

**A Preliminary Investigation into
The Experience of Pain for
Women with Unexplained Vulvodynia**

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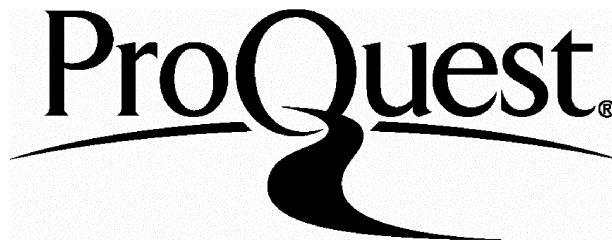
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ABSTRACT

Essential Vulvodynia is a genito-urinary condition characterised by vulval pain, psychological distress and associated sexual dysfunction. Various features of Essential Vulvodynia are shared in common with patients suffering from Chronic Pain syndrome: ongoing pain, lack of an apparent physical pathology, and resistance to traditional medical treatment. Research has demonstrated that patients with Essential Vulvodynia have considerable levels of distress (Stewart, Reicher and Gerulath, 1994), but it is unclear which factors in particular contribute to distress. The present study aims to substantiate the findings of psychological distress of Stewart et al (1994) among women with Essential Vulvodynia.

This study also aims to deconstruct the experience of Essential Vulvodynia in order to identify the aspects of the condition likely to give rise to psychological distress. Patients with Essential Vulvodynia may experience distress for a number of reasons: a) lack of organic findings which leads to feeling disbelieved; b) the sensitive site of the pain; or c) the experience and consequences of having any persistent pain. The present study compares Essential Vulvodynia (V) and three other groups that differ on the above variables. Chronic Pain (CP) - persistent pain with no organic pathology; Rheumatoid Arthritis (RA) - persistent pain with organic pathology; and Gynaecological Problems

(Gyn) - sensitive site but no pain. The groups are compared on depression, anxiety, pain beliefs, pain intensity, coping and quality of life.

Differences between the groups emerged in the following way: The V group had less physical pain than the CP group; and were less limited in physical activities than the CP and RA groups. The V group also had stronger beliefs than the CP and RA groups about their pain signifying damage and harm; about a medical cure being the appropriate treatment for chronic pain; and about significant others responding attentively when one is in pain. The V group did not believe as strongly as the RA group in the appropriateness of medication. Further, the V group were more limited in their roles and activities due to physical causes than the Gyn group.

The CP and V groups appeared to be similar on other measures of quality of life (e.g. social functioning and vitality); on anxiety and depression; beliefs (e.g. control); and use of active coping strategies. In light of the apparent similarity between Chronic Pain patients and Essential Vulvodynia patients, and the growing body of research indicating the efficacy of cognitive-behavioural pain management programmes for patients with chronic pain, it would seem likely that a similar approach to treatment may also be appropriate for patients with Essential Vulvodynia.

Therefore, the second aim of this study was to evaluate the efficacy of a cognitive-behavioural pain management programme for a group of women with Essential Vulvodynia. As Cognitive Behaviour therapy is the treatment of choice for patients with chronic intractable pain, it seems feasible that this approach to treatment will also be

effective for patients with Essential Vulvodynia. In this study, a pilot group of eleven women with Vulvodynia were assessed before and after an eight week treatment trial. The results suggest an increased use in coping strategies and a decrease in reported physical pain after treatment. However, other factors, such as depression, and anxiety remained unaffected. Findings are discussed with regards to future treatment for women with Essential Vulvodynia.

INTRODUCTION

1. Overview

Essential Vulvodynia is a gynaecological condition characterised by constant vulval pain, or in the case of Vestibulitis (a subset of Vulvodynia), pain on touch or sexual intercourse. These conditions have no apparent organic pathology to account for their symptoms (McKay, 1989).

Patients with Essential Vulvodynia frequently present with depression, having significantly reduced their participation in rewarding roles and activities (Lynch, 1986). Dyspareunia, or pain on sexual intercourse, is experienced by almost all Vulvodynia sufferers and many are consequently sexually abstinent, often resulting in relationship difficulties (Wesselmann, Burnett & Heinberg, 1997). Wesselmann et al estimated that although the incidence and prevalence of Vulvodynia are not known, there are at least 200, 000 women in the US who have significant vulval discomfort that greatly reduces their quality of life. Furthermore, they reported that 15% of all patients seen in a general gynaecological practice fulfilled the definition of vulvar Vestibulitis. At present, medical efforts to treat Vulvodynia are nearly always ineffective (Beard, Gamgar & Pearce, in Wall & Melzack, 1994). Consequently, each patient is seen by multiple physicians including dermatologists, gynaecologists and psychiatrists (Lynch, 1986), making

Vulvodynia, not only frustrating and distressing for patients, but demanding of healthcare services.

In order to understand more about the psychological factors involved, in this thesis Essential Vulvodynia is broken down into three components that are hypothesised to independently contribute to distress: the genital site, ongoing, intractable pain, and the lack of apparent organic pathology. Each of these three issues is looked at separately in the literature and findings are considered in relation to Vulvodynia.

a) Gynaecology

Evidence regarding the psychological effect on women of having a gynaecological condition will be considered. Specifically, Chronic Pelvic Pain is examined, as it is a gynaecological condition which in common with Vulvodynia has few identifiable physical findings. Chronic pelvic pain is far more researched, however, and it seems likely that Vulvodynia patients will share some of the features experienced by patients with Chronic Pelvic Pain.

b) Chronic Pain

Ongoing, intractable pain is a primary feature of Vulvodynia. It is likely that the experience of living with any ongoing, persistent pain will lead to a range of adverse consequences. Chronic pain is examined in terms of its effects and factors associated with adaptation.

c) Organicity

There is evidence to suggest that there are psychological implications to the experience of having no apparent physical cause for protracted painful symptomatology. This issue is covered within the above two sections. Chronic Pelvic Pain (CPP) within the gynaecology section; and Rheumatoid Arthritis (RA) and Phantom Limb Pain within the Chronic Pain section.

d) Treatment

Finally, cognitive-behavioural pain management, as the most promising treatment approach for chronic pain conditions, is critically reviewed as to how it might be an appropriate intervention for Essential Vulvodynia.

2. Vulvodynia

Despite references to Vulvodynia in the last century (Wesselmann et al, 1997), it was noticeably absent in the literature until the early 1980s when the International Society for the Study of Vulvar Disease Task Force defined Vulvodynia as “chronic vulvar discomfort characterised by the patient’s complaint of a burning and sometimes stinging

sensation in the vulvar area” (McKay, 1984). Vulvodynia is an umbrella term that includes several disorders that result in chronic vulvar pain: vulvar dermatoses, cyclic vulvovaginitis, vulvar Vestibulitis, vulvar papillomatosis and essential Vulvodynia (McKay, 1989).

Although various physical etiologies have been identified for several subsets of the syndrome, there remains a significant group of women without identifiable physical pathology: those with Essential Vulvodynia and those with Vestibulitis. Essential Vulvodynia differs from Vestibulitis in that it results in constant diffuse vulval pain that occurs with or without provocation and is usually diagnosed in elderly or post menopausal women. Vestibulitis tends to be diagnosed in younger women and the pain these women experience is primarily provoked by touch. Symptoms of Vestibulitis including severe pain on vaginal entry, a tenderness to pressure, and redness or inflammation of the area (McKay, 1989). This study will be investigating these patients with Essential Vulvodynia and Vestibulitis. For the purposes of this thesis, patients suffering with Essential Vulvodynia or Vestibulitis will be referred to as having “unexplained Vulvodynia”.

a) Psychological Implications of Unexplained Vulvodynia

Because of its location, embarrassment may prevent some patients with unexplained Vulvodynia from revealing symptoms to family members, friends or doctors. When they do approach medical professionals, their condition is often unrecognised which can lead

patients to feel disbelieved. Unsuccessful trials of medications and even invasive procedures follow examinations that revealed few clinical signs, thus confirming the absence of organic pathology and the feeling of being disbelieved. The need for acknowledgement from the medical profession may be heightened where a possible psychological cause has been queried. Although some patients resign themselves to the chronicity of their problems, others continue to visit clinics with intractable symptoms in search of a diagnosis and cure (Stewart et al 1994).

Stewart et al investigated the psychological distress of women suffering with Vulvodynia. Women presenting at a gynaecology clinic were divided into three groups : women with Essential Vulvodynia (with no abnormal organic findings); women with Vulvodynia for whom organic pathology had been diagnosed to account for their symptoms; and women with no symptoms of burning or pain but with other vulval pathology. Groups were compared on anxiety, depression, somatisation, and hypochondriasis. Stewart et al suggested that patients with Vulvodynia were more likely than patients with other vulval pathology to be anxious, somatising, and hypochondriacal, and tended to consult more doctors about their symptoms. They also found that the symptoms of the Vulvodynia patients interfered more seriously with their sexual functioning. In addition, Stewart et al found that women with Vulvodynia and no established cause had higher anxiety and suggestibility scores than women with Vulvodynia with organic pathology. Stewart et al suggested that Vulvodynia patients are hyper vigilant of normal bodily sensations which they attribute to serious causes and therefore consult medical professionals. Anxiety is a central issue which is amenable to

cognitive behavioural interventions and the somatising and hypochondriachal aspects may be addressed by reassurance regarding serious illness or sexually transmitted disease. These results suggest that both chronic pain and the stress of having chronic symptoms for which an etiology cannot be found, may independently contribute to psychological distress. Patients with unexplained Vulvodynia are therefore contending with both of these factors in addition to the consequences of having a gynaecological problem.

3. Psychological Approaches To Gynaecological Problems

a) Genital Site

Although there is little evidence about particular psychological problems associated with Vulvodynia, the relevance of pain site cannot be underestimated. Site of pain may be a significant predictor for appraisals of pain, affective response and disclosure of pain complaints (Klonoff, Landrine & Brown, 1993). When asked to imagine pain in their genitals, participants in Klonoff et al's study appraised themselves as more ill and more likely to have an emergency condition than if they were asked to imagine chest, stomach, head or mouth pain. They also reported that they would be least likely to disclose genital pain, and would be more worried, depressed and embarrassed by pain in the genitals than in any other area.

There is evidence suggesting that important psychological issues are associated with gynaecological conditions even in the absence of chronic pain. Studies have found that

women attending gynaecological clinics report higher levels of emotional distress than those in the general population or in women attending other out-patient clinics (Hunter, 1994). Gynaecological pain cannot be understood without considering factors such as attitudes to women's bodies, femininity and sexuality. Unlike pain in other functional systems, women learn from an early age that aspects of gynaecological functioning may be painful (Erskine & Pearce, in Davis & Fallowfield, 1991). Menstruation carries an almost universal negative attitude which is likely to have a negative impact on a woman's ideas about female identity. The Bible states that during menstruation a woman should be kept apart from others for seven days and anyone she touches during that time is considered unclean (Leviticus.15: 19-22). Many other cultures forbid the preparation of food by women while they are menstruating (Walker, 1997). Pervasive ambivalent attitudes towards female sexuality exist (Hunter, 1994) and even in Western society today, representations of menstruation (for example in advertising campaigns) are far from realistic. It is as though menstruation must be made more acceptable before it may be represented.

Some insight into the experience of women suffering with Vulvodynia can be gleaned by considering the powerful social images of femaleness. Attempts to live up to such images result in women feeling dissatisfied with themselves and it has been suggested that women tend to blame themselves for difficulties rather than acknowledging social constraints (Hunter, 1994). Women are often valued according to their roles in relation to other people and these pressures make it particularly difficult to come to terms with a situation such as ill health or growing older, which invalidate them (Hunter, 1994).

Where Vulvodynia results in loss of roles such as that of sexual partner, or makes that role unrewarding, it has a significant impact on the patient's identity (McKay, 1989). The distress of unexplained Vulvodynia may also be associated with the stigma of having a genital condition and the particular doubts that may arise in patients' or their partners' minds such as whether the condition is communicable (McKay, 1989).

b) Chronic Pelvic Pain

Chronic Pelvic Pain (CPP) is a comparable condition to Vulvodynia and indeed, Vulvodynia is often confused with CPP. With careful assessment, however, the site of the pain is found to be more vaginal (Beard, Gangar & Pearce in Wall & Melzack, 1994). CPP is one of the most common presenting problems among women attending gynaecological clinics with an estimated prevalence of about 350,000 and annual incidence of 14,000 in Britain (Beard, Gangar & Pearce in Wall & Melzack, 1994). The annual cost to the NHS of diagnosis and treatment was estimated at £163 million per annum (Linton, 1994). Many of the studies on CPP include vulvo-vaginal pain and consistent findings may therefore be generalisable to women with unexplained Vulvodynia (Wesselmann et al 1997).

Chronic Pelvic Pain has many similar features to unexplained Vulvodynia including its debilitating effects on the patient's sexuality. Women with CPP also have a high prevalence of emotional disturbance ranging from feelings of depression and chronic anxiety to loss of interest in social and physical pursuits (Beard, Gangar & Pearce in

Wall & Melzack, 1994). CPP not only potentially affects the patient's ability to work, but also threatens her ability to function as mother and sexual partner. Quality of life may, therefore, be seriously impaired. As with Vulvodynia, difficulty of diagnosis results in long periods of uncertainty and repeated investigations before patients feel that the problem is understood. Between a third and two thirds of women with pelvic pain are estimated to have no clear pathology. No progress has been made in effectively treating CPP and these patients sometimes continue to be described as hysterical (Hunter, 1994).

i) *Organicity and Chronic Pelvic Pain*

The question of how patients are affected by having no organic cause for their pain has been investigated in patients with CPP. Pearce (1986) carried out a prospective study in which all patients attending a gynaecological clinic with a complaint of CPP of more than 6 months duration were assessed. No difference was observed on measures of personality or mood, between women who later showed clear evidence of pathology and those who did not. The following differences on psychological measures did, however, emerge. Women experiencing pain in the absence of observed pathology were found to be more concerned that they had serious illness, and more hypochondriacal. Women with no organic pathology also reported higher rates of serious illness and early death of family members. This suggests that this group of women with no organic pathology were generally more concerned about their physical state and hence monitored bodily sensations more closely than the group who had organic pathology to account for their symptoms (Beard, Gangar & Pearce in Wall & Melzack, 1994).

Selfe, Van Vugt and Stones (1998) used focus groups of gynaecologists, GPs and patients to characterise medical attitudes towards the treatment of women with CPP. They suggested that the common theme that emerged from these groups was the need to find a pathological cause for the pain. Gynaecologists implied that identifying pathology would somehow validate the pain as “real”, as some patients worry that their problem may be thought of as psychological. Many hospital gynaecologists felt that GPs expected them to focus on organic pathology and that this forced them to investigate specifically to exclude certain conditions. Some gynaecologists felt that GP and patient colluded in the belief that a continued search for visible pathology would yield results. When organic conditions had been excluded, it was acknowledged that counselling a patient without a diagnosis was difficult.

