

THE EPIDEMIOLOGY OF CHRONIC PELVIC PAIN IN WOMEN

**by
Krina Tynke Zondervan**

**A thesis submitted for the degree of
Doctor of Philosophy**

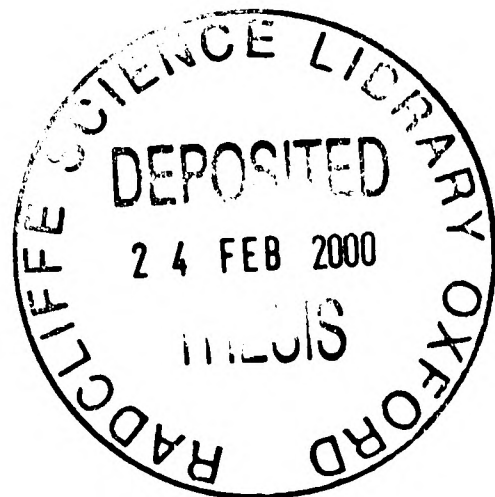


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St. Edmund Hall

Trinity Term 1999



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Abstract

Objectives – This study aimed to estimate for the first time in the UK:

- (1) the prevalence and incidence of chronic pelvic pain (CPP) in primary care, the duration of symptoms, and patterns of diagnosis and referral;
- (2) the prevalence of CPP in the community, and its overlap with other types of pelvic pain, irritable bowel syndrome (IBS) and genito-urinary symptoms. Pain severity, use of health care, functioning and well-being, and factors associated with CPP were also investigated.

Methods – (1) Retrospective analysis of the MediPlus UK Primary Care Database, using data for 1991-1995 of 278,509 women aged 12-70. CPP cases were identified on the basis of relevant contacts with practices. Duration of CPP and patterns of diagnosis and referral were investigated in a cohort of 5,051 incident cases followed for 3-4 years from their first contact for pelvic pain.

(2) Postal questionnaire survey of 4,000 randomly selected women aged 18-50 in Oxfordshire. Cases were women reporting CPP in the last 3 months, with sub-groups classified according to cumulative pain duration in the last 12 months.

Main results – (1) The annual prevalence of CPP in primary care was 38.3/1,000 (95% CI: 37.5-39.0), comparable to asthma (37/1,000) and back pain (41/1,000). The most common diagnoses given to incident cases were IBS and cystitis, but a quarter received no diagnosis and only 40% had a specialist referral. A third of incident cases had persistent symptoms after 2 years.

2) The community prevalence of CPP in women was 24.0% (95% CI: 22.1-25.8). CPP cases had a high prevalence of dysmenorrhoea (90%), dyspareunia (50%), IBS (39%), and genitourinary symptoms (24%). CPP cases of 'long' duration were much more affected in terms of pain severity, use of health care, and physical impairment than 'short' duration cases. All women with CPP appeared affected in terms of anxiety about their symptoms.

Conclusions – This study provided the first evidence of a high prevalence of CPP in primary care and the community. However, CPP cases varied substantially in the degree to which they were affected by their pain in physical terms. The anxiety in women with CPP about their symptoms emphasises the need for more information about CPP and its possible causes.

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When I arrived in Oxford in 1993 as an Erasmus exchange student from the University of Leiden, it was to work on a project in Biochemistry for the duration of one term. Now, 6 years on, I can say that I have enjoyed living and working here enormously, thanks to the support and friendship of a great many people.

I am particularly indebted to Professor Martin Vessey. He first engaged me to work on the Oxford FPA Contraceptive Study, for a re-analysis of the association between cervical neoplasia and oral contraceptives. His continued support and encouragement throughout my D.Phil. have been of tremendous value to me.

