & Stanish, 2006; Vowles, Gross, & Sorrell, 2004). A US national sample found that the rates of anxiety co-occurring with chronic pain were 35% (McWilliams, Cox, & Enns, 2003), with anxiety being associated with increased pain intensity and disability, and poor treatment outcomes (Dersh, Polatin, & Gatchel, 2002; Marks, 2009; McCracken & Gross, 1993; Scott et al., 2007). Similar results (i.e., depression and anxiety being linked with poorer outcomes) have been found in women with vulvodynia (Eanes, Bair, Martin, Iyer, & Zolnoun, 2011; Masheb, Wang, Lozano, & Kerns, 2005). In addition, people with comorbid depression and pain report more severe anxiety than those with pain only (Bair et al., 2013; Poleshuck et al., 2009), demonstrating a complex relationship between depression, anxiety and chronic pain. Moreover, other cognitive and behavioural factors have been implicated in the experience of pain (Linton & Shaw, 2011).

Cognition

Cognitions, or thoughts about pain, can negatively or positively influence pain coping, and include appraisals of pain and self-efficacy, catastrophising, vigilance and acceptance (Esteve, Ramírez-Maestre, & López-Martínez, 2007; Keefe, Rumble, Scipio, Giordano, & Perri, 2004; Linton & Shaw, 2011; Turk & Akifuji, 2002).

Pain appraisals.

Pain appraisals are notions about reality that shape the perception and experience of pain (Lazarus & Folkman, 1984). Positive pain appraisals (e.g., that pain is understandable) have been positively associated with treatment

compliance and positive coping strategies, while negative appraisals (e.g., belief that pain is mysterious) have been associated with poorer outcomes (Jensen, Romano, Turner, Good, & Wald, 1999; Jensen, Turner, Romano, & Lawler, 1994; Stroud, Thorn, Jensen, & Boothby, 2000; Williams & Keefe, 1991; Williams & Thorn, 1989). Moreover, changes in pain appraisals (from negative to positive) have been found to correlate with improved depressive symptoms and physical functioning, and decreased health care consultation (Jensen, Turner, & Romano, 1994; Nieto, Raichle, Jensen, & Miró, 2012).

Pain appraisals of women with vulvodynia have been investigated. Brauer, de Jong, Huijding, Laan, and ter Kuile (2009a) investigated the automatic responses versus the appraisals of sexually related content of women with vulvodynia and found that the automatic responses were positive, whereas the appraisals were largely negative. They concluded that pain appraisals are likely to modulate sexual arousal in women with vulvodynia. Meana and Lykins (2009) found that negative expectations of intercourse coupled with anxiety led to a fearful and threatening appraisal of intercourse. Another study found that women with high and low pain intensity experienced different levels of sexual lubrication (Farmer, Meston, Farmer, & Meston, 2007). The authors interpreted this to mean that there are different etiological factors for women with high and low pain levels. An alternative explanation could be that pain intensity affects the appraisal of sexual activity and therefore lubrication.

Self-efficacy.

Self-efficacy, or the personal belief in oneself to be able to successfully execute outcome-focused behaviour, determines whether behaviours will be initiated and how much time and effort will be given to the specific behaviours (Bandura, 1977). Coping behaviours are mediated by self-efficacy beliefs (Turk & Akifuji, 2002), with higher levels of self-efficacy being linked with positive coping skills, lower levels of disability and improved treatment outcomes (Brekke, Hjortdahl, & Kvien, 2003; French et al., 2000; Lefebvre et al., 1999). With regards to vulvodynia, Desrochers, Bergeron, Khalifee, Dupuis, and Jodoin (2009) found that lower levels of self-efficacy contributed to lower sexual functioning scores.

Catastrophising.

Catastrophising, or worry about or expectation of a major negative consequence from a particular event, has been found to be associated with increased pain, and decreased psychological and physical functioning in both clinical populations (Jensen, Turner, & Romano, 2007; Keefe, Brown, Wallston, & Caldwell, 1989; Richardson et al., 2009; Stroud et al., 2000; Turner et al., 2000) and community samples (Severeijns, van den Hout, Vlaeyen, & Picavet, 2002; Turner, Jensen, Warm, & Cardenas, 2002). High catastrophising scores have also been predictive of depression, pain intensity and disability (Keefe et al., 1989; Turner et al., 2000). Catastrophising has been given attention in the genital pain literature, finding similar results, i.e., higher levels being associated with increased pain intensity and decreased sexual function (Desrochers et al., 2009; Granot & Lavee, 2005).

Vigilance.

Vigilance (Aldrich, Eccleston, & Crombez, 2000), as an adaptive process, is a heightened awareness of danger and functions to prioritise threat and encourage action. When pain is chronic, vigilance may become maladaptive (hypervigilance). Hypervigilance has been linked to higher pain intensity, distress and disability (McCracken, 1997). In women with vulvodynia it is associated with reduced pain tolerance and poor sexual functioning, and may be implicated in the development, maintenance and exacerbation of the condition (Granot & Lavee, 2005; Landry & Bergeron, 2011; Meana & Lykins, 2009; Payne, Binik, Amsel, & Khalifeé, 2005; Sutton, 2013; Sutton, Pukall, & Chamberlain, 2009). The role of hypervigilance in sexual functioning and pain maintenance has been hypothesised. Payne et al. (2005) theorised that when attention is focused on pain during intercourse, less attentional resources are available for the processing of sexually arousing stimuli, reducing sexual function. Furthermore, when sexual functioning (in particular lubrication and genital swelling) is reduced, pain is exacerbated thus reinforcing the attentional focus on pain.

Acceptance.

Acceptance of chronic pain (McCracken & Vowles, 2006; McCracken, Vowles, & Eccleston, 2004) involves reducing attempts to avoid or control pain and focusing on participation in valued activities, despite pain levels. Aspects of acceptance include activity engagement, willingness to engage in activities regardless of pain, and recognising the chronicity of pain. Pain acceptance has been shown to be inversely related to depressive symptoms and disability (McCracken, 2007), while low levels of acceptance are

predictive of higher levels of pain intensity, depression, disability and anxiety (McCracken, 1998; McCracken & Eccleston, 2003). Research investigating acceptance and other cognitive facets of pain found that acceptance and catastrophising were comparable in predicting symptoms of depression (Vowles, McCracken, & Eccleston, 2008). Others found that catastrophising was a better predictor of emotional functioning and acceptance a better predictor of behavioural and functional outcomes (Esteve et al., 2007). A recent qualitative study investigating the impact of mindfulness, of which acceptance is a significant component (Thompson & McCracken, 2011), on vulvodynia treatment outcomes found that acceptance improved the participants' perceived psychological and relational health (Brotto et al., 2013). This indicates that acceptance may impact the experience of genital pain in a similar way to its impact on other chronic pain conditions.

Behaviour

Pain is a private event but can be observed through a person's behaviours, also known as pain behaviours (Kerns, Sellinger, & Goodin, 2011). Because pain behaviours are often reinforced by others (e.g., sympathy, verbal reinforcement of the pain symptoms, relieving the person of responsibilities), they can play a central role in the development and maintenance of chronic pain (McCracken & Samuel, 2007). Treatment that is designed to address pain behaviours has been shown to be effective in increasing activity levels, decreasing unhelpful pain cognitions (e.g., catastrophising) and decreasing affective distress. Moreover when treatment addresses cognitive as well as behavioural factors, outcomes improve further (Vlaeyen, Haazen, Schuerman, Kole-Snijders, & Eek, 1995a).

The pain behaviours of avoidance and guarding can be adaptive behaviours in response to acute pain by allowing and promoting healing. However, in chronic pain they may be maladaptive (Feldt, 2000; Philips, 1987). Avoidant behaviours have been shown to decrease pain tolerance, increase disability despite consistent pain intensity, and undermine self-efficacy (Gheldof et al., 2010; McCracken & Samuel, 2007; Philips, 1987; Woby, Watson, Roach, & Urmston, 2004). Guarding is defined as stiffness, limping, bracing a body part and flinching (Prkachin, Schultz, & Hughes, 2007), and is positively associated with poor treatment outcomes and pain interference, and negatively associated with physical and psychological functioning (Ferreira-Valente, Pais, & Jensen, 2013; Prkachin et al., 2007). Pain cognitions, self-efficacy related to pain management, and memories of past painful experiences influence the maintenance of avoidant behaviours (Leeuw et al., 2007), demonstrating the complex nature of coping.

Affective, cognitive and behavioural factors that are associated with vulvodynia include hypervigilance (Meana & Lykins, 2009; Payne et al., 2005), catastrophising (Payne et al., 2005; Sutton et al., 2009), avoidant behaviours (Arnold et al., 2006; Desrochers et al., 2008; Granot & Lavee, 2005; Landry & Bergeron, 2011), anxiety (Landry & Bergeron, 2011; Payne et al., 2005) and depression (Desrochers et al., 2008). This may indicate that genital pain, and vulvodynia in particular, can be conceptualised as a chronic pain condition (Binik & Binik, 2005; Desrochers et al., 2009) and therefore it may be possible to apply pain coping models to the experience of genital pain. A better understanding of how these affective, cognitive and behavioural processes are implicated in the experience of genital pain would

help HCPs to tailor and focus their treatment strategies and apply pain coping models effectively.

Pain Coping Models

A number of theoretical models have been proposed to explain how the specific processes described above interact and influence the experience of pain. The following models will be presented: stress-diathesis, misdirected problem solving, biopsychosocial, fear-avoidance and psychological flexibility. Table 2.9 presents a summary of each of these models.

Stress Diathesis Model

The stress-diathesis model (Linton & Shaw, 2011) suggests that when a person with chronic pain is under significant psychological distress or when coping resources are lacking, more significant functional limitation and higher levels of emotional distress are experienced. According to this model, stress, depression and anxiety are considered to play a central role in the experience of chronic pain, including genital pain (Eanes et al., 2011; Masheb et al., 2005). Evidence suggests that people with major life adversity, depression, high levels of distress or a history of psychiatric illness are at a higher risk of developing chronic and disabling pain (Linton, 2000; Pincus et al., 2002), providing support for this model. While this model has empirical support it falls short of explaining the complex processes implicated in chronic pain.

Misdirected Problem Solving Model

This model (Aldrich et al., 2000; De Vlieger, Crombez, & Eccleston, 2006; Eccleston & Crombez, 2007; Eccleston, Crombez, Aldrich, & Stannard, 2001) suggests that worry and rumination about pain, and pain

catastrophising are used to avoid or escape pain. It views worrying about pain as part of natural-born problem-solving strategy, but that it can have negative long-term consequences in the case of chronic pain. Pain is commonly viewed as a biomedical problem and therefore problem-solving efforts focus on strategies to alleviate or reduce pain. When these strategies fail, pain is often seen as the primary cause of a number of negative outcomes, reinforcing the need to find strategies that address the biomedical aspects of pain. Worries are reinforced, self-efficacy is destroyed and an endless loop of worry and failed problem-solving attempts ensue. Although this model explains certain cognitive aspects of pain, it does not satisfactorily explore the complex relationship between the cognitive, affective and behavioural processes inherent to chronic pain.

Biopsychosocial Model

The biopsychosocial model (Turk & Akifuji, 2002) provides an integrated approach to chronic pain that incorporates physiological, psychological and social-contextual processes that are dynamic and reciprocal in nature. This model presumes some form of physical pathology. The appraisal of pain is influenced by the belief that activity might aggravate the pain (Jensen et al., 1999; Stroud et al., 2000) and, on the basis of this belief and appraisal, behaviours are determined, e.g., decreasing activity level (Pfungsten et al., 2001). Interpersonal factors, such as responses from significant others (Campbell et al., 2012) and cultural beliefs, e.g., the Western biomedical model (Turk & Akifuji, 2002), also play a role in shaping behaviours. Given that the experience of genital pain includes biological,

psychological and social components (Landry & Bergeron, 2011), the biopsychosocial model may be applicable to vulvodynia.

While the application of these three models to FGP is supported in the literature, they only address part of the overall picture of chronic pain. Given the complexity of genital pain, models that address the dynamic nature of chronic pain may be more helpful in understanding genital pain, e.g., the dynamic model of affect, fear-avoidant model and the psychological flexibility model.

Dynamic Model of Affect

The dynamic model of affect (DMA) (Dima, Gillanders, & Power, 2011; Zautra, Smith, Affleck, & Tennen, 2001) posits that positive and negative affect are independent constructs, rather than extremes on the same continuum. However, when stress is present the degree of independence is decreased and the ability to discriminate between distress and pain is diminished. A number of concepts are important to understanding the DMA, including affect differentiation, generalised discrimination ability, resilience, vulnerability, coping and emotion regulation, and desynchrony.

Affect discrimination in the context of this model states that in normal circumstances people are able to perceive positive affect (PA) and negative affect (NA) as independent dimensions. However, when under stress, affect is experienced as a single positive-negative dimension (Dima et al., 2011). Furthermore, under non-stressful circumstances PA functions independently of pain, while NA and pain are positively correlated. Furthermore, PA can moderate the effects of NA during high pain periods (Strand et al., 2006; Zautra, Johnson, & Davis, 2005b). Under stressful circumstances NA

remains positively correlated to pain, however, PA becomes inversely correlated to pain (Potter, Zautra, & Reich, 2000). In addition, individual differences such as the ability for complex cognitive processing and interpersonal stress have been shown to moderate the association between pain and affect (Davis, Zautra, & Smith, 2004; Strand et al., 2006; Zautra et al., 2001).

Generalised discrimination refers to the ability to separate pain from its emotional consequences (Dima et al., 2011). It has been suggested that the frequent association of pain and distress, over time, may lead to difficulty in discriminating between pain and its emotional consequences (Fordyce, 1976). The DMA (Potter et al., 2000) theorises that the ability to distinguish between pain and its emotional consequences is facilitated by unlinking environmental, affective and somatic stimuli. This interrupts the motivation to participate in unhelpful coping behaviours such as avoidance.

Resilience in this model refers to the buffering effect of PA. During stressful periods PA and NA are inversely correlated, and therefore if PA is high NA will be low (Dima et al., 2011; Zautra et al., 2001; Zautra et al., 2005b). Vulnerability refers to pre-existing conditions (e.g., depression, anxiety, low attachment security) or personality traits (e.g., neuroticism, catastrophising), which predispose the person to increased distress when in pain, or increased pain when distressed (Dima et al., 2011).

Active coping and emotional regulation support resilience and counteract vulnerability, and play a central role in emotional adjustment to chronic pain (Dima et al., 2011). However, the relationship of coping and emotional regulation to adjustment to pain is complex. Pain levels (Affleck,

Urrows, Tennen, & Higgins, 1992; Brown, Nicassio, & Wallston, 1989), affect intensity (Hamilton, Zautra, & Reich, 2005; van Middendorp et al., 2008), relationship status and quality (Johansen & Cano, 2007), gender (Keefe et al., 2004; Riley, Robinson, Wade, Myers, & Price, 2001), personal control and self-efficacy (Dima et al., 2011) appear to have moderating effects on the relationship between coping and emotion regulation, and adjustment to pain.

Desynchrony (Dima et al., 2011) occurs when pain perception and disability do not match the level of pain stimulation. Research suggests that desynchrony is moderated by affective distress. Newth and DeLongis (2004) found that high levels of negative affect in people with rheumatoid arthritis were associated with increasing levels of pain throughout the day (measured in the morning and at night), whereas pain levels remained low throughout the day in people reporting high mood in the morning. Similar results have been found in sickle cell disease (Hoff, Palermo, Schluchter, Zebracki, & Drotar, 2006) and Raynaud's phenomenon (Brown, Middaugh, Haythornthwaite, & Bielory, 2001).

The experience of genital pain is distressing (Bond et al., 2012b) and women who report distress are more likely to record lower overall wellbeing, negative mood, decreased positive mood, more bothersome symptoms, more negative feelings for their partner, higher depression scores and a lower sexual function score (Dennerstein et al., 2008), indicating an applicability of the concepts of affect and generalised discrimination, and desynchrony to genital pain. Furthermore, higher levels of anxiety and depression are associated with genital pain conditions, however, the

direction of the relationship is unclear, indicating anxiety and depression may precede genital pain in some women (Bond et al., 2012b) and could be considered a vulnerability.

Fear Avoidance Model

The fear-avoidance model (Vlaeyen, Kole-Snijders, Boeren, & Van Eek, 1995b; Vlaeyen et al., 1995c; Vlaeyen & Linton, 2000) was proposed to explain how acute or subacute pain might evolve into a chronic pain condition. The essential elements of this model are catastrophising, pain related fear, avoidance, decreased activity, depression and disability. Following the experience of acute pain, catastrophising cognitions develop into a fear of pain, hypervigilance and avoidant behaviours. Avoidant behaviours then lead to decreased activity levels, deconditioning, reduced pain tolerance, disability and depression. Negative affect, in turn promotes catastrophising which reinforces fear, hypervigilance and avoidant behaviours, and so on. If, on the other hand, fear is absent from the acute pain experience, more active forms of coping are engaged and daily function is improved.

This model is supported by evidence that suggests that pain-related fear is associated with unhelpful cognitions and behaviours, such as hypervigilance and inactivity (Crombez et al., 2002; de Jong et al., 2005; Gheldof et al., 2010; Leeuw et al., 2007; Leeuw et al., 2008; Pflingsten et al., 2001; Philips, 1987; Trost, France, & Thomas, 2008, 2011; Verbunt, Smeets, & Wittink, 2010; Vlaeyen et al., 1995b; Vlaeyen & Linton, 2000; Wideman, Adams, & Sullivan, 2009; Woby et al., 2004). Essentially, this model purports that fear of pain and re/injury may be more disabling than the pain itself

(Waddell, Newton, Henderson, Somerville, & Main, 1993). Given the main components of this model – pain catastrophising, fear of pain, and avoidance – have been found to play a significant role in the experience of genital pain (Payne et al., 2005), the fear-avoidance model may contribute to our understanding of genital pain's development, maintenance and exacerbation (Landry & Bergeron, 2011).

Psychological Flexibility Model

The psychological flexibility model (McCracken & Morley, 2014) asserts that behaviour is coordinated through two sets of influences: direct experience (including sensory experiences); and verbal, language-based, or cognitive processes (including appraisals, expectations, judgements, rules, and instructions). Therefore, this model integrates both the cognitive and environmental influences on behaviour. This model includes six interrelated processes – acceptance, cognitive diffusion (the ability to distinguish between thoughts and the things they represent), flexible present-focused attention, self-as-observer (ability to experience our thoughts without being harmed by them), values, and committed action (ability to persist with goals despite difficulties) (Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Hayes, Villatte, Levin, & Hildebrandt, 2011; Levin, Hildebrandt, Lillis, & Hayes, 2012; Twohig, 2012). This model is relatively new in the area of chronic pain, however, research suggests that psychological flexibility may be linked to greater pain tolerance and reduced disability (Hayes et al., 2012; McCracken & Velleman, 2010; McCracken, Vowles, & Eccleston, 2005), indicating that psychological flexibility may reduce the impact of chronic pain. The positive

impact of mindfulness treatment on the experience of genital pain (Brotto et al., 2013) indicates that this model may be applicable to genital pain.

Research that specifically investigates the application of these models to genital pain would help determine the 'fit' of these models to genital pain. It may be that certain aspects of each of the models are applicable, while others are not. A specific model that addresses the experience of genital pain may be warranted to help HCPs and women with genital pain understand how the various aspects of pain symptoms and treatment seeking interact to produce the whole experience of genital pain.

Table 2.9 Summary of Pain Coping Models

Model	Description	Central Process
Stress Diathesis (Linton & Shaw, 2011)	Chronic pain in the context of significant stress leads to an increased chance of developing chronic pain.	<i>Learning:</i> Not a feature of this model <i>Affect:</i> depression, stress <i>Cognitions:</i> Not a feature of this model <i>Behaviours:</i> Not a feature of this model
Misdirected Problem Solving (Aldrich et al., 2000; De Vlieger et al., 2006; Eccleston & Crombez, 2007; Eccleston et al., 2001)	Worry about pain leads to problem solving approaches that focus on biomedical solution. When problem solving fails, pain is interpreted as the problem and the goal of alleviating pain becomes a stronger focus, leading to a perseverance loop.	<i>Learning:</i> Not a feature of this model <i>Affect:</i> Worry <i>Cognitions:</i> Hypervigilance <i>Behaviours:</i> Misdirected problem solving
Biopsychosocial (Turk & Akifuji, 2002)	Physiological, psychological and social-contextual factors dynamically and reciprocally interact in the experience of chronic pain.	<i>Learning:</i> Cultural learnings as well as reward or punishment by significant others (Campbell et al., 2012) <i>Affect:</i> Fear, anxiety and depression <i>Cognitions:</i> Beliefs and appraisals of pain <i>Behaviours:</i> Avoidance
Dynamic Model of Affect (Dima et al., 2011; Zautra et al., 2001)	The presence of stress moderates the ability to discriminate between distress and pain. Central factors include affect differentiation, generalised discrimination ability, resilience, vulnerability, coping and emotion regulation, and desynchrony.	<i>Learning:</i> Initial pairing of distress and pain lead to the inability to discriminate between pain and distress (Fordyce, 1976) <i>Affect:</i> Positive and negative affect as independent constructs under normal circumstances, but under stress they unify <i>Cognitions:</i> Ability to discriminate between distress and pain, and desynchrony <i>Behaviours:</i> Active versus passive behavioural coping strategies

Table 2.9 Summary of Pain Coping Models (cont.)

Model	Description	Central Process
Fear-avoidance (Vlaeyen & Linton, 2000)	Catastrophising and fear lead to avoidance, which leads to inactivity, disability, depression and increased pain; leading to further avoidance, inactivity, disability etc.	<p><i>Learning:</i> Initial reward of inactivity (decreased pain, rest) reinforces unhelpful behaviours and cognitions (Vlaeyen et al., 1995a)</p> <p><i>Affect:</i> Fear, depression</p> <p><i>Cognitions:</i> Catastrophising</p> <p><i>Behaviours:</i> Avoidance</p>
Psychological Flexibility (McCracken & Morley, 2014)	Integrates cognitive and environmental influences and includes six interrelated processes – acceptance, cognitive diffusion, flexible present-focused attention, self-as-observer, values and committed action	<p><i>Learning:</i> Not a feature of this model</p> <p><i>Affect:</i> Does not focus on specific emotions but includes key processes that reduce negative affect</p> <p><i>Cognitions:</i> Acceptance, cognitive diffusion, flexible present-focused attention, self-as-observer, values and committed action</p> <p><i>Behaviours:</i> Does not focus on specific behaviours but includes key processes that encourages functional dimensions of behaviour</p>

Conclusions

The information in this chapter provides a basis for understanding the methodology and results of this study. This chapter presented the background information about treatment seeking for FGP, including the historical and current constructs of female sexuality and sexual problems, the current understanding of the diagnosis and aetiology of FGP, and the efficacy of current treatments and models of treatment seeking. The key concepts related to treatment seeking for genital pain were also presented, including trajectory and survivorship, the intra- and interpersonal processes that influence treatment seeking and coping with chronic pain and genital pain.

HCP qualities play a significant role in the treatment seeking trajectory of women with FGP, with power being particularly salient to outcomes and patient satisfaction. HCPs who appropriately manage patient agendas and avoid illness contestation will empower women with FGP to effectively manage their pain. Narratives point to what is important to the woman, and understanding the narratives that women construct about their genital pain can help guide effective treatment. Further research is needed to understand how HCP qualities, patient agendas, illness contestation and personal narratives interact to shape the experience of FGP and treatment seeking. Qualitative inquiry is an ideal methodology to investigate these influences on the experience of FGP, and the following chapter outlines the methodology of this current qualitative study.

Chapter Three: Methodology

This chapter presents the research design of this study. It discusses why lived experience research and grounded theory methodology were selected and examines the features of grounded theory as applied to this study. It is presented in the following sections: (1) research design; (2) research procedures; (3) participants and setting; (4) data analysis; and (5) participant checking.

Research Design

Charmazian grounded theory within the context of a phenomenological (lived experience) exploration was used to answer the research questions (Charmaz, 2000; Goulding, 2005). Grounded theory is used when the goal of the research is to develop an integrated conceptual hypothesis that explains the relationship between concepts (Hall & May, 2001). Phenomenology is interested in finding out about the lived experience of a phenomenon, and is based on the assumption that there is an essential perceived reality with common features (Starks & Brown Trinidad, 2007). This study's goal was to develop a theory that explains the intra- and interpersonal influences on treatment seeking for genital pain conditions, based on a woman's lived experience. Therefore, a combination of grounded theory and phenomenology was chosen. See Table 3.1 for a summary of the methodologies considered for this study.

Table 3.1 Methodologies Considered

Theory and name	Goals/Characteristics	Audience	Applicable to this research?
Grounded Theory Charmaz (2006a)	Theory developed from data (Glaser & Strauss, 1967, p.1) Positionality, context, social location, race, gender and class are all important (Lempert, 2007) Does not seek truth but addresses human realities that are not uni-dimensional (Corbin & Strauss, 2008; Creswell, Hanson, Clark Plano, & Morales, 2007)	Clinicians, practitioners and researchers (Starks & Brown Trinidad, 2007)	Yes Good fit with goals of research: <ol style="list-style-type: none"> 1. to better understand the process of treatment seeking 2. to produce a theory 3. to represent the woman's point of view
Phenomenology Husserl and Heidegger (Goulding, 2005)	Provide understanding of the lived experience of a particular group of people (Barnacle, 2001; Starks & Brown Trinidad, 2007) Focuses on conscious experience rather than subconscious motivation (Goulding, 2005) Provides a deeper understanding of lived experiences by revealing taken-for-granted assumptions about ways of knowing (Starks & Brown Trinidad, 2007)	Clinicians and practitioners (Starks & Brown Trinidad, 2007)	Yes Research focuses on the lived experience of a phenomenon (Starks & Brown Trinidad, 2007)

Table 3.1 Methodologies Considered (cont.)

<p>Action Research John Collier and Kurt Lewis (McNiff & Whitehead, 2006)</p>	<p>Produces social change in oppressed and exploited communities (Creswell et al., 2007)</p> <p>Understands how individual relationships are formed and reformed through social interaction (Creswell et al., 2007)</p> <p>Focuses on bringing about change in practices (Creswell et al., 2007; McNiff & Whitehead, 2006, p. 7)</p> <p>Goal is to produce a community action plan (Creswell et al., 2007)</p>	<p>Community groups, policy makers, practitioners (Creswell et al., 2007)</p>	<p>No</p> <p>Goal of this research is to develop a theory, not a community action plan.</p> <p>Women with genital pain are not necessarily an exploited or oppressed group.</p>
<p>Case Study Research (Flyvbjerg, 2006; Yin, 2009)</p>	<p>Seeks to explain a phenomenon through in-depth examination of a single case (individual or group) (Yin, 2009)</p> <p>Interested in depth rather than breadth of a phenomenon (Flyvbjerg, 2006)</p>	<p>Academics, policy makers, practitioners (Yin, 2009)</p>	<p>No</p> <p>Interested in developing a theory based on the common experiences of a group of women rather than an individual.</p>

Lived Experience Perspective

The lived experience is the body situated in time and space, and in coexistence with others (Råheim & Håland, 2006). It encompasses the way a person attributes meaning to an experience, and explores a phenomenon, such as treatment seeking, from the perspective of the person experiencing the phenomenon (Grbich, 2004; Råheim & Håland, 2006). This lived experience research investigated how women with genital pain conditions make meaning of their experience of treatment seeking (Dierckx de Casterlé et al., 2011). The qualitative research methods used in this study allowed for a fuller understanding of the experience of treatment seeking by exploring the connection between the physical condition (i.e., vulvodynia and vaginismus), intrapersonal processes and interpersonal relationships, building on current health behaviour theory. It did this by illuminating the processes operating within these theories by exploring the content of the individual woman's experiences of treatment seeking for genital pain conditions (Smith, 1996).

Qualitative Interviews

In-depth, semi-structured interviews were used to gather data for this study (specific information about the instruments used can be found in the subsequent section entitled 'Instruments'), allowing the researcher to gain an understanding of the meaning women attribute to their experience of treatment seeking. The interviewing techniques (Minichiello, Madison, Hays, & Parmenter, 2004) of funnelling, proving and story-telling were used. Funnelling involves starting with more general questions and then moving to more specific questions. Proving is achieved by asking questions that elicit

more detail or clarification. Story-telling involves asking questions that encourage the participant to tell a story about their experience. Participant stories provided rich descriptions of the concepts being explored and allowed the researcher to understand and conceptualise the experiences of the participants (Liamputtong, 2009). Story-telling was a central technique used to develop a theory based on the lived experience of treatment seeking for genital pain.

Issues of Trustworthiness

Several of the techniques inherent to grounded theory methods help to preserve the trustworthiness of the research; specifically, the constant comparative method, purposeful sampling, saturation and reflexivity (Glaser, 1998). The constant comparative method was used to allow the theory to be modified as new codes and categories emerged, thereby verifying the analysis. The use of purposeful sampling meant the participants had experience with the phenomenon being investigated and allowed emerging analysis to be checked and verified by subsequent participants (Charmaz, 2006a; Cutcliffe, 2000; Morse, 2007). Saturation allowed for replication and validation of the data (Morse, 2007), and reflexivity was used by the researcher to examine biases, ground analysis in data and justify decisions (Dey, 2007; Mruck & Mey, 2007). Finally, two other procedures helped to preserve quality in this research, participant checking and triangulation (Tuckett, 2005). Participant checking refers to the process of reporting the findings to participants for their confirmation or added input (Charmaz, 2006a). Triangulation involves using a variety of data sources to investigate

the phenomenon (Denzin & Lincoln, 2000). (Further details of data analysis can be found in the subsequent section entitled: 'Data Analysis'.)

Research Procedures

When a woman agreed to participate, a screening tool was utilised to determine eligibility and gather demographic information (see Appendix A). An appointment was then made for the first interview. At the end of this screening phone conversation, the interviewer sent out the participant information sheet (Appendix B), the informed consent form (Appendix C) and the Female Sexual Distress Scale (FSDS) (Appendix D). The interviews were digitally recorded and transcribed by the interviewer using Express Scribe Transcription software. The remainder of this section will present the research procedures, including ethics, the sampling frame and recruitment, interview procedures and instruments.

Ethics

This project was given ethics approval by the University of Sydney Human Research Ethics Committee in December 2009. In line with the ethical conduct of research, participants were informed that their involvement in this study was completely voluntary, that they were not under any obligation to participate and could withdraw at any time. The participants were informed that every attempt would be made to ensure that no individual participant could be identified in any reports, presentation or documents produced from this research.

Sampling Frame and Recruitment

The sampling frame for this study was women who experience genital pain associated with non-sexual or sexual activity (including oral sex,

masturbation, intercourse, tampon use, pelvic exam, sporting activities etc.). The woman's pain must have been either intermittent or continuous for at least two months. Purposeful sampling was used to recruit participants with the knowledge and experience of the topic being researched. Theoretical sampling, or sampling to gather specific and pertinent data, ideally would have been used in this research to refine categories and clarify the theory (Charmaz, 2006a; Morse, 2007), however, recruiting participants was difficult and therefore theoretical sampling was not able to be employed.

The research process began in August 2009 (see Table 3.2 for a summary of the overall time frames of this study). Recruitment took place in several steps (see Figure 3.1 for a summary of these steps). The first step of recruitment involved contacting HCPs who treat women with genital pain to recruit women for face-to-face and phone interviews (participant details can be found in the subsequent section entitled 'Participants and Setting'). The Melbourne Sexual Health Clinic (MSHC) and a biofeedback practitioner successfully recruited participants. One of the doctors from the MSHC also worked at the Action Centre (a youth sexual health clinic) and agreed to recruit through that clinic as well. The research was advertised through Impotence Australia, The Australian Society for Sexuality Educators, Researchers and Therapists newsletter and the Victorian branch meetings, and a women's health physiotherapy clinic, however, no participants were recruited through these avenues. An attempt was made to recruit through the Royal Women's Hospital Vulvar Disorders clinic, however, they declined to participate.

The second step involved a press release through the University of Sydney which led to an advertisement the University of Sydney e-newsletter. Participants were successfully recruited through this advertisement, as well as through word of mouth.