4. Chronic Pain

a) Chronic Pain

Since unexplained Vulvodynia describes a condition characterised by the experience of pain and discomfort that has continued for at least six months, is not well accounted for by physical pathology and is resistant to traditional medical treatment, it can be classified as a chronic pain (CP) syndrome. Although unexplained Vulvodynia appears to fulfil the criteria of a CP syndrome, it remains unclear whether it affects patients in a

similar way as other CP syndromes. There is little research regarding the experience of this group of patients relating to their attitudes, behaviours and adjustment to living with the problem. Given the similarities, however, it seems appropriate to refer to the literature on chronic pain.

b) Nature of Chronic Pain

It is important to distinguish between acute and chronic pain. Acute pain serves the purpose of warning the individual that “something is wrong”, and also immobilises the area through muscle spasm in order to protect it. For acute pain there is usually a well defined cause and a characteristic time course in which the pain disappears after healing. Chronic pain can be seen as a “false alarm” where the pain continues after the period over which one would expect healing to have occurred. Chronic pain is often described as unresolved acute pain, and a clinical diagnosis may be solely based on the continuation of pain for a specified amount of time, (generally six months, and more recently three). This, however, is a simplistic categorisation of chronic pain as there are numerous cases, of pain persisting over time such as burns or cancer pain, which differ significantly from the usual presentation of chronic pain.

Although pain represents the single most important symptom indicating that something is wrong, it is too easy for pain to be regarded as only and always reflecting some underlying physical pathology. Once pain becomes chronic, a complex relationship develops between biological, psychological, and social factors. This necessitates a

biopsychosocial model with the contribution of different factors for each individual varying considerably.

CP is estimated to affect between 5% and 20% of the population, with about 1% of the population being severely disabled (Linton, 1994). Costs have been reported as in excess of \$70 billion per annum in the USA (Horn & Munafo, 1997). In the UK, several million working days are lost to CP each year, and the trend is for increased levels of disability (Nicholas, 1996). Chronic pain patients are a diverse group in terms of age, sex, cause and site of pain. Some sites of pain are underrepresented in the literature and genital pain is clearly one such area. Egan and Krieger (1997), in their study of prostatitis, investigated the frequency of published studies on genital pain from 1985 to 1995 in the journal PAIN and found that of 264 studies about chronic non malignant pain, only two concerned genital pain and only one of those female genital pain.

Patients and their families are significantly affected by the consequences of chronic pain which may include job losses, withdrawal from social activities and responsibilities, and depression. Significant demands are made on health service resources (Nicholas, 1996). To date, the effectiveness of conventional medical and surgical approaches for those whose pain becomes chronic, has been disappointing (Williams & Erskine in Broome & Llewelyn, 1989).

c) Gate Control Theory of Chronic Pain

Early models of pain proposed a purely somatic explanation where pain was described as an automatic response to an external stimulus with no place for interpretation or moderation. Where there was identifiable tissue damage, pain was labelled as organic. When no organic cause could be found, pain was considered to be psychogenic (Ogden, 1996). Melzack & Wall's (1965) Gate Control Theory (GCT,) was the first to overturn this dualistic notion and to acknowledge the role of cognitive processes in the understanding of pain. The central feature of GCT is that brain fibre transmission is modulated at the base of the spinal column by a "gate". The extent to which this gate, thought to be biochemically controlled, is open or closed determines the degree to which pain fibre transmissions pass to the brain stem and cerebral cortex, and consequently the degree to which pain is felt.

The gate mechanisms can be opened by physical, emotional, cognitive and behavioural factors. Factors such as injury, anxiety, depression, attributions and boredom are thought to open the gate. Medication, optimism or relaxation, and concentration, distraction or involvement in other activities are suggested to have the reverse effect of reducing the perception of pain (Ogden, 1996). Thus, athletes who continue playing without noticing they have injured themselves, are unaware of the damage because the signals ascending from the site of the injury are blocked at the gate by other descending factors such as intense concentration and the release of endorphines. As psychological factors influence

pain perception, this provides a theoretical basis for the use of psychological approaches as a primary treatment for chronic pain (Ogden, 1996). The model invalidates the dichotomy between organic pain and psychogenic pain. All pain is seen as real, but the factors maintaining pain may vary. Even when physical causes are identified, a person's mood and reactions to the pain will affect the way it is experienced. According to GCT, pain is seen as an experience and a perception rather than a sensation. The individual no longer just responds passively to painful stimuli, but actively interprets and appraises them.

d) Acute Disease Model

Despite general acceptance of GCT within the field of CP, Leventhal, Meyer and Nerenz's (1980) acute disease model remains the predominant conceptualisation of illness in the West (Turk, Holzman & Kerns, 1986). For most illnesses, a linear relationship is still seen to exist between the degree of tissue damage and the intensity of pain, and this model gives rise to a series of expectations regarding the treatment of illness within society. Patients and doctors alike, expect that when a series of symptoms are presented, the doctor will reach a diagnosis and provide treatment as a cure. Most medical interventions derived from the acute disease model are administered *to* the patient. This encourages patients to become passive recipients of intervention and relinquish responsibility for their health to the medical profession.

e) Chronic Pain Model

The nature of CP does not fit well with the acute disease model. In CP many patients present without a diagnosis and the cause can be unclear. The patient desperately seeks a diagnosis with the hope that this will lead to a cure. Negative findings from each investigation leave the patient feeling anxious and confused. Even when the cause is identifiable, the symptoms are usually disproportionate to the identifiable damage. Healing may have left little to detect on investigation, but central nervous system changes do not necessarily reverse on healing (Williams & Erskine, in Broome & Llewelyn, 1989). Consequently, most available treatments have limited effectiveness and patients often continue to search for the elusive cure.

The life of the CP patient may change significantly and a vicious cycle of reduced activities and responsibilities is perpetuated. Many patients tend towards rest and avoidance in order to promote healing and pain relief but inactivity may lead to deterioration of physical condition ((Williams & Erskine, in Broome & Llewelyn, 1989). The psychological effect of avoidance is to reduce the patient's self confidence, whilst adding to their boredom, depression, lowered self esteem and an increased preoccupation with bodily symptoms. These all add to the experience of pain. Anxiety about symptoms may lead to monitoring symptoms and seeking reassurance from medical professions. Eventually, doctors may refer the patient to a non medical treatment programme and the

implicit or explicit suggestion that the patient's pain is psychogenic is not unusual (Sherman, Sherman & Bruno, 1987).

f) Organicity and Chronic Pain

i) *Phantom Limb Pain*

Phantom limb pain is a very useful example of the difficulties patients without identifiable physical findings face. Chronic phantom limb pain has been found to be a series of complex types of referred pain that have substantial physiological bases (Sherman et al, 1987), although as with most other chronic pain states, it appears to be influenced by stress, depression and anxiety. Despite recent understanding of phantom limb pain as having an organic basis but with episodes being initiated and intensified by emotional and cognitive states, most people find it difficult to understand how pain from a severed limb could have a physiological basis and rather believe that the patient has a psychological problem that is manifested consciously or unconsciously through the pain. In one study, 69% of the 2700 veteran amputees assessed, reported that their physicians had directly stated or clearly implied that the pain was "just in their heads" (Sherman et al, 1987). These patients were afraid to tell their physicians that they had phantom limb pain for fear that the physician would think them insane. Phantom limb pain appears to be a typical example of a chronic pain state that pushes health care providers to the limit by eliciting frustration from lack of success. It seems likely that Vulvodynia to a certain extent is not dissimilar.

ii) *Rheumatoid Arthritis*

A group of chronic pain patients who *have* clear organic pathology to account for their symptoms are those suffering with Rheumatoid Arthritis (RA). RA is a chronic, systemic inflammatory disorder characterised by joint pain, swelling and stiffness, fever and fatigue and is usually accompanied by progressive destruction and deformity of the joints. Patients suffer recurring severe pain and reduced mobility. The prevalence of RA is approximately 1%, a rate that increases with age with women being almost three times as likely as men to be affected.

Pain is the symptom of greatest concern to RA patients and its reduction is the primary goal of seeking medical treatment. Traditional medical management of the disease aims to manage pain and inflammation and to modify the disease process in an effort to maximise patients' functioning. Despite advances made in the pharmacologic treatment of RA, its' course remains unpredictable and there is no known cure. Approximately 70% of RA patients experience unpredictable exacerbations and remissions of disease activity with progressive deformity and disability (Young, 1992).

Patients with seropositive RA (i.e. the presence of IgM rheumatoid factor in the blood), show fewer neurotic symptoms, fewer problems with the expression of anger, and less overall psychopathology on objective personality measures than seronegative RA patients (Lerman, 1987). As all RA patients have a clear diagnosis with an organic basis, this is

clearly not equivalent to comparing patients with and without physical findings to account for their symptoms. However, there is a similarity. Despite more severe disease among seropositive RA patients, what has been found here is that this group have less psychological difficulties than the group who have less severe RA. Lerman hypothesised that it may reflect a “special form of adaptation” to this more severe form of illness.

Another study reported by Lerman (1987) that may elucidate the experience of having no organic pathology to account for one’s symptoms, is by Lowery, Jacobsen and Murphy (1983). Lowery et al used structured interviews to assess attributions among RA patients. They found that patients who believe that their illness was caused by the environment or by their personal habits tend to score lower on self report measures of anxiety, depression and hostility than patients who give no cause for their illness, and those who blame heredity or chance factors. Lowery et al suggested that attributing RA to chance factors rather than to personal habits would lead the patient to give up or withdraw in response to illness stresses.

Research suggests that if patients are given the opportunity to reattribute their symptoms as the effects of a drug, even when it is a placebo, they are less troubled by their symptoms than controls not supplied with a plausible alternative explanation. It has also been suggested that patients who attribute somatically based symptoms to internal, psychological causes may be unnecessarily disturbed by them (Edwards, Pearce, Turner-Stokes & Jones, 1992). The way in which a patient explains illness to themselves will to some extent explain the way they cope with that illness and respond to interventions.

Attributions concerning the causation of pain and recovery from it will influence the way in which pain is experienced and communicated to others.

Edwards et al (1992) also looked at beliefs and attributions about the causes of pain amongst a group of mixed-site Chronic Pain patients and non-patient controls and found that in their group of Chronic Pain patients, beliefs concerning the organic component of pain were significantly associated with the belief that other people with power such as doctors, and chance or fate, control health status. A sense of dissociation is thereby created between the experience of pain and the individuals themselves. In contrast, belief that psychological factors may play a role was significantly associated with the belief that individuals have control over their own health and well being. Edwards et al found that Chronic Pain patients differed from non-patient controls in that they place greater emphasis on the organic aspects of pain, whereas non pain patients are more likely to believe that psychological factors play a role in pain experience.

The findings of Edwards et al (1992), and the study of Lowery et al are important in understanding unexplained Vulvodynia. Unexplained Vulvodynia patients have no identifiable organic findings, so how they attribute meaning to their symptoms is likely to influence their adjustment. This issue is a major focus of interest and research within the field of chronic pain and is consumed under the heading of control which is now addressed.

5. Psychological Sequelae Of Chronic Pain

The identification of factors that distinguish individuals who are functioning well from those who are not is important to understand the reasons for this variation in adaptation to pain. Because not all sufferers of chronic pain experience disability and depression, it is important to identify factors that promote adaptive functioning. The emphasis on cognitive variables in the study of chronic pain demonstrates the acknowledgement that it is the perceived world that is of relevance. It is how people construe events that determines how they will think, feel and what they will do about them. Similarly, pain depends on the meaning attributed to it and its consequences.

A person's attributional style is related to and can put a person at risk for depression . People are more likely to become depressed following uncontrollable events, if they attribute these events to internal, stable or global causes (Jensen, Turner, Romano & Karoly, 1991). Studies of cognition and pain have included a number of variables such as locus of control, coping style and self efficacy. The common ground among these constructs is the assumption that they are amenable to cognitive and behavioural modification, and that they are underpinned by the construct of control. A sense of personal control over events, whether real or illusory, appears to be a salient factor in the perception and management of pain (Horn, et al, 1997).

a) Control

The construct of control has been particularly implicated in relation to coping and adjustment, psychological dysfunction and the outcome of treatment (Rosentiel & Keefe, 1983). Cognitive appraisals of pain play a primary role in the coping process by initiating and evaluating coping efforts to manage pain. Appraisals of control, or the belief that the individual has the ability and resources to manage pain, appear to be one of the most important dimensions determining adjustment. Jensen et al (1991) in their extensive review of the literature of this area, reported the following findings related to control : that perceptions of helplessness predict depression , while perceptions of control over pain predict lower levels of pain and disability, and greater psychological well being. A relationship between belief in personal control over pain, and coping and adjustment has also been demonstrated in the literature. Affleck, Tennen, Pfeiffer and Fifield (1987) reported that patients' perceived control over the course of treatment for Rheumatoid Arthritis (RA) was associated positively with mood and with global adjustment. Patients who believed that their health care provider controlled their symptoms were more likely to be depressed.

i) *Locus of Control*

The belief that outcomes are under the control of one's own behaviour is described as reflecting an internal locus of control, whereas the belief that important outcomes are

controlled by factors such as luck or other people reflects an external locus of control. Researchers have demonstrated a relationship between internal locus of control and positive adaptation to chronic pain. Pain patients who have an internal locus of control orientation have been hypothesised to use more active coping strategies (Jensen & Karoly, 1991), to be less depressed (Crisson & Keefe, 1988), and to report lower levels of pain (Jensen et al, 1991) than individuals scoring low in internal locus of control. People with external locus of control perceive a lack of a relationship between their activities and consequent outcomes and might, therefore, be expected to rely on more passive pain coping strategies and lack optimism..

Haythornwaite, Menefee, Heinberg & Clark (1998) investigated whether specific pain coping strategies (as indicated by the CSQ, (Rosentiel & Keefe, 1983)) were associated with greater perceptions of control over pain, and found that two active coping strategies: coping self-statements and reinterpreting the pain sensations, were predictive of greater perceived control. These results support the emphasis in cognitive behavioural interventions on the use of these strategies for enhancing perceived control and self efficacy. Flexibility in coping with pain, which describes individuals who use multiple coping strategies rather than one strategy almost exclusively, also predicts perceptions of control over pain (Haythornwaite et al, 1998).

ii) *Self-Efficacy*

Self efficacy measures represent pain patients' views of their ability to perform various behaviours (Jensen et al, 1991). Social learning theory posits that people will engage in coping efforts that they believe are within their capabilities and will result in positive consequences. Consistent with this, Jensen et al (1991) found chronic pain patients' beliefs regarding their capabilities to be strongly related to reported coping efforts and pain tolerance.

iii) *Beliefs*

Pain beliefs are a subset of a patient's belief system which represents a personal understanding of the pain experience (Williams & Thorn, 1989). Cognitive behavioural theory suggests that patients' beliefs about their pain play a crucial role in their adjustment (Jensen et al, 1991). An attitude towards pain as a disabling condition was shown to correlate negatively with measures of physical function (Jensen et al, 1994). Jensen et al (1991) in their review reported the following pain beliefs found to be associated with physical disability: an expressed belief in oneself as disabled, a belief that medication use is an appropriate treatment for chronic pain, a belief that pain itself necessarily impedes normal functioning, not understanding why one is experiencing pain; and feelings of hopelessness and helplessness in the face of pain. Pain-related beliefs that have been found to be associated with psychological dysfunction include: the judgement

that pain is stressful, harmful and threatening, not understanding why one is experiencing pain, and a belief that one is hopeless and helpless in the face of pain.