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Preface

This thesis describes the results of a collaborative study between the Department of Public Health (DPH), the Department of Primary Health Care (DPHC) and the Nuffield Department of Obstetrics & Gynaecology (NDOG) at the University of Oxford. The study was supported by a steering group consisting of the following persons:

Prof Martin Vessey	Professor of Public Health (DPH)
Prof David Barlow	Nuffield Professor of Obstetrics and Gynaecology (NDOG)
Mr Stephen Kennedy	Senior Fellow in Reproductive Medicine (NDOG)
Dr Patricia Yudkin	University Research Lecturer (DPHC)
Dr Crispin Jenkinson	Deputy Director, Health Services Research Unit (DPH)
Dr Martin Dawes	Lecturer in Primary Care (DPHC)
Ms Krina Zondervan	Research Officer (DPH/NDOG)

To date, the study has resulted in the following publications:

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K.T. Zondervan, P.L. Yudkin, M.P. Vessey, M.G. Dawes, D.H. Barlow, S.H. Kennedy. Patterns of diagnosis and referral in women consulting for chronic pelvic pain in UK primary care. *Br.J.Obstet.Gynaecol.* **106**, 1156-61.

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List of abbreviations

CI	Confidence interval
COC	Combined oral contraceptive
CPP	Chronic pelvic pain
GCT	Gate control theory
GI	Gastrointestinal
GnRH	Gonadotrophin-releasing hormone
GP	General practitioner
HRT	Hormone replacement therapy
IASP	International Association for the Study of Pain
IBS	Irritable bowel syndrome
IMS	Intercontinental Medical Statistics Ltd
IQ	Interquartile range
MCS	Mental component summary (of SF-36)
MPA	Medroxyprogesterone acetate
NSAID	Non-steroidal anti-inflammatory drug
OC	Oral contraceptive
OHA	Oxfordshire Health Authority
OHLS	Oxfordshire Healthy Life Survey
OR	Odds ratio
ORS	Ovarian remnant syndrome
OTC	Over-the-counter
PCS	Physical component summary (of SF-36)
PID	Pelvic inflammatory disease
PRI	Pain rating index
RCT	Randomised controlled trial
ROS	Residual ovary syndrome
RR	Risk ratio
SF-36	Short-form 36 health survey
VAS	Visual analogue scale
VRS	Verbal rating scale

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Chapter 1

Introduction

1.1 What is pain?

Pain has been defined by the International Association for the Study of Pain (IASP) as ‘an unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in those terms’ (International Association for the Study of Pain, 1986). They defined chronic pain as ‘that which continues a month beyond the usual course of an acute disease or beyond the expected healing time after an injury’.

Several different models for pain perception have been developed over the years. Early pain theories (the ‘medical’ or ‘Cartesian’ model) postulated a direct relationship between tissue damage and pain perception through stimulation of specific pain fibres directly connecting to the cerebral cortex. This model explained acute pain fairly well, but led to an oversimplified categorisation of chronic pain into ‘real’ when associated with identifiable pathology or tissue injury, and ‘not real’ or ‘psychogenic’ if it occurred in the absence of obvious pathology (Reiter, 1998). The Gate Control Theory (GCT) added several new elements to pain theory (Melzack & Wall, 1965): 1) transmission of ‘nociceptive’ (uncomfortable) signals by several types of peripheral fibres, including those sensitive to extreme heat, mechanical pressure, or chemical mediators of inflammation; 2) bi-directional transmission of information between the periphery and the brain; 3) modulation of peripheral nociceptive signals by motivational and affective states (Steege *et al.*, 1993). This modulation occurs through the impact of descending signals on ‘control transmission cells’ of the spinal cord, which in turn act as a ‘gate’ that regulates the transmission of peripheral nociceptive signals to the brain. The GCT contradicts the notion that pain is either somatic or psychogenic, and suggests that both have potential aggravating or moderating effects on pain perception, particularly so in chronic pain (Milburn *et al.*, 1993).

Cognitive-behavioural theory has further refined the GCT: more recent models suggest that how one thinks about the pain ('cognitions') and the impact of these cognitive variables on behaviour (e.g. level of activity, investment in relationships) influences the intensity of the pain, associated disability, and the potential success of treatment and prognosis (Loeser & Melzack, 1999; Chapman & Gavrin, 1999). From this perspective, chronic pain is no longer seen as determined by purely physical factors, but is put in a 'biopsychosocial' context, i.e. resulting from complex inter-relationships between nociceptive stimulation, psychological factors, and socio-environmental factors, with each of these components capable of influencing each other (Reiter, 1998). The model could explain how somatic symptoms may be very prevalent in the general population, but could vary to a great extent in terms of levels of severity and disability depending on coexistence of specific psychosocial conditions. Similarly, it could explain how eradication of the nociceptive stimulus (e.g. by surgery) without alteration of the psychosocial state may not produce permanent pain relief (Milburn *et al.*, 1993).