Table 3.2 Summary of Research Time Frames

Activity	Date start	Date finish
Planning	August 2009	Sept 2009
Ethics application and approval	Sept 2009	Dec 2009 (approval received)
Recruitment for interviews	Jan 2010	March 2011
Interviews	May 2010	March 2011
Ethics modification for online survey	March 2010	April 2010 (approval received)
Online questionnaire	July 2011	March 2012
Data analysis	May 2010	June 2014
Write-up	Dec 2009	Jan 2015

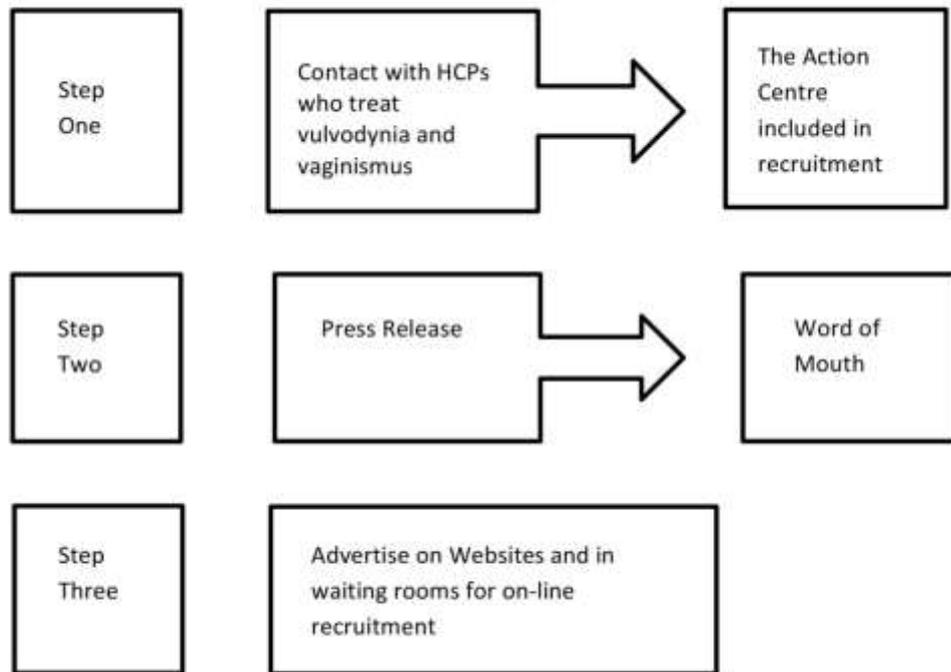


Figure 3.1 Recruitment Process

Participants for the online survey were recruited by placing advertisements on a number of women's health websites (participant details can be found in the subsequent section entitled 'Participants and Setting'). An article about genital pain and this research was placed in a women's health newsletter (see Appendix E). Advertisement postcards were placed in two physiotherapy clinics that treat women for genital pain conditions, and the MSHC (see Appendix F). Additionally, a private practitioner sent the email link for the survey to her contacts. See Table 3.3 for details of online recruitment sources.

Table 3.3 Online Recruitment

Organisation	Recruitment method
Melbourne Sexual Health Centre	Postcards in waiting room
Private practitioner (South Africa)	Email invitation and description
Physio in Melbourne	Postcards in waiting room
Impotence Australia website (national)	Description of research and link to survey
National Vulvodynia Association website (USA)	Description of research and link to survey
Howard Glaser website blog (USA)	Description of research and link to survey
Community Net - a news, information and resources website for the community sector	Description of research and link to survey
Central West Coast Women's Health Centre physios (NSW)	Post Cards in waiting room
Women's Health East website (Victoria)	Description of research and link to survey
Women's Health West website (Victoria)	Description of research and link to survey
Women's Health North (Victoria)	Description of research and link to survey
Hobart Women's Health (Tasmania)	Article and advertisement in their e-newsletter
Gay and Lesbian Health Victoria	Description of research and link to survey

Instruments

Three instruments were utilised to collect data – the Female Sexual Distress Scale (FSDS) (DeRogatis, Clayton, Lewis-D'Agostino, Wunderlich, & Fu, 2008; Derogatis, Rosen, Leiblum, Burnett, & Heiman, 2002), the Treatment Seeking for Genital Pain Interview Schedule (Part A and Part B) and the Treatment Seeking for Genital Pain Online Survey.

FSDS.

The FSDS is a 12-item, self-report measure of sexually related personal distress arising from female sexual problems, e.g., unhappiness, guilt, worry, inadequacy, regrets, embarrassment, anger, frustration, distress, stress, and dissatisfaction about the woman's sex life and her sexual problems. It rates both the frequency (0=never to 4=always) and intensity (0=not at all to 4=extremely) of distress and yields a score of 0 (no distress) to 48 (highly distressed). The FSDS is used to identify and discriminate between women who perceive that they have a sexual problem, and therefore are motivated to improve the quality of their sexual functioning, from those who, although they may have similar sexual symptoms, are not distressed by them and do not interpret them as negative (Derogatis et al., 2002). The FSDS correlates with more general measures of mood (e.g., Brief Symptoms Inventory) and demonstrates a stable unidimensional structure (Derogatis et al., 2002), demonstrating construct validity. It has demonstrated internal consistency (coefficients were generally above 0.80) and test–retest reliability (coefficients were .91) (Derogatis et al., 2002). Finally, it highly discriminates between sexually functional and sexually dysfunctional women (Derogatis et al., 2002). The cut-off points for the FSDS are: 0-14 no sexually

related personal distress; 15 and above significant sexually related personal distress (Bae et al., 2006; DeRogatis et al., 2008; Derogatis et al., 2002).

Treatment Seeking for Genital Pain Interview Schedule (Part A and Part B).

The interviews were conducted using the researcher-developed *Treatment Seeking for Genital Pain Interview Schedule, Part A and Part B*. Part A was a generic schedule developed using the literature around treatment seeking for and distress about genital pain conditions. The questions were designed to explore the quality and impact of symptoms, time frames of treatment seeking, any professional involvement, distress resulting from the symptoms or treatment seeking, and the barriers to and motivation for treatment seeking (see Table 3.4 for the interview schedule - Part A in the context of the research questions). Part B was used in the second interview and was developed using the preliminary analysis of interview one. See Appendix G for an example of interview schedule Part B.

Table 3.4 Interview Schedule in the Context of the Research Questions

Interview Questions	Research question
<p>Effects of the pain</p> <ul style="list-style-type: none"> • How did/does the pain affect you physically and emotionally? • What effect does the pain have on your relationships, your life? 	<p>3. What are the salient survivorship resources of women seeking treatment for genital pain across treatment seeking trajectories?</p>
<p>Treatment seeking</p> <ul style="list-style-type: none"> • What was the response of the health professionals you sought treatment from? • How did their response affect you? • What were the barriers to treatment seeking? • What were the things that motivated you to seek treatment? • If there was a delay in treatment seeking, what were the influences to the delay? What made you decide to seek treatment? 	<p>1. What are the perceived barriers to and motivations for treatment seeking?</p> <p>1.1 What are the facilitators of treatment seeking with genital pain that explain treatment seeking trajectory?</p> <p>1.2 What are the hindrances to treatment seeking with genital pain that explain treatment seeking trajectory?</p> <p>2. What personal agendas influence the treatment seeking trajectory with genital pain?</p> <p>2.1 How do self-beliefs moderate the treatment seeking experiences of the woman with genital pain?</p> <p>2.2 How do perceived illness contestations influence the treatment seeking trajectory of the woman with genital pain?</p>
<p>Distress</p> <ul style="list-style-type: none"> • What were the most distressing aspects of the pain? • What were the most distressing aspects of treatment? • What sorts of things reduced your stress? 	<p>4. How do women with genital pain construct survivorship identities from their treatment seeking histories?</p> <p>4.1 What personal narratives are survivorship identities constructed on?</p> <p>4.2 How do survivorship narratives align to statuses in treatment seeking trajectories?</p>

Treatment Seeking for Genital Pain Online Survey.

The *Treatment Seeking for Genital Pain Online Survey* was an open-ended survey designed using the analysis of the face-to-face and phone interview data. Its purpose was to increase the amount of data gathered, as well as to triangulate data. It was created using Survey Monkey software. Survey Monkey was chosen because it allowed for open ended questions that did not limit the volume of information that could be gathered from the

participants. In addition to demographic information and the FSDS questionnaire, the survey explored the woman's history of her pain and its impact on her life, her history of treatment seeking and her feelings about the treatment seeking process. It explored the impact that treatment seeking had on her, as well as the expectations and hopes she had/has for management of her condition (see Appendix H for a copy of the online survey.)

Participants and Setting

Participants were 26 women with genital pain. The average age of all of the participants was 27 (both the interview participants and on-line participants), with a range of 19-43. The inclusion and exclusion criteria (see Table 3.5) were set to increase the likelihood that participants had either vulvodynia or vaginismus, rather than pain that was caused by active infection, breast feeding or childbirth. Participant information will now be presented on interview participants and on-line participants separately.

Table 3.5 Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Between 18 and 55; • Pain in the vulvar area that is associated with non-sexual or sexual activity (including oral sex, masturbation, intercourse, tampon use, pelvic exam, sporting activity etc.); • Pain must be either intermittent or continuous for at least two months; and • Must speak English (conversational or better). 	<ul style="list-style-type: none"> • Peri-menopausal or menopausal; • Breast feeding; • Given birth within the last six months; and • Active vulvar infection.

Interview Participants

Participants were recruited through the Melbourne Sexual Health Clinic (MSHC) (n=11); the Action Centre (a sexual health clinic for youth) (n=1); a biofeedback practitioner who works in three Australian capital cities (n=3); an

advertisement in the University of Sydney e-newsletter (n=4); and through word of mouth (n=2). All but one of the participants participated in two semi-structured interviews lasting approximately 45 minutes each. Due to personal and health problems one participant (P003) only participated in one 65-minute interview. Another participant (P004) took part in two interviews, however, due to technical problems her second interview was not recorded (see Table 3.6 the method and time of interview).

Table 3.6 Interview Participants: Method and Time of Interview

Part. #	Number of interviews/type of interview	Total minutes	Recruited from
P001	2 face-to-face interviews	103 minutes	MSHC
P002	2 face-to-face interviews	132 minutes	PBP
P003	1 face-to-face interview	62 minutes	PBP
P004	2 telephone interviews (only one recorded)	53 minutes (approx. 50 min)	PBP
P005	2 face-to-face interviews	98 minutes	AC
P006	2 telephone interviews	94 minutes	USyd
P007	2 telephone interviews	99 minutes	USyd
P008	2 telephone interviews	80 minutes	WOM
P009	2 telephone interviews	128 minutes	WOM
P010	1 face-to-face and 1 telephone interview	85 minutes	USyd
P011	2 telephone interviews	48 minutes	USyd
Total	21 interviews	17 hours and 34 minutes	

Note. MSHC=Melbourne Sexual Health Clinic; PBP=Private Biofeedback Practitioner; AC=Action Centre; USyd=University of Sydney e-newsletter; WOM=Word of Mouth.

The average age of the participants was 24.5 with a range of 19-33.

The majority of the women were Anglo-Australian, however, two women had parents who were born in another country and two women were in Australia as students, having been born and raised in another country. All but one of

the women completed or were enrolled in post-secondary education, and all but four held either part-time or full-time work. Of those that were unemployed, all but one were full-time students. Ten of the women were in long-term heterosexual relationships. (See Table 3.7 for demographic information.) All but three of the women had been given a diagnosis from a doctor. For those without a diagnosis, one was assigned by the researcher using the woman's description of her symptoms.

Table 3.7 Interview Participant Demographics

Part. #	Age	Educational status	Employment status	ethnicity	Relationship status	Socio-economic status	Diagnosis	Length of time with symptoms
P001	22	Bachelor's Degree	Full-time employed	Anglo-Australian	Single (in short term relationships with both men and women)	Middle-class	U/G vulvodynia*	10 months
P002	26	Bachelor's Degree	Full-time employed	Anglo-Australian	Long-term heterosexual relationship, no children	Middle-class	P/L vulvodynia*	60 months
P003	19	Year 12	Unemployed	Anglo-Australian	Long-term heterosexual relationship	Living with parents who are middle-class	U/G vulvodynia*	60 months
P004	33	Master's Degree	Full-time employed	Canadian-Australian	Long-term heterosexual relationship	Middle-class	P/L vulvodynia*	72 months
P005	23	Bachelor's Degree	Part-time employed, Part-time student	Chinese-Australian	Long-term heterosexual relationship	Middle-class	U/G vulvodynia *	18 months
P006	26	Bachelor's Degree	Full-time student	Canadian, living in Australia	Long-term heterosexual relationship	Middle-class	Vaginismus*	120 months
P007	25	Bachelor's Degree	Full-time student	Anglo-Australian	Long-term heterosexual relationship	Middle-class	P/L vulvodynia**	60 months

Note. ^=sexual preference not stated; U/G vulvodynia=Unprovoked and generalised vulvodynia; P/L vulvodynia=provoked and localised vulvodynia; *=diagnosis from doctor; **=no diagnosis from a doctor, description of symptoms used to assign a diagnosis.

Table 3.7 Interview Participant Demographics (cont.)

P008	23	TAFE Certificate	Full-time employed	Anglo-Australian	Long-term heterosexual relationship	Middle-class	U/G vulvodynia **	108 months
P009	30	TAFE Certificate	Part-time employed	Anglo-Australian	Long-term heterosexual relationship with one child	Middle-class	P/L vulvodynia*	144 months
P010	23	High School	Full-time student	German, living in Australia	Long-term heterosexual relationship	Middle-class	P/L vulvodynia*	96 months
P011	19	High School	Part-time employed Full-time student	Iranian-Australian	Long-term heterosexual relationship	Middle-class	P/L vulvodynia**	9 months

Note. ^=sexual preference not stated; U/G vulvodynia=Unprovoked and generalised vulvodynia; P/L vulvodynia=provoked and localised vulvodynia; *=diagnosis from doctor; **=no diagnosis from a doctor, description of symptoms used to assign a diagnosis.

Online Participants

A total number of 34 women initiated filling in the online survey. Nineteen of the participants were excluded due to not meeting the selection criteria or not completing enough of the survey to provide meaningful data. A final number of 15 were included. The average age of the on-line participants was 29.4 with a range of 19-43. Two women identified as 'below average income', one as 'low-middle class', three as 'upper middle-class', and the remaining ten identified as 'middle class'. They were an educated sample, with all but three completing post high school education. All but six were in committed long-term relationships. All of the women who were unemployed were students. (See Table 3.8 for a summary of the demographics of the women who participated in the online survey.)

Table 3.8 Online Participant Demographics

Part. #	Age	Educational status	Employment status	ethnicity	Relationship status	Socio-economic status	Diagnosis	Time with symptoms
P104	28	Bachelor's Degree	Full-time student	Lebanese/Irish -Australian	Long-term heterosexual relationship	Upper middle-class	Vaginismus *	4 years
P106	43	Bachelor's Degree	Part-time employment	Anglo-Australian	Single^	Middle-class	U/G vulvodynia **	"years ago"
P108	30	Bachelor's Degree	Full-time employment	Anglo-Australian	Long-term heterosexual relationship	Middle-class s	P/L vulvodynia**	10 years
P111	24	Bachelor's Degree	Full-time student	Caucasian-American	Single^	Middle-class	P/L vulvodynia*	5 years
P112	24	High School	Full-time student	Caucasian-American	Single^	Below average income	U/G vulvodynia *	14 years
P117	19	High School	Full-time student	Caucasian-Australian	Single^	Below average income	U/G vulvodynia**	8 years
P118	36	High School	Full-time employment	Caucasian-American	Long-term heterosexual relationship	Lower middle-class	U/G vulvodynia **	4 months
P121	32	University Degree	Full-time employment	Asian-Australian	Long-term heterosexual relationship	Middle-class	Vaginismus*	3 years
P122	36	PhD	Full-time employment	Anglo-Australian	Long-term heterosexual relationship	Upper middle-class	P/L vulvodynia**	12 years

Note. ^=sexual preference not stated; U/G vulvodynia=Unprovoked and generalised vulvodynia; P/L vulvodynia=provoked and localised vulvodynia; *=diagnosis from doctor; **=no diagnosis from a doctor, description of symptoms used to assign a diagnosis.

Table 3.8 Online Participant Demographics (cont.)

P125	33	Degree	Full-time employment	Anglo-Australian	Single [^]	Middle-class	P/L vulvodynia*	Not stated
P126	27	University	Full-time employment	Anglo-Australian	Long-term heterosexual relationship	Middle-class	Vaginismus **	Not stated
P129	27	Graduate diploma	Full-time employment	Caucasian-Australian	Long-term heterosexual relationship	Middle-class	P/L vulvodynia**	9 years
P132	22	Bachelor's Degree	Full-time student	Anglo-Australian	Single [^]	Upper middle-class	U/G vulvodynia **	1 year
P133	27	Bachelor's Degree	Full-time employment	Anglo-Australian	Long-term heterosexual relationship	Middle-class	P/L vulvodynia**	12 years
P134	33	Bachelor's Degree	Part-time employment	Lebanese-Australian	Long-term heterosexual relationship	Middle class	P/L vulvodynia**	7 years

Note. [^]=sexual preference not stated; U/G vulvodynia=Unprovoked and generalised vulvodynia; P/L vulvodynia=provoked and localised vulvodynia; *=diagnosis from doctor; **=no diagnosis from a doctor, description of symptoms used to assign a diagnosis.

Comparison between the Two Groups

On the whole the two samples were demographically similar, making the use of the online data for triangulation meaningful. See Table 3.9 for a summary comparison of the two groups. The average age of the online sample was four years older, with a larger age range (14-year range for interview sample versus 24-year range for the online sample). With regards to education and employment, all participants had at least a high school education, with the majority holding or studying post-high school qualifications. All but one of the women were either working or studying. Both groups were predominately middle-class, with all of the interview group and 87% of the online group identifying as middle-class. The remaining 13% of the online group identified as having a below average income. The majority of both samples were in committed relationships (either long-term dating, cohabitating or married) with one participant in the interview sample and six of the online sample being single.

Diagnostically, the groups were similar as well. They had a comparable average length of time with symptoms. There was only a seven month difference in the average time with symptoms between the two samples. Slightly more women in the interview group had provoked vulvodynia (55% versus 47%) and slightly more were diagnosed with vaginismus in the online group (three versus one participant).

The participants were also similar ethnically, with the majority of both samples born and living in Australia. The online sample had a higher number of participants being born and living somewhere other than Australia, which is not surprising as the online survey was advertised internationally.

Table 3.9 Comparison of Interview Sample and Online Sample

Demographic information					
	Age and range	Educational status	Employment status	Socioeconomic status	Relationship status
Interview group	25; 19-33	73% post high school	45% employed 46% students 9% unemployed	100% middle class	9% single 91% long-term relationship
Online group	29; 19-43	80% post high school	67% employed 33% studying	13% below average 87% middle-class	40% single 60% long-term relationship
Diagnosis					
	Provoked Vulvodynia	Generalised Vulvodynia	Vaginismus	Length of time with symptoms (average and range)	
Interview group	55% (n=6)	36% (n=4)	9% (n=1)	5 yrs (9m to 12 yrs)	
Online group	47% (n=7)	33% (n=5)	20% (n=3)	6 yrs (4m to 12 yrs)	
Ethnic background					
	Born and living in Australia	Born elsewhere, living in Australia	Born elsewhere, living temporarily in Australia	Born elsewhere, living elsewhere	
Interview group	82%	9%	9%	0%	
Online group	73%	7%	0%	20%	

Participant Trajectory Duration

For the purposes of this research the duration of the trajectory is defined as being from the onset of symptoms until the final point of contact with the interviewer. The trajectory is divided into three phases – pre-seeking, treatment seeking and management, and measured in weeks, months and years. The pre-seeking phase is from the onset of symptoms until the first contact with an HCP. The treatment seeking phase is from the first contact with an HCP until correct diagnosis. The management phase is from diagnosis until final contact with the interviewer. Table 3.10 presents the time frames of the phases for each of the women in this study.

Participant Distress

The mean score for the frequency of distress subscale was 26.15⁶ (SD=11.99). The scores range from 0 to 45. The mean score for intensity of distress subscale of FSDS was 26.5 (SD = 13.12) with scores ranging from 0 to 47. A Kruskal-Wallis test did not reveal a statistically significant difference in frequency of distress for these women ($\chi^2 (2, 26) = .803, p = .66$).

Likewise, the intensity of distress subscale demonstrated no significant difference ($\chi^2 (2, 26) = 2.432, p = .29$).

⁶ The cut-off points for the FSDS are: 0-14 no sexually related personal distress; 15 and above significant sexually related personal distress

Table 3.10 Trajectory Duration

Part#	Diagnosis	Pre-seeking	Treatment Seeking	Management
P1	GV	0 months	5 months	5 months and currently effectively managing pain
P2	PV	12 months	0 months	24 months and currently seeking effective management
P3	PV	36 months	20 months	7 months and currently seeking effective management
	GV	0 months		
P4	PV	25 months	24 months	18 months and currently seeking effective management
P5	GV	0 months	6 months	18 months and currently seeking effective management
P6	Vaginismus	54 months	0 months	74 months, discontinued treatment seeking
P7	PV	1.5 months	66 months	12 months and currently effectively managing pain
P8	PV	60 months [^]	60 months	Currently seeking diagnosis and effective management
P9	PV	0 months	12 months	132 months and currently seeking effective management
P10	PV	0 months	19 months	16 months and currently seeking effective management
P11	PV	21 months	0 months	Had not yet started seeking management (only received diagnosis between interviews 1 and 2)
P104	Vaginismus	'several months'	within weeks	Asymptomatic after several months of treatment; had pain free sex for "next years"
	Pain retriggered	n/a	n/a	Unable to determine time frame; currently seeking effective management
P106	Vaginismus	Not stated and not seeking diagnosis, treatment or management		

Note. GV-generalised vulvodynia; PV-provoked vulvodynia; *-diagnosis determined by researcher using woman's description⁷; [^]This woman was asymptomatic for most of this time and will be treated as an outlier, i.e., not included in the time frames reported below.

⁷ It was not feasible to perform a gynaecology exam to determine diagnosis.

Table 3.10 Trajectory Duration (cont.)

Part#	Diagnosis	Pre-seeking	Treatment Seeking	Management
P108	Vaginismus	72 months	No diagnosis and no further treatment seeking	120 months with symptoms (but not currently seeking diagnosis or treatment)
P111	PV	0 months	12 months	60 months and currently seeking effective management
P112	GV	120 months	48 months	Unable to determine time frame; currently seeking effective management
P117	GV*	96 months	2 months and still seeking diagnosis and management	No official diagnosis, currently seeking diagnosis and management
P118	GV*	0 months	4 months and still seeking diagnosis and management	No official diagnosis, currently seeking diagnosis and management
P121	Vaginismus	36 months	n/a (Self-diagnosed)	n/a – Has not sought treatment
P122	PV	120 months	12 months year	12 months and currently seeking effective management
P125	GV	Not stated – feels she is managing well		
P126	Vaginismus	Not stated and not seeking diagnosis, treatment or management		
P129	PV	108 months	6 months	Diagnosed at time of survey completion
P132	GV	0	0	24 months and currently seeking effective management
P133	PV	48 months	0	96 months and currently seeking effective management
P134	PV*	84 months	Has not sought treatment	

Note. GV-generalised vulvodynia; PV-provoked vulvodynia; *-diagnosis determined by researcher using woman's description; ^This woman was asymptomatic for most of this time and will be treated as an outlier, i.e., not included in the time frames reported below.

Data Analysis

Data analysis was iterative and progressive, in that data was collected and analysed at the same time. Furthermore, analysis influenced decisions made in further data collection. Data was analysed using the grounded theory processes of coding, memoing, sorting and theory development (Charmaz, 2006a).

Coding

Coding is the process of defining and categorising the data (Charmaz, 2000). Initial coding (Charmaz, 2006a) occurred line by line and it broke the data down to allow categories to emerge. During initial coding a number of questions were asked of the data to illicit the meaning behind the data and to organise the data into categories and themes (Glaser, 1978). This included questioning the meanings behind the woman's.

As incident was compared to incident and category to category, the conceptualisation of processes being studied began to emerge (Strauss & Corbin, 1998). Coding became more directed and conceptual as the properties and dimensions of the categories, and the relationships between the categories were identified (Charmaz, 2006a). The use of the constant comparative method was used to verify the emerging categories and concepts (Glaser, 1998). See Table 3.11 for details about the coding process.

Table 3.11 Summary of coding process

<p>Initial coding word-by-word and line-by-line coding</p>	<p>Considered time lines, e.g., How long between appearance of symptoms and initial contact with HCP?</p> <p>Considered emotions behind the descriptions of consultation with the HCP, e.g., Could the consultation be considered positive or negative?</p> <p>Consider what processes are at play interpersonally and intrapersonally, e.g., Does she feel she is being listened to? Is negative self-talk at play?</p>
<p>Incident to incident coding</p>	<p>Considered the subsequent actions of the woman after her consultation, e.g., Did she seek further clarification of diagnosis? Did she discontinue treatment?</p> <p>Consider subsequent actions or beliefs after an interaction with others (partner, friend, HCP), e.g., Does she seek treatment after a fight with a partner?</p> <p>What are her motivations for following treatment protocols – her partner's desire for intercourse, her desire for pleasure?</p>
<p>Focused coding</p>	<p>Themes emerged and data was considered within these emerging themes, e.g., survivorship, personal narratives, illness contestation, motivators, barriers.</p>
<p>Axial coding</p>	<p>Themes, categories and subcategories were organised and linked, e.g., the impact of personal narratives on survivorship, the impact of an agenda that is met/unmet on the trajectory.</p>
<p>Theoretical coding</p>	<p>Themes are considered as a whole and integrated into the conceptual model.</p>

Memoing and Diagraming

Memoing and diagraming are very important processes in grounded theory. Memoing is the process of putting analytical thoughts to paper, and it occurs at all stages of research (Glaser, 1978; Lempert, 2007). Memoing was used to conceptualise the data and identify the relationships between the categories, as well as to develop the theoretical concepts. It was used in the context of reflexivity (see pg. 25 of this chapter) as a key element in developing this constructivist theory. This process (memoing in the context of reflexivity) allowed the researcher to conceptualise and interpret the data in a

way that acknowledged both the researcher's and the participants' emergent and multiple realities (Charmaz, 2006a).

Diagramming helped to reconceptualise the data in visual form and made it more easily manipulated (Lempert, 2007). As with memoing, diagramming assisted in 'forcing' the researcher to work with concepts rather than with raw data. Diagramming helped to produce a more conceptual and rich theory (Corbin & Strauss, 2008).

Theory Development

Theoretical coding is the process of theory development (Glaser, 1998). To develop theory the data that was fractured during the coding process was reintegrated in the form of a theory; this process is known as theoretical sorting (Glaser & Strauss, 1967). Theoretical sorting gave the theory a rich and integrated 'feel' and involved sorting memos and ideas to construct the connections between categories (Charmaz, 2006a).

Reflexivity and Author Positionality

Reflexivity is used to strengthen the trustworthiness of the research process. It is the researcher's awareness of the influence they have on the research process (Gilgun, 2010). The personal and professional meaning that the topic has for a researcher influences the collection and analysis of data, and informs the researcher's interactions with participants and the data (Charmaz, 2006a). Reflexivity was used to minimize this influence by giving the researcher an awareness of how her own experiences, attitudes and values impact on the research process.

As a woman with vulvodynia, the researcher has a unique knowledge about genital pain and its treatment, which assisted in data collection.

Reflexivity allowed the researcher to step out of her identity as 'a woman with vulvodynia' so that bias could be minimised (Corbin & Strauss, 2008). During the research process the researcher closely examined her experiences, decisions and interpretations. This 'reflexive stance' informed how the researcher conducted the research, interacted with the participants and how she represented the participants' experiences (Charmaz, 2006a)⁸.

NVivo

NVivo was used to aid data analysis by helping to organise and manage large amounts of data. It was also used for audit purposes, thereby increasing transparency in analysis. The NVivo program facilitated text searches, coding, comparing of incidents and categories and assisted in diagramming. It allowed for the researcher to easily access the original data behind codes, categories and themes. The computer did not do the analysis; the researcher asked the questions and interpreted the data and the computer assisted in maximising efficiency in data analysis (Bringer, Johnston, & Brackenridge, 2006; Bringer, Johnston, & Brackenridge, 2004). See Appendix 1 for evidence of researcher training in NVivo.

Participant Checking

All participants were asked if they would like to receive feedback about the study. All of the interview participants and 11 of the online participants agreed to receive feedback. The purpose of providing feedback was three-fold. First, it was a way to give something back to the participants. Many of the women expressed a desire to know if their experiences were unique, and the feedback gave them the opportunity to relate to others and feel less

⁸ The researcher did not document the specifics of the reflexive process, a limitation of this research.

'alone' in their journey. Second, the feedback allowed the women to see the results of their time and effort. Finally, it strengthened the validity of the research by allowing participant checking to take place.

Summary and Conclusions

The use of a qualitative research design, specifically a constructivist grounded theory approach, facilitated an understanding of the experience of treatment seeking for the participants in this study. This study included 26 educated, mostly middle class women with vulvodynia and vaginismus. Eleven of the women participated in face-to-face or phone interviews and 15 participated in an open-ended, online survey. Grounded theory methodology was used to analyse the data and to develop a theory about the lived experience of treatment seeking for genital pain conditions.

Chapter Four: Personal and Interpersonal Context

This chapter presents the main findings of this study that relate to the personal context of treatment seeking for genital pain. These findings are presented in three sections: (1) the trajectories of women seeking treatment for genital pain; (2) the perceived motivators for and barriers to treatment seeking for genital pain; and (3) the personal agendas about treatment seeking for genital pain. In presenting the substantive findings, specific treatment seeking trajectory types are considered. Furthermore, word clouds are used to present the salient ideas of the participants. Participant quotes are labelled with the participant number, age, self-reported diagnosis⁹, and relationship status.

Trajectories

This study used the concept of trajectories to organise the findings. A trajectory has both duration and shape (Corbin, 1998; Glaser & Strauss, 1968; Halcomb & Davidson, 2005; Henly et al., 2011). For the purposes of this research the trajectory's duration is expressed in time frames (i.e., immediate or delayed), while the shape of the treatment seeking trajectory is defined by the nature of treatment seeking, i.e., continuous, episodic or discontinuous. An immediate trajectory is defined as treatment seeking within two months of symptom development and a delayed trajectory is defined as more than two months. A continuous trajectory is when a participant seeks treatment on a consistent basis. An episodic trajectory is characterised by significant periods of time (more than two months) without participating in treatment seeking. A discontinuous trajectory is characterised by no contact

⁹ Diagnosis abbreviations: GV-generalised vulvodynia; PV-provoked vulvodynia; Vag-vaginismus.

with a HCP or participation in treatment strategies at all. Discontinuation of treatment seeking could be due to either 'giving up' on managing symptoms, or satisfactorily managing symptoms and therefore having no need for professional health care. For instance, a trajectory that has duration (i.e., delayed) but no shape (i.e., continuous, episodic or discontinued) indicates a trajectory characterised by no treatment seeking at all. Table 4.1 summarises treatment seeking trajectories for the women in this study. The discussion that follows considers the salient trajectory qualities for the women in this study.

Table 4.1 Summary of Participant Trajectories

	Immediate	Delayed	Total
Continuous	n=7 (26.9%)	n=9 (34.6%)	n=16 (61.5%)
Episodic	n=1 (3.8%)	n=1 (3.8%)	n=2 (7.6%)
Discontinuous	n=1 (3.8%)	n=2 (7.7%)	n=3 (11.5%)
No treatment seeking	n/a	n=4 (15.4%)	n=4 (15.4%)
Unable to determine	n=0	n=1 (3.8%)*	n=1 (3.8%)
Total	n=9 (34.5%)	n=17 (65.3%)	n=26 (100%)

Note. *This participant had only sought treatment between interviews one and two.

Perceived Motivators for and Barriers to Treatment Seeking

Motivators for treatment seeking reported by the participants included the expectations the women held for their relationships and health, and the explanations they had for their symptoms. The self-reported barriers to treatment were characterised in the beliefs, knowledge and cognitions the women held about their symptoms and treatment, and the lack of resources for and inaccessibility of treatment services. The women rarely identified a single motivator or barrier. Rather, they spoke of a number of factors that motivated and deterred them from seeking treatment. Many of the women

also expressed ambivalence about treatment seeking. As distress and tension about their pain increased, particularly in areas of salience (e.g., desire for pregnancy, desire for intercourse), the likelihood of treatment seeking increased. Figure 4.1 is a summary illustration of the motivations for, barriers to, and ambivalence about treatment seeking for genital pain as reported by the participants.