Conversely, beliefs associated with better functioning include : a belief in the right to have a solicitous response from others when in pain, a belief that pain patients should cope with their pain, and a belief in one's ability to cope with and accept the pain (Jensen et al, 1991). Some pain related beliefs have been found to be associated with coping efforts. Jensen, Karoly and Huger, (1987) found that the desire for solicitous responses was associated negatively with the use of rest; a belief in the appropriateness of using medication for pain control was associated positively with medication use; and belief in oneself as disabled was associated negatively with the use of rest.

iv) *Coping Strategies*

People with chronic pain use a variety of strategies to manage their pain and pain related stressors. Jensen et al (1991) reviewed the literature on coping with chronic pain and concluded that chronic pain patients who use passive coping strategies i.e. depending on others for help, typically have high levels of physical and psychological disability. Further, patients who rate their perceived control as high or who rely on active coping i.e. make efforts to function in spite of pain or disability, function much more effectively. Among RA patients, active coping has been found to be associated with lower levels of reported pain severity, depression and functional disability, whereas passive coping is associated with higher levels of these variables (Brown, Nicassio & Wallston, 1987).

Jensen & Karoly (1991) examined the relationship between CSQ coping subscales and three dimensions of adjustment (activity level, psychological functioning, and medical services utilisation) in a sample of CP patients while controlling for pain severity. CSQ subscales of Ignoring Pain, Coping Self Statements and Increasing Activities were all correlated positively with psychological functioning. Diverting Attention, Ignoring Pain and Coping Self Statements were all associated positively with activity level, but only for patients reporting relatively low levels of pain severity.

v) *Cognitive Errors*

Cognitive errors such as catastrophising and personalisation are also hypothesised to influence the severity and maintenance of depression. A number of studies have reported significant positive relationships between pain-specific cognitive errors and disability (Flor & Turk, 1988); and with pain intensity and psychological distress (Jensen et al, 1991). Catastrophising appears to measure judgements of an inability to persist in coping efforts, excessive worry about the future and the tendency to view pain and the individual's life situation as overwhelming (Geisser, Robinson, Keefe & Weiner, 1994). Catastrophising has been found to be significantly related to depression and has been found to be related to lower pain thresholds and pain tolerance in a group of normal controls (Geisser et al, 1994). Keefe, Brown, Wallston & Caldwell (1989) examined the relationship between catastrophising and adjustment in a longitudinal study of CP

patients and found that initial pain-related catastrophising scores were associated positively with pain intensity, disability and depression.

b) Affective Factors

High degrees of comorbidity between CP and depression have been reported in the literature with approximately 50% of CP patients displaying significant levels of depression (Romano & Turner, 1985). Although the early theories suggested that depression may cause CP, a causal relationship in one direction or other between depression and CP has not been firmly established. Overall, recent reviews have concluded that there is inadequate evidence to substantiate the view that depression precedes and generates pain in the majority of CP sufferers (Gamsa, 1990). What seems more likely is that the consequences of living with CP are likely to contribute to affective disturbance. As attempts at pain relief fail and as efforts to continue or resume activities are unsuccessful, patients often contend with the developing experience of helplessness, hopelessness and reduced self control. Strain on social and family relations frequently increases and may contribute to loss of self esteem as well as perceived quality of life, resulting in significant emotional distress (Turk, Okifuji, & Scharff, 1995).

Investigators seeking to understand the relationship between depression and CP have focused on a number of potentially mediating factors. Kerns & Haythornwaite (1988) compared depressed, mildly depressed and non depressed pain patients on whether they would differ reliably in pain severity, degree of perceived social support, activity levels

and coping. Results suggested that declines or deficits in activity and coping are related to the experience of depression among chronic pain patients and a lower perception of social support may be associated with elevated depression scores.

These findings have been substantiated by other researchers. Turk, et al (1995) suggested that patient's perceptions of the impact of pain on their lives, declines in activities associated with the resultant loss of social rewards, and declines in perceptions of self control and personal mastery influence the subsequent development of depression in CP patients.

The cognitive behavioural mediation model (Rudy, Kerns & Turk, 1988) suggests that pain alone is not a sufficient condition for the development of depressed mood among CP patients. Rather, depression can be explained by patients' appraisals of the degree to which pain interferes with important areas of functioning and perceptions of self control.

Clearly not all pain patients report significantly reduced activity levels or decreased satisfaction with their lives (Keefe, Brown, Wallston & Caldwell, 1989). For some patients, there may be no noticeable declines in participation in activities or life satisfaction as a function of their pain. Some patients may have compensated for declines by developing alternative sources of reinforcement; others may demonstrate declines but continue to perceive themselves as functioning at an acceptable level, thus emphasising the importance of patients' idiosyncratic appraisals of their pain problem.

There are specific difficulties associated with the assessment of depression in a population of chronic pain patients. Physical symptoms normally considered to be characteristic of depression (i.e. sleep disturbance, decreased libido, tiredness) may in the CP patient be viewed as secondary to the pain and therefore unrelated to the mood disorder (Williams & Richardson, 1993). The area of what is being measured and how this is achieved within the field of chronic pain is now turned to.

6. Measurement

The issue of whether it is the private experience or the observable manifestation of the experience that is being measured with pain has been argued. The assumption in the past has been that objective measures were more scientific and therefore superior. However, it has been suggested that both the perception of pain and its outward manifestation are moderated by social influences. For example, Horn et al, (1997) reported a study by Lipton and Marbach (1984) that showed pain tolerance was influenced by social modelling and group pressure. Therefore, the theory that pain behaviours and pain experience are two discreet entities is losing credibility. Research that supports their interrelationship demonstrates for example that although behavioural treatments for chronic pain are aimed at reducing the disability associated with pain, many patients report an associated decrease in their pain as a result of this (Horn et al, 1997).

Attempts to address the multidimensional nature of pain have resulted in many instruments of different types including patient self-report questionnaires, analogue scales, significant- other ratings, and video-taped behaviour. Measures aim to tap into and assess the separate components of chronic pain, such as : sensory and physiological, cognitive and affective, and behavioural.

The sensory component, or the pain intensity and quality is generally measured using numerical or visual analogue scales. There are, however, difficulties with these measures. For example, the assumption of equidistance between points where words such as “no pain, moderate pain, severe pain” are used. Measurement of anxiety and depression is carried out using patient self report questionnaires, but is complicated by the inclusion of somatic items which may be related to the patient’s physical rather than psychological state, as discussed above. The Hospital Anxiety and Depression Scale (HAD) was developed on medical patients and almost entirely avoids somatic items. It is therefore, useful within the field of chronic pain.

Function or disability is measured by self report and also by observed and measured relevant behaviours. Videotaped pain related behaviours provide a useful source of assessment of the impact of chronic pain on a patient’s physical functioning. Beliefs and thoughts are generally identified using self-report questionnaires such as the Survey of Pain Attitudes (SOPA, Jensen, Turner, Romano & Lawler, 1994). Quality of Life measures cover the domains of physical, psychological and social abilities and work. Quality of life is now claimed to be one of the most important contemporary measures in

health care (Skevington, 1998). It is seen to have personal meaning that is best assessed directly through subjective self-report (Skevington, 1998).

Before going on to the treatment of chronic pain, the issue evaluating treatment should be considered. There are specific difficulties that characterise research in this area. Most typically, the lack of control groups, failure to randomise, and lack of comparable patients within the groups.

Non specific components of therapy should be taken into account. There is consensus that the following variables can be manipulated to have an effect on outcome. the relationship between the doctor and patient; the instructions given; the way preparations are made; and the environmental milieu in which treatment is carried out (Skevington, 1996). Other factors include the patients expectations and needs about getting better; the patient's suggestibility; personality traits, psychological state, and the severity or discomfort of the symptoms (Skevington, 1996). To control for non specific factors affecting outcome, designs should have several times of assessment, including baseline information.

7. Treatment of Chronic Pain

Despite recognising the psychological sequelae of CP, until the last two decades, most patients only had access to traditional medical care. Indeed, even since the development of effective programmes, many patients continue to be offered invasive medical procedures even though the evidence suggests that they are unlikely to be effective.

Passive and ineffective treatments may reinforce unhelpful beliefs such as waiting in the expectation of an external solution and thereby discourage attempts by the patient to take a more active role in his or her rehabilitation (Nicholas, 1996).

a) Pain Management

The chronic pain model discussed above (in Section 4.e) suggests that a vicious cycle is perpetuated whereby ongoing pain in the absence of physical findings leads to inactivity and withdrawal from rewarding activities. Depression and anxiety follow and the activation of thoughts and beliefs that are not adaptive exacerbate the pain and perpetuate the cycle. These components are all potentially amenable to cognitive and behavioural modification, therefore providing the rationale for this approach to treatment.

Cognitive behavioural pain management clinics are becoming far more widespread as evidence is produced demonstrating the efficacy of programmes using operant and cognitive techniques to facilitate patient control over their pain (Nicholas, 1996). The aim of the cognitive behavioural approach is to change both the patient's view of their pain and their habitual maladaptive ways of coping with it (Skinner, Erskine, Pearce, Rubenstein, Taylor & Foster, 1990). Ideas of passivity and constant cure seeking are challenged and the notion of active control fostered. The patient is encouraged to optimise his physical, psychosocial and occupational functioning.

b) Cognitive Behavioural Treatment Programmes

Cognitive behavioural treatment for chronic pain that emphasises self management and self control has been reported to be successful in the literature (Turk, Holzman & Kerns, 1986). Rather than continuing to target the pain for treatment, the cognitive behavioural approach targets associated problem areas with the aim that by reducing these, the person will suffer less and while not cured, he or she would be far more capable of resuming a more active and fulfilling lifestyle, less constrained by the pain (Nicholas, 1996).

Patients are informed that a range of resources are available to deal with pain and they are encouraged to maintain a problem solving approach. A conceptualisation of pain based on the Gate Control Theory is contrasted with the unidimensional sensory-physiological model. The interaction of cognitions, affect and sensory aspects is presented using patients' experiences and the idea that the patient's experience of pain can be viewed as several manageable phases is introduced.

Graded exercise and pacing activities are introduced as many CP patients have developed a sedentary lifestyle or may alternate between doing nothing and overdoing things. Firstly, exercise programmes should be linked to restoration of function. Initial goals are set at a level that the patient should have little trouble achieving, with requirements increasing at a gradual rate. The second objective of the pacing programme is to introduce interests so that pain is no longer the focal point of the patient's life. Graded exercise provides for success experiences and will help reduce fear of activities, in addition to

reinforcing patients' perceptions of their own control. It is important that the activities undertaken in the programme have clear relevance to the patient (Nicholas, 1996), or poor adherence to the programme is likely to result (Turk & Meichenbaum in Wall & Melzack 1994).

Negative thoughts, appraisals and attributions are reviewed and worked with. Patients are encouraged to become aware of when they engage in such thinking and how such thoughts may exacerbate their pain. Relaxation and controlled breathing exercises are taught to aid control during periods of stress and pain. Methods of diverting attention such as imagery are taught, and patients are encouraged to add these to their repertoire. Attention diversion is based on the idea that people can only focus their attention on one thing at a time and that they can control to some extent what they attend ((Turk & Meichenbaum in Wall & Melzack, 1994). Although programmes vary in the components of treatment, skills such as assertiveness and problem solving can be included, Nicholas (1996) highlighted the benefit of basing a new programme on a well established set of principles such as those underlying cognitive behavioural programmes as that they can be adapted to different settings and circumstances and act as a guide in determining the content and approach of a programme.

c) Outcome Studies

The outcome literature on pain management programmes using cognitive behavioural techniques demonstrates favourable results. In their broad review, Turk & Meichenbaum

(in Wall and Melzack, 1994) report on studies demonstrating the clinical effectiveness of the cognitive-behavioural approach with a wide range of pain syndromes including headaches, arthritis, low back pain, atypical chest pain, Repetitive Stress Injury, and heterogeneous samples of chronic pain patients. Turk & Meichenbaum concluded that the cognitive-behavioural approach is promising for use with a variety of CP syndromes, and has great potential as a treatment modality by itself and in conjunction with other treatment modalities. They emphasised that it is still unclear which treatment combinations are most effective with specific types of patients, or how best to combine psychologically based interventions with somatically based interventions.

Flor, Fydrich and Turk (1992) evaluated the efficacy of multi disciplinary pain management programmes for patients with chronic back pain, using “meta-analysis” . Meta analyses consist of the integration and synthesis of research through statistical analysis of individual studies, and reduce the subjectivity that is inherent in traditional narrative reviews. 60% of the studies used in the analysis provided multimodal treatment. The number of experimental groups ranged from 1 to 3 with 92% of the studies having only one). The number of control groups ranged from 0 to 2 with 65% having no control group. The majority of treatments included a combination of psychological interventions, medical treatments, and physical or occupational therapy. The average duration of the therapy was 7 weeks with a range of 1 to 31 weeks with an average of 96 hours in treatment. Approximately 80% of the treatments were carried out by multidisciplinary treatment teams. The majority of the studies (50%) were performed in inpatient settings; 28% were in an outpatient setting and 13% were mixed.

Flor et al concluded that overall, multi disciplinary pain clinics are efficacious. Even at long term follow up, patients treated in a multi disciplinary pain clinic are functioning better than 75% of a sample that is either untreated or that has been treated by conventional , unimodal treatment approaches. Improvements were reflected on subjective ratings of pain and objective measures such as return to work and use of the health care system. However, methodological difficulties were highlighted that limit the generalisability of the results.

Skinner, Erskine, Pearce, Rubenstein, Taylor & Foster, 1990) evaluated the efficacy of an outpatient multidisciplinary programme based on cognitive behavioural principles. The study used a one group repeated measures design and the group consisted of one afternoon a week for seven weeks. Results indicated significant improvements after treatment for measures of analgesic consumption, anxiety, depression, physical disability and coping skills.

Nicholas, Wilson & Goyen (1992) investigated the efficacy of cognitive behavioural group treatment in comparison with a control condition in a sample of chronic low back pain patients. Their results indicated that the combined psychological and physiotherapy condition improved significantly more than the combined attention-control and physiotherapy condition at post treatment on measures of other-rated functional impairment, employment of active coping strategies, medication use and self efficacy beliefs.