1.2 What is chronic pelvic pain?

The topic of this thesis is chronic pelvic pain (CPP) in women, although it is acknowledged that CPP can also occur in men (Luzzi & O'Leary, 1999). The definition of chronic pain by the IASP given in the previous section, based on continuation of pain beyond an expected healing time, is not readily applicable to CPP. Different studies have therefore used different definitions, and no consensus yet exists on the most appropriate one.

The most commonly used definition of CPP only considers the location and duration of the pain: recurrent or constant pain in the lower abdominal region (excluding the vulva) that has lasted for at least six months (Campbell & Collett, 1994). Women with pelvic pain related to pregnancy or malignancy are usually excluded, as are those who *only* experience pelvic pain around menstruation (dysmenorrhoea) or during or shortly after sexual

intercourse (dyspareunia). However, dysmenorrhoea and dyspareunia are common symptoms in women with CPP and should be seen as part of their pelvic pain pattern. Indeed, pelvic pain in CPP patients is often exacerbated around the time of menstruation and intercourse.

Although the choice of six months' duration within this definition is arbitrary (is pain lasting for three months not chronic?), it does not carry the anatomic or affective-behavioural assumptions of other types of definitions used (Steege *et al.*, 1993). For example, CPP has been defined by the IASP (1986) as chronic or recurrent pelvic pain that cannot be sufficiently explained by an apparent physical cause¹. There are several problems with this type of definition. Firstly, it utilises the simple theories of pain perception and assumes that 1) it is possible to directly link pain with a form of tissue damage or pathology, and 2) that causes of pain can be divided simply into 'organic/anatomic' and 'non-organic/functional'. Furthermore, it assumes that all possible pathology underlying pelvic pain is known and well established, and that it can always be reliably detected through laparoscopy. It also assumes that all endoscopic surgeons irrespective of their training, skill, or clinical experience would interpret the pelvic findings in the same way. It is clear from the enormous diversity of opinion in the literature as to what causes CPP (see section 1.3) that these assumptions cannot be taken for granted.

Affective-behavioural definitions of CPP generally include a need for pain to be accompanied by 'significantly altered' physical activity or disturbance of mood, or 'significant' analgesics use (Steege *et al.*, 1993; Howard, 1993). These types of definitions are highly subjective. Who can determine whether the effect that CPP has on a woman's life is significant? Similarly, is it appropriate to classify women as CPP patients according to how well they can cope with their pelvic pain?

¹ This condition has also been referred to as 'the pelvic pain syndrome' (Robinson, 1993) or 'pelvalgia' (Reiter, 1990).

The definition of CPP chosen for this thesis is therefore the one that has been most commonly used and that carries no assumptions about causation or related effect on functioning and well-being:

*‘constant or recurrent pain in the lower abdominal region lasting for at least 6 months, excluding vulvodynia, pain related to pregnancy or malignancy, or pain that occurs **only** with menstruation or intercourse’*

1.3 Possible causes of CPP

Following modern multidimensional pain models, Howard *et al.* (1993) stated that chronic pain can have several possible causes or combination of causes: 1) chronic pathologic processes in somatic structures or viscera; 2) prolonged or permanent dysfunction of the peripheral or central nervous system; 3) psychological mechanisms; 4) (socio)environmental factors. This model has also been referred to by others as the ‘biopsychosocial model’ (Milburn *et al.*, 1993; Reiter, 1998). Below, an overview is given of the possible somatic, psychological and socio-environmental conditions associated with CPP. It should be noted that most diagnostic labels are assigned by individual specialists (e.g. gynaecologists or gastro-enterologists) within the context of clinical studies. They do not necessarily reflect a multi-disciplinary approach to the set of symptoms (Kamm, 1997).