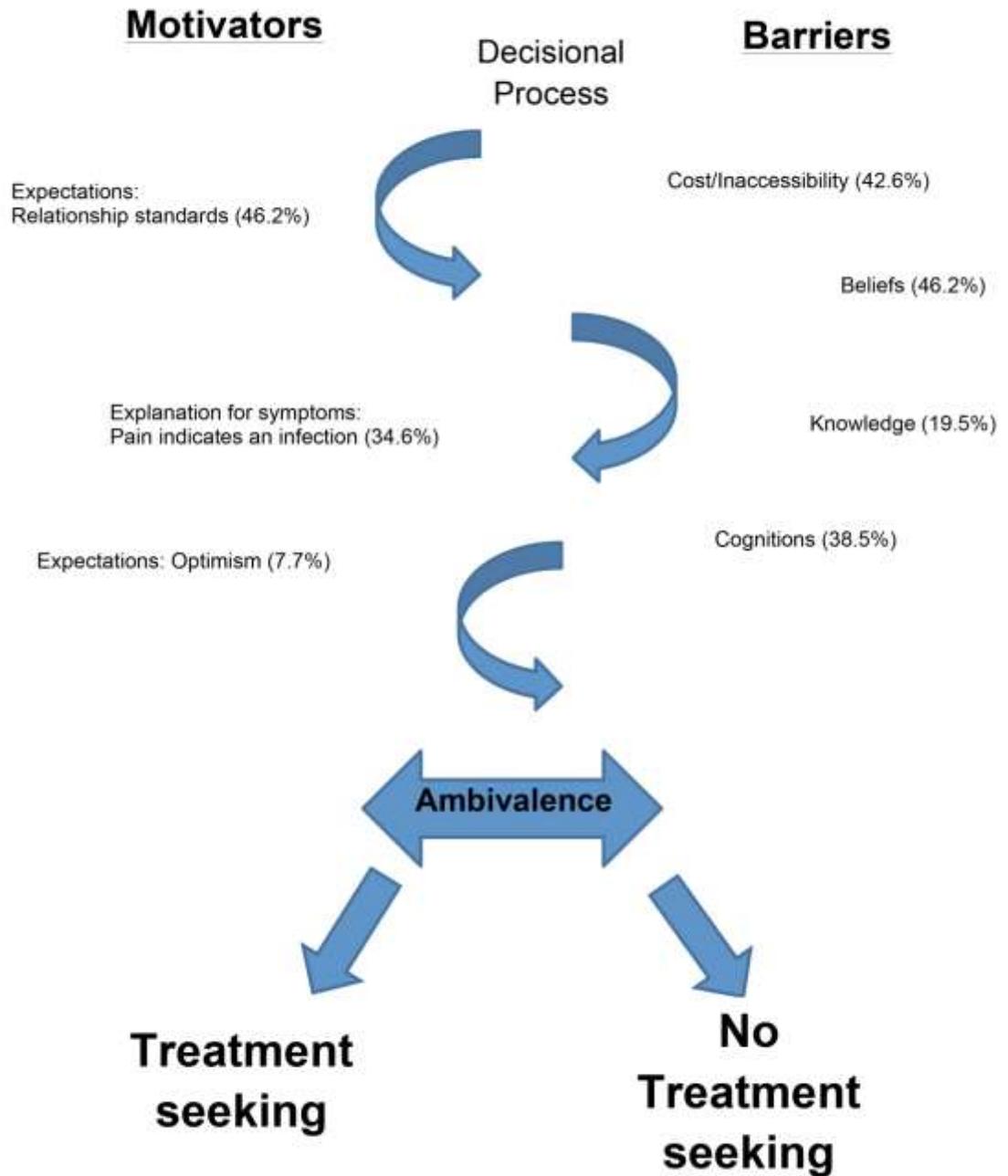


Figure 4.1 Motivators for and Barriers to Treatment Seeking

Note. The percentages represent the number of women whose trajectories were influenced by the particular motivator or barrier.

Motivators for Treatment Seeking

Fifteen participants (57.7%) identified factors that they perceived as motivating treatment; these were categorised as either an explanation for their symptoms or an expectation they held for their health or relationship. Ten of these women (66.7%) had a continuous trajectory, with six (60.0%) seeking treatment immediately and four (40.0%) delaying treatment (see Table 4.2 for a summary of the common characteristics of the women who identified motivators for treatment seeking).

Table 4.2 Summary of Common Characteristics Relating to Motivators

Motivators	Trajectory	Diagnosis	Age	Relationship status
Explanation: Symptoms indicate an infection (n=9)	IC, IE or ID (88.9%)	GV (55.6%)	>20 (88.9%)	n/a
Expectations: Optimism (n=2)	DC or IC (100%)	PV (100%)	n/a	n/a
Expectations: Relationship standard (n=12)	DC or IC (66.7%)	n/a	n/a	LTR (83.3%)

Note. IC-immediate and continuous; IE-immediate and episodic; ID-immediate and discontinuous; DC-delayed and continuous; GV-generalised vulvodynia; PV-provoked vulvodynia; n/a-not a noteworthy characteristic; LTR-long-term relationship.

Explanation of symptoms: Pain indicates an infection.

Nine women (60.0%) believed their pain was from an infection that needed short-term medical treatment. All but two of these women (77.8%) had an immediate trajectory, with five being continuous, one episodic and one discontinuous. Two of the women (22.2%) tried to self-treat for thrush, but when their symptoms did not resolve they consulted their HCP for further investigation.

Another two participants (22.2%) tested negative for infections, however, their HCPs were not able to find another medical explanation for their pain and so the women continued to worry that they may have an infection that they could pass on to their partner. One said, "Until you tell me what it (the pain) is, you know I am going to be really nervous [because I am worried I will pass an STI on to a partner]..." (P001, 22yo¹⁰, GV, casual dating). Another participant said, "[I worried that I was] running a risk of, for example, harming my boyfriend. Am I running a risk of harming me [or my partner]...long-term [if I have an infection that is untreated]" (P010, 23yo, PV, committed dating).

Just over half of the women (n=5; 55.6%) were diagnosed with generalised vulvodynia and all but one were older than 20 when their symptoms began.

Expectations: Optimism.

Two of the participants (7.7%) were motivated to seek treatment because they held the belief that they would be able to find a resolution to their symptoms. One woman stated, "[The pain] is not meant to be for me" (P008, 23yo, GV, committed dating), while the other said, "I think in my heart I knew that I would be able to get past this" (P009, 30yo, PV, married). Both of these women had a continuous trajectory (one immediate and the other delayed) and they were both diagnosed with provoked vulvodynia.

Expectations: Relationship standards.

Relationship standards are social cognitions about the expectations a person holds for their relationship (Baucom, Epstein, Sayers, & Sher, 1989).

¹⁰ yo=years old

Twelve of the women (46.2%) identified relationship standards that influenced treatment seeking and eight of the 12 (66.7%) women had continuous trajectories (half with immediate and half with delayed trajectories). These standards were categorised into two themes: intimacy standards and sexual role standards.

Intimacy standards.

Four participants (33.3%) thought that pain-free intercourse would increase the intimacy in their relationship. For example, one participant said, “[My relationship] triggers the urge [to seek treatment], because the relationship is so great I want to have a fulfilled relationship...[it] makes me want to solve the problem” (P010, 23yo, PV, committed dating). Another woman with high intimacy standards was, at times, demotivated to seek treatment, however, she said, “I try generally [to remain motivated for treatment because]...I can't see 10 or 20 years down the track [not being sexually active with my partner]” (P004, 33yo, PV, defacto relationship).

Sexual role standards.

Eleven participants (91.7%) were motivated to pursue treatment for their pain as they felt the pain interfered with their role as a sexual partner. In response to being asked what motivated her to seek treatment, one woman stated, “I can't be what my husband needs or wants” (P118, 36yo, GV, married). Another said, “Because I feel like there is something missing in my relationships, I feel guilty not being able to fully give myself to my partners” (P132, 22yo, GV, single). Another stated, “I want to be a better sexual partner. I feel like I am a disappointment to my partner who I know loves me...” (P133, 27yo, PV, living with partner).

These barriers were categorised into four main themes: (1) beliefs; (2) nescience; (3) cognitions; and (4) resources for and access to treatment.

Table 4.3 Summary of Common Characteristics Relating to Barriers

Barriers	Trajectory	Diagnosis	Age	Relationship status
Beliefs: Normalising (n=8)	D, DC, DE or DD (100%)	PV (62.5%) Vag (37.5%).	<20 (50.0%)	LTR (100%)
Beliefs: Discounting (n=9)	D or DC (100%)	PV (66.6%)	n/a	LTR (88.9%)
Beliefs: Negative treatment beliefs (n=3)	D or DE (100%)	Vag (100%)	n/a	n/a
Nescience (n=5)	DC (80.0%)	n/a	<20 (60.0%)	n/a
Cognitions: Shame and embarrassment (n=10)	DD (50.0%)	n/a	<20 (50.0%)	n/a
Cost of treatment (n=9)	n/a	n/a	n/a	n/a
Accessibility of services (n=6)	n/a	n/a	n/a	n/a

Note. DC-delayed and continuous; DE-delayed and episodic; DD-delayed and discontinuous; D-delayed; PV-provoked vulvodynia; Vag-vaginismus; n/a-not a noteworthy characteristic; LTR-long-term relationship.

Beliefs: Normalising, discounting and negative treatment beliefs.

The beliefs the women held about their symptoms and about treatment for genital pain impacted treatment seeking. Just under half (46.2%; n=12) of the women held beliefs that negatively impacted treatment seeking. These beliefs took the form of normalising, discounting and negative treatment beliefs.

Normalisation involved the woman interpreting the pain as routine and, as a result not recognising the need for medical care. Eight of the women (30.8%) considered genital pain to be a normal experience. For example one participant said, "Because I thought it (pain with sex) was normal, I wasn't

worried about it" (P011, 19yo, PV, committed dating). Another participant stated, "I think because [my husband] was my first and I had read a lot [about sex hurting] the first couple of times [I put off seeking treatment]" (P002, 26yo, PV, married).

All of the women who normalised their pain (n=8) had a delayed trajectory, with six having either a continuous or episodic trajectory, one discontinuous and one with no treatment seeking at all. All of the women who normalised were in committed, long-term relationships and half of these women were in their teens when their symptoms developed. Furthermore, they all had a diagnosis of provoked vulvodynia (62.5%) or vaginismus (37.5%).

Discounting is an internal process that leads to disregarding an explanation for symptoms (Ahn & Bailenson, 1996), obviating the perceived need for treatment. Nine of the women (34.6 %) discounted their pain symptoms. One participant said:

For a long time I thought, "*Well it's me, maybe it's me, I'm too small like my channel (vagina) is too small, maybe he's too big, maybe we're not [compatible],*" so I guess I didn't know that anything like [vulvodynia] was possible I sort of rationalized...I mean for a long time I thought I was allergic to... his semen...I just put other explanations in place." (P002, 26yo, PV, married)

Four of the women (44.4%) who discounted believed that although pain with intercourse is not a universally normal experience, for them it was. One woman felt painful sex was "something I have to put up with" (P006, 26yo,

vag, committed dating); while another three women (33.3%) thought their pain was due to their lack of interest in sex. For instance, one woman said:

I never really enjoyed sex before, I was never like, "*Hey I want to have sex, I want to enjoy it.*" I didn't really care about it. I just thought you know we'll have sex, I'll be hurting for like an hour or so after and then it will go away. [So I never thought about seeking treatment.] (P003, 19yo, GV, committed dating)

Another participant lived apart from her partner and thought she needed to get used to having sex again. She said, "...I kind of just thought, '*Oh maybe [the pain is] because we haven't been together again for a while*'" (P004, 33yo, PV, defacto relationship). Another woman doubted the legitimacy of her pain, feeling that perhaps she was exaggerating it, stating, "...maybe [the pain is] a somewhat normal feeling, like that the pain wasn't really that much to complain about" (P006, 26yo, vag, committed dating).

A delayed treatment seeking trajectory was associated with all of the women who discounted their pain, with the majority of the women having a continuous trajectory (n=5; 55.6%). Eight of the women (88.9%) were in committed relationships and just under half (n=4) were in their teens when their pain symptoms emerged. Six of the women (66.6%) were diagnosed with provoked vulvodynia.

Three of the women (11.5%) held negative treatment beliefs that led to a delay or discontinuation of treatment, including believing treatment would worsen the condition or that treatment required more personal strength than they had. One woman was diagnosed and underwent biofeedback as her first treatment. She found this treatment emotionally intolerable and felt it

made her symptoms worse. She was then left fearful of seeking further treatment:

I underwent...biofeedback therapy which was, I don't think really worked at all and it made things worse. It wasn't a very fun experience...I think that if I keep trying to find solutions (treatment for symptoms) it is going to mean more people going to have to examine me, and poke and prod at me, and I just feel it may make it worse.

(P006, 26yo, vag, committed dating)

Another woman stated she did not have "the psychological energy" to explore treatment options (P104, 28yo, vag, committed dating), while another woman felt her "personal memories" and past "trauma" made treatment too difficult for her to endure (P106,43yo, GV, single).

All of the women who held negative treatment beliefs had a delayed trajectory, one with episodic consultation and the other two having not sought treatment at all. All three of these women were diagnosed with vaginismus.

Nescience: About genital pain and its treatment.

Participant nescience, or lack of knowledge, negatively impacted treatment seeking decisions in five of the women (19.2%). The women lacked knowledge about the condition itself and about treatment for the condition.

The women felt they might have sought treatment earlier had they known what the condition was, how to treat it and who to go see. For example one woman said:

I guess I went through a long period of time having sex, it hurting and not knowing what was wrong with me...they just don't tell you this

(vulvodynia) is possible...whereas maybe [if I had known] I wouldn't [have left treatment seeking] so long. (P002, 26yo, PV, married)

Another participant said, "I wasn't really sure if a doctor could help me, I'd never heard of pain disorders so wasn't aware [a doctor] would understand my problem" (P133, 27yo, PV, living with partner).

One woman developed her symptoms in primary school and felt this negatively impacted on her ability to communicate her symptoms, "I lacked the vocabulary and knowledge base to adequately explain my symptoms to anyone in a capacity to help me" (P112, 24yo, GV, single).

The trajectory of four of these women was delayed and continuous, with the fifth woman's trajectory being immediate and discontinuous. Three of the five women were in their teens when their symptoms began.

Cognitions: Shame and embarrassment.

Shame and embarrassment are negatively valenced emotions that are responses to a perceived fundamental personal failure or violation of social convention (Tangney, Miller, Flicker, & Barlow, 1996). Shame and embarrassment were identified as significant barriers to treatment for ten of the women (38.5%). One participant delayed treatment for 12 months and identified shame as one of the most significant barriers to treatment seeking. She said, "There was a period (before seeking treatment) where I was sweeping it (the pain) under the carpet because I was ashamed and I thought there was something wrong with me, and I didn't want to do anything about it" (P002, 26yo, PV, married).

In response to a question asking about the barriers to treatment seeking, another participant wrote, "Social embarrassment, especially now

that I've [delayed treatment seeking for] so long" (P108, 30yo, PV, married). While another woman felt embarrassed to have to talk to her HCP about her sexual problem:

Participant: The biggest barrier that I felt was myself...I felt too ashamed to go to a doctor.

Interviewer: What was shameful about it?

Participant: There was no way that my young adult body was going to get semi-naked in front of my male adult doctor who has treated me since I was two...So it was my internal resistance. (P007, 25yo, PV, committed dating)

This participant went on to say:

I think there is a hierarchy of the deserving and the undeserving when it comes to illness...like in terms of how I have been treated by doctors and by health professionals and also in terms of how I have felt about it myself...how I have felt about having this pain and not being able to just have what I consider to be a normal sexual relationship...In some ways it is viewed as a dirty female problem [and] it is treated as mildly revolting." (P007, 25 yo, PV, committed dating)

Half of the women who experienced shame and embarrassment had a delayed and discontinuous trajectory. Half of the women were also in their teens when their symptoms started.

Resources and accessibility.

Lack of financial resources and access to treatment were identified as significant barriers by 46.2% of the women (n=12). Although these barriers were identified as significant, they were not associated with one particular trajectory (four women had an immediate and continuous trajectory, five had a delayed and continuous trajectory, two had a delayed and discontinuous trajectory, and one an immediate and discontinuous trajectory).

The cost of treatment was a significant barrier for ten of these women (83.3%). Their inability to pay for treatments limited their treatment options. One woman (P008, 23yo, GV, committed dating) spoke of spending \$10,000 without any resolution of her symptoms. Another woman stated, "Now all my savings is gone, now I'm like you know, everything is going down, I'm nearly 20 everything is going down" (P003, 19 yo, GV, committed dating). Other women spoke about not being able to afford treatment they felt they needed. For example, one woman commented, "That was a period of my life where I was moving out of home and had no money so I was less likely to go to the doctor (for my genital pain)" (P007, 25yo, PV, committed dating). Another stated, "She (the doctor) recommended physiotherapy but I remember not pursuing that immediately, I think she prescribed tricyclic anti-depressants and the physio was really expensive, so I thought I would try the anti-depressants first" (P005, 23yo, GV, committed dating).

Six of the women (50.0%) were limited by the accessibility of services. This was due either to a lack of specialist services or a lack of well-advertised services. For example, one woman said, "I come from a rural area and we don't have a specialist around, so I couldn't go to one except to go to

a big city somewhere. So that is a big barrier if you are just not from an area supplied with good doctors" (P010, 23yo, PV, committed dating).

Lack of knowledge of what services are available to women also hampered treatment seeking. The women themselves expressed a lack of knowledge about which HCP to go see, "Originally [I went to a General Practitioner (GP)]...and it didn't work (resolve the pain) and I didn't really know what to do next" (P001, 22yo, GV, casual dating). They also reported HCPs who did not know who to refer them to when initial treatment was not effective. For instance, one woman reflected:

I think back to 2006 and 2007 - trying to get treatment and just people not really knowing what to do...the doctors at the sexual health clinic not being able to even say it might be vaginismus...[or that]...there is a specialist, I'm sure there are other doctors, I am sure there is more than one. [Name of doctor] is well regarded in this area but I can't believe there wasn't [a doctor] who mentioned [him] earlier. (P004, 33yo, PV, defacto relationship)

There were no common characteristics amongst the women who identified inaccessibility of services as a barrier. Just over half of the women who identified the cost of treatment (n=5) as a significant barrier were not in full-time employment. Figure 4.3 is an NVivo word cloud that illustrates the data regarding the barriers to treatment seeking. Words relating to the cost of treatment (e.g., financial, money, afford) indicate the lack of money being a barrier. Furthermore, the words related to lack of knowledge feature frequently in this word cloud as did the words 'embarrassing' and 'embarrassment'.

abnormal accumulation affected afford amount answer antibiotic anxiety approach attempt
believe bothered boyfriend bugging capacity cleared common community concerned confide
connected conscious constantly couple coverage cream dates decision despairing
difference difficulties dissolution distress doctor don'tknow educated embarrassing
embarrassment enough especially experience explain extent financial frustrating genital
gynaecologist helpful important knowing looking medical money months never
noknowledge notknowing problem quickly relationships
specialist steroid symptoms testing thrush treat treatment wrong

Figure 4.3 Word Cloud: Barriers

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Ambivalence

Fifteen participant transcripts (57.7%) reflected ambivalence towards treatment seeking. Nine (60.0%) of these women had a continuous trajectory (either immediate or delayed) (see Table 4.4 for a summary of ambivalence). Some of the women's ambivalence was related to a lack of interest in sex and a recognition of the importance of sex for the health of their relationship. Ambivalence was also evident in the worries the women experienced about the side-effects of treatment and the time commitment required for treatment exercises.

Table 4.4 Ambivalence to Treatment Seeking

Ambivalence	Trajectory	Diagnosis	Age	Relationship status
Ambivalence: Sex (n=12)	DC (41.7%)	PV (58.3%)	n/a	LTR (91.7%)
Ambivalence: Side effects (n=4)	IC or ID (75.0%)	PV (75.0%)	n/a	LTR (100%)
Ambivalence: Time (n=7)	IC or DC (71.4%)	PV (71.4%)	n/a	LTR (85.7%)

Note. DC-delayed and continuous; DE-delayed and episodic; DD-delayed and discontinuous; D-delayed; PV-provoked vulvodynia; Vag-vaginismus; n/a-not a noteworthy characteristic; LTR-long-term relationship.

Twelve women (80.0%) expressed ambivalence towards sex, which influenced their motivation for treatment seeking. For example, one woman said, "I have no interest in sex, and that sort of feeds into seeking treatment...I can't be bothered, why bother treating it; I'm not really interested" (P004, 33yo, PV, defacto relationship). However, ultimately she persisted with treatment because sex was an important part of her relationship with her partner. She said:

My partner had a strong interest in me doing [treatment]. It is hard [to stay motivated for treatment] but it will be worth it down the track. I think maybe for a long time [my motivation for treatment] was actually more [for my partner]." (P004, 33 yo, PV, defacto relationship)

Four of the women (26.7%) also expressed concern about the side effects of the treatment, which lead to ambivalence about treatment seeking. For example one woman said:

You have the hope for wanting a better future and wanting a life free of [pain]...but everything you do to your body (treatment) is going to do something else or cause some kind of damage or side effect. I

suppose you have to keep those two things in balance.” (P007, 25 yo, PV, committed dating)

Seven of the women (46.7%) reported ambivalence about completing their treatment ‘homework’ because the exercises took a significant amount of time. One woman said:

It’s like an hour out of my day, every single day, which I probably should do, but I get so busy. There is so much to do that that you just get tired, but [I] have to make more of an effort, maybe [I] will put a bit of effort [into the exercises] this weekend. (P002, 26 yo, PV, married)

The majority of the women expressing ambivalence were in long-term relationships (93.3%). There were no other common characteristics of the women who expressed ambivalence. Figure 4.4 is an NVivo word cloud that illustrates the data regarding ambivalence to treatment seeking. The word ‘xbut’ was inserted into the text when a participant used the word ‘but’ to communicate ambivalence. This word appears on the word cloud confirming the theme of ambivalence. The word ‘nointerest’ (inserted into the text when the women spoke about a lack of interest in sex) indicates support for the notion that the women were ambivalent about sex and the words ‘madeworse’ and ‘treatment’ support the view that some of the women were ambivalent about treatment because of the perceived side effects.

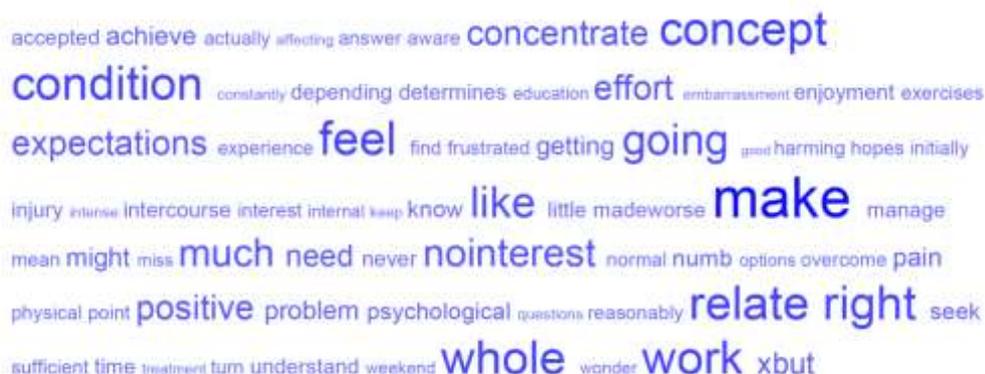


Figure 4.4 Word Cloud: Ambivalence

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Personal Agendas

Personal agendas are the expectations that a woman has for the consultation with her HCP (Middleton, McKinley, & Gillies, 2006). Twenty (76.9%) of the women identified expectations for their health care consultations; these were: (1) validation agendas; (2) informed HCP agendas; and (3) HCP–patient alliance agendas. These identified expectations were not always met in the first consultation and for some of the participants they were never met. Table 4.5 shows a summary of the common characteristics of the women according to agendas. Various factors influenced the expectations of the woman for her consultation, including minimisation of symptoms and receiving a diagnosis. Furthermore, the status of the agenda (e.g., being met or not) influenced the trajectory status. Figure 4.5 summarises the personal agendas that influenced treatment seeking and the outcomes of an agenda being met or not. When an agenda was met hope, relief and a continuous trajectory were often experienced by the

women. However, when they were not met the women often doctor shopped and experienced distress and an extended trajectory.

Table 4.5 Common Characteristics Relating to Agendas

Agenda	Trajectory	Diagnosis	Age	Relationship status
Validation: Not met at initial consult (n=9)	IC and DC (88.9%)	PV (66.7%)	n/a	LTR (77.8%)
Validation: Met at initial consult (n=4)	DC (75.0%)*	PV (100.0%)	75.0% were >25yo	LTR (100%)
Informed HCP: Not met (n=17)	IC and DC (70.6%)	PV (58.9%)	n/a	LTR (76.5%)
Informed HCP: Met (n=2)	IC and DC (100%)	n/a	n/a	n/a
HCP alliance: Not met (n=11)	IC and DC (63.3%)	GV (54.5%)	n/a	LTR (72.7%)
HCP alliance: Met (n=13)	IC and DC (81.8%)	PV (76.9%)	n/a	LTR (69.2%)

Note. IC-immediate and continuous; DC-delayed and continuous; GV-generalised vulvodynia; PV-provoked vulvodynia; n/a-not a noteworthy characteristic; LTR-long-term relationship.*The participant who did not have a continuous trajectory had only sought treatment between interviews one and two so her trajectory is not able to be determined.

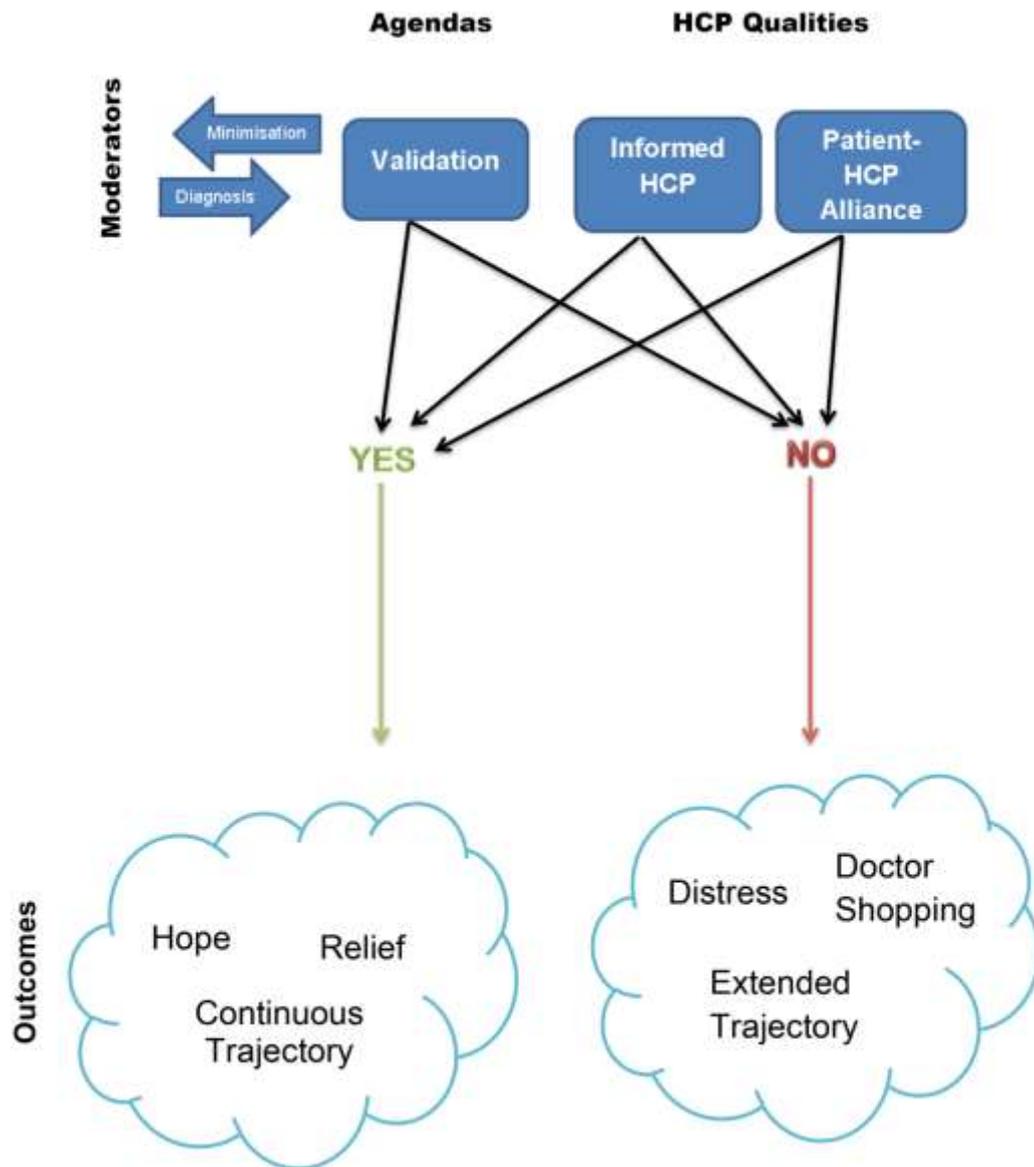


Figure 4.5 Summary of Agendas, Their Moderators and Results

Note. The moderators represent the processes that either lead to or detract from an agenda being met. The coloured arrows represent the results of an expectation being met or not.

Validation Agendas

When meeting with the HCP, some of the women in this study expected to receive validation that their pain symptoms were significant. If the woman perceived that her pain and the impact of the pain was dismissed she felt invalidated, leading to significant distress. The invalidation took the form of illness contestation and minimisation. Conversely, when the women received a diagnosis or felt the HCP understood the significance of their symptoms (i.e., the validation agenda was met), most experienced hope and a decrease in their distress.

Illness contestation.

Illness contestation is a process that occurs when an illness is rejected as illegitimate by others, including HCPs (Conrad & Barker, 2010). Eight women expressed the experience of illness contestation (30.8%). All of these women had a continuous trajectory, with half having an immediate trajectory and half a delayed trajectory. The women perceived that their educational status and age influenced contestation, and that the results of contestation led to feelings of invalidation and despair. For example, one woman found the status of her doctors (and their education) intimidating. She stated:

I find doctors so like frustrating to talk to, like to push your point you know they're just like, "*I'm the doctor, I went to medical school, I know stuff...I'm just going to tell you this*" and [I'm] just like well, '*you're wrong, you know like, I know I didn't go to medical school but I know that you're wrong.*'...I found that very distressing. (P001, 22yo, GV, casual dating)

Another woman felt that because she was young it was always assumed that she had a sexually transmitted infection (STI) and therefore her pain was never fully explored. She and three other women felt that because it was a female sexual problem genital pain gets less attention from the medical field. For example one participant stated:

Like in some ways it is viewed as a dirty female problem, [the HCPs] don't want to deal with [genital pain]...it is treated as mildly revolting or like it is not a big deal and [I should] stop complaining about [the pain], it can't be that bad... "*Why don't you just put on a brave face about it.*" It's related to sex and it is considered to be a condition that only affects women, so it is less important. (P007, 25yo, PV, committed dating)

Three of the women experienced their genital pain as contested when the condition or the symptoms were not validated by their HCP. One woman came to her doctor with the hypothesis that she had vulvodynia, only to have her pain invalidated:

I had seen a gynaecologist and stopped seeing her because even though I told her about my symptoms she was way, way too rough with me. It hurt heaps and she said, "*You definitely don't have vulvodynia because if you did I wouldn't be able to insert my fingers inside you.*" But I was in wild burning pain, but I wasn't screaming or anything. I just felt that we were on two completely different planes, so I was like I am not going to keep seeing this gynaecologist. (P005, 23yo, GV, committed dating)

Another said, "I had seen [a gynaecologist] one or two years earlier, who said, *'just put up with it'* - he was a man – surprise, surprise" (P122, 36yo, PV, married). While another said, "I had told my GP about it all previously and she didn't think it necessary for me to see a gynaecologist until I insisted, on my sister's strong recommendation" (P129, 27yo, PV, committed dating).

All of the women who experienced illness contestation felt despair about the uncertainty of their symptoms and their interactions with the HCP. One woman found her need to be very persistent and assertive with her doctors distressing:

It was really hard to be really insistent about, you know, I know you (the HCP) are going to tell me it's thrush, I know it's not...I would have gotten further quicker and I would have also like it's really hard to be really insistent with a doctor, like, "*No listen to me, listen to what I am saying!*" (P001, 22yo, GV, casual dating)

This woman felt her symptoms increased during the time that she was seeking a diagnosis, "I don't know if I was getting all stressed out about it or whether it was just getting worse, but it just kind of, it (the pain) was more on my mind" (P001, 22yo, GV, casual dating).

Another woman said:

I was pushed from doctor to doctor being told that nothing was wrong. I had so much testing done with different specialists. I was very concerned at first, knowing that the pain I was feeling was real and no one could tell me what was wrong. (P111, 24yo, PV, single)

While another woman said:

I would be completely depressed after seeing a doctor, I would be bawling my eyes out...because I would feel like they are not listening or they don't understand, or you said your story again and they don't get it. (P008, 23yo, GV, committed dating)

None of the women with vaginismus experienced contestation. Half of the women who had experienced contestation had provoked vulvodynia and half generalised vulvodynia. Six of the women (75.0%) were in long-term relationships.