The literature is positive about cognitive behavioural management of CP but there are differing views about the most suitable setting for this treatment to take place and there is a wide diversity in the type of pain management programmes that are run.

Outpatient programmes are less expensive to run and may facilitate generalisation of behavioural changes as patients remain in contact with their normal home work and social environment, while learning and practising new behaviours at the clinic (Skinner et al (1990). Advantages of inpatient programmes include not having to travel, and removal of the patient from the factors in their environment which maintain the disability and preoccupation with pain .

Williams, Richardson, Nicholas, Pither, Harding, Ridout, Ralphs, Justins and Chamberlain (1996) compared inpatient and outpatient pain management programmes for mixed CP patients. Their findings showed that there was significant pre to post treatment improvement in both treatment groups, on measures of mood, physical performance, overall function and medication use, many of which were maintained up to a year follow up. The results showed that in the longer term, however, the inpatient programme was superior in effecting cognitive and physical gain. Clearly, there are marked differences between the programmes which different clinics run, and further comparison of the benefits of the different types of service offered to patients with different needs is important.

Evidence is accumulating supporting the efficacy of cognitive behavioural treatment programmes for Chronic Pain patients. It could therefore be inferred that if Vulvodynia is similar to other Chronic Pain conditions, the treatment should also be beneficial for Vulvodynia patients. To date, these patients have been offered no hopeful treatment to end the spiral of more and more invasive procedures. The suggestion is that they might also respond well to cognitive behavioural pain management and therefore this needs to be tested.

8. Research Aims

Study 1 aims to investigate the psychological characteristics of a group of women with a diagnosis of Vulvodynia. In order to investigate the distress of Vulvodynia patients, they will be compared to a group of mixed-site Chronic Pain patients, a group of gynaecological patients not experiencing pain and a group of Rheumatoid Arthritis patients. This will allow the contribution of various factors to be assessed.

Both Mixed-Site Chronic Pain patients & Vulvodynia patients will have constant pain which is not accounted for entirely by the physical findings. However, the site of pain between these two groups will vary. The gynaecological group will have problems in a similar site to the Vulvodynia group, but they will not be experiencing constant levels of pain. The Rheumatoid Arthritis patients will also experience pain in an ongoing, chronic way, but they will have a clear explanation for their symptoms, and will not have had

doctors suggesting that it is “all in their head”. They were compared with Vulvodynia patients to assess the contribution of having no physical findings.

Table 1 Illustrating the distribution of the three suggested distressing factors in the groups

	chronic pain	genital site	no pathology
vulvodynia	*	*	*
chronic pain	*		*
gynae		*	
RA	*		

* presence of factor

This design will allow some preliminary conclusions to be made between the contribution of different factors, namely, pain, presence or absence of identified organic pathology, and site of the problem, to the distress experienced by this group of patients.

As an exploratory study, in addition to comparing levels of psychopathology of patients with Vulvodynia and other related health problems, this study further investigates different attitudes across the four groups to establish both similarities and differences between them. It is hypothesised that there will be marked similarities between the Vulvodynia and Chronic Pain groups on measures of attitudes and quality of life. On the

basis of this prediction, Study 2 incorporated a pilot study of the effectiveness of a cognitive behaviour approach to the management of unexplained vulvodynia.

Research Questions

Study 1 aims to examine the impact of ongoing pain in unexplained Vulvodynia patients in terms of quality of life, anxiety, depression and coping to see how they compare to chronic pain patients.

It also aims to examine the cognitions of unexplained Vulvodynia patients to see how they compare to chronic pain patients.

Study 2 aims to assess the benefit of a Cognitive Behaviour Pain Management programme for patients with unexplained Vulvodynia.

METHOD

1. Design

Study 1 uses a between groups design to compare the four groups of patients on measures of SF-36 and HAD. This study aims to investigate the factors which contribute to the experience of distress in V patients. The second part of Study 1 again uses a between groups design to further compare the three groups of pain patients (i.e., V, RA and CP) with regards to pain related beliefs and coping strategies. Study 2 is a preliminary pilot study which evaluates a pain management programme using a repeated measures, within subjects pre- test post- test design. The measures are administered at time 1) at the beginning of the pain management programme; and 2) at the end of the pain management programme.

2. Participants

There are four groups compared in Study 1.

a) The Vulvodynia group (V) comprised 20 patients with a diagnosis of Vulvodynia with no identifiable pathology, i.e. Essential Vulvodynia or Vestibulitis. They were referred to the study by either the Consultant Dermatologist or Consultant Gynaecologist of a general hospital. Patients were contacted by the Consultant and asked whether they were interested in further treatment. Those who expressed interest were subsequently asked to volunteer for this study. Of the 54 patients who were

initially contacted, 28 agreed to be contacted about further treatment. Of these 28, 20 came for an assessment. All 20 patients who came for assessment agreed to complete the battery of questionnaires.

b) The Chronic Pain (CP) group were patients who were assessed for pain management programmes at the service that coincided with the timing of the programme of the Vulvodynia group. The questionnaires of 20 consecutive patients who were assessed at this time were used for this study. This consisted of 20 patients who were referred to the Pain Management Service for a variety of chronic pain syndromes (other than genital pain), with no identifiable pathology. They were recruited into the study by the staff team (psychologist, physiotherapist, occupational therapist and nurse) at the service. The majority of these referrals came from local GPs and the Pain Clinic in the general hospital.

c) The Gynaecological group (Gyn) comprised 20 patients who attended a clinic of the combined Gynaecology/ GUM/ Dermatology disciplines at the hospital and had an organic genital condition that did not result in pain. They were recruited by the Consultant Dermatologist, and were asked to complete the questionnaires excluding those pertaining to pain i.e., the HAD Scales and the SF-36.

d) Twenty patients with a diagnosis of Rheumatoid Arthritis (RA) were derived from an ongoing research cohort at the same hospital. All had a diagnosis of RA according to ARC criteria. Of 48 letters sent, 23 agreed to participate and the first 20 returns were used for this study.

Study 2.

Of the initial 20 patients with unexplained Vulvodynia who were assessed, 11 agreed to take part in the Pain Management programme. Of those who attended assessment but did not go on to participate in the programme, most cited practical reasons such as not being able to take the time off work to attend the group at this time. Those who participated in the programme, completed the questionnaires initially at assessment, and then at the end of the programme.

Participants were to be included if they were between the ages of 20 and 75. Participants were to be excluded if they were currently psychotic or suicidal, or were identified as misusing drugs or alcohol. No exclusions on any of the above grounds were made. Ethical approval for this study was granted by the West Surrey Health Authority (see Appendix 1). Data were also collected from other grant-funded research (the Rheumatoid Arthritis and Gynaecological groups) that had ethical approval from the appropriate bodies.

3. Measures

a) Beliefs

The Survey of Pain Attitudes (SOPA, Jensen, Turner, Romano & Lawler, 1994) was designed to measure attitudes towards and beliefs about pain. The SOPA assesses beliefs about: 1) Control, belief in one's personal control over pain; 2) Solicitude,

belief in the appropriateness of concerned responses from one's family when in pain; 3) Medication, belief that medications, in general, are appropriate for chronic pain problem; 4) Disability, belief in oneself as unable to function because of pain; 5) Emotion, belief in a relationship between emotion and pain; 6) Medical Cure, belief that a medical cure exists for one's pain problem; 7) Harm, belief that pain signifies damage and that exercise and activity should, therefore, be restricted.

A sample item from the Control subscale is: "There are many times when I can influence the amount of pain I feel". The response choices are: 0 = This is very untrue for me, 1 = This is somewhat untrue for me, 2 = This is neither true nor untrue for me (or it does not apply to me), 3 = This is somewhat true for me, or 4 = This is very true for me. The instrument consists of 57 items. The scales have good internal consistency, ranging from 0.71 to 0.81. Test-retest stability coefficients ranged from 0.63 to 0.68 (Jensen et al, 1994).

b) Affect

The Hospital Anxiety and Depression Scale (HAD; Zigmond & Snaith, 1983) is a brief, self-administered rating scale consisting of 14 statements referring to affect. It is divided into two subscales, anxiety and depression, of seven items each. There are four possible responses which are scored using a Likert method and items scores ranged from 0-3. It was developed in order to eliminate the possible contamination by real illness that has been a problem with the usual standardised measures of depression and anxiety for assessing CP patients that included somatic items and is

the only questionnaire developed and standardised on an appropriate population (Williams, 1993). Reliability and validity computations appear to be moderate (Chandarana, Eals, Steingart, Bellamy & Allen, 1987). Evidence for the concurrent validity of the HAD has been reported in psychiatric patients, in a heterogeneous group of patients with physical illness and in patients attending a genitourinary clinic (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991).

The authors of the HAD scale recommend a borderline range for both anxiety and depression subscales; i.e. scores of 7 or less as non cases, 8-10 as borderline cases, and 11 or more as definite cases. It is not unusual, however, for cut-off scores for psychiatric cases to be taken as 8/9 for depression and anxiety (Chandarana et al, 1987).

c) Quality of Life

The Short Form-36 Health Survey (SF-36, Ware, 1993) measures a person's physical well-being and health-related quality of life. It is a self administered questionnaire that consists of 36 questions inquiring about the respondent's health and functioning. The areas covered include general health perceptions, physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/fatigue, bodily pain and overall health change. A sample item from the Social Functioning subscale is:

“During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?”

There are five response choices for this question: Not at all, Slightly, Moderately, Quite a bit, and Extremely.

The questionnaire aims to give information about how a person is functioning in the real world - how a disease might be affecting the ability to go about normal tasks and activities. Validity and internal consistency of the subscales has been endorsed (Ware, 1993; Burke, Burke, Hurt-Baker & Hillis, 1995). Test-retest reliability using a group of psychiatric outpatients was found to be acceptable (Burke et al, 1995). They found the reliability of the scores over a one month period is good to excellent with the exception of Role Functioning which is fair.

Normative data is available for the SF-36 (Ware et al, 1992). Table 2 presents mean scores for a sample of women aged between 45 and 54 in the general US population.

Table 2. SF-36 norms (N = 193) for females aged 45-54. (Ware et al., 1992.)

	PF	RP	BP	GH	V	SF	RE	MH
Mean	82.86	79.93	72.14	70.48	60.62	82.71	81.92	74.36
SD	21.72	35.38	23.34	20.58	21.32	20.84	33.34	18.08

The SF-36 raw scores are transformed into linear scores from 0 to 100. For the purposes of this study, for increased face validity, the following subscales of the SF-36 are not reversed scored as recommended in the manual: (bodily pain, general health, social functioning, vitality and mental health). Rather than a high score indicating better health status on each item, the scores represent a higher score for the specific construct they measure i.e. a higher score on bodily pain means more bodily pain. Therefore, solely for the purpose of comparing the scores to the norms, these subscales have been subtracted from 100. A score of 48 on bodily pain thereby became a score of 52. These calculations have been made for Table 3 below.

Table 3. Mean Scores on the SF-36 for the Vulvodynia, Chronic Pain, Rheumatoid Arthritis and Gynaecology groups.

		PF	RP	BP	GH	V	SF	RE	MH
V	<i>Mean</i>	30.25	53.75	52.00	41.75	45.25	46.87	33.33	35.40
	<i>SD</i>	30.11	41.58	17.65	9.90	11.86	13.98	41.89	10.57
CP	<i>Mean</i>	63.61	68.06	38.33	44.17	45.83	50.00	48.18	39.56
	<i>SD</i>	21.54	37.19	15.43	15.93	9.59	8.57	41.58	13.36
GYN	<i>Mean</i>	20.00	15.00	76.00	47.50	48.75	47.50	25.01	42.00
	<i>SD</i>	18.92	28.56	23.49	11.75	11.68	14.96	41.71	10.66
RA	<i>Mean</i>	52.25	68.75	50.00	44.00	45.50	48.75	46.75	37.00
	<i>SD</i>	23.65	42.82	17.77	11.31	9.30	12.10	43.80	10.04

d) Coping

The Coping Strategies Questionnaire (CSQ; Rosentiel & Keefe, 1983) is a 44 item questionnaire that measures 1) the extent to which subjects report using each of six different cognitive coping strategies and one behavioural coping strategy when they feel pain, and 2) the degree to which subjects perceive themselves as able to use these strategies to control and decrease pain. The CSQ has seven subscales consisting of six items each. The cognitive coping strategy subscales are diverting attention, reinterpreting pain sensations, ignoring pain sensations, coping self statements, praying or hoping, and catastrophising, and increasing activity level. Each item on these subscales is rated using a 7 point scale to indicate how often the strategy is used to cope with pain (0 = never, 6 = always).

The reliability of the CSQ subscales have been supported (Snow-Turek, Norris & Tan, 1996). Research studies have also demonstrated that coping strategies measured by the CSQ are predictive of pain, psychological distress, and activity in patients suffering from a variety of chronic pain conditions (Beckham, Keefe, Caldwell & Roodman, 1991).

The CSQ items can be used to obtain an active and passive coping score (Nicholas et al, 1998) which measures whether the patient is relying on internal or external resources to control pain. Five scales (Coping Self Statements, Diverting Attention, Increased Behavioural Activities, Ignoring Sensations, and Reinterpreting Pain Sensations) which are composed of 30 items are summed to create the Active Coping score ranging from 0 to 180. An example of an active coping item is : “I leave the house and do something. such as going to the movies or shopping”. The remaining two scales, (Catastrophising and Praying/Hoping) which consist of 12 items which meet the definition of passive coping are summed for a Passive Coping score from 0 to 72. An example of a passive coping item is : “ I worry all the time about whether it will end”. Snow-Turek et al (1996) provide support for the validity and clinical utility of the active and passive coping dimensions.

e) Pain

The McGill Pain Questionnaire (McGill, Melzack, 1975) was designed to measure the quality of the pain in addition to intensity. The words participants are asked to select to describe their pain, are categorised into sensory, affective and evaluative classes,

and further the words in each group imply increasing pain intensity from mild to excruciating. e.g. 1. Sharp, 2. Cutting, 3. Lacerating. Although these dimensions are often separated, a combined measure can be used by taking a total score which has been found to correlate with pain severity. For the purposes of this study, the McGill is used in this way as one total score to indicate pain severity. Internal consistency among the different categories of the McGill have been shown to be high. It has been shown to provide valid indices of some of the dimensions of pain ((Melzack, 1975).

Measures are attached in Appendix III.

4. Procedure

The four groups of patients, the Vulvodynia (V) group, the Gynaecological (Gyn) group, the Mixed Site Chronic Pain (CP) group and the Rheumatoid Arthritis (RA) group were asked to complete questionnaires that were part of a research project about pain management. Each patient was asked by a professional involved in their care, if they would agree to participate. The Vulvodynia, Chronic Pain, and Rheumatoid Arthritis groups completed a battery of 5 questionnaires: the HADS, the McGill, the SF-36, the SOPA, and the CSQ. The gynaecological group did not experience pain as part of their symptomatology and therefore were not asked to complete the questionnaires pertaining to pain. The questionnaires they did complete were the : SF-36 and the HADS.