Minimisation.

Nine of the women (56.3%) experienced minimisation of their symptoms, eight (88.9%) had a continuous trajectory (five immediate and three delayed) and one (11.1%) had a delayed and episodic trajectory. One woman retold her experience of having an exploratory procedure that exacerbated her pain, but her experience of pain during the procedure was minimised by the HCP:

[The procedure] was absolutely excruciating, like and the guy said, '*It will be uncomfortable but you won't be in any pain, you will be fine*',...I was crying, I was like, '*Stop!*'...and he was like, '*You're fine.*' They thought I was a sook...I was not just being a wuss... they said it shouldn't hurt but I was in agony. I was like, listen to me, it was horrible. (P003, 19yo, GV, committed dating)

Another woman stated:

[The doctor] made some comment like, '*It will be interesting to see what happens after you have a baby because your pain threshold changes.*' And I thought...I can't even have sex...It sort of made me

feel like I was hypersensitive to the pain or that I couldn't cope. (P009, 30yo, PV, married)

Four women experienced validation from their first consult and three of these women (75.0%) had a delayed and continuous trajectory. All but two of the women who initially experienced invalidation went on to find HCPs who they felt validated their condition, either through diagnosis or through their symptoms being taken seriously.

A correct diagnosis brought validation to the woman that her pain was significant because it confirmed that she had something 'real' and that her symptoms were not 'all in her head'. It also brought hope that there could be a successful treatment. One woman said, "I am not the biggest freak in the world; someone else in the world has this and is getting treatment for it" (P001, 22yo, GV, casual dating). Another woman said, "I felt very good once someone told me what was actually wrong with me and to a certain extent it gave me hope to know I had a diagnosis" (P111, 24yo, PV, single).

Four women were distressed by their diagnosis because they knew that the diagnosis of vulvodynia or vaginismus meant a chronic condition with little hope of a cure. One participant said:

I remember looking it (vulvodynia) up on the internet and I thought it was a life sentence, I thought from what I read [the pain would be] for the rest of my life...and I was breaking down. (P005, 23yo, GV, committed dating)

When the women felt they consulted an HCP that took the impact of the symptoms seriously, they felt validated, resulting hope. For example, one woman had seen numerous doctors over a number of years before she

found her current gynaecologist. The woman described her first appointment as follows, "The consultation went well, I felt that he listened to me and took my condition seriously" (P007, 25yo, PV, committed dating). She then saw another specialist on his suggestion and said:

[Although] I was sceptical [of her treatment recommendations]... at the same time I felt that...[she] had an intuitive grasp of what was going on with me...She understood that what was happening to me was terrible, both psychologically and physically...Put in the simplest terms, she understood that it was not my fault...The improvement in my quality of life is hard to quantify – I feel like I have been set free.
(P007, 25yo, PV, committed dating)

Sixty-seven per cent of the women whose validation agenda was not met were diagnosed with provoked vulvodynia and 77.8% of them were in long-term relationships. All of the women whose validation agendas were met from the first consultation had provoked vulvodynia and were in long-term relationships, while 75% were over 25years of age. Figure 4.6 is an NVivo word cloud that illustrates the data regarding validation. The frequent use of the words 'explained', 'knows', 'listens', and 'understands' (notions associated with validation) and 'doctor' support the salience of the expectation to be validated by the HCP.

better boyfriend cause change completely cream definitely different distress doctor
emotionally experience explained friends frustrating genital guess helping infections
intercourse interesting issue knows listen looking medication negative never normal
nothing often physio **problem** proper relationship relax remember right
seeing seemed sense seriously sexual sometimes specialist stressed tests thrush
treating **treatment** understand vulvodynia whole working worried worse wrong years

Figure 4.6 Word Cloud: Validation

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Informed Health Care Professional Agendas

The women expected their HCP to be well informed about their condition and its treatment. Seventeen of the women (65.4%) had seen HCPs whom they thought did not have the appropriate knowledge to treat their genital pain. The majority of women (70.6%) whose expectation of an informed HCP was not met had a continuous trajectory (either immediate or delayed). Of note, however, is that all of the women who had either an episodic or discontinuous trajectory reported that their expectation that the HCP was informed about genital pain was not met. These women often 'doctor shopped' and had an extended treatment seeking trajectory. For example, one woman felt that "doctors don't know [about genital pain] and just guess [at how to treat it]." (P118, 36yo, GV, married). Another woman said, "No one knew anything (about vulvodynia) except for my last gynaecologist" (P003, 19yo, GV, committed dating). The experience of seeing an HCP that they felt was uninformed led some of the women to discontinue treatment. For example, one woman stated:

The number of people who have looked at me in the face and said, *'you know, you should really just stop wearing tight clothes'* or *'you should really just stop having baths'*. I don't wear tight clothing, I'm not having baths...there needs to be more wisdom. I didn't really see the point of continuing to seek treatment for it (the pain). I hadn't really got very far with that. It had been a number of years and I had seen a number of people and I got the same response every time. (P007, 25yo, PV, committed dating)

One woman felt that the lack of knowledge led to discontinuous trajectory. She then sought treatment for fertility problems. She said, "We are having fertility issues [and] in the course of this obstetrician seeing me...[he referred me to] another specialist [to treat my pain]" (P004, 33yo, PV, defacto relationship).

Three other women 'doctor shopped' because they thought their doctor was uninformed about genital pain. For example, one woman said:

I think in that early period [of having pain symptoms] I shopped around [for a doctor who was knowledgeable] and I think that was possibly the wrong thing to do because it made it hard for them to start establishing a pattern of when the pain was happening. (P007, 25yo, PV, committed dating)

Two of the women (7.7%) reported that their HCP was informed about their pain condition from the first consultation and they both had a continuous trajectory. Ten of the women who initially felt their HCP was not informed about their pain (58.8%) felt that they eventually found a knowledgeable doctor who brought relief to their distress. The women described positive

outcomes when the HCP could clearly explain why the woman was having pain and how the treatment addressed her pain. For example, one woman explained:

He (the HCP) really helped me by explaining [my symptoms]. It's quite good because now I'm not as emotionally involved with it, it's more of an, '*OK it's a physical thing and I'll get over it.*'...I've been noticing a lot of progress. (P002, 26yo, PV, married)

Another participant contrasted the frustration of seeing an HCP that she perceived to be unformed, with the relief of seeing a knowledgeable HCP. She said, "It wasn't until I saw the physio that I was like, '*OK now I am speaking to someone who has dealt with this before*'" (P001, 22yo, GV, casual dating).

The majority of the women whose informed HCP agendas were not met had provoked vulvodynia (58.9%) and were in long-term relationships (76.5%). Figure 4.7 is an NVivo word cloud that illustrates the data regarding informed HCPs. The frequency of the use of the words 'answers', 'explained', 'knowledge', 'understand' and 'options' supports the notion that women expect an informed HCP.

answers basic **better** cared cause change clinic connected damage **different**
 distress **doctors** emotionally empathic ending enough entire **exercises**
 experience explained frustrating genital giving **great** guess happening health helpful
 hopeful injections intercourse **knowledge** levels listening little looking lower making
 management maybe medical **muscles** negative nerve never normal **nothing**
 options physio **problem** progress quite relax remember saying
seeing seemed **sense** someone **specialist** stretched supposed symptoms system
 systematic terms therapy **treating** **treatment** trying understand vulvodynia
 wanted whole **working** worry years

Figure 4.7 Word cloud: Informed Health Care Professional

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Health Care Professional and Patient Alliance Agendas

An alliance between the patient and the HCP involves negotiation, mutual respect and reciprocity (Chewning & Wiederholt, 2003). Knowledge and patient-centred communication were key HCP qualities that assisted in the HC –patient alliance agenda being met for the women in this study. Eleven women (42.3%) experienced a poor HCP alliance, with seven (63.3%) of these women with a continuous trajectory (either immediate or delayed). Of note, however, is that three of the four women with discontinuous trajectories had a poor HCP alliance. When the woman felt like she did not have a good HCP–patient alliance she experienced distress. For example one woman said:

It had been put to me that I had psychological issues, which probably was reasonable under the circumstances. I looked haggard. I was absolutely miserable, so I think that was probably quite a reasonable assumption to make. I just didn't understand, like I still don't

understand what's happened to me...I was sick of it, I was so sick of being patronized and being treated like an idiot. (P007, 25yo, PV, committed dating)

HCP–patient alliance requires patient-centred communication which involves the quality of the exchange of information between the patient and the HCP (Arora et al., 2009). The women expected the HCP to effectively communicate their knowledge about genital pain and its treatment, and also expected the HCP to listen to them. Six of the women (23.1%) felt their HCP did not listen to them. One woman summarised her experience of seeing specialists, "I would feel like they are not listening, or they don't understand, or you said your story again and they didn't get it" (P008, 23yo, GV, committed dating). Another woman stated, "I wasn't really happy with that gynaecologist...I just found it frustrating because I had always been quite aware of my body yet he didn't seem to listen to what I was saying to him" (P009, 30yo, PV, married).

One woman felt like HCPs always assumed that she had a sexually transmitted infection despite the fact that she had explained that she had been tested for STIs and had not participated in unsafe sexual practices:

Probably because of my age and various other factors it was always assumed [by the HCP]...that I had an STI...I don't know how many doctors I have seen, who I have gone to with genital pain and been told it is probably because I have herpes...If they had just listened to me it would have saved me weeks of time before I got to the specialist. (P007, 25yo, PV, committed dating)

Others echoed the frustration of not being listened to or believed:

The doctors with whom I spoke to...thought that I was lying when they would ask me if anything had ever happened to me, such as sexual abuse...I often felt as if the doctors felt this was the only possible explanation for my disorder and therefore I must have been lying.

(P006, 26yo, vag, committed dating)

Another woman saw four HCPs before going to the local sexual health clinic and being diagnosed with vulvodynia. Each previous HCP tested her for infection and, although the tests came back negative, they recommended she be treated for thrush:

I went to one doctor and she was like, '*yeah its thrush.*' I was like, '*it's not thrush*' and she was like, '*yeah its thrush, here have this prescription*' and I was like, '*fine I'll take the thrush medication*'...I'd had thrush before...knew what [thrush] was and also like they had done the thrush test and I [didn't have thrush]. (P001, 22yo, GV, casual dating)

As can be seen from this data, being tested and treated for thrush unnecessarily and not being listened to frustrated the participant. This participant was greatly relieved when she found an HCP who listened to her. She said:

They (sexual health clinic) were really good, but they still did all the tests again...I kind of said to her, '*look they've done the test you know, it's gonna come back negative*'...and [then] she (the doctor) made the suggestion of vulvodynia...The doctor, she listened to me when I was like, '*...what happens when they come back*

negative? ...that was the first time I felt like [someone listened to me].

(P001)

Thirteen of the women (50.0%) had a strong alliance with their HCP and of these women, 81.8 % had a continuous trajectory (immediate or delayed). One woman summed up her alliance with her HCP by saying, “She [is] really empathic and she is very knowledgeable and she, you know she cared, she listened to every aspect...of the problem” (P009, 30yo, PV, married).

Of the women with a poor alliance with their HCP the majority (54.5%) were diagnosed with generalised vulvodynia, as opposed to the group of women with a satisfying alliance with their provider, where the majority were diagnosed with provoked vulvodynia (76.9%). The majority of the women with agendas that were met and not met were in long-term relationships (72.7% and 69.2%, respectively). Figure 4.8 is an NVivo word cloud that illustrates the data regarding an HCP–patient alliance. The frequency of the use of the words ‘confidence’, ‘explained’, ‘listen’ and ‘helping’ support the notion that an alliance with the HCP was important to many of the women in this study. The words ‘progress’, ‘relationship’ and ‘relax’, and ‘difficult’ and ‘distress’ appear in each of the word clouds representing the identified agendas, supporting the identified outcomes of agendas being met or not met.

always answers better cause clinic confidence cream crying difference difficult distress
doctor emotionally exercises experience explained figure friends frustrating great guess
health helping levels listen looking making medication muscles negative never
normal notice physio problem progress referred relationship relax remember right
seemed seriously sexual specialist stressing taking talking tests therapy thrush times
treating treatment trying understand vaginismus vulvodynia whole women working
worried worse wrong years

Figure 4.8 Word cloud: Health Care Professional and Patient Alliance

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Summary and Conclusions

Using the concept of a trajectory, this study characterised the influences on treatment seeking by women living with vulvodynia and vaginismus. It explored the motivations for and barriers to treatment seeking, as well as identified the personal agendas that influenced treatment seeking.

Women were motivated to seek treatment for their pain when they thought they might have an infection, held optimistic views about their health or when they expected their relationship to include intercourse. The women experienced barriers when they normalised or discounted their symptoms or held negative treatment beliefs. Nescience, shame and embarrassment, and the cost and inaccessibility of services were also identified as barriers to treatment seeking. Unsurprisingly, the identified barriers were associated with a delayed trajectory. Furthermore, when the woman experienced symptoms as a teenager she was more likely to experience the barriers of normalising, nescience and shame and embarrassment.

The women described three significant personal agendas for their treatment consultation with an HCP – validation, informed HCP and patient-

HCP alliance. Whether an agenda was met or not did not significantly impact the treatment seeking trajectory, however, met agendas played a significant role in decreasing the distress the women experienced during their treatment seeking trajectory.

These findings suggest that treatment seeking for genital pain is a complex phenomenon that is influenced by social context. The intra- and interpersonal factors that influence the treatment seeking trajectory are shaped by gender and power dynamics, and social discourse. Gender and social discourse around the importance of intercourse are particularly persuasive in the decisions women make about treatment seeking, while power and gender dynamics influence the relationship a woman has with her HCP. HCPs who understand the influence of social discourse, and gender and power dynamics will have a positive influence on the outcomes for women with genital pain.

Chapter Five: Survivorship

This chapter presents the main findings related to survivorship two parts: (1) survivorship resources for women who seek treatment for genital pain; and (2) survivorship identities of women who seek treatment for genital pain. In presenting the substantive findings, specific treatment seeking trajectory types are considered. Furthermore, word clouds are used to present the salient ideas of the participants. Participant quotes are labelled with the participant number, age, self-reported diagnosis¹¹, and relationship status.

Salient Survivorship Resources

Self-reported survivorship resources identified by the participants were communion with the HCP, family and friends, and others with genital pain, and personal agency (see Table 5.1 for a summary of the salient survivorship resources). These survivorship resources are considered next.

¹¹ Diagnosis abbreviations: GV-generalised vulvodynia; PV-provoked vulvodynia; Vag-vaginismus.

Table 5.1 Salient Survivorship Resources

Resource	Who?	What?	Trajectory	Common characteristics
Communion (n=22)	Supportive HCP (n=17)	Solution focussed Empathy Understanding	DC or IC (70.6%)	n/a
	Supportive partner, family and friends (n=14)	Selflessness Non-judgmental Practical support and advice Perspective	DC or IC (78.6%)	n/a
	Shared narratives with others with genital pain (n=12)	Less isolation Meaningful suffering	DC or IC (66.7%)	n/a
Agency (n=13)	The woman herself (n=13)	Symptoms	IC or IE (61.5%)	>20yo (100%)
		Treatment		LTR (61.5%)
		Relationships		PV (76.90%)
		Sexual activity		Vag (0.0%)

Note. IC-immediate and continuous; IE-immediate and episodic; DC-delayed and continuous; PV-provoked vulvodynia; Vag-vaginismus; n/a-not a noteworthy characteristic; LTR-long-term relationship.

Communion

A total of 22 (84.6%) of the women identified communion, or interpersonal connection with others (McAdams & McLean, 2013), as an important survivorship resource. The quality of the relationships the women had with their supportive HCP, family and friends and with other survivors were of particular salience to the women.

Supportive HCP.

Altogether 17 (65.4%) of the women in this study reported that a supportive relationship with the HCP was a significant survivorship resource. Twelve of the women (70.6%) with a supportive HCP had a continuous

trajectory (six with immediate and six with delayed). All of the 17 women reported that the support from the HCP was influential in decreasing their distress and maintaining motivation for management. The women characterised a supportive HCP as one who was committed to finding solutions to their genital pain symptoms, empathic, and understanding of her situation. For example, one woman said:

[The doctor] said that she wasn't going anywhere, that she would support me through this. That together we would move forward...[My doctor] was really empathic and...very knowledgeable...she cared, she listened to every aspect of it. I can't remember what treatment she gave me, I can't really remember what we ended up doing but it was the emotional side of it that was the best part. (P009, 30yo, PV, married)

Distress may have ensued when the woman did not feel her HCP was supportive. For instance, one woman stated, "I don't think doctors put much effort into finding a solution for it" (P006, 26yo, vag, committed dating).

Another woman said:

I think they don't ever really want to help, they do but...like I don't know, I have never really had a doctor who has gone out of their way to try and...figure out what is going on with me. (P008, 23yo, GV, committed dating)

Another said, "I felt I really had to push the point with the doctor, like they weren't really into solving my problem" (P001, 22yo, GV, casual dating).

A supportive HCP contributed to a more satisfactory and successful treatment seeking trajectory. The women characterised a supportive HCP as

one who listened to her and who demonstrated an understanding of her situation. One woman compared her experience with a past HCP, who contributed to her feelings of hopelessness, with her current HCP:

The first [gynaecologist] seemed kind of helpless... like, '*What are we going to do with you?*'...I reached that point that I said, '*No, it is useless, I don't want to go to her anymore.*' I haven't had that feeling with my new gynaecologist because she just manages to give me a feeling of confidence, of like, '*We are getting there, just be patient.*' (P010, 23yo, PV, committed dating)

Another participant had met with two different HCPs whom she felt were not sympathetic or understanding. She then met with a third HCP and said, "After meeting my very sympathetic and understanding physio...the distress levels reduced a lot" (P122, 36yo, PV, married).

Another participant felt the process of getting a diagnosis and effective treatment was delayed, due in part to the lack of empathy:

The process [of receiving a diagnosis] was long! I inadvertently made it longer by switching doctors for a second opinion because the first doctor I felt was not making any headway...[and the second doctor] I felt...lacked empathy and didn't tell me a great deal about what was going on...I'm [now] seeing a women's physio and she is very understanding and caring. (P125, 33yo, PV, single)

Three of the women sought treatment from HCPs who were empathic and supportive, and although they did not personally experience treatment from an HCP who was lacking in these skills, they did recognise their good fortune. One participant said, "I was lucky to go to a sexual health centre

where the doctors are great...very understanding...I don't think I would get this level of help from many other places" (P133, 27yo, PV, living with partner).

There were no characteristics that were common to the women who described a supportive relationship with their HCP, neither were there any common characteristics among the women who reported a lack of a supportive relationship with their HCP.

Supportive partner, family and friends.

Support from partners, family and friends was a significant resource that provided emotional support and in some cases had a direct impact on the treatment seeking trajectory. Fourteen women (53.9%) reported appreciation for a supportive partner, family member or friend, and 11 (78.6%) of these women had a continuous trajectory (either immediate or delayed). The women expressed gratitude for the supportive people in their lives for being selfless and non-judgemental. The supportive partners, family members and friends provided practical support and advice and helped the women gain a realistic perspective about their situation.

One woman discussed her partner's response once he realised intercourse was causing her pain, "He was very good...and supportive...He would say, '*It (intercourse) shouldn't hurt..., it's not meant to hurt you know.*' And he would say, '*we won't [have sex] now*'" (P002, 26yo, PV, married). He then gave her the control over initiating sex, which was emotionally helpful, but she wondered if she would have progressed faster through her physio homework if he were less understanding. She said:

[Having control over when we had sex] felt quite good in the sense that I didn't feel pressure, I didn't feel any pressure from him...but it might have, if he had a bit more control of that (deciding when they would have sex) it might have meant that I might have dealt with it quicker because I would have felt that pressure a bit stronger by him saying, "*Well I want to have sex.*" (P002, 26yo, PV, married)

Another two women said:

[The pain has not affected the relationship] as negatively as it could have because my partner is really understanding and really supportive...it was hard but at the same time we were pretty committed to facing it together. (P005, 23yo, GV, committed dating)

I am very lucky with my boyfriend because he is so understanding...if he for example just sees the slightest hint that I am having pain he stops. (P010, 23yo, PV, committed dating)

The relationship with other family members was also a significant survivorship resource for five of the women. One of the most significant ways others supported the women was to listen non-judgementally and offer appropriate advice. One woman said:

I did talk about it with my grandmother because my grandmother used to be head of a hospital in Sydney...so she sort of sees sex as more of a, '*well it's part of life and its natural*' and she is very open...She knew all about [vulvodynia], she sort of discussed it with me and she still sometimes says to me, "*How's it going, how's your sex life?*" (P002, 26yo, PV, married)

Others provided emotional support, as well as practical support:

The only person who supported me through the years I have lived with this condition is my mother. It occurred to me that I may not have volunteered that fact previously and I wish to do so now. My mother talked me through the problems and provided advice and support to manage the pain. She took time off work to take me to specialists and helped financially by paying for specialist visits and medication. She supported me to overcome my feelings of guilt and worthlessness and she supported me when health care professionals were rude, ignorant, sexist or just plain stupid. She would not come with me to the GP (I asked her not to), but the fact that she acknowledged that my pain was real made a world of difference. (P007, 25yo, PV, committed dating)

Two participants reported how support from siblings led directly to treatment seeking. One participant said, “[Treatment seeking was] really disheartening...I had spoken to my brother because I had been upset when...I was living with him...and he suggested his GP” (P009, 30yo, PV, married) . This GP became one of her most helpful survivorship resources.

Another participant had a sister who was a gynaecologist and who strongly encouraged her to seek a second opinion after her GP said there was nothing that could be done, “If it wasn't for my sister recognizing the problem from my complaining and her pushing me and helping me the whole way I would still be really frustrated and not treated” (P129, 27yo, PV, committed dating).

Finally, another woman found her friends provided perspective that brought a sense of peace. She said:

I think that it must happen to a lot of people (sexual problems). Not just vulvodynia but disabilities...I would talk to my friends about it and I would be like, '*This is so unfair!*'...They would say to me, '*Oh you don't know what goes on behind closed doors*'...They (the friends) said they sometimes had problems - sometimes physical, sometimes mental, that stopped them from having sex...everyone has, like sometimes people have their own things going on (sexual problems).
(P005, 23yo, GV, committed dating)

Lack of support from family and friends had a negative impact on survivorship. Three of the women experienced significant distress as a result of what they perceived as lack of support. For instance, one participant said:

Sometimes I talk to my mother about this, who is a nurse actually, but I almost feel she is not that understanding about it. She just says you need to do what you need to do and focus on making it better, but I don't know how. (P006, 26yo, vag, committed dating)

While another said, "My mom's...just not really supportive. [She's] like, '*Get over it, grow up, you'll be right, you'll be fine*'" (P003, 19yo, GV, committed dating). Another participant was able to reflect on the effects of an unsupportive partner and how it directly impacted the treatment seeking trajectory:

I felt that my previous partner had placed a great deal of blame and shame on my shoulders because I had genital pain. I think that this made it difficult for me to relate positively to the doctors who were

trying to help me. I felt like I needed to get better as fast as possible so that I could go back to having sex with my partner or he would leave me, this made me impatient about finding a solution and depressed when my symptoms did not improve; it was like a chain of blame. My partner blamed me for having the problem in the first place, I blamed the doctors for failing to diagnose and treat me effectively and for failing to understand the seriousness of my condition and respond accordingly. I felt that the doctors blamed me for somehow being responsible for the problem either through my behaviour (hence the STI thing) or some psychological problem. (P007, 25yo, PV, committed dating)

The only common characteristic among the women who described supportive partners, friends or family was that none had a discontinuous trajectory.

Shared narratives.

Seventeen of the women (65.2%) experienced isolation because of their genital pain. For example, one participant said, "I guess I'd come to think that I am alone with it" (P004, 33yo, PV, defacto relationship). For all but five of these women the sense of isolation was alleviated when they read other women's narrative of living with genital pain. For the women who reported less isolation due to the shared narratives of other women with genital pain, eight (66.7%) had a continuous trajectory (three with immediate and five with delayed); of the women who did not feel a sense of shared narrative, four (80.0%) had a continuous trajectory (half being delayed and half immediate). These shared narratives were helpful in several ways. The

women either felt less isolated knowing there were other women going through similar difficulties, or they felt their suffering had meaning when they could help other women with genital pain.

Eleven of the women who had felt isolation expressed feeling less isolated and a sense of hope when they realised there are other women who have experienced and been treated for genital pain, "I am not the biggest freak in the world, someone else in the world has this and is getting treatment for it" (P001, 22yo, GV, casual dating). Another woman said:

[I had gotten] to a bit of a dead end and then I [searched the internet] and I was reading [a] blog and [it] really helped because I was hearing you know, women who had the same issue and I was like, '*Oh there's like a community of people out there who are going through what I am going through...*' and they are able to lead completely normal sex lives. (P002, 26yo, PV, married)

And another said, "But it is heartening to read the responses of other women...and to see how familiar they are to mine. Genital pain is an isolating experience and it helps to know that others have faced it" (P007, 25yo, PV, committed dating).

Three of the women found it helpful to learn that they did not have the worst case scenario with their genital pain, "Reading the other women's stories was interesting. I feel like I got off really light, with doctors and symptoms" (P001, 22yo, GV, casual dating). However, for two of the women hearing other's stories also resulted in some distress. For one of these participants reading other women's stories made her realise her symptoms were extreme, "He (the HCP) said I was one of the highest persons

(meaning the scores of her pelvic floor biofeedback)...he has seen" (P003, 19yo, GV, committed dating). The other woman found her symptoms were not exactly like the women she read about and she found this distressing:

[My symptoms are] not the same like other women describe it with vaginismus so I think [my symptoms are] something in between [vaginismus and vulvodynia] with me...it [is] like an additional barrier because I had hoped that I would have found [something] on the internet...that could help me, but since I figured out that my case is not [like other women's] it is like an additional barrier so like it is even harder to get help, to find a solution...because I think I can't get through with normal therapy or normal books or whatever but I might need to see a specialist...that is frightening. (P010, 23yo, PV, committed dating)

Another participant found reading other women's stories motivated her to treat her pain:

There are quite a few blogs on the internet by women who have it and that pretty much describes their day in day out, like down to the tiniest details and a lot of them have it much worse than I do...They also have lives that I would find really not enviable...I am really interested in that stuff (hearing other people's stories) and seeing other peoples bravery, or seeing like their lack of bravery. I'd be like...inspired or I don't want to be like that. (P005, 23yo, GV, committed dating)

For three of the women, connecting with other women with genital pain brought meaning to their experience, especially if they could offer assistance to other women with genital pain. One participant said:

I found once I started opening up, so many of my friends would call me up out of the blue and be like, "*I am having this problem. What do you think?*", or "*Who have you seen?*"...I have become a vagina guru. I find once I talk about it [I find out] so many girls have similar problems. (P008, 23yo, GV, committed dating)

Women who reported shared narratives as a survivorship identity were varied in their characteristics. Figure 5.1 is an NVivo word cloud that illustrates the data regarding communion. The notion of communion being important to survivorship of genital pain is evident in the word cloud as many of the words that were frequently used relate to the people the woman has relationships with, e.g., 'boyfriend', 'husband', 'relationship', 'women'. Other frequently used words described characteristics of the relationship, e.g., 'listen', 'helping', 'happy', 'understanding', 'supportive', 'alone', 'frustrating', 'pressure'.



Figure 5.1 Word Cloud: Communion

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Agency

Agency, or the degree of perceived ability to affect change, influence others or impact their environment (McAdams & McLean, 2013) was a salient survivorship quality evident in 13 of the women's narratives (50.0%). Of the women whose stories were permeated with strong agency, 61.5% (n=8) had an immediate and continuous or episodic trajectory.

The highly agentic women (50.0%) made well thought out decisions about treatment and management of their pain symptoms, and about their intimate relationships and sexual activities. Management of vulvodynia, particularly generalised vulvodynia, involves avoiding pressure on the vulva, e.g., wearing certain clothing, such as jeans. One agentic woman reported how she made conscious decisions about what she wore depending on her circumstances:

If I am going to go to a bar and I'm going to be standing up all night I'll just wear my jeans for a couple of hours and that always makes me feel better (about her self-image). (P001, 22yo, GV, casual dating)

The highly agentic women made well thought out decisions about treatment as well. One woman emailed the interviewer some months after despite discontinuing treatment. She said:

In terms of my vulvodynia, I pretty much stopped treatment a bit after speaking to you...I felt really frustrated and the whole process, I felt, was overwhelmingly intrusive. I guess I could deal with the burning discomfort more than the discomfort of treatment. (P001, 22yo, GV, casual dating)

Knowledge about their condition was a resource that strengthened agency. For instance, five of the women (38.5%) spoke specifically about how their experience of and knowledge about treatment made the thought of future flare-ups of their symptoms less daunting. One woman wanted to get pregnant, although her first pregnancy and birth significantly worsened her condition. She said, “[If I get pregnant] we will just see if it all starts up again (the pain symptoms)” (P009, 30yo, PV, married). In responding to the possibility of worsened pain symptoms post-partum she said, “Well to be honest, I think I would be OK with [a flare-up] because I know that there is help, like there are things that I can do and I have a lot more knowledge” (P009, 30yo, PV, married). Another woman said, “The fear of it (vulvodynia symptoms) coming back is definitely there because...[actually the fear of it coming back is] probably not so bad because I know how to deal with it” (P002, 26yo, PV, married).

One woman reported her highly agentic status with symptom management as follows:

[When I first sought treatment the doctor] told me that I had herpes without any kind of pathology. I was a young scared girl...Now I am a bit more assertive about the advice I am given...I am also a bit less shy and embarrassed about explaining what is going on...[because] having the history now of treatment experience [I can] be sort of a bit more demanding about what [I] want. (P007, 25yo, PV, committed dating)

Another woman reported her conscious decision to not seek out a relationship at this time:

I think I had to review my identity...[I decided] to not seek 'companionship' for the last nine months...[Its been] liberating. It has helped me maintain plutonic relationships better - I think I often resort to flirting just because I can, or because I undervalue my other skills and charms. (P125, 33yo, PV, single)

One woman reflected on a time when she was unable to find a diagnosis and effective treatment. She felt her sexless relationship was not satisfactory, however, she felt she and her partner were good together in all other ways. She described one decision she contemplated:

But I think that I probably would have [come to] a kind of arrangement maybe where we both get sex from other relationships which sounds kind of radical but [we are really good together in so many other ways]. (P004, 33yo, PV, defacto relationship)

The women with perceived control made informed decisions about their sexual relationships, including when to have sex despite the pain and when to relinquish decisions about the types of sexual activities they would engage in. One participant reported not telling her partner when she was having small amounts of pain so that her partner would still be willing to engage in sexual activity:

There [is] a point where I ... weigh up the benefits with the bad stuff and say I would rather, you know, have sex and put up with [the pain] later. (P001, 22yo, GV, casual dating)

Another woman felt like she held most of the control over when they would have sex:

[My partner] always knows that I initiate [sex] and I think that would be difficult [for him], I think that that takes a bit of control from him. (P002, 26yo, PV, married)

She reported choosing to relinquish control over the types of sexual activity they participated in, including non-penetration activities, she said:

[He] says that if we're doing oral sex he gets frustrated because it can't lead to [intercourse] and for him oral sex should lead to intercourse...I would be happy for us to do just oral sex at the moment but when he told me that [oral sex alone frustrates him], I was like, I'm not going to even push it because...I'm controlling all these aspects [of our sexual relationship] he has the right to say, "*You know what? I don't want [oral sex.]*" (P002, 26yo, PV, married)

All of the highly agentic women were in their 20s or older and 61.5% were in long-term relationships. Seventy-seven per cent were diagnosed with provoked vulvodynia and none of the highly agentic women were diagnosed with vaginismus. Figure 5.2 is an NVivo word cloud that illustrates the data regarding agency. The notion of agency within symptoms, treatment and sexual activity is represented in the words 'control', 'certain', 'decided', 'burning', 'tests' 'medical', 'sexual' and 'intercourse'.