The questionnaires were given to the patients at the end of their assessment session and they were asked to sit and complete them before they left. They were told that if they had any questions about any of the forms, they could ask advice. The RA group was the only group that had the questionnaires sent out to them with a covering letter and they returned them by post.

All questionnaires were then collected and subsequently coded to protect identity of patients, scored and then analysed using SPSS. The analysis of the data for this first part of the study was intended to evaluate any similarities and differences between the groups. Of particular interest was the comparability of the V and CP groups

The second part of the study was a preliminary trial of patients with unexplained Vulvodynia in a cognitive-behaviour pain management programme. Eleven patients were recruited for the treatment trial when they came for assessment at the Pain Management Service following referral from their Consultant. The purpose of the assessment session was to elicit background information about the patient and the history of their condition. The assessment session was also used to provide the patient with information about the pain management service, the pain management programmes that exist for other pain patients, and what they might expect from the programme they were considering taking part in. A rationale for the programme was presented. The current conceptualisation of pain as being partly physical and partly psychological was introduced with examples such as phantom limb pain and the ability of athletes to continue with their event after sustaining an injury because of concentration and motivation. Patients were informed that the programme was an established and effective treatment for other chronic pain syndromes and it was,

therefore, predicted that the same benefits might apply to Vulvodynia. However, it was made clear that this was not proven.

The group consisted of 8 weekly two-hour sessions. The topics covered on the programme were as follows:

1. The introduction to the vicious cycle of pain and the Gate Control Theory of pain.

This session covered concepts of chronic pain, and how certain patterns of behaviour feed into each other and into the cycle.

2. Relaxation and Goal setting and Pacing.

Differential relaxation exercises of tensing and relaxing muscle groups were taught and participants were given tapes to practise at home between sessions. Short and long term goals were set and patients were shown how to increase their time of activity in manageable increments.

3. Attention Diversion and Imagery.

Techniques were taught to divert attention away from the pain, ranging from counting and taking note of the surroundings, to transforming the pain sensation, for example from burning to cooling by visualising the sensation of a mountain stream.

4. The Role of Thoughts.

This session introduced the use of cognitive techniques to identify unrealistic and unhelpful thoughts and beliefs.

5. Challenging Thoughts.

Participants were taught the use of cognitive techniques to challenge unrealistic and unhelpful thoughts and beliefs.

6. Sexuality.

This session included a group discussion on how Vulvodynia had impacted on participant's sexual identity and sexual relationships. It then introduced sensate focus and graded exposure.

7. Assertiveness.

Assertiveness was discussed in relation to how it might be helpful when people make demands that are unrealistic because of chronic pain.

8. Relapse Prevention.

The final session covered maintaining progress and preparing and planning for difficult times.

Participants were assessed and offered a place in one of two groups which was more convenient for them. Each session was conducted by a Clinical Psychologist in training with one session on goal setting by a physiotherapist and one session on the medical viewpoint by the Consultant dermatologist. A counselling psychologist was involved as a co-therapist.

RESULTS

1. Study 1

a. Sample characteristics

The demographic data for each of the four groups are given in Table 4. It may be seen that though the V, CP and Gyn groups appeared well matched for age, the RA group was rather older on average. Kruskal-Wallis 1-Way Anova (corrected for ties) revealed that this difference was significant, $\chi(3) = 9.34, p = .025$. Similarly, though the V and CP groups appeared well matched for chronicity, the RA group had not been experiencing their pain for as long on average. Kruskal-Wallis 1-Way Anova (corrected for ties) revealed that this difference was significant, $\chi(2) = 6.45, p = .04$.

Table 4: Age and Chronicity for the Vulvodynia, Chronic Pain, Gynaecology and Rheumatoid Arthritis Groups.

Diagnosis	Age in Years		Chronicity in Years	
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>
Vulvodynia*	47	16	6	6
Chronic Pain	50	11	5	2
Gynaecology	51	15	**	**
Rheumatoid Arthritis	60	10	3	1

* N = 19

** Information not available for this group.

The marital and work status of the patients in the Vulvodynia, Chronic Pain and Rheumatoid Arthritis groups is presented in Table 5. It can be seen that there are more patients with Rheumatoid Arthritis who are not working than in the other two groups. Marital status is comparable across the groups with the majority of patients in each being married.

Table 5. Frequency of the Vulvodynia, Chronic Pain, and Rheumatoid Arthritis patients in different Marital and Work Status categories.

	V ^a	CP	RA
Work			
Full Time	9	8	5
Part Time	5	5	1
Not Working	5	7	14
Married			
Married	15	15	14
Divorced	2	4	2
Widowed	1	0	1
Single	1	1	3

^a n = 19

Table 6 presents the frequency and percentage of patients in each group who score in the normal, borderline and clinical ranges for anxiety and depression. It can be seen that more Chronic Pain patients score in the clinical range for both anxiety and depression than patients in the other groups, although this difference is not statistically significant (see Table 8).

Table 6. Number and percentage of people scoring in the normal, borderline and clinical ranges of anxiety and depression.

	V		CP		GYN		RA	
	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>
Anxiety								
<7	8	40	6	30	8	40	8	40
8-10	6	30	3	15	8	40	8	40
>11	6	30	11	55	4	20	4	20
Depression								
<7	13	65	11	55	17	85	16	80
8-10	6	30	5	25	1	5	3	15
>11	1	5	4	20	2	10	1	5

b. Comparing the Groups

The groups scores on each of the distress, beliefs, coping, pain and quality of life measures are presented in Table 7. Scores on the pain-related measures were subjected to individual one-way ANOVAS with the factor Group (EV, CP and RA), while scores on all the other dimensions were subjected to ANOVAS with the factor Group (EV, CP, RA and Gyn.). The resulting F statistics and associated probabilities are gathered together in Table 8.

On the SF-36, main effects for Group were observed for the Bodily Pain, Physical Functioning and Role Physical (role limitations due to physical cause) subscales. Because of the lack of specific hypotheses about group differences, and to preserve

statistical power, post hoc Dunnett's t-tests were used. This compares only the Vulvodynia group to each of the other groups. These revealed that the Vulvodynia group scored significantly higher than the Gyn group on Bodily pain, Mean Difference (MD) = 24, $p < .001$ (not surprising since the Gyn group were not experiencing chronic pain). For SF-36 Physical Function, Dunnett's t-tests revealed that the Vulvodynia group scores were significantly higher than those of both the CP group, MD = -33.36, $p < .001$, and the RA group, MD = -22.00, $p = .014$. For the SF-36 Role Physical subscale, the Vulvodynia group scores were significantly lower than those of the Gyn group, MD = 38.75, $p = .005$.

For the SOPA, main effects for Group were observed for the Harm, Medication, Medical Cure and Solicitude subscales. Dunnett's t-tests were used to compare the Vulvodynia group to each of the other groups. These revealed that the Vulvodynia group scored significantly higher than the CP group on the SOPA Harm subscale, Mean Difference (MD) = -5.26, $p = .012$; and on the SOPA Medical Cure subscale, MD = -6.00, $p = .006$. On the SOPA Medication subscale, the Vulvodynia group scored significantly lower than the RA group, MD = -5.03, $p = .001$. On the Solicitude subscale, though the ANOVA yielded a main effect, Dunnett's t-tests revealed no statistically significant differences between the groups.

The variables identified above yielded (statistically) significant differences between the groups. However, in order to examine the independence of such differences (or conversely, the inter-relatedness of the variables yielding difference) the relevant variables for the RA and CP groups were subjected to separate Discriminant Function

Analysis. For the RA and V groups, the scores for SF-36 Bodily Pain, SOPA Medication and SOPA solicitude were entered stepwise as factors in a Discriminant Function Analysis. This revealed that only SOPA Medication made an independent contribution to discriminating the groups, λ (Wilks Lambda) = .864, $p = .005$. For the CP and V groups, the variables SF-36 Bodily Pain, SF-36 Physical Function, SOPA Solicitude, SOPA Medical Cure and SOPA Harm were entered stepwise as factors in a Discriminant Function Analysis. This revealed that three variables were statistically independent discriminators of these groups: SF-36 Bodily Pain, $\lambda = .421$, $p = .043$; SF-36 Physical Function, $\lambda = .429$, $p = .035$; and SOPA Medical Cure, $\lambda = .505$, $p = .005$.

Note that to preserve statistical power, the Discriminant Function Analysis tests above were not corrected for Type I errors. Therefore, rather than treating these results as tests of hypotheses, they should be understood as descriptive.

Table 7. Mean scores on the questionnaires for the Vulvodynia, Rheumatoid Arthritis, Mixed-Site Chronic Pain, and Gynaecological groups.

Measure	Vulvodynia		Chronic Pain		Gynae.		Rheum. Arthritis	
	<i>Mean</i>	<i>Sd</i>	<i>Mean</i>	<i>Sd</i>	<i>Mean</i>	<i>Sd</i>	<i>Mean</i>	<i>Sd</i>
HAD								
anxiety	8.90	3.97	10.10	4.05	8.00	4.61	7.80	5.29
depression	5.50	3.32	7.40	4.27	4.40	3.39	5.15	3.37
SF-36								
bodily pain	48.00	17.65	61.67	15.43	24.00	23.49	50.00	17.77
general health	58.25	9.90	55.83	15.93	52.50	11.75	56.00	11.31
physical func.	69.75	30.11	36.39	21.54	80.00	18.92	47.75	23.65
role emotion	66.66	41.89	51.82	41.58	74.99	41.71	53.32	43.80
role physical	46.25	41.58	31.94	37.19	85.00	28.56	31.25	42.82
social func.	53.13	13.98	50.00	8.57	52.50	14.96	51.25	12.10
vitality	54.75	11.86	54.17	9.57	51.25	11.68	54.50	9.30
mental health	64.60	10.57	60.44	13.36	58.00	10.66	63.00	10.04
SOPA								
control	18.78	5.45	18.30	8.84	*	*	22.50	5.59
disability	16.83	5.64	23.20	6.89	*	*	18.95	7.57
emotion	14.22	6.59	15.10	7.80	*	*	13.25	6.32
harm	17.56	6.07	12.30	4.03	*	*	15.20	3.19
medication	15.72	5.17	16.40	3.41	*	*	20.75	2.73
medical cure	18.00	5.45	12.00	4.78	*	*	20.55	4.19
solicitude	11.39	4.89	7.40	5.38	*	*	7.95	4.26
McGill								
CSQ active	20.45	8.68	27.18	12.82	*	*	22.60	12.15
	38.10	22.84	47.27	24.07	*	*	51.50	23.77

* Data not applicable.

Table 8: ANOVA results for the groups EV, CP, RA and (where applicable) Gyn. on HAD, SF-36, SOPA, McGill and CSQ.

Measure	F (df)	p*
HAD		
anxiety	F (3, 76) = 1.08	.36
depression	F (3, 76) = 2.39	.07
SF-36		
bodily pain	F (3, 74) = 13.50	.00
general health	F (3, 74) = 0.74	.53
physical function	F (3, 74) = 13.26	.00
role emotion	F (3, 74) = 1.34	.27
role physical	F (3, 74) = 8.69	.00
social functioning	F (3, 74) = 0.22	.88
vitality	F (3, 74) = 0.46	.71
mental health	F (3, 74) = 1.34	.27
SOPA		
control	F (2, 45) = 2.22	.12
disability	F (2, 45) = 2.85	.07
emotion	F (2, 45) = 0.27	.77
harm	F (2, 45) = 4.19	.02
medication	F (2, 45) = 8.68	.00
medical cure	F (2, 45) = 10.58	.00
solicitude	F (2, 45) = 3.32	.04
McGill		
CSQ active	F (2, 52) = 1.68	.19

* Significant results are highlighted. The increased risk of Type 1 errors is discussed in chapter 4 section 1.g).

3. Study Two

The intervention group's mean scores on the psychological measures are presented in Table 9. Some features of interest are obvious to inspection. First, scores for SF-36 Bodily Pain were lower after participation in the intervention than before, suggesting that the Vulvodynia group were experiencing less physical pain than previously. A paired samples t test confirmed that this decrease was statistically significant, $t(10) = 3.13, p < .02$. Similarly, on the SF-36 Role Emotion subscale, which indexes the extent to which respondents perceive role limitations to be due to their emotional problems, the Vulvodynia group scored lower after intervention than before, and this decrease also proved reliable, $t(10) = 2.47, p < .05$. Next, scores on the control subscale of the SOPA increased over the intervention period, which suggests that the group believed more strongly in their control over pain after treatment than they had before. A paired samples t test confirmed that this increase was statistically significant, $t(10) = -2.29, p < .05$. The CSQ Active subscale scores were higher after treatment. A paired samples t test confirmed that this increase was statistically significant, $t(10) = 6.85, p < .01$ which indicates that participants were using more active coping strategies after treatment. Inspection of the specific coping strategies revealed increases after treatment which proved to be statistically significant following paired samples t tests on the following subscales: CSQ da, $t(10) = -7.44, p < .01$; CSQ iba, $t(10) = -2.77, p < .05$; CSQ is, $t(10) = -2.44, p < .05$; CSQ rps, $t(10) = .005$. These scores indicate that after treatment, participants reported using diverting attention, increased behavioural activities, ignoring sensations, and reinterpreting the pain sensations, more than before treatment.

There was an increased score after treatment on the emotion subscale of the SOPA which suggests that respondents believe that there is a relationship between their emotions and their pain. This was tested with paired samples t tests but did not reach significance $t(9) = -2.23, p < .06$

Table 9: Means and Standard Deviations for the Vulvodynia group Before and After Intervention.

Measure	Before		After	
	<i>Mean</i>	<i>Sd</i>	<i>Mean</i>	<i>Sd</i>
HAD				
anxiety	8.36	3.29	7.73	4.13
depression	5.36	3.72	5.91	2.98
SF-36				
bodily pain	51.82	18.34	39.09	19.73
general health	58.64	10.51	52.73	22.40
physical function	72.73	26.02	80.91	12.41
role emotion	75.75	36.80	42.41	42.40
role physical	52.27	42.51	38.64	39.31
social functioning	51.14	16.25	48.86	8.76
vitality	53.18	12.70	58.64	4.52
mental health	66.18	9.53	64.36	8.85
SOPA				
control	19.82	5.13	23.70	4.30
disability	15.45	4.93	16.30	6.86
emotion	14.27	5.78	16.70	7.96
harm	16.73	5.02	15.10	6.89
medication	14.64	5.92	14.90	5.67
medical cure	17.60	5.15	14.30	4.76
solicitude	11.18	5.84	13.70	4.74
McGill	17.64	7.27	22.74	10.67
CSQ				
active coping	42.64	23.32	75.00	17.37
catastrophising	11.73	6.89	10.73	7.71
coping statements	22.82	8.04	26.64	4.41
diverting attention	7.45	7.08	18.82	8.40
increased activities	12.91	7.11	19.27	5.04
ignoring sensations	16.18	8.13	19.27	5.04
praying/hoping	9.73	6.26	12.27	9.52
reinterpreting pain	4.73	3.88	13.18	8.44

The frequencies and percentages of Vulvodynia patients scoring in the clinical range for anxiety and depression both before and after the intervention are presented in Table 10. It can be seen that for both anxiety and depression, more patients have moved from the borderline into the normal range after treatment. However, no patients have moved out of the clinical range.