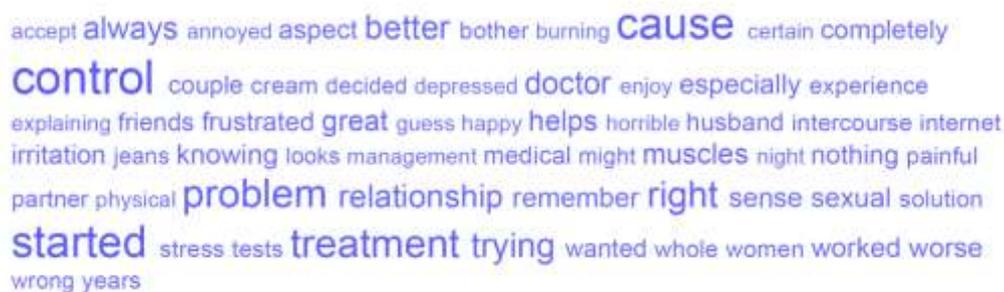


Figure 5.2 Word Cloud: Agency

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Survivorship Identities

This study sought to identify the personal narrative identities that contributed to survivorship of those living with FGP. Survivorship is a way of conceptualising the overall course of an illness (Naus et al., 2009) and encompasses the physical, psychosocial and economic aspects of an illness trajectory (National Cancer Institute, n.d.). The narrative identities associated with survivorship were redemption, contamination, creating meaning of suffering, sexual self-schema (SSS), and positive resolution. This section will present the narrative identities evident in the data and, where relevant, compare the trajectories and the characteristics of the women with specific narrative identities. Table 5.2 summarises the narrative identities associated with survivorship for the women in this study.

Table 5.2 Survivorship Identities

Identities	Narratives	Trajectory	Common characteristics
Redemption (n=12)	Personal strength Personal growth Relationship growth Supporting others	IC, IE, DC, or DE (75.0%)	LTR (75.0%) PV (83.3%)
Contamination (n=3)	Negating the positives Discounting help Isolation	DC (100%)	GV (66.7%) Vag (33.3%) 26 or younger (100%)
Creating meaning (n=22)	About their symptoms and diagnosis About the delay of treatment About management	IC, IE, DC, or DE (72.7%)	n/a
Positive sexual self- schema (n=8)	Positive sexual identity Sexual openness	IC, IE or ID (62.5%)	LTR (87.5%) PV (87.5%)
Negative Sexual self- schema (n=7)	Sexual disconnection Sexual inadequacy Sexual embarrassment	DC, DD or D (100%)	LTR (71.4%) GV (57.1%) Vag (14.3%)
Positive Resolution (n=4)	Personal resolution Relational resolution Lack of worry Clarity Endings and Beginnings	IC or IE (100%)	LTR (50.0%) PV (75.5%) GV (25.0%)

Note. IC-immediate and continuous; IE-immediate and episodic; ID-immediate and discontinuous; DC-delayed and continuous; DE-delayed and episodic; DD-delayed and discontinuous; D-delayed; GV-generalised vulvodynia; PV-provoked vulvodynia; Vag-vaginismus; n/a-not a noteworthy characteristic; LTR-long-term relationship.

Redemption Identity

Redemption involves finding the 'silver lining' in a negative event (McAdams & McLean, 2013). This was when the women were able to recognise something positive or good despite their suffering. Twelve women (46.2%) had narratives that demonstrated highly redemptive qualities. The

redemptive narratives were categorised as personal strength, personal growth, strengthened relationship and supporting others. Of the women with redemptive narratives, eight (66.7%) had a continuous trajectory (four with immediate and four with delayed) and one an episodic trajectory.

Two of the women with redemptive narratives thought that the experience of having and seeking treatment for genital pain helped them to recognise strengths within themselves. For instance, one woman said:

I don't think [having genital pain] reflects on me particularly. In fact, the fact that I persist in trying to maintain a sexual relationship with my husband despite the pain is a positive about me. I could have just said, '*stuff this*' years ago. (P108, 30yo, PV, married)

Three of the women reflected on how the experience of genital pain had changed them personally. One woman said, "I had to stop doing pilates... [but] I've started doing yoga, which is great. So one door closes, another one opens" (P125, 33yo, PV, single). Another woman felt her experiences had led her to be healthier:

Life [before getting] sick and after getting sick are just like so different. Like it probably changed me in good ways...I have always cared about my health but I probably didn't practice it enough...I used to do [illicit] drugs...in the past I would have to force myself [to cut down on using drugs]...whereas now I don't have to try. I am actively interested in being healthy. (P005, 23yo, GV, committed dating)

This woman also felt her experiences of suffering and her boyfriend's response to her suffering had positively changed her general view of men:

I think seeing the response from my boyfriend because, I've always [been] pretty harsh on men in general...I can be really, really critical [of men]...seeing his response [to my suffering] has been really uplifting. (P005, 23yo, GV, committed dating)

Five of the women's silver lining was a strengthening of their sexual relationship with their partner. For example, one woman said that she would not take her sexual relationship with her husband for granted:

[After reflecting on my genital pain] I started to think that maybe this experience is going to be beneficial for my sex life...I'll appreciate it more, I'll view sex from a different perspective as just someone normally. I won't take it for granted...I'll view it as a really important thing because I lived without it and I believe I've gone through so much to get to a stage where I can have sex...For most people it's just been, *'Oh sex, oh I got to have it again?'* (sighing). I've had to get to a point where I can have sex, so from that perspective maybe it's a good thing you know. (P002, 26yo, PV, married)

Another woman felt her suffering had strengthened her intimate relationship, "In many ways not being able to enjoy intercourse has brought us closer. We are intimate in other ways (kissing, touching etc.) and that has been quite satisfactory for both of us" (P122, 36yo, PV, married). While another woman felt she may not have met her husband if she had not experienced vulvodynia. She said:

It (the vulvodynia) has been a blessing in disguise because I weeded through a lot of assholes. [Relationships] may not have fizzled out quite so quickly if we could have had intercourse but it really kind of

showed a lot of people's true colours in the beginning and that is something that I always sort of look at – I may not have gotten to my husband... it was a good way to weed out the jerks. (P009, 30yo, PV, married)

Another redemptive narrative experienced by three of the women focused on being able to help others with genital pain. One woman said:

[A] friend who is going through similar things now, the constant thrush and the pain...it is nice to be able to give her some guidance because she feels very lost and distressed about it. To be able to refer her to doctors, it does sort of make me think that at least some good can come out of [my vulvodynia]. (P009, 30yo, PV, married)

All but three of the women were in long-term relationships and all but two were diagnosed with provoked vulvodynia. Figure 5.3 is an NVivo word cloud that illustrates the data regarding redemption. The concept of redemption is represented in the words 'accept', 'beginning', 'better', 'happy', 'hopeful', 'improvement', 'management', and 'solution'.

accept actually afterwards aspect beginning better bother boyfriend cause
 changed completely constant cream cured definitely different disappointed distressed
 doctor enjoy expect experience friends frustrating genital great guess happens happy
 health helps hopeful husband important improvement intercourse interested internet leave
 light listen lived looking management might normally nothing physio positive
 pretty problems quite relationship remember response sense solution
 started stretched treatment trying wanted without worked worse years

Figure 5.3 Word Cloud: Redemption

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Contamination Identity

Contamination narratives are ones that are saturated with dramatically bad or negative scenes that overwhelm, destroy or erase any positivity (McAdams & McLean, 2013). Three of the women's narratives reflected contamination. These three women all had delayed trajectories. Two of the women were diagnosed with generalised vulvodynia and had continuous trajectories, while the other woman was diagnosed with vaginismus and had a discontinuous trajectory.

The perception of being contaminated by the pain experience led to isolation and discounting any help offered them. For example, this participant discounted the positive aspect of receiving a diagnosis:

When [the HCP] first [diagnosed me] and she printed something out and gave it to me I was like, ah I felt so, so, so good... Oh my god I felt like crying; I wanted to cry I was that happy... I kind of left feeling like a little like there was, I felt good, but I felt bad at the same time cause I was like, *'How long am I going to have this? Am I going to have this for my whole life? I can't deal with this for my whole life. I won't be able to live my life.'*... So I was thinking oh, you know, why me? Because I have just got the worst luck with everything. (P003, 19yo, GV, committed dating)

When talking about the impact of having vulvodynia she said:

Everything, absolutely everything is going down. I can't work, I can't. I did all these courses after school, I did Year 12, I did all these courses to get into real estate because that's what I wanted to do... The pain, I thought it might go away so I started having interviews to see real

estate people and um like to get a job and I was offered all these jobs. I thought nope I can't work because I had a previous job and I was having to call in sick all the time or having to leave. (P003, 19yo, GV, committed dating)

This participant also reported several incidences of meeting with her HCP and talking about her concerns and fears about her pain. She reported initially feeling better after hearing what her HCP had to say, however, she would go home and ruminate on what the HCP had said and found ways to discount what he had told her. She said:

When I saw [the HCP], I felt better. I came out feeling better, but then about three or four hours later I started thinking into it (his explanations for her pain and the treatment for her pain) and like how can that, I don't understand how its joined (her pelvic floor muscles and her pain)...[After seeing the HCP again I would] feel better again but then...more things came to my head...I have always been really sceptical about it I think there is more to it than what he is [saying]. (P003, 19yo, GV, committed dating).

Another woman with contaminated narratives was pessimistic about her sexual problems:

Even if it is that reason (genital pain being the reason for her low libido), [even if] there is a physical reason why [I have a low libido], I still don't think that would change anything with my partner, because although he would be understanding for a while, [ultimately nothing would change]. (P006, 26yo, vag, committed dating)

This participant reported discounting the ability of local doctors to help her: "I will look into contacting those doctors just to see what they have to say. At the same time I don't even want to bother because I think I will just be disappointed and nothing will come out of it so, I don't know" (P006, 26yo, vag, committed dating).

In retrospect, another woman discounted help by her HCP as follows:

I was seeing um, [name of HCP] and she was great...but I think she just got lucky and thought that she had helped me out. But looking back on her exercises and things like that it was like a lot of bullshit.

(P008, 23yo, GV, committed dating)

She reported being negative about all of her HCPs:

I am kind of going down the 'thinking that it (genital pain) is emotional' path so I am trying to see like more counsellors or sex therapists or whatnot. But it is pretty hard because I think what they are saying is bullshit, but I think that about a lot of doctors. I don't know, they don't ever really want to help. They do but I think it is more for the money.

Like I don't know I have never really had a doctor who has gone out of their way to try and you know really try and figure out what is going on with me. So I don't really trust them. (P008, 23yo, GV, committed dating)

Two of these women talked about the isolation they feel from those who might be able to provide support. They felt their family and friends did not understand their situation:

No one can really understand, they just think you're being a wuss you're whinging...I try my hardest to try to explain to [my friends] why I

can't go out to work but when they go, "*You just need to get a job*", because I obviously have no money...no one understands they think I am just joking because I am pretty good at hiding my pain and just dealing with it. (P003, 19yo, GV, committed dating)

The other woman said:

I don't think people really understand the whole painful intercourse thing. Like anybody I have ever talked to about it, like it is not something they've experienced so I don't think it's something they understand...It's kind of frustrating but at the same time even if I did have someone to talk to about it I don't think they would have any solutions anyway. (P006, 26yo, vag, committed dating)

All of the women were in long-term relationships and two of the three women were under 25 with the third being 26. Figure 5.4 is an NVivo word cloud that illustrates the data regarding contamination. The words in this word cloud that support the notion of contamination are 'fault', 'harming', 'worse' and 'wrong'.

affected anymore aspect better bother boyfriend brain CAUSE completely connected control definitely differently disappointment distressing drive emotional enjoy example explaining fault friends frustrating guess guilt happy harming husband infections infertility intercourse interested knows least moment muscles normal partner physical possible pretty problems proper quite relationship right running sense sexual stretch stuff taking treatment trying understand vagina wanted whole worked worried worse wrong

Figure 5.4 Word Cloud: Contamination

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Creating Meaning Identity

Creating meaning in this context relates to the degree to which the woman learns something or discovers a message from a particular event. The learnings can be concrete lessons or a deep insight about life (McAdams & McLean, 2013). The majority of the women's narratives (n=22; 84.6%) exhibited attempts at creating meaning. Of the women who expressed meaning in their narratives, 72.7% (n=16) had a continuous or episodic trajectory. Meanings were constructed around symptoms and diagnosis, the delay or discontinuation of treatment seeking, and the management of symptoms and sexual identity. There were no common characteristics in the women who exhibited attempts at creating meaning. Of the women who did not exhibit attempts at creating meaning (n=4), half had a discontinuous trajectory or had not sought treatment.

Symptoms and diagnosis.

For three women the meaning of their symptoms and diagnosis focused on past events. One woman only experienced symptoms when she had a pelvic exam and she attributed this to the death of her mother:

I now believe this internal investigation (pelvic examination) triggers a deep sense of loss - a loss of mother and female identity. I'm continuing to receive psychotherapy that surrounds my fear of abandonment and loss. (P104, 28yo, vag, committed dating)

One woman hypothesised that she perpetuated her symptoms by continuing to have sex while experiencing symptoms:

Probably what I did wrong at that time (when her symptoms reappeared after a period of being asymptomatic) was to try and push

through it, push through the pain you know. I wasn't enjoying it so possibly at that point I had an association in my mind between the pain and sex. (P004, 33yo, PV, defacto relationship)

Another woman reported that her symptoms were due to a medical procedure when she was a child:

I am not sure where it (vaginismus) actually started. It might be further back than I think because when I was a child, my mother brought me to the doctor and they noticed that there was obviously a hymen there but there was also the skin was covering the vaginal opening bit so they had to do [a procedure], I was really young so I don't really remember it. (P006, 26yo, vag, committed dating)

Others ascribed psychosocial meanings, at least in part, to their symptoms. Two women wondered if they were romantically attracted to, or in love with their partner. For instance, one woman said:

My body wasn't [sexually] responding [and I thought] maybe, it confuses you, it really confuses you, you think well maybe I'm not attracted to my husband because my body's not reacting to him. (P002, 26yo, PV, married)

When this woman saw her current HCP and he explained the physiological reasons for her pain, the meaning of her pain changed and she experienced less distress and felt more capable of managing it. She said:

Just the way he (the HCP) explained it all, he took a bit of the emotion out of it so suddenly I didn't feel as emotionally connected to this...it is a physical thing and I'll get over it. (P002, 26yo, PV, married)

Another woman said:

I wondered how much my psychology affected the outcome – i.e., was my body sabotaging my physical relationship because my brain didn't want to admit that I was unhappy and bored. (P125, 33yo, PV, single)

Two other women felt their pain meant they were experiencing stress and tension:

I am sort of getting this feeling [that] part of the reason that it (the pain) got worse when I started seeing [my girlfriend] was just that...when I start seeing someone I get really anxious about it...So, as much as it was to do with sex, it's also an anxious thing as well, so it gets worse when I am more anxious. (P001, 22yo, GV, casual dating)

Delay of treatment.

In talking about treatment seeking, the women offered meanings for their delay of treatment. One woman attributed the delay to her young age, lack of knowledge about vulvodynia and a lack of sexual experience. She said, "I just had no idea that [vulvodynia] was possible...I know that sounds silly but I guess I was young and I was naïve and I hadn't had any sexual partners before my husband, so I was really naïve" (P002, 26yo, PV, married). While another attributed it to being older:

When it first started I thought this is just...part and parcel of getting older and the responsibilities of a relationship...but [when] I had to actually refuse sex all the time...that [was] the point where I [went] to the doctor. (P007, 25yo, PV, committed dating)

Another woman cited a number of meanings for her delayed treatment seeking, "The delay was partly due to feeling ashamed of my problem, partly

due to not knowing who to ask, and partly because I thought nothing could be done" (P122, 36yo, PV, married).

Management.

Trajectories were influenced by the varied meanings the women constructed, including the management of pain symptoms. For some of the women, management of symptoms meant failure of treatment, while for others it meant successful treatment. One woman had a friend with vulvodynia who was satisfied with managing her symptoms; however, for this participant management was not acceptable. She said, "My friend talks about management, but that is not for me" (P008, 23yo, GV, committed dating).

Other participants grappled with the meaning of management. One participant initially felt that management was not good enough, but as she discussed the concept of management she considered the possibility of not being cured. In response to being asked if she thought her 'case' was management versus cure she said:

The doctors are kind of like it's a management thing, like as long as it's not bothering me too much that's good enough for [the doctors]...But I'm kind of like, "*Well fine, that's good enough for you.*" But like also they kind of said that it can come on spontaneously and then spontaneously go away but that can be like years so I don't really know...I suppose it really, I suppose it's just a management thing.

(P001, 22yo, GV, casual dating)

Another participant wrestled with the meaning of 'cured'. She said:

Looking at this (the meaning of 'cured'), well once [(the HCP) says, "*OK, you're cured,*" then what happens if I go...two months without

sex? Is it going to go back to [tight pelvic floor muscles] or is it going to stay stretched, like when does it get to the point where it...stays stretched for the rest of your life? Or am I always going to have...if I'm not stretching [my pelvic floor muscles] is it going to...go tight again? Will I always have this sort of issue? Will my muscle always retain that memory of tightness?...I should actually ask [my HCP] what the definition of cured means. (P002, 26yo, PV, married)

Another woman knew she would need to manage her symptoms, but struggled with what that meant for her life and what it meant to those around her, including her HCP:

The other thing about it that has been really frustrating is that it never stops...You're always waiting for the next time it is going to happen, or it is going to catch you off guard when you least expect it...It is distressing at having to then tell your partner or tell someone else...the chronic nature of it...Like if you have an incurable condition, like if you have herpes or one of those chronic STIs or something, people understand that that is a really difficult thing and it takes long-term management and coping and support. Whereas the way I felt my genital pain was treated by doctors, and by myself even, and by my partner, was that you know it was a one off type thing and the fact that it kept coming back just confused and upset everybody. (P007, 25yo, PV, committed dating)

The goal for other women was to manage their symptoms well, so that the pain impacted their life as little as possible. One woman said:

We can have sex (intercourse) again, which is good...[It is] not completely [pain free], it's not like in the past were it just happened. But like the degree to which it happens with relative spontaneity I am happy with. Look if it was like this for the rest of my life I would be OK with it even if it doesn't get any better. (P005, 23yo, GV, committed dating)

Another woman said:

It is something I have sort of come to accept...that for me it is going to be a management problem. Um, not a management problem but a management thing rather than something that will go away completely. You know I think in my early 20s I was more optimistic about [a cure] but I'm 30 now you know I think, I mean it would be lovely if it would go away completely but it has been a long time you know. (P009, 30yo, PV, married)

Figure 5.5 is an NVivo word cloud that illustrates the data regarding creating meaning. Words such as 'cause', 'explaining', 'guess', 'sense' and 'understanding' suggest the women made meaning of their experience of pain and treatment seeking.

affects anymore aspect better bother boyfriend cause completely control couple
 definitely different difficult doctor drive emotionally enjoy especially experiences explaining
 fault found friends frustrating genital great guess guilt happy helps husband important
 infections intercourse interested issue jeans knows months motivated muscles normally
 nothing painful partner physical point pretty problem proper relationship
 right sense sexual starts talked time together treatment trying understanding
 wanted whole women worked worry wrong years

Figure 5.5 Word Cloud: Creating Meaning

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Sexual Self-Schema Identity

Sexual self-schema (SSS) is the woman's cognitive view about sexual aspects of herself (Andersen & Cyranowski, 1994). Eighteen of the women (69.2%) spoke of their SSS and its impact on the treatment seeking trajectory. Four SSS narrative identities¹² were evident: (1) sexual openness; (2) positive sexual identity; (3) sexual disconnection; and (4) sexual inadequacy and embarrassment

The reported SSSs reflected negative narratives (sexual disconnection, sexual inadequacy and sexual embarrassment) and positive narratives (sexual openness and positive sexual identity). Nine of the women held predominately positive SSS narratives and five of them (55.5%) had an immediate trajectory (three continuous, one episodic and one discontinuous). Seven (77.7%) of the women were in long-term relationships and seven (77.7%) were diagnosed with provoked vulvodynia.

¹² Andersen and Cyranowski's definition of sexual self-schema was used to organise the themes around sexual self-beliefs. However, as the women's meanings emerged from the data, the concept of narratives seemed to be a more apt way of presenting the data.

All of the women with predominately negative narratives (n=9) had a delayed trajectory (five with continuous, one discontinuous and one with no treatment at all). Five of these women (55.5%) were in long-term relationships and four had generalised vulvodynia and one vaginismus.

Sexual openness.

Six of the women talked about sexually satisfying intimacy that did not involve penetration, and therefore did not involve pain. One woman contrasted the times in her relationship when they had non-penetrative sexual activity to the times where she avoided sexual contact:

[The times when I avoided sexual contact completely] were heart wrenching. It was better [for our relationship] when we were having non-intercourse sex...I enjoyed that. (P004, 33yo, PV, defacto relationship)

Another woman said:

There are other things you can do, other positions where you don't have to penetrate...still we love each other and we can [make] the best out of [the situation]...we have a normal sexual relationship. (P010, 23yo, PV, committed dating)

Another participant said, "We are intimate in other ways (kissing, touching etc.) and that has been quite satisfactory for both of us" (P122, 36yo, PV, married).

Of the women who were sexually open, half sought treatment immediately and half delayed, with one of the women not seeking treatment at all. None of the women in this group had vaginismus.

Positive sexual identity.

Two of the women had a positive sexual identity and reflected on how their genital pain had altered their sexual expression. One woman said, "I enjoyed sex immensely previously, and in a way, the vulvodynia has changed my sexual identity" (P125, 33yo, PV, single). One of the participants was also diagnosed with endometriosis and she was considering a treatment that had significant side effects. In responding to how this might affect her future fertility, she said:

I don't know if it is just the time of life or the lifestyle that I lead, like I would happily have the endometriosis pain, I would happily accept any consequences of the endometriosis if I could get rid of the genital pain...I don't wish to become infertile because of the endometriosis but...I am not the sort of happy, plump, mumsy sort of woman anyway. Um, its more debilitating to me and it affects my self-esteem much more that I have the genital pain...It is much more of a priority for me to get that under control than anything else, because I can live with having bad period pain... but I could not live with what I was having [genital pain]. I sought treatment for the genital pain much more than I did you know....[for] the endometriosis. (P007, 25yo, PV, committed dating)

Both these women sought treatment immediately and their trajectory was either episodic or continuous.

Sexual disconnection.

Eleven of the women felt a sense of disconnection from their body or their sexuality. The women used a variety of words to describe the

disconnection with their body and their sexuality, including: broken, shut-down, numbed out, cut-off, and neutered. For one woman her disconnection with her sexuality was protective in nature, "I think I was feeling a bit down...but by and large I would just cut that part of my life off - [my] sex drive" (P004, 33yo, PV, defacto relationship).

This disconnection was distressing for the women. For instance, one woman said:

That is quite distressing (the thought of her always having to stretch her pelvic floor muscles before sex) because then there is that whole thing of, well I'm not in control of my body anymore...I think I'm cured [but] there is still that element of you're never going to be completely in tandem with the...sexual side...of your body and that's annoying.
(P002, 26yo, PV, married)

This woman reflected on a life without sex and what that meant for her and her partner:

There were periods where I thought I'll just have to, I should divorce my husband I can't do this to him...I'll just have to live the rest of my life being celibate which means I'll never be in a relationship because how can I be in a relationship with someone I can't have sex with.
(P002, 26yo, PV, married)

Another woman said:

I feel like the relationship that I am in now it seems like such an important thing and it is constantly something we fight about...If he wasn't the type of person that needed [sex] then we wouldn't fight so much. So maybe that is the type of person I need to find, someone

who doesn't need sex very often...I am not sure if that exists. (P006, 26yo, vag, committed dating)

This woman perceived mismatched libido between her and her partner as driving their sexual activity. She agonised over the meaning behind her perceived lower libido:

I kind of try to avoid sex at this point and I am not sure if it is due to the pain, or if it is something else, or if it is a mixture of things. It's quite a big issue in my life; it makes me quite anxious to think about it...I don't normally use the excuse that sex is painful because I don't know for sure if that is why I don't want to [have sex]. All I know is that I just don't want to. It's hard because he thinks, '*Why doesn't she want sex? It is obviously something wrong with me.*' And I say, '*No it's me, I just don't feel like it*'...it is almost on a daily basis so it is pretty dreadful. (P006, 26yo, vag, committed dating)

She blamed herself for her partner's sexual problems, tying it back to her low libido and pain:

For some reason I think after I orgasm the muscles contract, and if I orgasm before my partner, I have to stop because it is too painful. And I think it's come, another reason why I think that [sex] is not happening as frequently is because it has become an elephant in the room...there are these little problems that happen all the time like you know I can't keep having sex once I orgasm because it hurts too much... and my partner, because it doesn't happen very often, he is to the point where when [we do have sex] he feels like he needs to last for a long time and if he doesn't he gets upset with himself...it is at the

point where he can't get an erection because he is trying so hard to keep that erection. Just so many problems that have come out of nowhere. (P006, 26yo, vag, committed dating)

Some of the women had no desire to be sexually active and showed no inclination to finding sexually satisfying activities that would not aggravate their pain. One woman had provoked vulvodynia for several years before developing generalised vulvodynia. She reported:

[My boyfriend and I have] never had a good sex life because of [the vulvodynia] because it has always just kind of hurt, been uncomfortable for me. Now [that I have pain all of the time]...it's just like no way am I going to [having sex]." She also said, "The only good thing that [has] come out of [the vulvodynia is that] I have an excuse not to have sex. (P003, 19yo, GV, committed dating)

While another woman said:

[Sex] is anxiety producing for me, I mean who wants to engage in something that is painful...It isn't something my mind wants to do or my body wants to do...I kind of try to avoid sex at this point...It's quite a big issue in my life...I would rather just not ever have to do it (have sex)...Sometimes I just wish that I was in a relationship where we didn't need to be sexually active at all." (P006, 26yo, vag, committed dating)

Two of the women perceived their pain had prevented them from getting involved in intimate relationships. For one woman, this barrier to intimate relationships was not a distressing notion. She said:

I have had to accept that I will not be able to tolerate a sexual relationship, nor bear children, as a result of the pain. Having never had such relationships before, this does not feel like the sacrifice it might otherwise. I am a relatively unemotional and very logical person; I find dwelling on the emotional aspects of this fact of my life to be an exercise in futility. (P117, 19yo, GV, single)

Eight of the women who were sexually disconnected had delayed trajectories (72.7%) and one of the women had not sought treatment at all.

Sexual inadequacy and embarrassment.

Another aspect of sexual self-schema is the woman's perception of her sexual performance and how others perceive her sexually (Cyranowski, Aarestad, & Andersen, 1999). Four women felt they were sexually inadequate, with one participant saying, "I used to cry after we tried [to have sex] and I just used to feel hopeless and that I was a terrible lover." (P002, 26yo, PV, married) Another said, "No guy wants a girlfriend who...isn't super enthusiastic in bed" (P133, 27yo, PV, living with partner).

Seven of the women reported embarrassment about their genital pain or because of the way the pain impacted on their daily lives. Two of the women were distressed about the types of clothing they were limited to wearing and felt this negatively impacted on how others perceived them. For example, one participant said:

Participant: When I go out, if I am going out to a girl (lesbian) bar I feel like if I'm being girly among lots of lesbians who are all like a little bit tough...they'll treat me more girly or they will be like, '*Oh we'll play a butch femme [thing].*' and I'm just like, '*Nooooo.*' I hate that.

Interviewer: Do you feel it's different with men? Do you feel they treat you different when you are dressed up girly? (This participant dates both men and women).

Participant: No not necessarily, men just think I'm a girl where as you know if you're in a gay bar there are people who are like 'manly' girls and 'girly' girls, you can kind of have that thing...

Interviewer: Yeah and you're not the girly girl type?

Participant: I am, but I'm not, I'm not only that. (P001, 22yo, GV, casual dating)

This participant felt limited in her ability to express herself fully because the pain limited what clothing she was able to wear comfortably. She also said:

I don't like how [the pain] alters my life, because I have been wearing skirts a lot and stockings, I just feel like a girly, girl all the time and I just started this job...and I'm just like you (her new co-workers) just think I am this massive girly, girl. And when you're girly, I feel like you lose a few IQ points just by definition or something...it makes me feel a little bit uncomfortable when I'm not wearing something that I feel myself in. (P001, 22yo, GV, casual dating)

Another participant said:

It is a bit shallow...when you have genital pain one of the things they tell you is to wear cotton underwear. Like even just the fact that I can't ever wear nice underwear for my boyfriend, it's the small things because you want to explain why, that it is not some kind of attitude problem you have about sex. (P007, 25yo, PV, committed dating)

Three of the women felt they lived a double life, that their public persona was different to their sexual persona. One woman said:

One night we (she and her husband) were out and we were holding hands you know sort of leaning on each other and this other couple said, '*Ah you look like newlyweds*' and we were like, if they only knew, they probably think we bonk every night...It is pretty much a sexless marriage despite the fact that we're, there is still that intimacy...but there's no sexual intimacy. (P002, 26yo, PV, married)

Another participant said:

I love to wear jeans too and I have a figure that looks good in jeans and I can't wear them a lot of the time. I look...normal and I feel like I am not. There is this whole sense of abnormality and dysfunction that colours the way I have to behave for people. (P007, 25yo, PV, committed dating)

Another participant, who was distressed about how her genital pain negatively impacting her libido, said:

I feel like people are constantly putting me down and telling me you know, this is not normal and you're not normal and you need to do something about it (the pain). But I have been trying everything...It is really upsetting me...Why is it abnormal if a woman doesn't want sex?...I often get tired of being beaten up by others and myself - telling myself that I am not normal and I should be acting in a different way. (P006, 26yo, vag, committed dating)

Another woman did not feel like the pain affected how she felt about herself sexually, but felt a sense of public embarrassment that she could not 'fix' her sexual pain:

It didn't make me feel less when I was with a guy or something, or in myself, I didn't feel less of a woman. But there was an aspect of sort of being embarrassed...a few friends would think, '*Oh are you still dealing with that?*' and it is like, 'Yes.' You know, little comments like, '*You should really get that sorted.*' [And I think], '*Oh really? You think?*' (P009, 30yo, PV, married)

Of the women who perceived themselves as sexually inadequate, three (75.0%) of their trajectories were delayed and one had not sought treatment at all. All of the women whose narratives reflected sexual embarrassment sought treatment, however, 57.1% (n=4) of the women delayed treatment seeking. Figure 5.6 is an NVivo word cloud that illustrates the data regarding SSS. The words that appeared frequently that indicate the saliency of SSS were 'sexual' and 'intercourse' and the words relating to relationships, e.g., 'husband', 'relationship', 'partner'.

affects allergic anymore around aspect better bother boyfriend cause comfortable coming completely control couple definitely differently difficult drive emotionally enjoy especially experiences explaining fault friends frustrating genital great guess guilt happy helped husband important infections intercourse jeans months never normally nothing often painful partner physical problem properly relationship right sense sexual started still stuff talked time together trying uncomfortable understanding upset wanted whole women worked worry wrong years

Figure 5.6 Word Cloud: Sexual Self-Schema

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Positive Resolution Identity

Positive resolution is the extent to which the conflict in the narrative is resolved to yield closure and a positive ending (McAdams & McLean, 2013). Four of the women (15.4%) expressed positive resolution in their narratives. All of these women had immediate trajectories (three continuous and one episodic). Three of the women had provoked vulvodynia and one generalised vulvodynia, and half were in a long-term relationship and half were single.

Resolution of intra- and interpersonal conflict was evident in the narratives of the women who exhibited positive resolution. For example, one woman expressed liberation because her pain had required her to rely more on skills and personal characteristics that she avoided in the past. She said:

[I have not sought] 'companionship' for the last nine months; [that] is different, actually liberating. It has helped me maintain plutonic relationships better - I think I often resort to flirting just because I can, or because I undervalue my other skills and charms. I feel more self-reliant I suppose, less defined by my sexuality, or what my sexuality can offer someone. (P125, 33yo, PV, single)

Two of the women were grateful because their experience of genital pain resulted in positive relationship outcomes. For example, one participant said, "[My boyfriend] dumped me just after [I developed genital pain]. But it was for the best - he was a tool" (P125, 33yo, PV, single). Another woman reported not developing long-term relationships early in her trajectory because she could not consistently have intercourse. She felt that her lack of relationships led her to meeting her husband. She said, "I think [my

vulvodynia] was a good way to weed out the jerks...I can certainly say I am so grateful that I found my husband" (P009, 30yo, PV, married).