Table 10. Frequency and percentage of Vulvodynia patients scoring in the normal, borderline and clinical ranges for anxiety and depression, before and after the intervention.

	V Before		V After	
	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>
Anxiety				
<7	5	45	7	64
8-10	3	27	1	10
>11	3	27	3	27
Depression				
<7	7	64	9	82
8-10	3	27	1	10
>11	1	10	1	10

Feedback on the treatment programme

At the end of the eight week intervention, participants were asked to rate on a scale of 0 to 10 how useful they found the different topics covered during the programme. (0 indicated that they did not find the topic useful at all, 10 indicated they had found it extremely useful). Table 11 summarises the group ratings. An example feedback sheet is attached in Appendix 2.

Table 11: Mean Feed-Back Ratings, and Scores Greater or Less Than Five (Counts) for Intervention Topics.

Topic	Mean	SD	N	No. of Scores <5	No. of Scores >5
Goal setting & Pacing	5	3	11	5	6
Relaxation	8	2	10	1	9
Attention diversion and Imagery	8	2	11	1	9
Cognitive(negative thoughts)	7	2	11	1	10
Sexuality	7	3	11	2	9
Assertiveness	7	3	8	1	8

DISCUSSION

1. Study 1. Comparison of Vulvodynia (V) with the Chronic Pain (CP), Gynaecology (Gyn) and Rheumatoid Arthritis (RA) groups.

a. Summary of the Results

The results showed that the V group experience less pain than the CP group, and have better physical functioning than CP and RA. Vulvodynia patients also report greater role limitations due to physical problems than the Gyn group. These results are as would be expected in view of the physical conditions of the four groups, but become more interesting when looked at together with the results of the SOPA. The Vulvodynia group believe to a greater extent than the CP group that pain signifies damage, and that exercise and activity should therefore be avoided; and that a medical cure exists for their problem. They also believe to a greater extent than CP and RA that significant others should respond with concern and assist them when they are in pain. They do not believe as strongly as RA patients that medication is appropriate for chronic pain problems.

b. Beliefs

(i) *Harm*

It is an interesting finding that in spite of the fact that they have less bodily pain and better physical functioning than Chronic Pain patients, Vulvodynia patients believe

more strongly that pain signifies damage. Why might a group of patients who are less physically disabled believe more strongly that pain is dangerous for them and that they must, therefore, avoid activity? One possible explanation for this is to do with the activities concerned, (primarily sexual), and their association with valued personal roles. The pain that patients experience when they engage in sexual activities may, therefore, have more impact emotionally, contributing to a greater perception of harm and damage. This is supported by the findings of Klonoff, Landrine and Brown (1993), who found that pain in certain body sites, such as the chest, may be appraised as more life-threatening than genital pain. However, patients reported feeling more worried about genital pain, and saw genital pain as more of a medical emergency than chest pain. Klonoff et al suggested that appraisals of pain's danger may entail not only its literal danger to life, but also its danger to gender roles and identity. The physical pain involved in sexual intercourse is also likely to be more intense at the time. Many women seem to repeatedly try to have sex, either because they genuinely want to, or more frequently because they feel they owe it to their partner. They may begin and then due to the intense pain, have to stop. If, on occasion patients do succeed in having sex, they might "pay for it" by suffering intense pain later. It may also be a consequence of the connotations a genital problem may have of serious and transmissible disease which may add to perceptions of harm and damage.

Another explanation for the strength of this belief among the V group is related to the quality of their experience of pain. Vulvodynia is characterised by a "burning" sensation. Patients even have difficulty relating to the word "pain", due to the apparent appropriateness of the word "burning" to describe their experience. This

sensory experience of burning, with its connotations of being on fire, might be implicated in increased perceptions of harm and damage. Specific strategies could be employed to address this issue if, indeed, this hypothesis was substantiated by future research. For example, reinterpreting the pain sensations and imagery techniques can be used to replace the sense of burning with cooling images.

Furthermore, it is not an entirely surprising belief to hold with regards to ongoing pain that one has not been given any physical explanation for. An example of an item on the SOPA that constitutes the Harm subscale, include “something is wrong with my body which prevents much movement or exercise”. It seems likely that people *would* assume that pain was signalling damage. If one does not know what is causing the pain and it is unclear what might make it worse, the context is created for people to imagine the worst. What has been demonstrated in previous research is that the belief that pain is harmful and that activity might exacerbate the pain, is associated with psychological dysfunction and poorer outcomes (Linton, 1994; Regan et al, 1988). This belief would, therefore, need to be explored and challenged where appropriate, to facilitate better adaptation.

(ii) Medical Cure

Vulvodynia patients believe more strongly than Chronic Pain patients that a medical cure exists for their problems. Both of these groups suffer with ongoing, intractable pain for which there is no identifiable physical pathology, so it is the additional factors pertaining to the Vulvodynia group that need to be considered to understand

the difference in the results. Again, the site of the pain and its associated psychological impact could be a contributing reason for the increased scores of the Vulvodynia group on these SOPA subscales. Previous research has found essential Vulvodynia patients to be more anxious than Vulvodynia patients for whom physical findings have been identified (Stewart et al, 1994), suggesting the importance of medical validation to this group of patients. The increased anxiety reported by Stewart et al may reflect the beliefs Vulvodynia patients have or develop in the absence of physical findings, about the nature and cause of their condition. It may reflect their perception that their condition is psychological and they are thought to be “mad”. Further, a medical diagnosis and cure would validate any changes they may have made in their lives that have impacted on significant others. For example, partners would know that the reason a sexual relationship is difficult *is* for a medical reason. Vulvodynia patients may believe strongly that a medical cure exists for their condition as this would bring with it the validation they seek.

An important difference between the V group and the CP group, and implication of the genital site of the problem is that the Vulvodynia patients are unable to talk about their condition to anyone, making them far more isolated. Not only is their condition not acknowledged by the medical profession, but they are not supported by friends and family either. The CP group can discuss their condition when they choose to or when people ask how they are. This offers the possibility of some support and comfort not available to patients with Vulvodynia. Possibly, this isolation adds to the sense of being let down by the medical profession and makes it harder for them to let go of the medical model. They may feel they are not believed and that only a medical cure

would validate their experience. Being alone with a “proper” recognised medical condition that has treatment for it might make them feel better than being alone with a condition that is debilitating but no one believes you have. These suggestions pertaining to the site of the pain and its’ impact, need to be assessed more directly.

(iii) Solicitude

The V group believe to a greater extent than CP and RA that when they are in pain, they should receive more concerned responses from significant others. Items on this scale include: “My family does not understand the pain I am in”, “When I am hurting, people should treat me with care and concern”, and “My family needs to learn how to take better care of me when I am in pain”. The sense of isolation that Vulvodynia patients experience seems to be at the core of these beliefs. They are relatively high functioning in some areas and as genital pain is less obvious to others, they may not feel that they get adequate support and care from significant others. Possibly, because of the “blow” to their sense of self and identity, women with Vulvodynia might be reluctant to complain, in the hope that they will be seen to be the same person they used to be. However, they may still feel disappointed if significant others are not sensitive and considerate enough when they are in pain. Perhaps, this issue might be well addressed within an assertiveness component of the intervention, where women can think about how to ask for what they need. Further, because of dyspareunia, Vulvodynia patients may have relationship difficulties, and therefore feel more strongly the need for more caring responses from family. It seems likely that inclusion

of significant others in part of the treatment programme of Vulvodynia patients would be very useful.

(iv) . Medication

The finding that Vulvodynia patients believe less strongly than RA patients in medication as appropriate treatment for chronic pain is not in line with the above suggestions. In light of the above discussion of the unwillingness of the Vulvodynia group to let go of the medical model, one might expect them to believe strongly that medication is an appropriate cure for chronic pain. However, there is a straightforward explanation for RA patients to believe strongly in medication. Unlike either of the other pain groups, CP or V, there are medicines that are essential to the management of RA.

(v) Shared beliefs

The scores of three pain groups were similar on the SOPA control, disability, and emotion. These beliefs have been found in the literature to have important implications for positive adaptation. Appraisals of control, or the belief that the individual has the ability or resources to manage pain appear to be one of the most important appraisal dimensions determining adjustment (Haythornwaite, Menefee, Heinberg & Clark, 1998); whilst the belief that one is disabled by pain has been associated significantly with both psychological and physical dysfunction (Strong et al, 1990; Jensen & Karoly, 1991).

c. Affect

(i) *Anxiety*

The four groups had very similar levels of anxiety on the HADS (i.e. in the borderline range). This is not in line with Stewart et al's (1994) finding that patients with Essential Vulvodynia were more anxious than the Vulvodynia patients with organic findings. One might also expect the impact, generally, of having a genital condition to contribute to anxiety, for the reasons discussed in Section 3 of the Introduction about psychological approaches to gynaecological conditions. What is more surprising here, therefore, than the similar levels of anxiety, are the *low* levels across these groups.

Table 6 presents numbers and percentages of patients' anxiety scores. This provides more detail than group means. What can be seen from table 6 is that the CP group have more patients in the clinical range for anxiety (i.e. > 11) than the other three groups. There are more patients in the Vulvodynia group scoring in the clinical range of anxiety, than in the RA or Gyn groups. However, in these three groups, it can be seen that most patients are scoring in the normal range (i.e. < 7). As discussed above, this is a surprising finding.

(ii) . Depression

The literature suggests that approximately 50% of chronic pain patients present with depression (Romano & Turner,1985). However, number of patients in the different score ranges showed that the majority of patients in each group scored in the normal range (i.e. <7).

The cognitive-behavioural mediation model (Kerns & Haythornwaite, 1988) suggests that perceived disability and reduced physical function are related to increased levels of depression. Based on these present findings of lower levels of disability amongst the Vulvodynia group, we might expect the CP group to report higher levels of depression than the Vulvodynia group. However, this was not the case - possibly due to differences between the groups. The V group are contending with all three of the factors discussed in this study, hypothesised to contribute to distress: namely, ongoing pain, lack of organic findings, and genital site. The CP group are contending with two of these factors : ongoing pain and lack of physical findings. In view of the surprisingly low scores for anxiety and depression, it would be interesting for further research to shed light on whether these groups are atypical in some way.

d. Quality of Life

The results showed that the V group experience less pain than the CP group, and have better physical functioning than CP and RA. Vulvodynia patients also report greater role limitations due to physical problems than the Gyn group.

With regards to the measure of physical functioning using the SF-36, items enquire about respondent's ability to engage in various activities. Examples of the activities are running, vacuuming, carrying groceries, climbing stairs, and bathing. It can be seen that there is a range of activities included here, from strenuous to light. However, Vulvodynia patients are hindered from more specific activities. Measures that do not tap into their difficulties more accurately can give a false impression of their level of functioning and adaptation This also gives some insight into how these patients may be regarded by others, both family members and medical professionals, and consequently, how they might feel isolated. It may be far more difficult to feel sympathetic towards a person who is suffering with pain but outwardly able to continue with many physical tasks. Chronic vulval burning is not visible to others in the same way as chronic back pain. Therefore, it is more difficult for others to understand the distress Vulvodynia patients experience.

The scores on the following SF-36 subscales: general health, role emotion, social functioning, vitality and mental health, were similar for all four groups. It is not surprising that there is comparability between these groups when considering the chronic conditions they have.

e. Coping

For study 1, a composite score of active coping was used. All the groups scored similarly on this scale. As these patients have not begun the cognitive-behavioural programme at the initial assessment time, it is unlikely that they will be using active coping strategies to a great extent. Many patients prior to cognitive behavioural treatment are still hoping and waiting for a medical cure, rather than adopting a self-management approach.

f. Pain intensity

There was also no difference between the groups on the McGill PPI present pain intensity scale. This is not consistent with the SF-36 bodily pain score, which indicated that the V group had less pain than CP. A more accurate rating of pain may have been achieved with the use of a pain diary completed over a week. This is discussed below in section 2.a.iv.

g. Methodological issues in Study 1

There are a number of difficulties with the design and methodology of Study 1, including the sample size, the suitability of the comparison groups and the adequacy of the measures. This means that the results should be interpreted with caution.

Firstly, there were 20 participants in each of the four groups in Study 1. This is a smaller sample than was initially anticipated but due to time constraints, it was not possible to recruit more participants to the study. The small sample size clearly

increases the risk of Type 2 errors, and it must be acknowledged that due to the large number of anova results presented in table 8, there is also an increased risk of Type 1 errors. However, in the interest of statistical power, Dunnett's post hoc t-tests were used which only compare the reference group (ie the vulvodynia group) with the other groups.

There were difficulties with the comparison groups used in Study 1 to elucidate the experience of Vulvodynia patients. The RA group were included as they represented a group of patients who had an identifiable physical pathology to account for their pain. They were compared with Vulvodynia patients to assess the contribution of having no physical findings. The Chronic Pain group, like the Vulvodynia group, had ongoing, intractable pain with no organic pathology to account for it, and were therefore included to assess the contribution of the genital site. The Gynaecology group had the genital site of their problem in common with the Vulvodynia group, and had a clear diagnosis and physical findings. However, they did not experience chronic pain as a primary symptom. They were compared to assess the contribution of having ongoing, intractable pain.

There were various confounding variables, however, that made these comparisons more complicated. Firstly, the RA group were older and had suffered with their pain for fewer years on average than the Vulvodynia group. Chronicity of pain conditions has been shown to have a marked impact on emotional difficulties (Jensen & Karoly, 1992), although the present results do not demonstrate any difference between the groups on distress as rated by the HADS. There is also no significant difference

between the three pain groups in pain intensity as measured by the McGill, although there is a difference in bodily pain on the SF-36. Further, more patients in the RA group were not working than in the CP and V groups.

The V group and the RA group are not similar enough on all other parameters to be able to say with any confidence that difference between them is due to organicity or genital site. The nature of the physical conditions these patients are contending with are markedly different. The impact of having, or not having, a diagnosis is not, therefore, adequately addressed by comparing these two groups.