Two of the women expressed the ability to not worry about their symptoms worsening in the future. The first woman said:

Over the last year and a half I feel like I've had a huge emotional lift - unrelated to the vulvodynia - but somewhere in there my symptoms went away too. Mostly anyway...I haven't been seeing anyone for quite a while, so I guess if I actually do have sex it might come back, but I feel so good that I'm just not worried about it. I'll worry about it if it happens. (P001, 22yo, GV, casual dating)

Another woman wondered about her symptoms worsening if she were to get pregnant as this was her experience with her first pregnancy. She was asked how she felt about her symptoms coming back and she replied:

To be honest I think at least, I think I would be OK with [my symptoms coming back], because I know that there is help, and there are things that I can. I have a lot more knowledge [about treating vulvodynia].
(P009, 30yo, PV, married)

One woman expressed her experience as 'chapters in a book'. She said:

The improvement in my quality of life is hard to quantify – I feel like I have been set free, like a truly terrible chapter is over and I can aspire to a remotely normal sexual relationship, one I might actually enjoy. Not to mention some peace of mind. (P007, 25yo, PV, committed dating)

Figure 5.7 is an NVivo word cloud that illustrates the data regarding positive resolution. The words that supported the salience of positive resolution are 'accept', 'better', 'happy', 'hoping', 'management', 'positive' and 'solution'. Some words were repeated in many of the word clouds including 'distress', 'frustrating', 'stressed' and 'worried' indicating that the experience of seeking treatment for genital pain for many of the women in this study was difficult.

accept affects better bother cause change coming completely depressed different
 difficult disappointed distress experience found friends frustrating great guess happened
 happy helps hoping important intercourse interested knowing living looking management
 moment months muscles normal physio positive pretty problem proper
 relationship relax remember right sense sexually solution stage started still stressed
 stretched stuff times treatment trying understand wanted whole worked worried
 worse years

Figure 5.7 Word Cloud: Positive Resolution

Note. 'Filler' and non-thematic words and words less than five letters long were eliminated. Words were changed to ensure the context of the word was understood. For example, the phrase "did not know" was changed to 'notknow' to ensure the meaning of the phrase was communicated correctly.

Summary and Conclusion

The salient survivorship resources and narrative identities that influenced the treatment seeking trajectory of women with genital pain were identified. Salient survivorship resources were a supportive HCP, family and friends, a shared narrative with others with genital pain, and personal agency. A supportive relationship with an HCP was characterised by solution focused treatment, empathy, and understanding, which led to a less distressing treatment seeking experience. Support from a partner, family member or friend was characterised as selfless, non-judgemental, practical and providing advice and perspective. These resources encouraged

consistent treatment seeking. A shared narrative with other women with genital pain provided a sense of community and brought meaning to the woman's suffering, leading to decreased distress. Personal agency relating to management and treatment of symptoms, and relationships and sexual activity was associated with an immediate and continuous or episodic treatment seeking trajectory.

The personal narratives that contributed to a more consistent trajectory were personal agency, communion, redemption, creating meaning of suffering, positive sexual identity and positive resolution. Identities that were characterised by contamination and negative sexual self-schema were associated with no treatment or a delayed trajectory.

These findings suggest that relationships and personal narratives strongly influence the quality of the treatment seeking trajectory. HCP skills that support and empower women to self-manage their symptoms positively influence the trajectory. The relationship with the partner can also be influential, particularly when the partner is able to challenge the coital imperative. The personal narratives that women construct about their pain and its treatment influence the experience of the trajectory with more realistic narratives affecting a more positive trajectory.

Chapter Six: Discussion and Conclusion

The present study explored the lived experience of seeking treatment for FGP using grounded theory methodology. This research was interested in identifying the perceived motivators for and barriers to treatment seeking for genital pain. The research also sought to ascertain the personal agendas that influenced treatment seeking for FGP, specifically the influential self-beliefs and perceived illness contestations. It also sought to investigate the salient intra- and interpersonal survivorship resources, and the personal narrative that influenced treatment seeking. This discussion of the findings overlays social constructionist and gendered perspectives to the understanding of the lived experience of FGP. Applying a social constructionist perspective enables critical evaluation of assumptions about how FGP is understood and recognises that knowledge about FGP and its treatment is derived from social interactions (Burr, 2003). Taking a gendered perspective involves exploring how gender affects the experience of treatment seeking for FGP (Bradley, 2013). The discussion of the findings addresses the gendered response to FGP, power in the HCP–patient relationship, and the processes that, and people who, co-create the treatment seeking experience. The influence of the symptoms of the various types of genital pain is also discussed. It also considers the evidence for a grounded theory informed conceptual model of treatment seeking for FGP. The implications of the findings for theory, practice and research are presented. The study concludes that education for women and HCPs, and further research is crucial to improving the experience of treatment seeking for genital pain.

The Gendered Response to FGP

The participants in this study identified four barriers that led to delayed treatment – normalising, discounting, shame and stigma. The data indicate that the experience of these barriers was gendered¹³. In this case the term gendered refers to the shaping of treatment seeking through the choices and constraints experienced because of the social constructions of being male, female or gender queer (Moen & Chermack, 2005).

Normalising and Discounting: A Gendered Response

Findings reveal that the participants in this study both normalised and discounted their pain, which led to a delay in treatment seeking, i.e., delayed trajectory. Normalising a health condition involves interpreting symptoms as routine, and as a result not recognising the need for health care (Dowrick, Ring, Humphris, & Salmon, 2004). The women who normalised their pain believed the gendered discourse that first intercourse is painful and therefore they delayed treatment seeking, often beyond their initial experiences of intercourse. In this study discounting refers to a process of disregarding the significant medical explanations for symptoms (Ahn & Bailenson, 1996), obviating the perceived need for treatment. A little over a third of the women (35%) discounted their pain. Some of these women believed they had an allergy to semen, or that their partner's penis was too big for them to accommodate. Others believed that a lack of interest in sex, or in their partner, led to pain during intercourse. The women who discounted their pain were of the view that medical intervention could not address these problems, which led to significant personal distress.

¹³ The gendered perspective in this section may seem overstated, however, the data indicates that this was a strongly felt experience for some of the women in this study, justifying this approach.

Normalising and discounting FGP resulted in different experiences for the women in this study. Normalising was not accompanied by the experience of distress because the women perceived their pain to be normal and they had hope that the pain would go away. Discounting, however, was associated with distress. Discounting was accompanied by a belief that there was something wrong and that nothing could be done about the pain, e.g., their partner's penis being too big. Both normalising and discounting could occur, over time, in a woman's treatment seeking experience. For instance, a woman may have a period of normalising her pain, however, when the pain does not dissipate, hope that it will go away diminishes. The woman may then begin to seek other explanations, which may include discounting and resultant distress.

Normalising and discounting genital pain may be due to the way women are socialised to experience pain; menstrual pain, labour pain and first intercourse pain are all considered a 'normal' part of being a woman (Bendelow, 2000; Grace & MacBride-Stewart, 2007). Women are often socialised to normalise and discount their 'female pain' by mothers, sisters, peers, other significant female role models, and sexual partners (Cox et al., 2003). This gendered response and the process of illness contestation may also play a role in normalising and discounting FGP. For instance, many of the participants believed pathology was responsible for their pain, however, the women's HCPs were often unable to identify the pathological cause of their symptoms, leading to contestation. This experience combined with a gendered response to pain (i.e., pain is a normal part of being a women) worked to normalise not just the pain, but the pathology of the pain as well

(Grace & MacBride-Stewart, 2007). This process of normalising the pathology led to internalising the pathology and was evident in the data, for example, "Although pain with sex is not universally normal, for me it is." This internalising of the cause of the pain led some of the women to experience shame and embarrassment.

These findings of normalising and discounting pain are similar to findings of studies about women who delay seeking treatment for endometriosis and other chronic pelvic pain conditions (Ballard et al., 2006; Cox et al., 2003; Donaldson & Meana, 2011; Toye, Seers, & Barker, 2014). As previously noted, research indicates that women normalise endometriosis because they believe pain is an integral part of being a woman (Ballard et al., 2006; Cox et al., 2003; Toye et al., 2014). Furthermore, Donaldson and Meana (2011) found that women delay treatment for early genital pain because they doubt their symptoms will be addressed by medical intervention. The current study extends the literature by indicating that discounting and normalising may occur for women with chronic FGP as well as early genital pain, and can occur in various ways. Normalising may precede discounting as noted above, but may also occur concurrently with discounting as the woman explores various meanings and causes of her pain. Discounting could occur without normalising when a woman has had a period of pain-free intercourse and therefore she recognises that pain with intercourse is not normal. Findings suggest that educating women to dispel the inaccurate beliefs around painful first intercourse may be partially helpful in reducing the delay of treatment seeking for FGP. Training GPs to ask about painful intercourse during well women's checks may also be helpful in

diagnosing women with FGP earlier. Educators and advocates for women's health can also publically challenge social discourses that promote the normalisation and discounting of FGP.

Further research is needed to fully understand the implications of normalising, discounting, and potential resultant shame on the experience of FGP. Research investigating why some women do not normalise, discount or experience shame may give some indication of what can be done to prevent normalising and discounting.

Stigma and Shame: “Dirty Female Problems”

Results indicate the women experienced stigma and shame as a result of their FGP. Stigma and shame are distinct but related constructs (Corrigan & Penn, 1999; Engebretson, 2013; Lewis, 1998; Link & Phelan, 1999).

Stigma is a social label or attribute that separates a person from others (Corrigan & Penn, 1999; Engebretson, 2013; Lewis, 1998; Link & Phelan, 1999). It ties the person to adverse characteristics, including the inability to fulfil a social role such as being a good sexual partner. Shame is a negative emotion that is elicited when a person feels responsible for a personal or social failure (Corrigan & Penn, 1999; Engebretson, 2013; Lewis, 1998; Link & Phelan, 1999). The person with shame attributes the failure to self-inadequacy rather than inappropriate behaviour. Research indicates that people with chronic pain, chronic illnesses and problems related to sexuality can experience stigma and shame related to their condition due to negative societal and personal attitudes about chronic illness and sexuality, i.e., chronic illness or sexual problems are the result of a flawed character (Conrad, Garrett, Cooksley, Dunne, & MacDonald, 2006; Cunningham,

Tschann, Gurvey, Fortenberry, & Ellen, 2002; Earnshaw & Quinn, 2012; Engebretson, 2013; Fortenberry et al., 2002; Gott & Hinchliff, 2003; Jackson, 2005; Johnston-Robledo & Chrisler, 2013; Kilinc & Campbell, 2009). The person experiences stigma and shame because they attribute their illness to personal weakness that prevents them from overcoming the effects or symptoms of their chronic condition.

The effects of stigma.

Stigma (Chrisler, 2011; Dunnivant & Roberts, 2013; Johnston-Robledo & Chrisler, 2013; Scambler, 2009; Ussher, 2006) is a multi-layered construct and can be enacted, anticipated or internalised. Enacted stigma is overt acts of discrimination on the basis of a label or attribute and anticipated stigma occurs when the person fears and expects overt stigma. When a person believes the stigmatising views of others to be true, stigma becomes internalised. The women in this study experienced enacted and anticipated stigma within their social networks and in their interactions with their HCPs. For instance, one woman reported friends wondering why she had not 'sorted out' her genital pain. She interpreted her friends' comments to indicate a weakness in her character because she had not put in the effort to resolve her pain. Another woman thought that friends and family believed that she was using her genital pain as an excuse to not fulfil her role as sexual partner. When reflecting on seeing doctors about her FGP, another woman felt that her "female problems" were seen to be "dirty and mildly revolting", which she identified as a barrier to treatment seeking.

The stigmatising of female sexuality is not uncommon in Western culture. For example, Ussher (2006, pg.1) cites multiple examples

throughout history of society's negative view of the "seeping, leaking, bleeding" female body, from the Christian Levitical laws demanding menstruating women separate themselves from society, to the current views on the use of female hygiene products to hide any indication of menstruation. The experience of contestation of FGP as an illness strengthened the experience of enacted and internalised stigma. For instance, when the women perceived their FGP was contested by their HCP they expressed feeling that the HCP believed they were weak because they were making up or exaggerating their symptoms. After perceiving stigma from the HCP it was not uncommon for the women to internalise their stigma and question whether their symptoms were really that bad. When this happened the women described feelings of inadequacy, weakness and sometimes shame.

The effects of shame.

Internalised stigma was evident in the data when the women indicated that they felt 'broken' and 'not normal' which led to deep feelings of shame (Scambler, 2009). The women's shame not only centred around their bodies being broken, but also included shame about their inability to be an enthusiastic and skilled lover. The data suggests that partners of women with FGP also experience internalised stigma and shame when the women reported that their partners questioned whether the genital pain was due to a lack of sexual desirability on their part. Kaler (2006, p. 66) describes the internalising of stigma and shame from genital pain as a "disorder of the essential self" because the woman fuses the experience of the body, sexuality and self. Some of the women in this study expressed shame about and disappointment in their bodies, which they perceived as hindering their

role as a sexual partner. These self-perceptions were associated with a sense of personal failure beyond what they might experience if they were unable to perform other roles, such as the role of companion to their partner.

The current study found that half of the women who reported experiencing stigma and shame related to their FGP had delayed seeking treatment and discontinued treatment before they could satisfactorily manage their symptoms, i.e., delayed and discontinuous trajectory. Research indicates that stigma negatively influences treatment seeking for other chronic conditions (Earnshaw & Quinn, 2012). However, the current finding that stigma is related to delayed and discontinuous treatment seeking for FGP contradicts other research investigating stigma and treatment seeking for FGP (Nguyen et al., 2013). Nguyen et al. (2013) found that women who agreed with a statement endorsing HCP stigma were significantly more represented in the group of women who sought treatment, which is counter-intuitive. The authors note that this unexpected finding may be due to reverse causality; that is that women only experienced stigma once they started seeking treatment, meaning the stigma is HCP consultation-related (Nguyen et al., 2013). This may have occurred when the HCP was not able to find physical causes of pain and may have inadvertently or explicitly expressed that the pain was imaginary or due to a character flaw in the woman.

This current study extends the scholarship on stigma and shame surrounding FGP in that it elucidates the ways in which women with FGP may experience internalised and enacted stigma. Specifically, internalised stigma was experienced as a result of feeling broken and not normal,

something the women felt was due to a personal failure. Furthermore, the women reported experiencing reactions from HCPs, friends, family and partners that indicated they believed the woman was exaggerating or making up her pain, again indicating a character flaw in the woman. This research also clarified the relationship between stigma, shame and treatment seeking, that is that shame and stigma may lead to delaying and discontinuing treatment seeking because the women perceive the emotional pain of shame and stigma to be more difficult to cope with than the physical pain of FGP.

Further research comparing women who experience shame and stigma to those who do not may identify the contributors to shame and stigma. HCPs who understand the contributors to shame and stigma may be able to support women in a way that increases the likelihood that a woman will continue treatment. Discourse analysis that investigates the interaction of an HCP and woman with FGP may elucidate the language HCPs use that may intensify or reduce shame and stigma. In addition to the previously discussed intrapersonal processes of normalisation, discounting, shame and stigma, interpersonal processes, such as minimising and invalidating, also impact the experience of genital pain.

Minimising and Invalidating: Gendered Responses to Pain

The findings indicate that some of the women felt their HCPs minimised or invalidated their genital pain and the impact of their pain symptoms. In this research, minimising of symptoms by the HCP involved communicating a sense of negation or disbelief in the impact of the symptoms on the woman (see also Sakalys, 1997), whereas invalidation of genital pain involved a lack of endorsement of a legitimate medical condition. For instance, two of the

women experienced minimisation during medical procedures where they were told by the HCP that their pain during the procedure was “not that bad”. Another woman reported that her HCP implied that once she had a baby the genital pain would be put in perspective. She perceived this comment to mean that she was exaggerating her pain. Invalidation was experienced when an HCP could not diagnose the pain and did not attempt to investigate symptoms further or when the HCP continued to believe the pain was due to thrush, despite the lack of pathology and thrush treatment being ineffective. A minority of the women were told or perceived comments from an HCP to suggest that she should learn to put up with the pain, leading to feelings of invalidation.

Although the women reported being invalidated and minimised by both male and female doctors, a number of comments from the women indicated that they felt minimisation and invalidation were more likely with a male doctor, e.g., “[He] said, 'just put up with it' – he was a man – surprise, surprise.” Research suggests that some male doctors find it difficult to discuss sexual issues with female patients (Abdolrasulnia et al., 2010; Burd, Nevadunsky, & Bachmann, 2006; Gott, Galena, Hinchliff, & Elford, 2004; Hinchliff, Gott, & Galena, 2004; Sobacki, Curlin, Rasinski, & Lindau, 2012). This may affect the quality of information they gather, making diagnosis of a sexual problem difficult. This lack of diagnosis may lead to feelings of invalidation. Additionally, research indicates that some male doctors are more likely to minimise the physical symptoms of women, which leads to an under assessment of symptoms and misdiagnosis of physical complaints as mental health problems (Elderkin-Thompson & Waitzkin, 1999; Redman,

Webb, Hennrikus, Gordon, & Sanson-Fisher, 1991). This is not to minimise the gynaecological expertise of male doctors in general, as some of the world's leading FGP experts are male (Goldstein, 2009; Goldstein, 2011).

Women may present health symptoms with an emotive style, which may bias HCPs to diagnose a mental health problem rather than a physical problem (Elderkin-Thompson & Waitzkin, 1999). Furthermore, women may avoid talking about certain symptoms (e.g., pain and its disruption to sexual activity) because of beliefs about what is socially appropriate (Govender & Penn-Kekana, 2008). This may also explain why the women in this study reported experiencing invalidation. For instance, if a participant did not fully disclose her pain symptoms, the HCP may have found it difficult to properly diagnose her condition, leading to inappropriate treatment (or lack of treatment) and an extended and distressing trajectory.

Invalidation and minimising could occur independently or in conjunction with one another. Invalidation occurred when an HCP could not diagnose the problem, but the HCP may have fully acknowledged the significance of the pain for the woman. Likewise a woman could have her symptoms minimised when she is told to put up with the pain, while being diagnosed (validated) with vulvodynia. Both validation and minimisation can occur when an HCP cannot find a pathological cause for the pain stating that the pain is 'in her head' and at the same time minimising her symptoms by insinuating or suggesting that she is using her pain as an excuse to avoid sexual activity with her partner.

Research that explores the common HCP attitudes and beliefs that are associated with the invalidation and minimisation of FGP could lead to

improved education and training of HCPs. In addition to minimisation and invalidation, the data suggest that power may have played an influential role in the experience of treatment seeking for FGP by the women in this study.

Power in the HCP–Patient Relationship

Findings indicate the women perceived balanced power in the HCP and patient consultation relationship to be important to survivorship of FGP. In interpersonal relationships power (Asbring & Narvanen, 2004; Goodyear-Smith & Buetow, 2001) originates from three sources – knowledge, force and material resources. In the HCP–patient relationship, power is mainly sourced from knowledge – the HCP having medical knowledge and the woman lived experience knowledge. An unbalanced HCP–patient relationship is when either the HCP or the patient has power at the expense of the other. At one extreme the doctor is in control of the decision making with patient input disregarded or not offered. At the other extreme the doctor's only role is to provide information and the patient is the sole decision-maker (Charles et al., 1997, 1999; Goodyear-Smith & Buetow, 2001; Mead & Bower, 2000; Mead & Bower, 2002). A balanced HCP–patient relationship promotes self-efficacy and both the HCP and the patient are equally empowered to use available information, resources, skills and social authority to enable positive health outcomes (Goodyear-Smith & Buetow, 2001).

Power Balance

The women in this study valued appropriately balanced HCP–patient power, as evidenced by their identification of the HCP–patient alliance as an expectation, or agenda, for their health care consultations. An alliance between the patient and the HCP involves negotiation, mutual respect, and

reciprocity (Chewning & Wiederholt, 2003), suggesting a balanced power relationship. Previous research found that effective HCP communication of knowledge, good HCP listening skills and HCP empathy are important to a balanced HCP–patient alliance (Venetis, Robinson, Turkiewicz, & Allen, 2009). Knowledge and patient-centred communication were identified as valued HCP qualities for the women in this study.

Findings suggest positive outcomes are partly dependant on mutual respect of the HCP's professional knowledge and the woman's lived experience knowledge. In this scenario the woman feels safe to fully disclose her symptoms, making correct diagnosis and effective treatment more likely. When the woman experiences effective management of symptoms respect for the HCP ensues, improving the chance of treatment compliance. Conversely, when there is not mutual respect of both the HCP's knowledge and the woman's experience, the consultation may become strained, leading to distress for the woman, possible doctor shopping and even discontinuation of treatment (see also Thorn, 2006). A strong HCP–patient alliance empowers patient agency in managing symptoms in a way that increases quality of life (Arora et al., 2009; Epstein & Street, 2007; Masalla et al., 2010; Roter, 2000).

Personal Agency

Findings indicate that patient agency was an important resource to many of the women in this study. Agency is the degree of perceived ability to effect change, influence others or impact the environment (Epstein & Street, 2007; McAdams & McLean, 2013). An HCP who provides relevant information to their patients (Beck et al., 2002; Pawlikowska et al., 2012), is

positive and supportive in the way they talk to their patients (Little et al., 2001; Pawlikowska et al., 2012), and is friendly, warm and sympathetic (Cooper et al., 2003b; Eide et al., 2004; Mercer & Reynolds, 2002; Paasche-Orlow & Roter, 2003; Pawlikowska et al., 2012; Price et al., 2006) promotes a sense of personal agency in their patients. The data suggest personal agency to be associated with immediate and continuous treatment seeking. The highly agentic participants made considered decisions about treatment and management of their pain symptoms, and about their intimate relationships and sexual activities. In making these decisions the women felt a sense of control over the impact that the symptoms had on their lives.

The HCP–patient relationship is an important factor in the experience of personal agency for FGP management. An HCP can build personal agency through encouraging reciprocal exchange of knowledge between themselves and the woman, and through empowering the woman to be an active participant in decision making. Equally, an HCP can destroy personal agency by discounting the woman's lived experience knowledge or by denying her voice in the decision making process.

Research that investigates the specific interactions between HCPs and women with FGP may reveal how an HCP can build agency in their patients and balance power in the HCP–patient relationship. HCPs play an important role in the experience of personal agency and other aspects of FGP management, as do the woman's social networks.

Co-creating the Treatment Seeking Experience

Findings show social networks, specifically the interactions the woman has with her partner, friends and family, influence the experience of

treatment seeking. The majority of the women (85%) described their social networks as being supportive and non-judgemental. Support from people within a social network (Cohen, 2004) can be described as instrumental, informational or emotional. Instrumental support involves providing material support, including help with daily tasks or financial assistance. Informational support involves providing relevant information, advice or guidance in dealing with the problem. Emotional support refers to the expression of reassurance, empathy and care, and allows opportunities for emotional expression. When describing social supports other than the partner, the majority of women spoke of mothers, sisters and female friends as supportive. This suggests that it may be taboo to speak to male friends and other family members (fathers, in-laws, brothers) about genital pain. There were, however, exceptions, with one woman discussing her pain with male friends, another with a brother, and another finding her grandmother easier to talk to than her mother or other family members. The women in this study reported their social networks to provide practical and emotional support, which reduced the distress the woman experienced and improved her quality of life. In some cases a supportive person in their social network led directly to a woman seeking treatment. For instance, one woman sought treatment because her sister "pushed" her to do so, and another woman received financial support for treatment from her mother. Partners who provided support, particularly emotional support, were identified as an important survivorship resource.

The Partner as Co-creator of the Treatment Seeking Experience

The evidence indicates that a supportive and empathic relationship with the partner was particularly salient to treatment seeking survivorship of FGP. The women who were in supportive, long-term relationships expressed gratitude and wonder towards their partner for loving them and remaining with them despite their inability to consistently engage in intercourse. The women described a supportive partner as one who demonstrated empathy, showed an interest in the progress of treatment and the impact of pain on the woman, and were flexible in their approach to sexual activity. This is a finding that is consistent with other genital pain research (Ayling & Ussher, 2008; Buchan et al., 2007). Buchan et al. (2007) and Ayling and Ussher (2008) found that women described a supportive partner as one that did not pressure the woman for sex. However, research (Bergeron, Rosen, & Morin, 2011) suggests that partner support can be unhelpful when it is solicitous, (i.e., when pain behaviours are reinforced through sympathy and attention). In women with vulvodynia, partner solicitousness is associated with higher pain scores and avoidance of sexual activity.

This current research extends the genital pain scholarship by providing a nuanced definition of 'supportive partner'. This nuanced definition includes not only the lack of pressure for sex, but also incorporates partner empathy around the impact of the FGP and the partner's interested engagement in treatment seeking. Although the women often questioned the intimacy in their relationships because of the inability to engage in intercourse, the women who reported supportive relationships were able to challenge this perception. These women were able to recognise the intimacy they

experienced through other avenues, e.g., empathy and concern for the impact of symptoms and encouragement when treatment was difficult. Research comparing women in supportive relationships to those not in relationships and those in unsupportive relationships would help clarify the role of a supportive partner in the survivorship of treatment seeking for FGP. In addition to their view of intimacy (i.e., sexual intimacy as the basis of an intimate relationship) being challenged, their role as sexual partner was also challenged.

The Influence of Expected Social Roles

Even with FGP, almost a third of the participants considered themselves full sexual partners. These women participated in sexually satisfying activities that did not involve penetration, allowing them to enjoy sexual intimacy with their partner without pain. The women reported that being sexually active with their partner was not only beneficial for them, but that it also provided sexual satisfaction for their partner and was healthy for their relationship. To enact their role as sexual partners, the women perceived to have to negotiate two common social discourses - the male sex drive discourse (Gavey, McPhillips, & Braun, 1999) and the coital imperative (McPhillips, Braun, & Gavey, 2001). The male sex drive discourse states that men need and want intercourse to be sexually satisfied (Gavey et al., 1999) and the coital imperative states that mature heterosexual sex always involves intercourse. When endorsed these discourses can lead to significant distress for women with FGP. The women may also feel guilt for not being able to provide their partner with intercourse or they may feel inadequate as a woman, leading to feelings of shame.

In studies exploring these common discourses with both men and women, McPhillips et al. (2001) and Gavey et al. (1999) found most participants were able to explore multiple positions around sexual activity and intercourse when encouraged to do so. For these participants the automatic assumptions were that 'real' sex always involved intercourse, however, as the participants were interviewed they realised that sex also included other sexual activities and meanings, thus challenging the coital imperative and the male sex drive discourse.

The women in this study successfully navigated these discourses by contrasting the times when they were not sexually engaged with their partner with times when they engaged in non-penetrative sexual activity. The women found their relationships to be healthier and they themselves to be happier. The women also recognised that as a couple they successfully navigated a significant challenge together that strengthened their relationship. One woman who dated both men and women recognised that for her, dating women was easier because there was no need to challenge either discourse.

The women also reported being able to renegotiate the parameters of what it means to be a woman and a good sexual partner. In renegotiating these identities the women's narratives demonstrated a tension between the coital imperative (McPhillips, Braun, & Gavey) and their experience of a satisfying sexual relationship without intercourse. This tension allowed some of the women to reconceive their bodies and their experiences of genital pain from being broken and abnormal to a state of acceptance which might have freed them to explore sexually satisfying relationships without intercourse (Kaler, 2006; McPhillips et al., 2001; Moss & Dyck, 2002). This tension also

may have allowed the women to experience aspects of themselves and their relationship they may not otherwise have experienced, including viewing men more positively, a greater appreciation for sexual intimacy, and a closer relationship with their partner.

Many of the women in this study reported being less successful in negotiating the coital imperative and the male sex drive discourse. These participants expressed a sense of disconnection from their body or their sexuality. They also expressed feeling guilty for not being able to provide their male partners with intercourse, leading to significant personal and relationship distress. These women agonised over the meaning behind their pain. Two of the women considered the possibility that the pain meant they were no longer attracted to their partners. The potential lack of attraction to their partner coupled with guilt about a sexless relationship led some of the women to contemplate ending their relationship.

Phenomenological research into how women with FGP successfully negotiate the male sex drive discourse and the coital imperative could help women with FGP and other sexual dysfunctions negotiate these discourses. It could also give clinicians insight that may be helpful in guiding women to find more helpful meanings for their genital pain. Finding meaning in their pain was an important process for the women in this study who experienced successful survivorship of FGP.

The Woman as Co-creator of the Treatment Seeking Experience

The findings reveal that the woman's personal narratives, or meanings about FGP coloured the treatment seeking experience. Personal narratives are the stories people construct in order to make sense of their experiences,

their lives and the world around them (Anderson, 2008; White & Epston, 1990), and are crafted to provide one's life purpose and unity (Adler, 2012; McAdams, 2001). Personal narratives shape one's sense of identity, thereby influencing the person's actions and attitudes (White & Epston, 1990). The narrative identities that contributed to survivorship for the women in this study were redemption, contamination, creating meaning of suffering, sexual self-schema (SSS), and positive resolution. While most of the women's stories included narratives that illustrated both helpful and unhelpful features, the woman's narratives predominately displayed a more pessimistic or optimistic motif. Two pessimistic narratives, contamination and negative SSS, were related to a negative treatment seeking trajectory, while the optimistic identities of redemption, positive resolution, creating meaning and positive SSS were associated with a positive treatment seeking trajectory.

Optimistic narrative identities.

Optimistic narratives demonstrate a process of personal growth and adaptation, which is associated with increased well-being (McAdams & McLean, 2013). The chronic pain literature demonstrates that optimism buffers the impact of pain and is associated with less distress, higher pain tolerance and improved coping (Finan, Zautra, & Tennen, 2008; Fredrickson, 1998; Geers, Wellman, Helfer, Fowler, & France, 2008; Ramírez-Maestre, Esteve, & López, 2012; Zautra, Johnson, & Davis, 2005a). The women in this study whose narratives were optimistic sought treatment earlier and once initiated, did so continually. Two of the optimistic narratives, redemption and positive resolution, were particularly salient to positive survivorship of FGP.

Redemptive identities were narratives in which the woman was able to identify a 'silver lining' or positives despite the suffering experienced because of their FGP (McAdams & McLean, 2013). The participants with redemptive identities recognised personal strength for being able to persist with treatment seeking or that the experience of FGP led to a healthier lifestyle and a more positive outlook towards their relationships and their partners.

Four of the women with optimistic narratives expressed positive resolution in their narratives conveying a sense of closure and a positive outcome despite their continued experience of genital pain. Narratives of positive resolution usually involve deep and meaningful exploration of the negative experience in order to understand what role this event plays in the person's life (McAdams & McLean, 2013) leading to personal growth (Bauer, McAdams, & Sakaeda, 2005; McLean, Pasupathi, & Pals, 2007) and happiness (Lilgendahl & McAdams, 2011). The women with positive resolution narratives were those who sought and sustained treatment, i.e., an immediate and continuous treatment seeking trajectory. Their narratives contained stories about resolution to intra- and interpersonal conflict. Resolution led to hope for a future where the symptoms can be satisfactorily managed, freedom from distress and worry about their symptoms, gratitude for a strong and intimate relationship with a partner, and a stronger sense of self.

Pessimistic narrative identities.

Pessimistic narratives involve rumination and a sense of being 'stuck' (McAdams & McLean, 2013; Pals, 2006). The pessimistic narratives shared by the women in this study involved contamination, or narratives that are

saturated with dramatically bad or negative scenes that overwhelm, destroy or erase any positivity (McAdams & McLean, 2013). These narratives were associated with delayed treatment seeking. Two areas were evoked in contamination narratives: impaired feminine role in intimate relationships and public sexual persona.

Contamination narratives characterised some of the women's self-perceived femininity so that the women grieved about lost sexual identity. These findings support other research that found women with FGP expressed what could be interpreted as a contamination narrative involving "loss of femininity" (Marriott & Thompson, 2008) and a sense of being "de-gendered" (Kaler, 2006).

The women also perceived their public sexual persona, or the public expression of their sexuality, to be negatively impacted with some of the women (39%) reporting feelings of embarrassment because they felt others perceived them as asexual or sexually repressed. For two of the women, this negative public persona translated into a sense of embarrassment stemming from the clothing they had to wear to minimise their pain, e.g., inability to wear tight clothing, sexy underwear or jeans.

Understandably, women with these disabling narratives delayed treatment seeking. One woman felt her pain provided her with a reasonable excuse not to have sex and was therefore demotivated to find resolution to her pain. Others expressed a lack of motivation for sexual intimacy and therefore saw no need for treatment.

Figure 6.1 is a conceptual model of the influence of narratives on the treatment seeking trajectory for FGP. This conceptual model illustrates how

narratives may influence the trajectory from the initial decision to seek treatment through to positive, ambivalent or negative resolution. An episodic or continuous trajectory may result in positive or ambivalent resolution. Positive resolution is described above. Ambivalent resolution is when both optimistic and negative narratives occur simultaneously or when the woman vacillates between these narratives. A woman may discontinue treatment seeking and experience negative resolution because the experience is so deleterious she 'gives up' on finding resolution of her pain. A woman may also discontinue treatment because she feels content with the way she is managing her pain.