The gynaecological group was included in order to assess the contribution of the site of the problem. The only criterion for the inclusion of the gynaecological group was that they had a gynaecological condition that did not directly result in pain. Not enough information was available, however, about this group of patients to be able to exclude other confounding variables. The SF-36 and the HADS allowed certain important factors to be compared and therefore eliminated as confounding variables. But more information about the characteristics of the participants of the gynaecological group would have been useful. This information was not possible to obtain, again due to time constraints. Furthermore, the measures used in this study did not adequately tap issues pertaining to the site of the pain. Future research might address this issue more adequately by using measures that relate, for example, to embarrassment, sexual dysfunction, and relationship difficulties. As the SOPA pertains to pain, it was not administered to the Gynaecological group. This meant that interesting information about the attitudes of this group was not available.

Using a group of patients with Chronic Pelvic Pain would have been a more appropriate comparison group at this stage. It would then have been possible to compare the Vulvodynia group with another group of patients with chronic pain, gynaecological problems and no organic findings, to see whether they are similar on various measures. This was not possible at this time but may be interesting for future research. With the groups used in the present study, it has been necessary to surmise the reasons for many of the findings.

The Chronic Pain group represented a typical sample of patients who have been found in the research to benefit from cognitive-behavioural pain management programmes. This made it possible to ascertain whether the Vulvodynia group were similar to the CP group on various measures, and whether they might therefore also be suitable candidates for such treatment.

2. Study 2. Intervention Outcome

a. Summary of the results

(i) Beliefs

The results of the 8 week cognitive-behavioural pain management programme indicated that Vulvodynia patients believed more strongly after treatment that they had control over their pain. This is a positive and encouraging result. To some extent,

this is the cornerstone of the programme and the primary goal of this approach. It indicates that patients have, to some extent, adopted the self management principles and understood that they can effect their experience of pain themselves by their actions and cognitions. Patients who rate their perceived control as high have been found to function much more effectively (Turner et al, 1991).

Scores on the following SOPA subscales that did not change after intervention included disability, emotion, harm, medication, medical cure, and solicitude. It is particularly disappointing that the beliefs pertaining to harm and medical cure were not modified after intervention. It has been suggested that the patient's willingness to accept a chronic model of pain, along with its implications for rehabilitation, is crucial to treatment planning (Turk & Rudy, 1992). Consistent with this, Herman and Baptiste (1981 in Turk & Rudy, 1992) noted that successes and failures in their programme, defined according to several functional criteria, could be distinguished on the basis of changed vs unchanged thought patterns related to the prospect of living useful lives despite the pain. Clearly it is important for patients with chronic pain to develop adaptive beliefs about the relation between pain and impairment and to de-emphasise the belief that pain per se can lead to dysfunction (Turk & Rudy 1992). This should be addressed more fully in future cognitive behavioural pain management with this group of patients.

As discussed above, belief in solicitude - concerned responses from others when one is in pain - might be best addressed in the assertiveness component of the programme as it may link in to patients' fears about appearing impaired. It is clearly a complex

issue, however, and would also be relevant to the sexuality component. It seems likely that including significant others would be appropriate to facilitate change in this area.

(ii) Affect

There was no change on anxiety or depression mean scores after intervention. Although the HADS scores did not indicate high levels of anxiety or depression before intervention, it is disappointing that there was no improvement. The particular measure used could explain this finding to some extent. The HADS, as a clinical measure of depression specifically designed for a hospital population, omits the somatic items. For this reason, however, it is less sensitive and may not pick up depression or change over time as accurately. Table 10 presents the frequencies and percentages of patients before and after treatment in the normal, borderline and clinical ranges. These scores show that although the percentage of patients in the clinical anxiety and depression range had not changed after treatment, the percentage of patients who were in the normal range after treatment *had* increased for both anxiety and depression. This means that for patients who were initially in the borderline anxiety and depression range, the intervention had helped them into the normal range.

(iii) Quality of Life

Vulvodynia patients reported less pain after the intervention than they had before. An improvement in the perception of pain is not an explicit goal of cognitive-behavioural pain management programmes. Research has demonstrated however, that it is a by-product of improvements in other self management and self control areas (Skinner et

al, 1990). This is clearly a positive and encouraging result. It is not, however, supported by the McGill. This is discussed below in section 2.a.iv. Vulvodynia patients also reported fewer role limitations due to emotional causes. This is also a positive outcome of the programme, and suggests that participants were able to influence the extent to which their mood interfered with their activities. As levels of mood did not improve after treatment, it may be that patients' increased perception of control over pain contributed to this finding.

Scores on the following scales of the SF-36 did not change after treatment : general health, physical function, role limitations due to physical problems, social functioning, vitality and mental health. Although it would certainly be very positive if participants had reported improvements in these areas after intervention, it must be remembered that the programme was only eight weeks. During the eight weeks, participants had to take on board a new approach to the condition they had lived with for several years. It would be unrealistic to expect improvements on all the dimensions measured by the SF-36. However, it may be that over time, if coping strategies are beneficial, that more general improvements in quality of life will be seen. Unfortunately, follow up data could not be collected for the present study

(iv). Coping

After intervention, Vulvodynia patients reported using more active coping strategies, specifically diverting attention, increased behavioural activities, ignoring sensations and reinterpreting the pain sensations. This is a positive result as there is evidence in

the literature about the association between use of active coping strategies and positive adaptation. Skevington (1996), in her review of coping, also supported the association of coping strategies with reduced pain, helplessness and psychological distress. However, because the second time of assessment was immediately after the intervention, the possibility of compliance influencing the scores, i.e. participants saying what they thought was expected of them, cannot be ruled out. A follow-up score would have been useful here to assess whether positive increased use of strategies is maintained.

CSQ scores that did not change after treatment were CSQ coping self statements, CSQ catastrophising, and CSQ praying and hoping. Catastrophising and hoping and praying are considered to be passive strategies and therefore, it would have been encouraging for scores to have decreased. The lack of improvement in coping self statements suggests that more emphasis on the cognitive aspects of the programme might be useful.

(v) Pain intensity

The McGill measure of pain intensity was slightly elevated after treatment. Although this was not significantly higher, it is a surprising result. It is not consistent with the SF-36 bodily pain scores which showed a decrease in pain after treatment. There are several possible explanations for the increase on the McGill.. It may be possible that after focusing on Vulvodynia for the duration of the programme, participants are more aware of their bodily sensations and therefore perceive more pain. It is also possible that participants were influenced by their feelings about ending the group and,

consequently, about no further treatment. They may, therefore, have been more negative about the intensity of their pain because they did not want to be seen to be “cured” and in need of no further help. A further explanation for this finding relates to the McGill, itself. The total score on the McGill has been used in this thesis to compare level of felt pain between groups. The McGill does differentiate between pain experience but it is a subjective report of the quality of the pain, whereas the SF-36 bodily pain scale enquires more explicitly about pain severity. Initially, as a measure of pain intensity, it was intended to use a Pain Diary. Pain Diaries ask for a rating of level of pain on a scale of 1 to 5, every day for a week (in addition to level of distress caused by the pain on a scale of 1 to 5). The average of the week’s scores is then taken. Participants had only brought to our attention at the end of the programme that they had difficulties with the diary and had not completed it correctly, making it impossible for it to be used in the analysis. A pain diary consisting of ratings over a week which could be averaged, is generally thought to be more reliable than a one-off pain rating.(Follick, Ahern, Laser-Wolston, 1984). Because the pain diaries were completed incorrectly, the total score of the McGill was used instead, and may not have provided a totally reliable rating of pain intensity.

b. Essential Vulvodynia and Vestibulitis

For the purposes of this study, to investigate the experience of patients with unexplained Vulvodynia, women were included in the study if they had a diagnosis of Essential Vulvodynia or Vestibulitis. As discussed in Section 2 of the Introduction, although these constitute the two subsets of Vulvodynia that do not have organic

pathology to explain their painful symptomatology, there is a difference between the two subsets. Women who have Essential Vulvodynia suffer with ongoing, intractable pain. Women who have Vestibulitis may suffer with pain only when the genital area is touched, although there is often some degree of overlap between the subsets. It should, therefore, be pointed out that the individual needs of these patients may differ to some degree although clearly the similarities between them outweigh the differences. In any programme of chronic pain patients, there are differences between patients, even when they have the site of the pain in common. However, it may be of interest for future research to compare the psychological characteristics and response to treatment, of women from these two subsets of Vulvodynia. Further, there were two groups running concurrently for study 2. The data from these two groups were analysed together. It may have been interesting to confirm that the two groups showed no significant differences.

c. Multi-disciplinary or uni-disciplinary?

As this study was an exploratory investigation for the pain management service, in conjunction with the clinicians from the vulval clinic, the Vulvodynia patients were not funded in the usual way. This meant that for financial reasons, the programme could not be run as a multi-disciplinary programme. It was decided that in order to assess whether patients with Vulvodynia would respond positively to the approach and the programme, it would be satisfactory to run the treatment trial as a uni-disciplinary cognitive behavioural programme with a psychologist. In fact, there was input into this programme from the Physiotherapist for one session and also from the

Consultant Dermatologist for one session. The pain management programmes that are run for the mixed- site CP groups at this service include a Psychologist, a Physiotherapist, OT and a Nurse. There have been positive results reported in the literature from uni-disciplinary pain management programmes (Wall & Melzack, 1994), but it is generally held in the field that multi-disciplinary programmes are superior (Flor et al, 1992). It could be argued that the results of this trial , for example on the affect measures, might have been improved, if the programme had been multi-disciplinary. Conversely, with the findings of this study regarding the nature of a group of Vulvodynia patients, this may be a group of patients who would benefit more from psychological input than from the input of other disciplines. The group may need tailoring to the needs of Vulvodynia patients, but it is additional psychological input that may be more valuable, such as including partners or significant others in components of the programme, and working with the sexual dysfunction.

d. Methodological issues in Study 2.

There were again difficulties with the sample and design. The sample size for the intervention was particularly small with 11 participants. Therefore, the increased risk of Type 2 errors, and also of Type 1 errors and reduced statistical power, pointed out in section 1.g above, also apply to Study 2. The design for the intervention trial was initially planned as a randomised control trial and clearly this would have been methodologically more sound. Due to difficulties recruiting sufficient numbers this design was impossible. Despite the lack of a control group, however, it was clear that

these patients had failed to respond to various treatments over the years before their referral to the pain management programme.

It was also not possible to collect baseline data for participants prior to the intervention for the same reason. After it became clear that a control group could not be used, the goal was to collect data at three stages. Firstly at assessment, secondly immediately before treatment and thirdly immediately after treatment. Unfortunately, the assessments were very spaced out so that the final assessments were shortly before the first session of the group. For this reason, there is data only for before and after treatment. Clearly, as discussed in section 6 on measurement, the possibility of improvement due to non specific factors cannot be ruled out. It is also acknowledged that follow-up data 6 months after the completion of the intervention would have provided valuable information and made the results more reliable.

e. Recommendations

Feedback from the group suggested that the relaxation, and imagery techniques were very popular and helpful. As participants confessed that they found it difficult to practice the homework assignments diligently, it may be advisable to include a relaxation exercise at each session as reported by Skinner et al (1990).

The sexuality session was particularly positive. It was the most interactive session as participants shared their thoughts and feelings about how Vulvodynia had affected this aspect of their lives. The session was clearly salient to the group who felt relieved

to share their experiences and to discover how much their experiences overlapped. The Chronic Pelvic Pain literature suggests that sexual dysfunction is included in any treatment programme for that group of patients and it seems clear that the same applies for Vulvodynia.

The intervention included a component explaining Gate Control Theory and the cognitive-behaviour model, or vicious cycle, of chronic pain. The purpose of this component is to enable participants to modify their entrenched beliefs about medical cure and consequently to “take on board” the principles of a self management approach. Patients are assured that their referral and inclusion in the programme is not a reflection of the fact that their problem is considered to be “all in the head”. This point is supported by reporting the efficacy of the approach for patients with clear physical pathology, such as Rheumatoid Arthritis. It would seem likely, when considering the present findings pertaining to beliefs about harm and medical cure, that this component of the programme needs more emphasis in the future. One person admitted at the end that she realised that her anger about no medical cure and being referred to psychology had interfered with her applying herself to practising the tasks at home. It was only at the end of the programme that she had accepted the situation and felt ready to try to manage and control her pain.

The feedback presented in Table 5 also shows that the “goal setting and pacing” topic was rated less positively than the other topics covered in the programme. The reason for this may be related to the higher physical functioning of the Vulvodynia group to the chronic pain group. The goal pacing session was presented in the same way in this

programme as it is presented in the clinic's programme for a mixed-site chronic pain group, and was not adequately tailored to the needs of this group. Although it was explained that the principles of goal setting and pacing could be applied to activities including sexual activity, and graded touch was discussed briefly, it seems likely that a substantial component of the programme for this group of patients should be related to sexual difficulties.

f. Summary

Limitations of the study have been discussed. However, in spite of these limitations, the present study has identified characteristics about Vulvodynia patients that are important for the management of this group of women. Vulvodynia patients are presenting more frequently to pain management clinics and clinicians are in need of information to help them to plan and implement interventions. It has been seen that there is a clear overlap and degree of comparability between the V and CP and RA groups. This can be explained by the chronic nature of the conditions they have and the implications and consequences of having such conditions. However, inspite of the similarities between the groups, it seems clear the Vulvodynia patients have additional and separate issues that can be better addressed in a group of their own than in a group of mixed-site Chronic Pain patients. The sense of support the women in this study reported , from talking for the first time with others who share their experience, was invaluable. Women with Vulvodynia experience distress that is associated with gender identity, sense of themselves as women, partners and sexual beings. These issues are paramount to their experience and therefore require a corresponding proportion of time to address. This would not be relevant to the same extent to a different group of Chronic Pain patients.

Of particular interest are the findings about the cognitions of Vulvodynia patients, including increased belief of the Vulvodynia group in pain signifying damage, reluctance to let go of medical cure, and belief that others should respond with more

caring when they are in pain. These beliefs are important to be aware of, as they are likely to minimise possible benefit from a self management programme. In spite of this, Study 2 indicated that patients with Vulvodynia *did* benefit from a cognitive-behavioural pain management programme in terms of increased use of coping strategies. Future research might investigate whether explicitly incorporating cognitive work to address the maladaptive beliefs identified here, facilitates better outcome. This study has begun to identify the salient issues for women with unexplained Vulvodynia. The next useful step might be to use a qualitative approach to explore these issues further.

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Appendix I

Ethical Approval

WEST SURREY HEALTH AUTHORITY
NORTH WEST SURREY LOCAL RESEARCH ETHICS
COMMITTEE

The Ridgewood Centre, Old Bisley Road, Frimley, Camberley, Surrey GU16 5QE
Switchboard: 01276 671718 Fax: 01276 605496 DX: 118800 Frimley 2

Ms Louise Sharpe
Principal Clinical Psychologist
Pain Management Service
St Peter's Hospital
Guildford Road
Chertsey
Surrey KT16 0PZ

Direct Line:
01276 605556

Ref: PW/JP

13 October 1997

Dear Ms Sharpe

PRO/89/97 - Vulvodynia Pain Management Programme

Thank you for attending the meeting of the Ethics Committee with your colleague Naomi Scott on 3 October 1997 at St Peter's Hospital when your study was formally considered. I am pleased to inform you that the decision of the committee was to grant the study ethical approval subject to the following conditions:

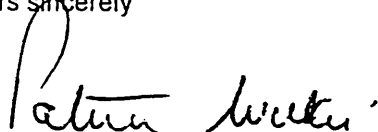
- (i) Amendment of wording of Patient Information Sheet.
- (ii) Submission to and approval of copy of letter for participation by patient in project.
- (iii) Inclusion of confidentiality clause in patient participation letter.