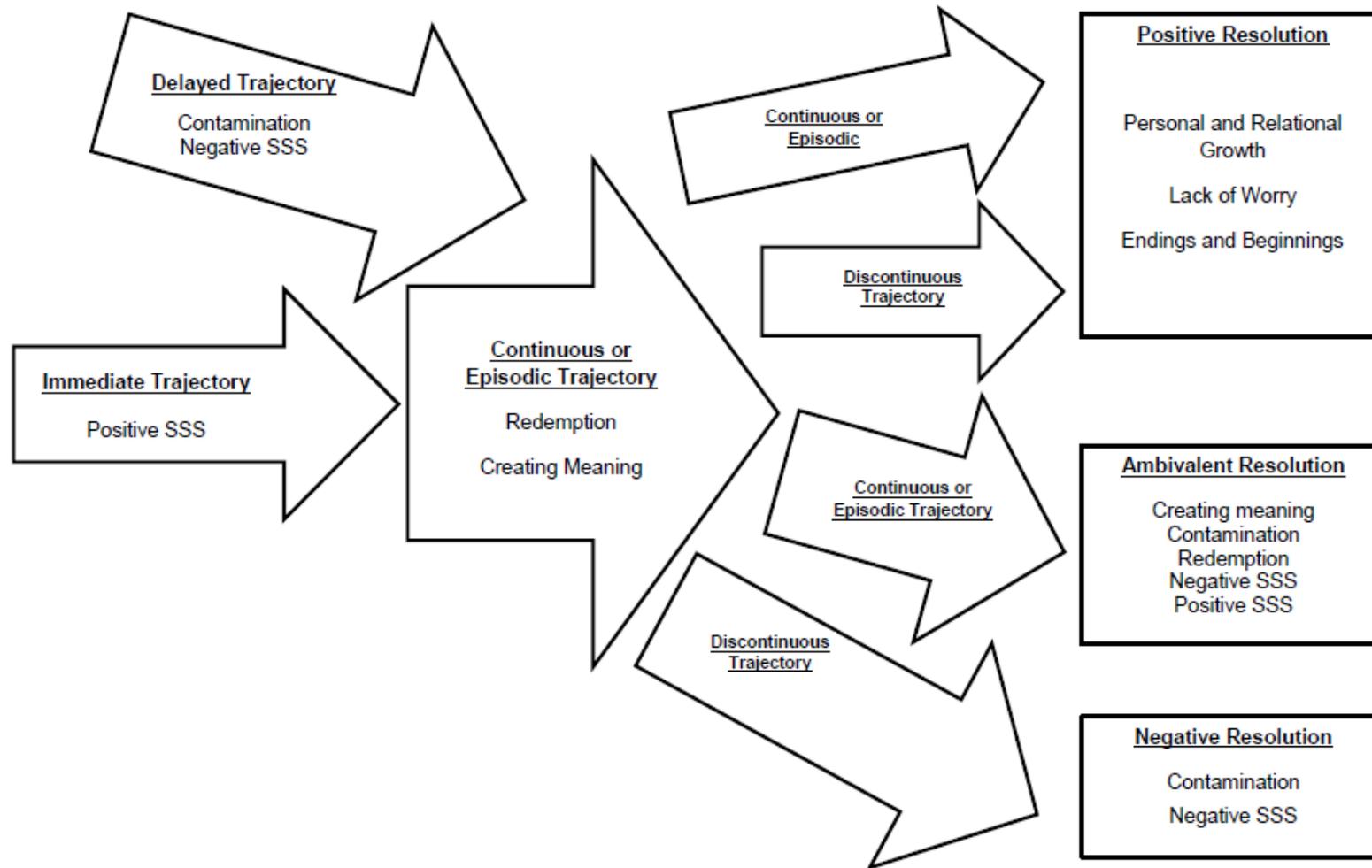


Figure 6.1 Treatment Seeking Trajectory and Narrative Identities

The influence of diagnosis on treatment seeking for FGP

Findings indicate that the experience of treatment seeking may vary according to diagnosis. Both provoked and generalised vulvodynia (Haefner, 2007) are neuropathic pain conditions, however, the pain is differentially elicited. The pain of provoked vulvodynia is experienced when pressure is applied to the vulva, whereas women with generalised vulvodynia can experience pain without an obvious trigger. Furthermore, the pain of generalised vulvodynia can be unpredictable and unrelenting (Haefner, 2007). Vaginismus pain is triggered when penetration is attempted (e.g., sexual penetration or tampon use) and is accompanied by fear and anxiety about penetration (Lahaie et al., 2010).

There appears to be some trends in the current data that link various barriers, survivorship resources and narrative identities to specific diagnoses (see Table 6.1 for a summary). Normalising and discounting may be related to diagnosis, with around two thirds of the women who normalised and discounted having provoked vulvodynia or vaginismus. The pain of provoked vulvodynia and vaginismus are primarily related to sexual activity as opposed to generalised vulvodynia where pain may occur at any time and under any circumstances (Haefner, 2007). The nature of the pain of generalised vulvodynia may make normalising and discounting less likely because the pain can intrude on all aspects of life making it difficult to ignore or explain away the pain. Another identified barrier was negative treatment beliefs and all of the women in this study who reported negative treatment beliefs were diagnosed with vaginismus. Treatment for vaginismus that addresses the components of fear and anxiety about penetration involves exposure to

penetration (Ter Kuile et al., 2009). While exposure therapy is an effective treatment, it would be an activity that women with vaginismus would find challenging at best¹⁴. Asking women to face an anxiety producing activity is likely to lead some women to hold negative beliefs about treatment.

The data reveals that agency (a survivorship resource) was also related to diagnostic status, with less than one quarter of the highly agentic women being diagnosed with generalised vulvodynia and vaginismus. The unpredictable pain of generalised vulvodynia (Haefner, 2007) may have led to feelings of helplessness, weakened self-efficacy and decreased agency. Often women with vaginismus avoid gynaecological examinations making it difficult to find effective medical treatment. If the woman's experience of her pain is that it is unpredictable regardless of previous pain management attempts or she is unable to find effective treatment, her sense of efficacy and agency may be destroyed. Bandura (1990) described the relationship of self-efficacy to agency, stating that efficacy beliefs are, at least in part, determined by successful mastery over an activity (such as pain management). This may possibly explain why the women with generalised vulvodynia and vaginismus were under-represented in the highly agentic group of women.

Findings suggest that narratives identities may also be linked to diagnosis. A majority of the women with redemptive or positive resolution identities were diagnosed with provoked vulvodynia. Women with provoked vulvodynia only experience pain when pressure is applied to the affected area (Haefner, 2007), making pain more predictable and manageable,

¹⁴ This was demonstrated in the data in that the women with vaginismus in this study who had sought treatment had declined to participate in exposure therapy.

thereby promoting a sense of control and well-being. Conversely, the women with narratives that were dominated with contamination were more likely to be diagnosed with generalised vulvodynia and vaginismus, conditions that are difficult to treat for the reasons explained above.

Finally, women with vaginismus were not represented in the group of women who reported positive sexual self-schema. This may be explained by the fear and anxiety component of vaginismus – if a woman has a fear of penetration she is unlikely to feel positive about sex and her sexuality.

Further exploration of the possible links between diagnosis and barriers, survivorship resources and narrative identities is needed. Quantitative research in particular would be able to confirm, or deny, the significance of the links observed in this study.

Table 6.1 Summary of Links to Diagnosis

Barriers to treatment seeking	Diagnosis		
	Provoked Vulvodynia	Generalised Vulvodynia	Vaginismus
Normalising	63%	0%	38%
Discounting	66%	22% (n=2)	11% (n=1)
Negative treatment beliefs	0%	0%	100%
Survivorship Resources			
Agency	77%	23%	0%
Narrative Identities			
Redemption	75%	8% (n=1)	8% (n=1)
Positive resolution	75%	25%	0%
Contamination	0%	67%	33%
Positive SSS	88%	12%(n=2)	0%

This research has demonstrated the significant influences on the treatment seeking trajectory. It has also elucidated what factors impact the treatment seeking decisional process. This research can be summarised in a conceptual model of treatment seeking that was modified from an earlier proposed model (see Figure 1.1 in chapter one).

Evidence Informed Conceptual Model of Treatment Seeking for FGP

A preliminary grounded theory conceptual model was hypothesised in which intra- and interpersonal processes mediate the treatment seeking trajectory (see Figure 1.1 in chapter one). The model proposed that the salient interpersonal influences were the woman's relationships with the HCP and her partner, family and friends. The proposed salient intrapersonal influences were her experience of symptoms and distress, and the meanings she makes of her experiences. On the basis of the evidence from the women self-reporting on treatment seeking for FGP, a final grounded model has been developed (see Figure 6.2) to explain influences on living with and seeking treatment for FGP.

The Evidence Informed Grounded Model

This research supports and adds to the preliminary model (see Figure 1.1 in chapter one) by identifying the specific intrapersonal processes that influence the initial decision to seek treatment, namely the woman's gendered response to pain and the coital imperative (see A and A1 of Figure 6.2) and the barriers and motivators to treatment seeking (A2). The woman makes a decision about treatment seeking which may or may not involve ambivalence (B). If she chooses not to seek treatment (C) she may try to manage her symptoms herself (C1). If her symptoms persist or intensify and

if the impact of her symptoms increases (C2), she may go through another decisional process about treatment seeking (B1). When a woman decides to seek treatment (E), her treatment seeking agendas and the HCP's response (E1), plus her narrative identities (E2), influence her experience of survivorship of FGP (F).

Extension of a Previous Model of Treatment Seeking for FGP

The model of treatment seeking for early dyspareunia proposed by Donaldson and Meana (2011) states that upon experiencing dyspareunia women will first attempt to manage the pain without medical intervention. When negative consequences accumulate the woman will seek treatment. The present study extends Donaldson and Meana's work by investigating the trajectory of women with chronic, rather than early genital pain. This study considered the entire treatment seeking trajectory, not just the initial decision to seek treatment as was the case with Donaldson and Meana. This current conceptual model more intricately captures the complex interpersonal (social supports and the relationship with the HCP) and intrapersonal processes (narrative identities and agendas) that influence treatment seeking for FGP than prior existing models of treatment seeking for FGP.

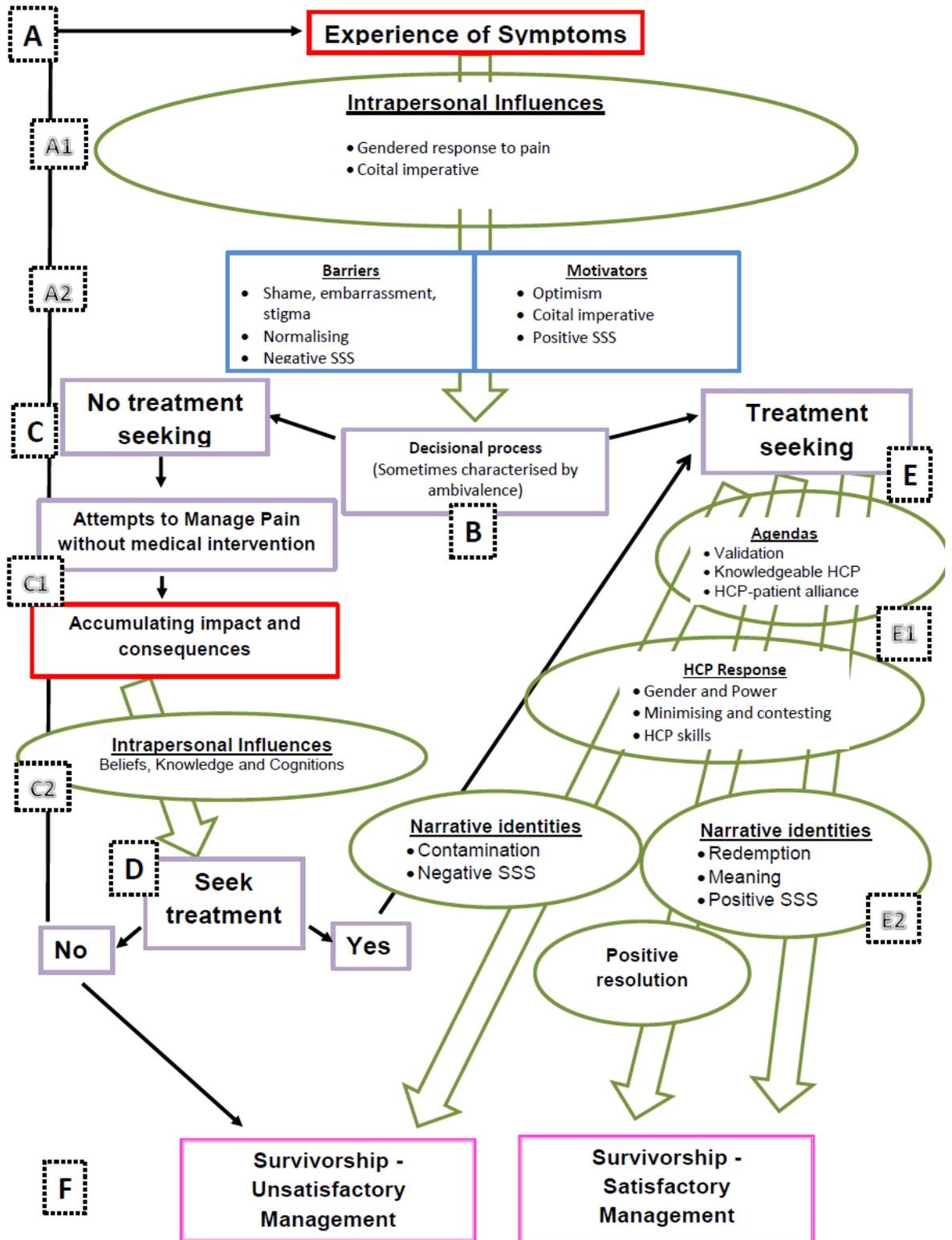


Figure 6.2 Conceptual Model of Treatment Seeking

Note. Thin arrows=decisions made; Thick arrows=influences on the trajectory.

Implication of the Study for Theory, Research and Practice

The findings of this research have implications for the theory, research, and clinical practice in treating women with FGP. This research demonstrates the feasibility of the integration of two seemingly divergent qualitative method inquiry approaches (grounded theory and phenomenology). Further, the study proofed the use of internet survey software (e.g., Survey Monkey) for data collection, and the insider perspective for the hidden population of women with FGP. The implications for practice are that HCPs need significantly more training to be able to recognise, diagnose and treat women with chronic genital pain from a patient oriented perspective.

Implication for Theory

This research utilised constructivist grounded theory to develop an explanatory model of the social interactions, intrapersonal processes and structures that influence treatment seeking for FGP (Charmaz, 2006a; Starks & Brown Trinidad, 2007). The grounded theory approach was conducted within the context of a phenomenological (lived experience) exploration of the woman's experience of treatment seeking for FGP, capturing the common meanings and features for these women (Starks & Brown Trinidad, 2007).

A constructivist lived experience perspective underpinned this research, in which multiple and emergent realities around FGP were co-created by interacting with the participants on their own terms and in their own language. Although constructivist grounded theory and phenomenology differ in philosophy and methodology (Starks & Brown Trinidad, 2007), this study

shows how they can be used in a complementary fashion to investigate a very private matter such as FGP.

Figure 6.3 is a summary of this grounded phenomenological approach. Phenomenology (see section A of figure 6.3) is interested in finding out about the lived experience of a phenomenon and is based on the assumption that there is an essential perceived reality with common features (Starks & Brown Trinidad, 2007). The common features are elucidated through close examination of in-depth descriptions of the lived experience of the participants (Sokolowski, 2000), in this case women with genital pain. Grounded theory (C) is based on symbolic interactionism which posits that meaning is understood through social interactions (Dey, 1999). Grounded theory (Charmaz, 2006a; Corbin & Strauss, 2008; Glaser & Strauss, 1967) seeks to develop a theory that explains how social processes influence a particular phenomenon. The theory is developed through examining concepts that are grounded, or embedded in the data. In this study phenomenology and grounded theory converge (B) in that both focus on the experiences of the individual to determine the meanings of those experiences. There are also significant overlaps in the way data is analysed, and the findings produce results that are relevant to similar audiences – in this case clinicians and practitioners (Starks & Brown Trinidad, 2007). By using a combined phenomenological and grounded theory approach the results produced a useful and empathic model rich in woman-centred content.

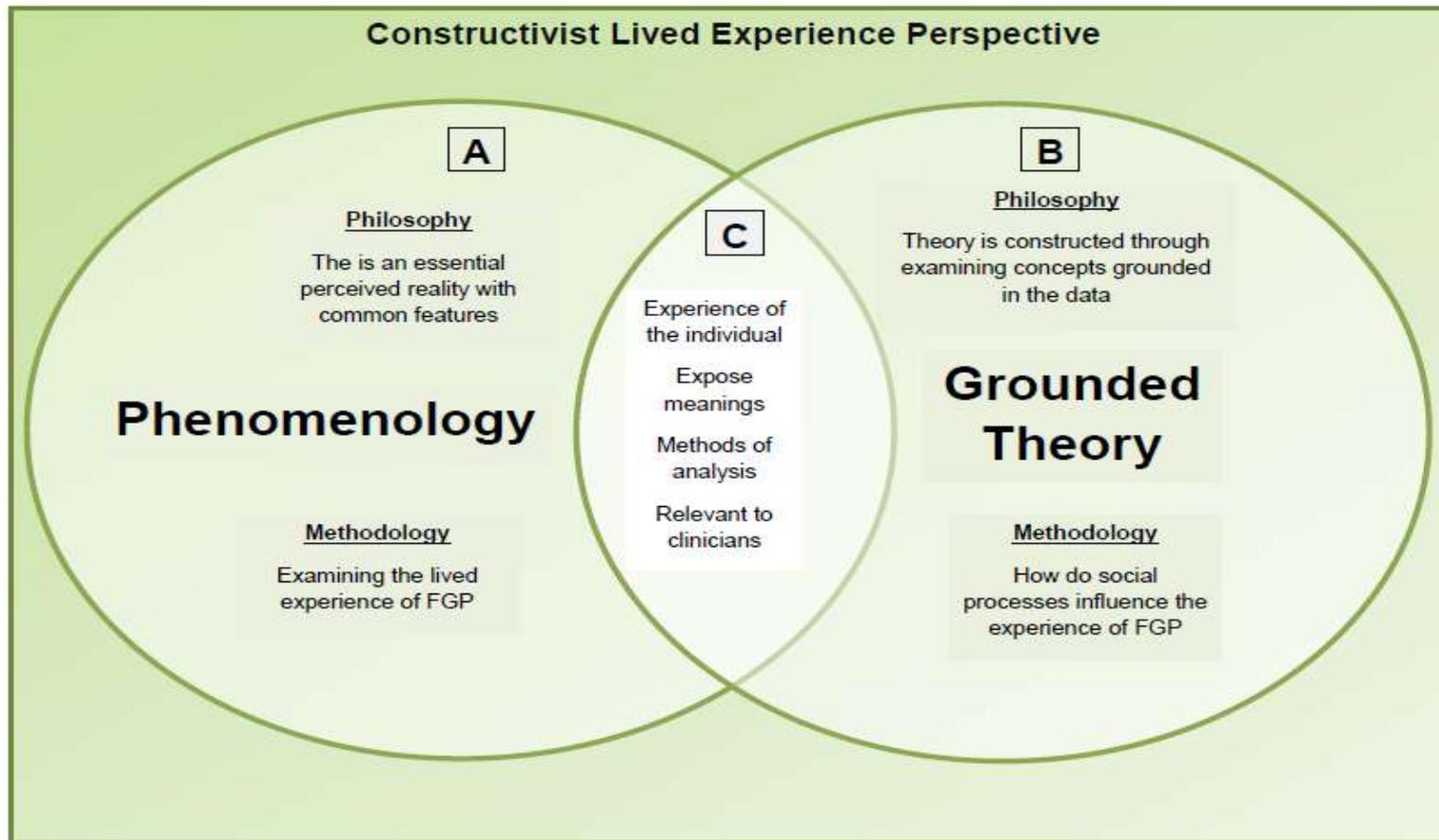


Figure 6.3 Model of the Grounded Phenomenological Approach

Exploratory descriptive approach.

To date bio-psycho-behavioural models for genital pain have focused on the psychosocial, biomedical and behavioural correlates of genital pain, relying on expert others rather than the women living with FGP (for example see Landry & Bergeron, 2011). This limits the information gathered to the knowledge of those who developed the survey. The approach used here employed semi-structured interviews to gather data, which allows for participants to offer the data they deemed relevant. Another previous explanatory theory considered the cognitive-behavioural influences on treatment seeking for early dyspareunia (Donaldson & Meana, 2011). The current model expands on the model proposed by Donaldson and Meana (2011) to include the woman's perspective on the intra- and interpersonal factors that influence the treatment seeking experience, specifically HCP qualities, social networks, narrative identities and survivorship resources.

Implication for Research

This study expanded the current research evidence on the influences of treatment seeking for FGP by utilising the lived experience of the hidden population of women with genital pain. Its unique research contribution is that it adds to the understandings of the treatment seeking needs and processes that influence health care consultations with the hidden population of women with genital pain. The study's design and sampling frame also expanded on the current understanding of FGP to include treatment seeking from the initial decision to seek treatment through to satisfactory management of genital pain for peri-menopausal women.

Hidden population research.

The definition of a hidden population, as it relates to this research, is one where membership in this group may be considered stigmatising (Heckathorn, 1997). Previous research on hidden populations such as injecting drug users and people with HIV/AIDS used qualitative face to face interviews and profiling of HIV services, respectively, to investigate treatment seeking for these stigmatised conditions (Morrison, Elliott, & Gruer, 1997; Wong, Chng, & Lo, 1998). For instance, Morrison et al. (1997) interviewed people visiting a needle exchange service which may have captured both those willing to seek treatment and those unwilling. However, potential participants who are reticent to seek treatment due to the potential of being exposed as an illegal drug user may have also declined to participate in this research. These participants may have provided useful insights into fear of treatment seeking for health concerns related to illegal drug use. Wong et al. (1998) profiled six community based HIV programs to determine facilitators and barriers to service use. This approach has merit because it circumvents trying to recruit people who may be reticent to participate due to having a stigmatising condition, however, this approach disregards the important contribution that the person with the lived experience can provide.

This study extends knowledge based on research with the hidden population of women with FGP. Women with FGP could be considered a hidden population because FGP is often contested and, as a sexual problem, is a stigmatised condition. FGP can be considered a contested illness because its aetiology and treatment are unclear which can lead to questions about its legitimacy and about the woman's character. This research's study

design – allowing women to self-select in to either interviews or an online survey, potentially opened up the sampling frame to include women who are reticent to identify as a woman with FGP. Another study of women with vaginismus used an online survey, however, it gathered quantitative data about treatment seeking (Reissing, 2012). This current study is unique in that it gathered online qualitative data about treatment seeking for FGP.

Insider perspective.

As the researcher herself is a person living with FGP, the study is an insider perspective approach in which the researcher was also a research tool in the nuanced interpretation of the data. An insider perspective (Asselin, 2003; Dwyer & Buckle, 2009; Kanuha, 2000) is one where the researcher shares membership, identity and experiences with the participants. This perspective poses both advantages and potential disadvantages. As a woman with vulvodynia, the researcher had an insider's knowledge about genital pain and its treatment. Membership in the studied group may have given the researcher legitimacy in the eyes of the participants allowing for a quicker rapport to be developed (Dwyer & Buckle, 2009). Researcher insider information may have also enhanced the authenticity of the data gathered by shaping data collection. However, insider research has been criticised due to possible limitations, including researcher assumptions that may limit the collection of relevant data, or that can overly bias analysis (Dwyer & Buckle, 2009; Kanuha, 2000). In the current research these potential limitations were

minimised through the use of reflexivity and collaboration¹⁵ with another researcher who was not positioned as an insider.

Implication for Practice

This research identified the significant factors that influence treatment seeking for FGP. Patient preferences for how HCPs and significant others can positively and negatively influence treatment seeking for FGP were identified. For instance, HCPs may be able to support women with genital pain more effectively by developing and utilising strong communication and listening skills, demonstrating empathy, transferring knowledge, encouraging personal agency and helping the woman to develop strong social supports.

HCP skills when consulting for FGP.

The data indicates that there are two phases to the treatment seeking trajectory and that the HCP must use different skills in each phase. The first phase involves diagnosing and trying various treatments. This requires the HCP to have specific knowledge about FGP and its treatment, and to be solution-focused, empathic and able to demonstrate an understanding of the woman's situation. The second phase involves supporting the woman as she comes to terms with the chronicity of her condition. The skills important in this stage are listening, empathy and supporting self-efficacy. The women in this phase do not expect easy remedies for their chronic pain, rather they require a strong and supportive alliance with their HCP. This speaks to both complications and complexities related to treatment seeking for FGP. The complications to treatment seeking are that it is a difficult condition to diagnose, requiring the exclusion of other conditions, such as an infection

¹⁵ This collaboration involved discussions about the analysis where the meanings of analysis and resultant themes were questioned and discussed. Ideally a second researcher would have analysed the data independently, however, this was not possible.

(Andrews, 2011), and that it is a chronic condition. As a chronic condition FGP requires lifelong management involving different strategies during different life phases. For instance, a woman who is at the stage of life where she may be dating in order to find a life partner may require interventions that support assertive communication with potential partners. A woman who is of childbearing years may need fertility support. The complexities of treating women with FGP are that it is a condition that not only affects women physically, but also may significantly impact upon sexuality, relationships and self-perceptions. It is also complicated due to the stigma and shame that can be experienced by women with FGP.

This study supports the chronic pain literature that identifies important HCP communication skills that enhance a supportive relationship: the provision of relevant information (Beck et al., 2002; Pawlikowska et al., 2012), positive and supportive talk (Little et al., 2001; Pawlikowska et al., 2012), and a friendly, warm and sympathetic approach (Cooper et al., 2003b; Eide et al., 2004; Mercer & Reynolds, 2002; Paasche-Orlow & Roter, 2003; Pawlikowska et al., 2012; Price et al., 2006). This study extends the sexual health practice literature on HCP–patient relationships in that it identifies the specific HCP interpersonal skills necessary to supporting women with FGP. Although the identified necessary HCP skills include many of the skills any HCP needs to provide quality care (e.g., empathy, active listening, and patient empowerment), there are also skills specific to treating women with FGP. These are HCP knowledge about FGP and its treatment, and the ability to address the sexual impact of FGP in a sensitive manner.

Social networks and treatment seeking for FGP.

The social networks of a woman with FGP influence treatment seeking and sexual health practices. A woman's social network can provide emotional, informational and financial support for a woman seeking treatment for FGP. Emotional and informational support may help a woman decide to seek initial treatment for genital pain or it may help her to continue to seek treatment when her motivation for treatment wanes. Partner support was of particular salience to the women in this study.

From a practice point of view, HCPs who understand the significance of a supportive social network will be well placed to identify the significant treatment needs of women with FGP. For instance, in addition to a referral to a knowledgeable gynaecologist, a GP may offer referral to a relationship counsellor to strengthen the support mechanisms in the intimate relationship. Given the importance that the social network can play in supporting treatment seeking, the HCP may also consider a consultation with the partner or other significant support persons to assess any needs she or he may have.

Education about treatment seeking for FGP.

Education of women through high schools, well-women checks and public campaigns would likely enhance a woman's ability to negotiate both external and personal attitudinal barriers to treatment seeking for FGP. HCP and woman barriers to treatment seeking for FGP were identified in this study. There are several potential solutions to the barriers that women face when seeking treatment for genital pain with the main overarching solution being the development of a national organisation that supports women with

genital pain and the HCPs who treat them. Functions of a national FGP organisation would be to lobby the government and community organisations for funding for treatment and research for FGP. Other functions include educating women about genital pain through public campaigns and education in schools to address the misinformation that leads to stigma, and normalising and minimising symptoms; educating HCPs about genital pain at a university or continuing professional development level; developing a women's health checklist that HCPs can use to help identify women who may be experiencing genital pain; and developing specific educational resources for HCPs about HCP–patient alliance.

There is a similar organisation in the United States called the National Vulvodynia Association (NVA) (National Vulvodynia Association, 2013). The NVA is a non-profit organization created to improve the lives of individuals affected by vulvodynia. It does this through education of women, their family, the public and HCPs about vulvodynia and its treatment; provision of a support network for affected women; promotion of multi-disciplinary and coordinated treatment; and encouragement of further vulvodynia research. An Australian genital pain organisation would greatly improve the treatment seeking trajectory and the quality of survivorship for women with genital pain.

Figure 6.4 summarises the identified barriers to and facilitators of treatment seeking for FGP. The antecedents to treatment seeking include the education and resources available to women with FGP and the HCPs who treat them. The barriers to treatment seeking include woman, HCP and environmental factors. The facilitators to treatment seeking are related to a FGP organisation, quality HCP skills and the woman's social networks.

Social networks also mediate the treatment seeking experience in that they can provide emotional support for women who are finding treatment seeking difficult or distressing.

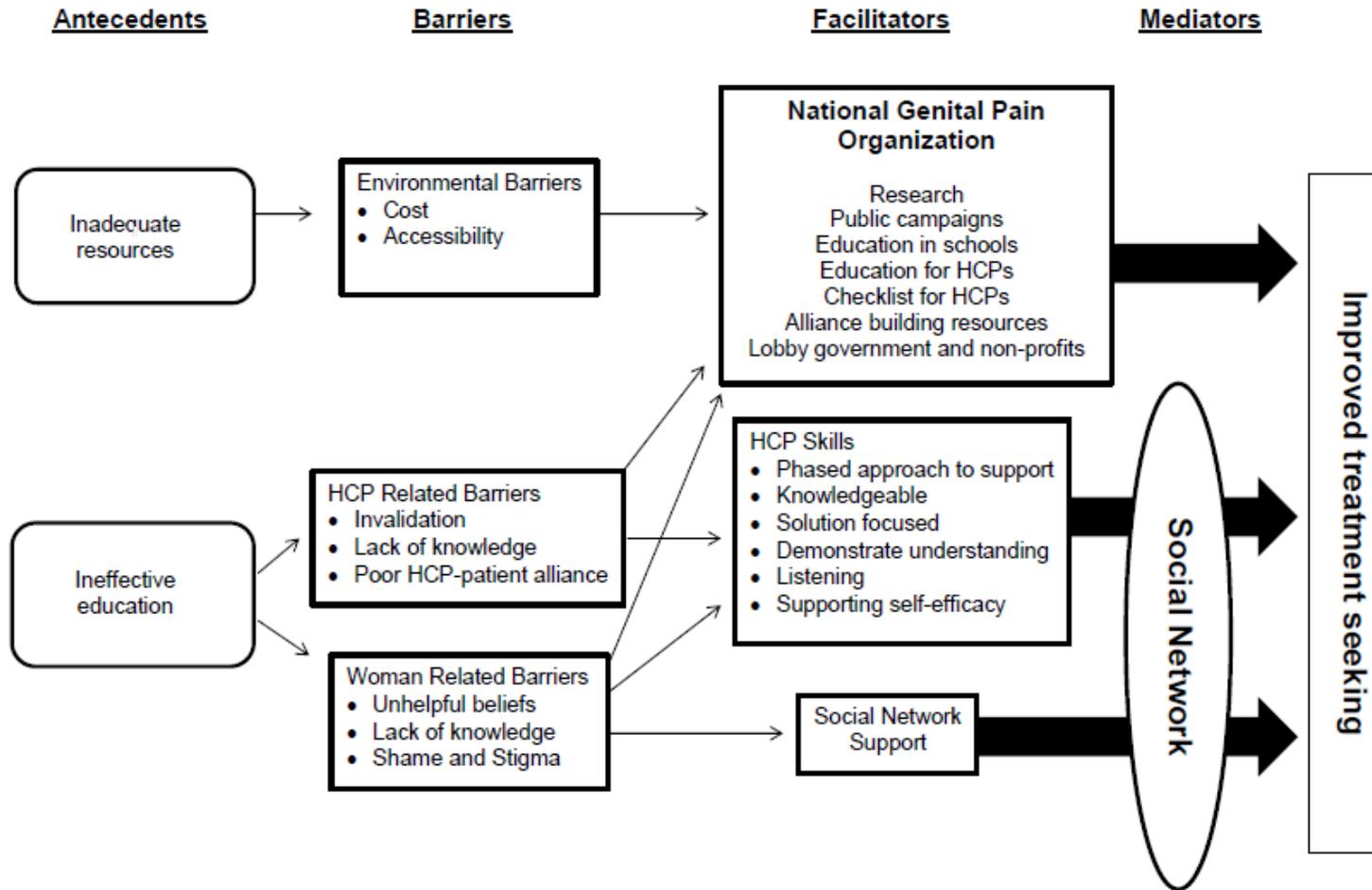


Figure 6.4 Implications for Practice

Strengths and Limitations

The strengths of this study include its sampling, that is, it included women of a larger age range than previous FGP research investigating treatment seeking for FGP (for example Landry & Bergeron, 2011). The exclusion criteria also allowed for the likelihood that only women with chronic genital pain were included in the sample as opposed to previous genital pain research that investigated early dyspareunia (Donaldson & Meana, 2011). Other strengths are the use of a lived experience approach and diagnostic homogeneity. Limitations included cultural homogeneity, restrictions related to grounded theory methodology, the lack of a pilot study and restricted member checking. Diagnostic homogeneity could also be considered a limitation because women with the various genital pain diagnoses may approach treatment seeking differently.

Strengths

The sampling frame used in this study broadened previous research investigating models of treatment seeking to include women between 18 and 55, and excluded women who did not have chronic genital pain. Donald and Meana (2011) investigated treatment seeking decisions in women with an early experience of genital pain. This means that some of the women in their sample may have had genital pain due to diagnoses other than chronic genital pain, e.g., infection. Landry and Bergeron (2011) investigated the bio-psycho-social correlates of genital pain in adolescent girls making it difficult to generalise to older women. While these studies are helpful in understanding the experience of FGP and seeking treatment for genital pain

they may not be generalisable nor do they bring understanding to the factors that influence the entire treatment seeking trajectory.

By taking a lived experience approach, the phenomenon studied (the experience of treatment seeking for FGP) was investigated holistically, rather than from the predefined parameters of a quantitative survey (Yin, 2009). The lived experience methodology of this study allowed the participants to guide data collection, which provided a multidimensional understanding of treatment seeking for FGP. This resulted in a nuanced, empathic and comprehensive model of treatment seeking for genital pain.

Diagnostic homogeneity could be considered both a strength and a limitation. The majority of women in this study were diagnosed with vulvodynia (84.6%), with most of these women having provoked vulvodynia (59.1%). This is beneficial because it strengthens the confidence to be able to generalise the findings to women with provoked vulvodynia. However, given the strong psychological component of vaginismus (e.g., phobia/fear) and the difference in pain quality between generalised vulvodynia and provoked vulvodynia, there may be differences in the way women with the various genital pain diagnoses approach treatment seeking. Research that focuses on each of the diagnostic groups would elucidate the function of diagnosis in treatment seeking.

Limitations

One limitation of this study is that this study's sample was culturally homogenous. The majority of the participants in this study were middle class (92.3%), Caucasian (80.8%) women, in long-term relationships (73.1%), and with post-secondary education (92.3%). As such, the participants of this

study may only represent a restricted range of social and sexual experiences and, therefore the findings may not accurately represent the experiences of those from culturally and linguistically diverse backgrounds (Baum, 2003).

For instance, a woman from a non-Western culture may hold different meanings of sexual relationships and sexual activities, which may have implications for how they respond to genital pain and its treatment.

Socioeconomic status may have also been a significant confound.

Presumably, women with genital pain from middle-class backgrounds have the financial ability to seek and explore a greater variety of treatment.

Research that includes participants with socioeconomic diversity would clarify the role of social class in treatment seeking for genital pain.

The methodology used for this study also poses some limitations.

Grounded theory allows for some data contours to be emphasized more than others (Mayoux, 2006). For instance, the data collected is mediated by the researcher's ability to ask questions and explore participant responses that allow participants to thoroughly articulate their thoughts and conceptualisations of genital pain and treatment seeking. The impact of this limitation was minimised by the phenomenological focus on the lived experience, allowing for the woman's experience to guide data collection and analysis. While the in-depth interview technique used within the study provides insight about the treatment seeking experiences of women with genital pain, other methods may have also been useful, such as diary methods. The diary method involves frequent reporting of the events and experiences of participant's daily lives over a period of time, allowing for

more accurate or more in-depth exploration of treatment seeking (Bolger, Davis, & Rafaeli, 2003).

Another limitation related to the methodology of this study was the cross-sectional design. It may be that women move in and out of the various phenomenon described in this study (i.e., agendas and narrative identities) depending on a combination of interpersonal, intrapersonal and environmental factors (McAdams & McLean, 2013; McLean et al., 2007). For instance, a woman with vaginismus who is in a nurturing relationship may be able to find meaning and redemption in her story of suffering whereas prior to this relationship she could not. Another woman with provoked vulvodynia may feel like no one can help her (contamination) until she meets a knowledgeable HCP who prescribes treatment that brings her some relief and a feeling of control over her symptoms. Once her distress has been reduced she may be able to reflect on the past and feel positive about the future, leading to narratives of redemption and positive resolution. A longitudinal study may have captured this possibility.

A final limitation of this study was the lack of a gynaecological exam to definitively diagnose the women in this study. This would have enabled a more nuanced understanding of the intra-personal aspects of the treatment seeking trajectory. For example, women with phobic components will experience treatment seeking quite differently from women without phobic components, therefore likely altering their personal narratives. Research that includes a gynaecological exam would further distinguish the influence of diagnosis on the treatment seeking experience.

A pilot study to investigate the validity of the measures used could have strengthened the results of this study (Lincoln, 1985; Morse, Barrett, Mayan, Olson, & Spiers, 2008). A pilot study was not undertaken due to time and recruitment constraints. Opportunities for member checking were offered to all of the participants, however, only three of the women responded. The results and the interpretations presented in this thesis are based on the investigator's understanding and interpretations of participant's thoughts. In order to maintain participant agency and voice in the generation of knowledge in future research more thorough member checking should be attempted.

Summary Suggestions for Future Research

This research highlights the need for further FGP research. While the motivators and barriers to treatment seeking were identified in this study, further research is needed to fully understand the impact the barriers of normalising, discounting, shame, stigma, invalidation and minimisation on treatment seeking. Future research could investigate why some women do not normalise or discount, which may give some indication of what can be done to prevent normalising and discounting in other women. Shame, stigma, invalidation and minimisation were also identified as significant barriers to treatment seeking. Further research comparing women who experience shame and stigma to those who do not may identify contributors to shame and stigma. Discourse analysis that investigates the interaction of an HCP and woman with FGP may elucidate the language HCPs use that may intensify shame, stigma, invalidation and minimisation. Research that explores the common attitudes and beliefs of HCPs that are associated with

the invalidation and minimisation of FGP could lead to improved education and training of HCPs. Such studies could also guide public campaigns and sex education programs to help reduce the impact of these identified barriers. The participants in this study were a culturally homogenous group. Research investigating the perceived motivators and barriers to treatment seeking and the consultation agendas of non-dominant cultures could potentially increase treatment seeking for these groups.

This study also identified the personal agendas that women held that influenced their experience of treatment seeking for FGP. A balanced HCP–patient alliance that includes the HCP encouraging personal agency was identified as an expectation of the women when seeking treatment from an HCP. Research that identifies the specific interactions between HCPs and women with FGP that build personal agency and a strong alliance is needed.

Social networks were identified as a significant survivorship resource, particularly the relationship with the partner. The male sex drive discourse and the coital imperative were identified as negatively influencing the relationship with the partner. Phenomenological research investigating how women with FGP successfully negotiate the male sex drive discourse and the coital imperative could help other women with FGP negotiate these discourses and improve their intimate relationships. This type of study could also give clinicians insight that may be helpful in guiding women to find more helpful meanings for their genital pain.

Narrative identities positively and negatively influence treatment seeking for FGP. A study that focuses on each of the significant narratives identified in this study could further explicate the influence that these

narratives have on the experience and treatment of FGP. Survivorship resources and narrative identities may be different for women from other cultures and research investigating this would bring increased understanding to the treatment of genital pain conditions in varied groups of women. These potential research studies could investigate treatment seeking for FGP in non-dominant culture groups such as lesbian women, trans men, intersex or asexual people, and women from non-Australian cultures to investigate if the impact of FGP is different on these groups.

Further exploration of the possible links between diagnosis and barriers, survivorship resources and narrative identities is needed. Quantitative research in particular would be able to confirm, or deny, the significance of the links observed in this study. Finally, this study's design, (i.e., qualitative research) led to a comprehensive model of treatment seeking for genital pain. Quantitative research could investigate the generalisability of this model to women with FGP generally, and to women with the specific genital pain diagnoses specifically.

Conclusions

This study sought to identify the intra- and interpersonal factors that influence the treatment seeking trajectory of women with genital pain conditions utilising the concepts of lived experience, narrative identities and survivorship resources. It identified the qualities of an HCP that are of particular salience to the treatment experience of women with genital pain, namely the ability to diagnose and validate the woman's experience of symptoms and the ability to develop a strong alliance with the woman. It also identified the narrative identities that positively and negatively influence the

treatment seeking trajectory. Of particular importance was the identification of the negative impact that contamination identities can have on women seeking treatment for genital pain. Equally important was the recognition of the positive influence that the narratives of redemption and positive resolution have on treatment seeking. The findings of this study indicate that gender and power are salient influencers on the experience of treatment seeking for FGP. Furthermore, social roles, networks and discourses also significantly influence treatment seeking for FGP.

This study provides significant and important support and extension to previous research that applied a cognitive behavioural model to treatment seeking for early dyspareunia by identifying the intra- and interpersonal factors that influence treatment seeking. It also elucidated a unique lived experience insight into the entire treatment seeking trajectory from onset of symptoms to successful management of genital pain.

The significant implications for theory, practice and future research were identified. The elucidation of the intrapersonal, interpersonal and contextual barriers, the elucidation of the narratives of women with genital pain, and the identification of salient resources for survivorship of genital pain will allow HCPs and researchers to better understand the needs of women with genital pain. Furthermore, this research will help guide future research and the development of future initiatives to improve the treatment of genital pain conditions, thus improving the outcomes and quality of life for women with genital pain.

On the basis of this research, significant effort should be invested in educating women and HCPs about FGP. This can be achieved through

modified school sex education programs and HCP university and continuing education curriculum. This research also supports the utilisation of opportunities such as well women's checks to screen for and educate women about genital pain. Although further research is needed to better understand the experience of treatment seeking for genital pain, this research significantly advanced the scholarship of FGP.

Appendices

Appendix A: Interview Screening Sheet

Date of Contact	What happened?	Action

Screening

Inclusion:

- Are you between 18 and 55?
- Do you live in Sydney or Melbourne or would you be willing to travel to either city?
- Do you have pain in the vulvar area associated with non-sexual or sexual activity (including oral sex, masturbation, intercourse, tampon use, pelvic exam, sporting activities etc)?
- Has your pain been either intermittent or continuous for at least the last two months?
- Do you speak and understand English (conversational or better)?

Exclusion:

- Are you peri-menopausal or menopausal?
- Are you breast feeding?
- Have you given birth within the last six months?
- Do you have an active vulvar/vaginal infection?

Diagnosis

Yes/No? What is it?

Demographics

Age:

Marital/relationship status:

No. of children:

Ethnicity:

Education level:

Employment status:

Family income:

under \$25 \$25-\$50 \$51-75 \$76-100
over\$100

Availability

Time of Interview 1	
Time of Interview 2	
Sent :	
Informed consent	Yes No
Information sheet	Yes No

FSDS	Yes	No
Addressed/stamped envelope	Yes	No
	.	

Appendix B: Participant Information Sheet



The University of Sydney

C 42 Office
Graduate Program in Sexual
Health
Faculty of Health Sciences

ABN 15 211 513 464

Dr Patricia Weerakoon

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PARTICIPANT INFORMATION STATEMENT Research Project

Title: Female Sexual Pain: Women and Their Treatment Choices

(1) What is the study about?

This study is investigating women's distress over their sexual pain and how it affects why they choose to seek treatment when they do.

(2) Who is carrying out the study?

The study is being conducted by Kathy Bond and will form the basis for the degree of PhD at The University of Sydney under the supervision of Dr Patricia Weerakoon, Senior Lecturer and Coordinator of the Graduate Program in Sexual Health.

(3) What does the study involve?

The study requires you to participate in two interviews approximately 1 month apart. In the interview you will complete a 12 item questionnaire about the distress you feel regarding your sexual pain. You will then participate in a semi-structured conversation about your distress and treatment choice.

(4) How much time will the study take?

Each interview will take about 45 minutes.

(5) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with the University of Sydney or the health professional treating you.

You may stop the interview at any time if you do not wish to continue, the audio/video recording will be erased and the information provided will not be included in the study.

(6) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

(7) Will the study benefit me?

Your participation in this study may have benefits for the women who have female sexual pain.

(8) Can I tell other people about the study?

Yes

(9) What if I require further information?

When you have read this information, Kathy Bond will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Kathy Bond on 0425 798 425 or kbon3355@uni.sydney.edu.au or Patricia Weerakoon on 02 9351 9256 or P.Weerakoon@usyd.edu.au.

(10) What if I have a complaint or concerns?

Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on (02) 8627 8176 (Telephone); (02) 8627 8177 (Facsimile) or human.ethics@usyd.edu.au (Email).

This information sheet is for you to keep

Appendix C: Participant Consent Form



The University of Sydney

C 42 Office
Graduate Program in Sexual
Health
Faculty of Health Sciences

ABN 15 211 513 464

Dr Patricia Weerakoon
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PARTICIPANT CONSENT FORM

I,[PRINT NAME], give consent to my participation in the research project

TITLE: Female Sexual Pain: Women and Their Treatment Choices

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s), the health professional treating me or the University of Sydney now or in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.
5. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio/video recording will be erased and the information provided will not be included in the study.

7. I consent to:

- | | | | | |
|-------------------------|-----|--------------------------|----|--------------------------|
| i) Audio-taping | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| ii) Video-taping | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| iii) Receiving Feedback | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |

If you answered YES to the "Receiving Feedback Question (iii)", please provide your details i.e. mailing address, email address.

Feedback Option

Address: _____

Email: _____

Signed:

Name:

Date:

Appendix D: Female Sexual Distress Scale (FSDS)

Think about when you decided to speak to a health professional about your genital pain. At that time, how often and how intensely did you feel:

	<i>Frequency</i>					<i>Intensity</i>						
1. Distressed about your sex life <i>extremely</i>	0	1	2	3	4	0	1	2	3	4		
	<i>Never</i>					<i>not at all</i>						
					<i>always</i>							
2. Unhappy about your sexual relationship <i>extremely</i>		0	1	2	3	4		0	1	2	3	4
		<i>Never</i>					<i>not at all</i>					
						<i>always</i>						
3. Guilty about sexual difficulties <i>extremely</i>	0	1	2	3	4	0	1	2	3	4		
	<i>Never</i>					<i>not at all</i>						
					<i>always</i>							
4. Frustrated by your sexual problems <i>extremely</i>	0	1	2	3	4	0	1	2	3	4		
	<i>Never</i>					<i>not at all</i>						
					<i>always</i>							
5. Stressed about sex <i>extremely</i>		0	1	2	3	4		0	1	2	3	4
		<i>Never</i>					<i>not at all</i>					
						<i>always</i>						
6. Inferior because of sexual problems <i>extremely</i>	0	1	2	3	4	0	1	2	3	4		
	<i>Never</i>					<i>not at all</i>						
					<i>always</i>							
7. Worried about sex		0	1	2	3	4		0	1	2	3	4

	<i>Never</i>				<i>always</i>		<i>not at all</i>			
<i>extremely</i>										
8. Sexually inadequate	0	1	2	3	4	0	1	2	3	4
	<i>Never</i>				<i>always</i>		<i>not at all</i>			
<i>extremely</i>										
9. Regrets about your sexuality	0	1	2	3	4	0	1	2	3	4
	<i>Never</i>				<i>always</i>		<i>not at all</i>			
<i>extremely</i>										
10. Embarrassed about sexual problems	0	1	2	3	4	0	1	2	3	4
	<i>Never</i>				<i>always</i>		<i>not at all</i>			
<i>extremely</i>										
11. Dissatisfied with your sex life	0	1	2	3	4	0	1	2	3	4
	<i>Never</i>				<i>always</i>		<i>not at all</i>			
<i>extremely</i>										
12. Angry about your sex life	0	1	2	3	4	0	1	2	3	4
	<i>Never</i>				<i>always</i>		<i>not at all</i>			
<i>extremely</i>										

When sex hurts

What you can do about Genital Pain

by Kathy Bond*

Good sexual functioning is an important part of *sexual health* and overall health and well-being. Research indicates sexual dysfunctions, such as genital pain, negatively impact quality of life, emotional health, relationships and general happiness. Genital pain that does not have an identifiable cause, such as an active infection, is diagnosed as either vulvodynia (also called vulvar vestibulitis) or vaginismus. It is believed around 15% of women experience vulvodynia and up to six percent experience vaginismus. The symptoms of vulvodynia include burning, itching, stinging or sharp pain involving either the entire vulva or specific areas of the vulva such as around the vagina, urethra or the clitoris. Vulvodynia is a chronic pain condition with various causal factors including past infections, inflammation, genetics, hormones, neurological changes and muscle dysfunction. It is thought that any of these factors can lead to changes in (1) the nervous system of the vulva and spinal cord leading to chronic pain, (2) the pelvic floor muscles and (3) psychosexual function which can lead to problems with sexual arousal, desire and orgasm. Treatment for vulvodynia includes medication to address neuropathic pain, infection and inflammation; surgery to remove the affected vulval tissue; physiotherapy and biofeedback to address dysfunctional pelvic floor muscles; and cognitive behavioural therapy/treatments (CBT) and psycho-education to reduce pain and improve sexual and relationship function.

Vaginismus is a tightening of the vaginal muscles that can make penetration painful or even impossible. It is thought to be a conditioned response to factors including negative sexual attitudes, strict religious beliefs, poor sexual education and sexual trauma. In vaginismus, a cycle evolves whereby fear and anticipation of pain increases muscle tightness of the pelvic floor - which in turn increases pain and/or makes penetration impossible, which then re-enforces the anticipation and fear of pain and penetration. Current treatments for vaginismus consist of pelvic floor physiotherapy, medication to address anxiety, general psychotherapy, sex therapy and cognitive behavioural therapy.

A current research project being conducted by the University of Sydney** investigating treatment seeking for genital pain conditions has found this condition is very distressing for women and has a significant impact on the lives of women with genital pain. The remainder of this article will look at the impact of genital pain on the lives of

women who participated in this study and will incorporate quotes from these women.

Women with genital pain often consult multiple doctors and have pain for between two and five years before receiving a diagnosis and appropriate treatment. This lengthy road from onset of symptoms to effective treatment contributes to the development of a chronic pain condition which can significantly impact the woman's life experience. Although genital pain is relatively common, women with these conditions often feel alone and isolated. There is also a tendency for the woman to blame herself and feel like she is crazy or somehow bringing this on herself.

"you feel a bit of relief [when you get a diagnosis] knowing that it is something that other people have, [that] I am not the only one."

"I didn't have any idea and I thought I was the only one, like maybe it's in my head, maybe I made myself think that I've got this pain when I don't"

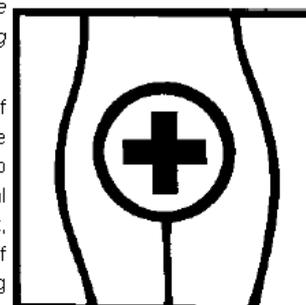
"[I felt like] it's my fault and that it's maybe a somewhat normal feeling, like that the pain wasn't really that much to complain about."

Society and the media enforce a belief sex is something that should be instinctual and that encountering a problem with sex is odd and unnatural, when in fact most people at some point in their life will experience a sexual problem. When women experience pain with sex they often feel bewildered, confused and distressed. It can also lead to questioning their relationship.

"My body wasn't responding [the way I thought it should], it confuses you, you think well maybe I'm not attracted to my husband because my body's not reacting to him or maybe I'm just broken."

"There were periods where I thought I should divorce my husband, I can't do this to him and I'll just have to live the rest of my life being celibate."

There are a number of reasons why it can be uncomfortable talking to a doctor about genital pain (embarrassment, feelings of shame, fear of finding something



serious), but prompt treatment is key to preventing pain becoming chronic and long term. If you are experiencing genital pain, remember you are not alone and there is likely to be real and treatable reasons for your pain. Your GP or the local sexual health clinic is a good place to start for a referral to a specialist. There are also a number of books and websites that provide good evidence-based information:

The National Vulvodynia Association - The National Vulvodynia Association (NVA) is a non-profit organisation created to improve the lives of individuals affected by vulvodynia (www.nva.org).

Vaginismus.com - a website for helping women overcome painful sex and penetration problems (www.vaginismus.com)

The Behavioural Institute of Australia has a website dedicated to information on vulvodynia and its treatment (www.vulvodynia.com.au)

Dr Howard Glazer, who developed a treatment for the pelvic floor muscles involved in vulvodynia and vaginismus, has a website and a book dedicated to information about vulvodynia (www.vulvodynia.com and [The Vulvodynia Survival Guide](#), published by New Harbinger Publications, Inc.)

**Kathy Bond is a Melbourne based sex therapist and PhD candidate at the University of Sydney.*

***If you are experiencing genital pain and would like to participate in this research please see the advertisement below or contact Kathy Bond directly via email at kbon3355@sydney.uni.edu.au.*

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Female Genital Pain: Women and their treatment choice

The University of Sydney (Online Study)

Subject: An online questionnaire investigating treatment decisions in women with genital pain conditions (vulvodynia and vaginismus).

Contact: Kathy Bond, PhD candidate

kbon3355@uni.sydney.edu.au or +61 425 798 425 or go directly to the on-line survey at <http://www.surveymonkey.com/s/FemaleGenitalPain>

Requirements: This research will help health professionals to better understand vulvar pain and its effects on women and treatment seeking. It is being conducted by the Faculty of Health Sciences at the University of Sydney and has Human Research Ethics Committee approval (ref # 11-2009/12243).

The survey will take approximately 45-60 minutes depending on how much detail you choose to give. To be eligible you must be a woman between 18 and 55, have pain in the vulvar/vaginal area associated with non-sexual or sexual activity (including oral sex, masturbation, intercourse, tampon use, pelvic exam, sporting activities, etc) and your pain must be either intermittent or continuous for at least the last 2 months. You must not be peri-menopausal or menopausal, breast feeding, have given birth within the last 6 months or have an active vulvar/vaginal infection.

Participation in this project is completely voluntary - you can withdrawal at any time. The information you give will be treated with the utmost confidence.

Appendix F: Postcard Brochure

Postcards: Front side



Postcards: Reverse side



Appendix G: Sample of Interview Schedule – Part B

Second Interview Part005

1. Ask about her new job at Myer and her bands National Tour ?
2. So you talked about getting misdiagnosed and a lot of waiting to see if one treatment worked before moving on. If my calculations are right it took at least one year to sort out the infections and get a diagnosis of vulvodynia. Tell me what this was like for you in terms of your attitude towards treatment.
3. You talked several times about you feeling the muscles lock up or tighten, but not being able to stop it from happening. Tell me more about this, how it affected you, your thoughts, your emotions.
4. You said when you started physio you noticed a difference straight away even though it took a while to get better. What was that like for you emotionally?
5. When we talked about sex before vulvodynia I asked was everything fine and you said pretty much. Can you explain what you meant by this?
6. You talked about trying intercourse when you thought things might be better and then being in heaps of pain after? Later you talked about it being failed sex. Tell me more about what was going on in your thoughts and emotions when this happened.
7. Then you said it got to the point where you decided it (meaning intercourse) wasn't worth pursuing? What was that like for you?
8. You said when talking about sex before vulvodynia compared to after that it is not completely the same, its not like in the past were it just happened but like the degree to which it happens with relative spontaneity I am happy with. Tell me more about this.
9. You said you don't expect sex to be 'wham bam', why do you think that is?
10. You talked about it being the darkest time and being really depressed and at the same time being committed to getting better and recognizing that some people have it worse. Tell me more.
11. You talked about feeling guilty about not being active/not getting things done and then you resigned yourself to the fact that you wouldn't get things done. Tell me about that process.
12. You talked about it being a really difficult time and you don't like to think about it. What has it been like for you to have to talk about it and think about it for these interviews?

13. You talked about the vulvodynia changing you in good ways and talked about being more health conscious and taking fewer drugs. What were the emotional, internal, attitudinal changes if any?

14 What about relational changes?

15. When you saw the family planning doctor you said you felt like she was the first person who really knew what she was doing. What was that like for you?

16. You talked about a time when you almost gave up. What was that like what kept you from giving up?

17. Explore the aloneness she felt during this period.

Appendix H: Online Questionnaire

Information about this research

(1) What is the study about?

This study investigates women's personal and relationship distress about their genital pain and how it affects their treatment seeking choices.

(2) Who is carrying out the study?

The study is being conducted by Kathy Bond and will form the basis for the degree of PhD at The University of Sydney under the supervision of Dr Patricia Weerakoon, Senior Lecturer and Coordinator of the Graduate Program in Sexual Health.

(3) What does the study involve?

The study requires you to complete an on-line questionnaire that asks you mostly open ended questions about your genital pain, personal and relationship distress and treatment choices.

(4) How much time will the study take?

It should take approximately 45-60 minutes depending on how much detail you choose to give.

(5) Can I withdraw from the study?

Participation in this study is completely voluntary - you are not under any obligation to participate and you can withdraw at any time prior to submitting the questionnaire without affecting any relationship you may have with the University of Sydney or any health professional that may be treating you. Once you have submitted the questionnaire your responses cannot be withdrawn. Submitting your questionnaire is an indication of your understanding of this and your consent to participate in the study.

(6) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information about participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

(7) Will the study benefit me?

Your participation in this study may have benefits for women who have female sexual pain.

(8) Can I tell other people about the study?

Yes

(9) What if I require further information?

If you would like to know more at any stage, please feel free to contact Kathy Bond on +61 425 798 425 or kbond3355@uni.sydney.edu.au or Patricia Weerakoon on +61 2 9351 9256 or P.Weerakoon@usyd.edu.au.

(10) What if I have a complaint or concerns?

Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or human.ethics@usyd.edu.au (Email).

Information about this survey

Questions marked with an "*" must be answered.

You can leave the survey and resume it later. The [Next] button on a page or the [Done] button at the end of the survey must be clicked to save the page(s) of answers.

NOTE: Cookies must be enabled. The cookie placed by the program tracks the page where you exited. If your browser is set to dump cookies each time it is closed, the cookie will be refreshed and a new or blank survey will open every time the survey is accessed.

The link MUST be accessed on the same browser.

If you would like a copy of the questions before you begin the survey we would be happy to send you a copy via email. Please send a request to Kathy Bond at kbon3355@uni.sydney.edu.au.

Eligibility to participate in this research

To be eligible to complete this questionnaire you must answer 'yes' to the following questions.

***1. Are you between 18 and 55?**

Yes

No

***2. Do you have pain in the vulvar area associated with non-sexual or sexual activity (including oral sex, masturbation, intercourse, tampon use, pelvic exam, sporting activities, etc)?**

Yes

No

***3. Has your pain been either intermittent or continuous for at least the last 2 months?**

Yes

No

4. Please provide any comments or further information regarding the questions on this page.

Eligibility to participate in this research (cont)

To be eligible to complete this questionnaire you must answer 'no' to the following questions.

***5. Are you peri-menopausal or menopausal?**

- Yes
- No

***6. Are you breast feeding?**

- Yes
- No

***7. Have you given birth within the last 6 months?**

- Yes
- No

***8. Do you have an active vulvar/vaginal infection?**

- Yes
- No

9. Please provide any comments or further information regarding the questions on this page.

Demographic Information

*** 10. Age:**

*** 11. Marital/Relationship status:**

- Single
- Casual dating
- Committed dating
- Married
- Living with partner

*** 12. Number of children:**

- 0
- 1
- 2
- 3
- 4
- 5 or over

*** 13. Highest level of education completed:**

*** 14. Employment status:**

- Full-time
- Part-time
- student
- unemployed

*** 15. Ethnicity**

*** 16. What country do you live in?**

*** 17. Where were you born (country)?**

18. If you were born in a different country to where you are currently living, how long have you lived in this country?

***19. Family income(compared to other people living in your country):**

- below average income
- lower middle class
- middle class
- upper middle class
- above average income

20. Please provide any comments or further information regarding the questions on this page.

Female Sexual Distress Scale

The following questionnaire addresses the frequency and intensity of distress you felt regarding your genital pain.

***21. Think about when you decided to speak/or thought about speaking to a health professional about your genital pain*. At that time, how often did you feel (please select the number that best represents the frequency of your feelings):**

***If you have not thought about seeking treatment please indicate this below in the further comments section and indicate the number that best represents how you feel about your genital pain now.**

	Never (0)	(1)	(2)	(3)	Always (4)
Distressed about your sex life	<input type="radio"/>				
Unhappy about your sexual relationship	<input type="radio"/>				
Guilt about sexual difficulties	<input type="radio"/>				
Frustrated by your sexual problems	<input type="radio"/>				
Stressed about sex	<input type="radio"/>				
Inferior because of sexual problems	<input type="radio"/>				
Worried about sex	<input type="radio"/>				
Sexually inadequate	<input type="radio"/>				
Regrets about your sexuality	<input type="radio"/>				
Embarrassed about sexual problems	<input type="radio"/>				
Dissatisfied with your sex life	<input type="radio"/>				
Angry about your sex life	<input type="radio"/>				

***22. Think about when you decided to speak/or thought about speaking to a health professional about your genital pain*. At that time, how intensely did you feel (please select the number that best represents the intensity of your feelings):**

***If you have not thought about seeking treatment please indicate this below in the further comments section and indicate the number that best represents how you feel about your genital pain now.**

	Not at all (0)	(1)	(2)	(3)	Extremely (4)
Distressed about your sex life	<input type="radio"/>				
Unhappy about your sexual relationship	<input type="radio"/>				
Guilty about sexual difficulties	<input type="radio"/>				
Frustrated by your sexual problems	<input type="radio"/>				
Stressed about sex	<input type="radio"/>				
Inferior because of sexual problems	<input type="radio"/>				
Worried about sex	<input type="radio"/>				
Sexually inadequate	<input type="radio"/>				
Regrets about your sexuality	<input type="radio"/>				
Embarrassed about sexual problems	<input type="radio"/>				
Dissatisfied with your sex life	<input type="radio"/>				
Angry about your sex life	<input type="radio"/>				

23. Please provide any comments or further information regarding the questions on this page.

Open ended questions

The remainder of the survey consists of open ended questions. Please type in your responses with as much detail as you wish.

History of Your Pain

24. Please give us a brief history of your pain, when it started and what it has been like for you since it started.

History Treatment Seeking

25. Some women with genital pain seek treatment immediately and others take considerable time to decide to seek treatment.

How long did it take you to seek treatment for the pain and if there was a delay between onset of pain and treatment seeking, what were the factors involved in the delay?

Diagnosis

26. For some women with genital pain the period from deciding to go see a doctor about her genital pain and getting a diagnosis is a long process and for others it is not.

Have you received a diagnosis?

- Yes
 No

27. If you have received a diagnosis please tell us more about that journey for you. How long did it take to get a diagnosis and what was that process like for you? Tell us what you were thinking and feeling during this time.

28. If you are still in the process of getting a diagnosis please tell us about this journey for you. How long has it been since you started seeking treatment and what has that process been like for you? Tell us what you are/were thinking and feeling about the process of finding a diagnosis.

Expectations and hopes for treatment and management

Many women find the path to effective treatment a long journey.

29. Regardless of where you are on the path to finding effective treatment please tell us your hopes and expectations for treatment.

30. For some women genital pain is a long term, chronic condition that involves management and not a cure. If you feel you fall into this category tell us how you have come to believe this is the case for you.

Motivation for treatment

Women seek treatment for their genital pain for different reasons.

31. What motivated or motivates you to find a diagnosis and/or effective treatment?

Emotional aspects of genital pain

For many women the journey of treatment seeking is an emotional one.

32. If you have a diagnosis what was it like for you to receive a diagnosis?

33. Does your genital pain affect the way you think and/or feel about yourself? If so how?

34. What are the most frustrating aspects of having genital pain?

35. Has the genital pain affected your intimate relationship/s? If so, how?

36. At this moment how do you feel about your genital pain? Do you feel differently than you have in the past and if so please explain the difference?

37. What are the most distressing aspects of having genital pain?

38. Did or does treatment seeking affect your distress levels? If so how?

39. Did or does distress affect treatment seeking? If so how?

Barriers to treatment seeking

It is not uncommon to encounter barriers when seeking treatment for genital pain.

40. What barriers did you experience in seeking treatment for your genital pain?

41. What would make or would have made treatment seeking easier for you?

Additional comments

42. Is there anything else you would like to tell us about your experience of having genital pain or your journey of diagnosis and treatment of genital pain?

43. If you would like feedback about the results of the research please provide your e-mail address:

Thank you

Participation in this study is completely voluntary - you are not under any obligation to participate and you can withdraw at any time prior to submitting the questionnaire without affecting your relationship with the University of Sydney or the health professional treating you. Once you have submitted the questionnaire your responses cannot be withdrawn. Submitting your questionnaire is an indication of your understanding of this and your consent to participate in the study.

Appendix I: Evidence of NVivo Training



Reference List

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