Questions were raised regarding the scientific validity of the current control group. If you would like advice regarding this issue, Dr Barnes, Consultant Neurologist at St Peter's will be happy to answer your questions directly.

I would appreciate your written confirmation that the above will be taken into account before the trial commences and perhaps you would let me have copies of the relevant documents referred to for our information before the study commences.

Would you please notify the committee in advance of any significant proposed deviation from the original protocol. Would you also please report if there are any unusual or unexpected results which raise questions about the safety of the research, once the study is under way. The committee would be interested in the final results of your study and wish you every success in carrying it out.

Yours sincerely



Patricia Wilkie PhD
Chairman
North West Surrey Local Research Ethics Committee

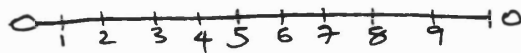
PLEASE QUOTE OUR PROTOCOL REFERENCE NUMBER IN ALL CORRESPONDENCE

Appendix II

Group Feedback

Please rate on a scale of 0 to 10 how useful you found the following topics

1 indicates that you did not find it useful at all, 10 indicates that you found it very useful



1. Goal setting & Pacing activities 10
2. Relaxation 10
3. Attention Diversion & Imagery 10
4. The role of thoughts & Challenging negative thoughts 7 - useful but difficult because rate depression
5. Sexuality & Vulvodynia 8
6. Assertiveness 8

Were there aspects you think should have had more time allocated to them? or less time?

It was all useful.
Would have enjoyed a regular "relax with ~~relaxing~~" sessions!

Possibly some more education (discussion about symptoms? - but reading list also useful - maybe could have this - sooner?

What were the best aspects of the group and why?

Being in a group - finding others had so much in common. finding that there are things I can do for myself which do help.

What were the worst aspects of the group and why?

Forgetting to do my homework + feeling guilty.
Realising how stressed my lifestyle is - I do not prioritise my own needs very highly, and I do not want to turn into a martyr!

What did you think about discussing these issues in a group setting? Would you have preferred individual therapy? Why?

Fine - no problem. Most people seemed relaxed and joyful. Occasionally I was unable to identify, as vestibulitis is quite distinct, but I was able to explain when things were not relevant to me.

Please make any other comments you have about the programme (we appreciate both positive and negative feedback)

Extremely useful - if it could be offered/mentioned that a group exists when one is first diagnosed, it would give much support and help during the depression that follows the realisation you may have an incurable condition.

Practice

Not so good on the relaxation, but I do use it at work (including before my -successful!- job interviews). Will make time in future.

Appendix III

Measures

HAD Scale

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more. This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Date:

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':

Most of the time	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A lot of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Time to time, Occasionally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

I feel as if I am slowed:

Nearly all the time	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very often	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I still enjoy the things I used to enjoy:

Definitely as much	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not quite so much	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only a little	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hardly at all	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Occasionally	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Quite often	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Very often	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Yes but not too badly	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A little, but it doesn't worry me	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I have lost interest in my appearance:

Definitely	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't take so much care as I should	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I may not take quite as much care	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take as much care as ever	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I can laugh and see the funny side of things:

As much as I always could	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not quite so much now	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely not so much now	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I feel restless as if I have to be on the move:

Very much indeed	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Quite a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not very much	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Worrying thoughts go through my mind:

A great deal of the time:	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A lot of the time	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
From time to time but not too often	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only occasionally	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I look forward with enjoyment to things:

As much as ever I did	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather less than I used to	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely less than I used to	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hardly at all	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I feel cheerful:

Not at all	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most of the time	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I get sudden feelings of panic:

Very often indeed	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quite often	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not very often	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I can sit at ease and feel relaxed:

Definitely	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Usually	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I can enjoy a good book or radio or TV programme:

Often	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very seldom	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do not write below this line

COPING STRATEGY QUESTIONNAIRE

Individuals who experience pain have developed a number of ways to cope, or deal with, their pain. These include saying things to themselves when they experience pain, or engaging in different activities. Below are a list of things that patients have reported doing when they feel pain.

For each activity, I want you to indicate, using the scale below, how much you engage in that activity when you feel pain, a 0 indicates that you never do that when you are experiencing pain, a 3 indicates you sometimes do that when you are experiencing pain, and a 6 indicates you always do it when you are experiencing pain.

0	1	2	3	4	5	6
Never Do			Sometimes Do			Always do
			That			That

When I feel pain.....

- | | | |
|----|--|-------|
| 1 | I try to feel distant from the pain, almost as if it was in someone else's body | |
| 2 | I leave the house and do something, such as going to the movies or shopping | |
| 3 | I try to think of something pleasant | |
| 4 | I don't think of it as pain but rather as a dull or warm feeling | |
| 5 | It is terrible and I feel it is never going to get any better | |
| 6 | I tell myself to be brave and carry on despite the pain | |
| 7 | I read | |
| 8 | I tell myself that I can overcome the pain | |
| 9 | I count numbers in my head or run a song through my mind | |
| 10 | I just think of it as some other sensation, such a numbness | |
| 11 | It is awful and I feel that it overwhelms me | |
| 12 | I play mental games with myself to keep my mind off the pain | |
| 13 | I feel my life isn't worth living | |
| 14 | I know someday someone will be here, help me and it will go away for a while | |
| 15 | I pray to God it won't last long | |
| 16 | I try not to think of it as my body, but rather as something separate from me | |
| 17 | I don't think about the pain | |
| 18 | I think years ahead, what everything will be like after I've got rid of the pain | |
| 19 | I tell myself it doesn't hurt | |
| 20 | I tell myself I can't let the pain stand in the way of what I have to do | |
| 21 | I don't pay any attention to it | |
| 22 | I have faith in doctors that someday there will be a cure for my pain | |

0	1	2	3	4	5	6
Never Do			Sometimes Do			Always do
			That			That

please turn over the page

COPING STRATEGY QUESTIONNAIRE

		0	1	2	3	4	5	6	
		Never Do			Sometimes Do That			Always do That	
23	No matter how bad it gets, I know that I can handle it
24	I pretend it is not there
25	I worry all the time about whether it will end
26	I replay in my mind pleasant experiences in the past
27	I think of people I enjoy doing things with
28	I pray for the pain to stop
29	I imagine that the pain is outside of my body
30	I just go on as if nothing happened
31	I see it as a challenge and don't let it bother me
32	Although it hurts, I just keep on going
33	I feel I can't stand it any more
34	I try to be around other people
35	I ignore it
36	I rely on my faith in God
37	I feel like I can't go on
38	I think of things I enjoy doing
39	I do anything to get my mind off the pain
40	I do something I enjoy, such as watching TV or listening to music
41	I pretend it is not part of me
42	I do something active, like household chores or projects

Based on all the things you do to cope with your pain, on an average day, how much control do you feel you have over it? Please circle the appropriate number. Remember, you can circle any number along the scale.

	0	1	2	3	4	5	6	
	No Control			Some Control			Complete Control	

Based on all these things you do to cope or deal with your pain, on an average day, how much are you able to decrease it? Please circle the appropriate number. Remember, you can circle any number along the scale.

	0	1	2	3	4	5	6	
	Can't decrease it at all			Can decrease it somewhat			Can decrease it completely	

MCGILL PAIN QUESTIONNAIRE

SOME OF THE WORDS BELOW DESCRIBE YOUR PRESENT PAIN. CIRCLE ONLY THOSE WORDS THAT BEST DESCRIBE IT. LEAVE OUT ANY CATEGORY THAT IS NOT SUITABLE. USE ONLY A SINGLE WORD IN EACH APPROPRIATE CATEGORY - THE ONE THAT APPLIES BEST.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
Flickering Quivering Pulsing Throbbing Beating Pounding	Jumping Flashing Shooting	Pricking Eoring Drilling Stabbing Lancinating	Sharp Cutting Lacerating
<u>5</u>	<u>6</u>	<u>7</u>	<u>8</u>
Pinching Pressing Gnawing Cramping Crushing	Tugging Pulling Wrenching	Hot Burning Scalding Searing	Tingling Itchy Smarting Stinging
<u>9</u>	<u>10</u>	<u>11</u>	<u>12</u>
Dull Sore Furting Aching Heavy	Tender Taut Rasping Splitting	Tiring Exhausting	Sickening Suffocating
<u>13</u>	<u>14</u>	<u>15</u>	<u>16</u>
Fearful Frightful Terrifying	Punishing Gruelling Cruel Vicious Killing	Wretched Blinding	Annoying Troublesome Miserable Intense Unbearable
<u>17</u>	<u>18</u>	<u>19</u>	<u>20</u>
Spreading Radiating Penetrating Piercing	Tight Numb Drawing Squeezing Tearing	Cool Cold Freezing	Nagging Nauseating Agonizing Dreadful Torturing

SURVEY OF PAIN ATTITUDES (SOPA) AND SCORING KEY

Instructions: Please indicate how much you agree with each of the following statements about your pain problem by using the following scale.

0 = This is very untrue for me.

1 = This is somewhat untrue for me.

2 = This is neither true nor untrue for me (or it does not apply to me).

3 = This is somewhat true for me.

4 = This is very true for me.

- | | |
|---|-----------|
| 1. There are many times when I can influence the amount of pain I feel | 0 1 2 3 4 |
| 2. The pain I usually experience is a signal that damage is being done | 0 1 2 3 4 |
| 3. I do not consider my pain to be a disability | 0 1 2 3 4 |
| 4. Nothing but my pain really bothers me | 0 1 2 3 4 |
| 5. Pain is a signal that I have not been exercising enough | 0 1 2 3 4 |
| 6. My family does not understand how much pain I am in | 0 1 2 3 4 |
| 7. I count more on my doctors to decrease my pain than I do on myself | 0 1 2 3 4 |
| 8. I will probably always have to take pain medications | 0 1 2 3 4 |
| 9. When I hurt, I want my family to treat me better | 0 1 2 3 4 |
| 10. If my pain continues at its present level, I will be unable to work | 0 1 2 3 4 |
| 11. The amount of pain I feel is completely out of my control | 0 1 2 3 4 |
| 12. I do not expect a medical cure for my pain | 0 1 2 3 4 |
| 13. Pain does not necessarily mean that my body is being harmed | 0 1 2 3 4 |
| 14. I have had the most relief from pain with the use of medications | 0 1 2 3 4 |
| 15. Anxiety increases the pain I feel | 0 1 2 3 4 |
| 16. There is little that I or anyone can do to ease the pain I feel | 0 1 2 3 4 |
| 17. When I am hurting, people should treat me with care and concern | 0 1 2 3 4 |
| 18. I pay doctors so they will cure me of my pain | 0 1 2 3 4 |
| 19. My pain problem does not need to interfere with my activity level | 0 1 2 3 4 |
| 20. My pain is not emotional, it is purely physical | 0 1 2 3 4 |
| 21. I have given up my search for the complete elimination of my pain through the work
of the medical profession | 0 1 2 3 4 |
| 22. It is the responsibility of my loved ones to help me when I feel pain | 0 1 2 3 4 |
| 23. Stress in my life increases my pain | 0 1 2 3 4 |
| 24. Exercise and movement are good for my pain problem | 0 1 2 3 4 |
| 25. Just by concentrating or relaxing, I can "take the edge" off of my pain | 0 1 2 3 4 |
| 26. I will get a job to earn money regardless of how much pain I feel | 0 1 2 3 4 |
| 27. Medicine is one of the best treatments for chronic pain | 0 1 2 3 4 |

28. I am unable to control a significant amount of my pain	0 1 2 3 4
29. A doctor's job is to find effective pain treatments	0 1 2 3 4
30. My family needs to learn how to take better care of me when I am in pain	0 1 2 3 4
31. Depression increases the pain I feel	0 1 2 3 4
32. If I exercise, I could make my pain problem much worse	0 1 2 3 4
33. I believe that I can control how much pain I feel by changing my thoughts	0 1 2 3 4
34. Often I need more tender loving care than I am now getting when I am in pain	0 1 2 3 4
35. I consider myself to be disabled	0 1 2 3 4
36. I wish my doctor would stop prescribing pain medications for me	0 1 2 3 4
37. My pain is mostly emotional, and not so much a physical problem	0 1 2 3 4
38. Something is wrong with my body which prevents much movement or exercise	0 1 2 3 4
39. I have learned to control my pain	0 1 2 3 4
40. I trust that the medical profession can cure my pain	0 1 2 3 4
41. I know for sure I can learn to manage my pain	0 1 2 3 4
42. My pain does not stop me from leading a physically active life	0 1 2 3 4
43. My physical pain will never be cured	0 1 2 3 4
44. There is a strong connection between my emotions and my pain level	0 1 2 3 4
45. I can do nearly everything as well as I could before I had a pain problem	0 1 2 3 4
46. If I do not exercise regularly, my pain problem will continue to get worse	0 1 2 3 4
47. I am not in control of my pain	0 1 2 3 4
48. No matter how I feel emotionally, my pain stays the same	0 1 2 3 4
49. Pain will never stop me from doing what I really want to do	0 1 2 3 4
50. When I find the right doctor, he or she will know how to reduce my pain	0 1 2 3 4
51. If my doctor prescribed pain medications for me, I would throw them away	0 1 2 3 4
52. Whether or not a person is disabled by pain depends more on your attitude than the pain itself	0 1 2 3 4
53. I have noticed that if I can change my emotions, I can influence my pain	0 1 2 3 4
54. I will never take pain medications again	0 1 2 3 4
55. Exercise can decrease the amount of pain I experience	0 1 2 3 4
56. I'm convinced that there is no medical procedure that will help my pain	0 1 2 3 4
57. My pain would stop anyone from leading an active life	0 1 2 3 4

THE SF-36 HEALTH STATUS QUESTIONNAIRE

A survey of what people think about their own health

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer each question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking half a mile	1	2	3
i. Walking one hundred yards	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

(circle one)

- Not at all 1
- Slightly 2
- Moderately 3
- Quite a bit 4
- Extremely 5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

- None 1
- Very mild 2
- Mild 3
- Moderate 4
- Severe 5
- Very severe 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and the housework)?

(circle one)

- Not at all 1
- A little bit 2
- Moderately 3
- Quite a bit 4
- Extremely 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

(circle one)

- All of the time 1
- Most of the time 2
- Some of the time 3
- A little of the time 4
- None of the time 5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

THANK YOU