1.3.1 Gynaecological diagnoses

1.3.1.1 Endometriosis

Endometriosis is a condition characterised by the presence of implants of endometrium outside the uterine cavity (Olive & Schwartz, 1993). It is distinguished from adenomyosis, defined as the presence of endometrium in the uterine muscle (myometrium). The pathologic mechanism of endometriosis is unknown, but several hypotheses have been proposed. It is thought that uterine endometrium may be transplanted through ‘retrograde menstruation’

(menstrual blood flowing up the fallopian tubes and into the peritoneal cavity) or via lymphatic, vascular or iatrogenic dissemination. It has also been proposed that endometriosis may develop through the metaplastic transformation of cells lining the pelvic peritoneum ('coelomic metaplasia'). Another theory combines these two hypotheses and suggests that unknown substances from shed endometrium induce undifferentiated cells in the peritoneum to form endometriotic tissue.

Several theories have been suggested to explain how endometriosis could cause pain (Mahmood *et al.*, 1991). Fibrotic tissue, adhesions, and scarring around the endometrial deposits have been implicated (Beard & Reginald, 1992). Higher production of prostaglandins by the endometrium of women with endometriosis (Mahmood *et al.*, 1991), local inflammation and the release of prostaglandins by endometriotic deposits, and increased amounts of peritoneal fluid with high prostanoid content (Barlow & Glynn, 1993) have also been suggested as a cause for the pain.

Endometriosis can only be reliably diagnosed by laparoscopy or laparotomy (Olive & Schwartz, 1993). In a review of 16 studies, prevalence rates of endometriosis in women with CPP having undergone laparoscopy varied from 4% to 65% (Mahmood & Templeton, 1991). Disease severity has been classified by the American Fertility Society into four stages on the basis of the size of the implants, whether they are superficial or deep, and the severity of adhesion formation (The American Fertility Society, 1985). The severity of endometriosis, however, correlates poorly with pain severity (Barlow & Glynn, 1993). Although it is likely that severe disease, e.g. with bowel involvement, is likely to be associated with pelvic pain, the relationship between milder forms of endometriosis and pelvic pain is much more questionable. Indeed, minimal to mild endometriosis is found in approximately 20% of asymptomatic women undergoing laparoscopy for tubal sterilisation (Waller *et al.*, 1993). Some investigators have therefore proposed that minimal and mild endometriosis should not be seen as pathological (Wardle & Hull, 1993; Balasch *et al.*, 1996).

1.3.1.2 Pelvic inflammatory disease

Pelvic inflammatory disease (PID)² is defined as inflammation of the upper genital tract, comprising the endometrium, ovaries, fallopian tubes, myometrium, and parametrium (Pearce, 1990). It most commonly manifests itself as endometritis (infection of the endometrium) or salpingitis (infection of the fallopian tube), and results from ascending bacterial infection of the lower genital tract (Grodstein & Rothman, 1994). The organisms most commonly implicated are *Neisseria gonorrhoeae* and *Chlamydia trachomatis*, which are sexually transmitted (Lee *et al.*, 1991).

The mechanism by which infection progresses from the lower to the upper genital tract remains unclear. Suggested pathways have included retrograde menstruation, iatrogenic factors (termination of pregnancy, insertion of intra-uterine contraceptive devices), hormonal factors (thinning of the cervical mucus during menstruation and ovulation), and coital factors (uterine contractions and spermatozoa as organism carriers). If left untreated, PID can have serious consequences such as infertility and ectopic pregnancy (Padian & Washington, 1994; Mitchell, 1993).

A distinction is often made between acute and chronic PID. Although chronic PID implies some persistent subclinical infective process, it is more often thought to be due to recurrent infections. It is hypothesised that CPP is a consequence of multiple, acute pelvic infections leading to permanent damage to pelvic tissues, although it is uncertain whether the pain is linked to recurrent infections or to resulting adhesions (Beard & Reginald, 1992).

As with endometriosis, laparoscopy is the reference method for diagnosing PID, although this method may not be able to detect infection that is not visible on the peritoneal surface (Padian & Washington, 1994). In CPP patients undergoing laparoscopy, PID has been found in 16-30 % (Beard & Reginald, 1992). Often, though, a diagnosis is made on the basis of

² Although PID is here given under the heading of 'gynaecological diagnoses', women are often referred to and diagnosed in genito-urinary clinics.

non-invasive criteria, which are much less specific (Pearce, 1990). These include cervical or uterine tenderness combined with a high temperature, abnormal cervical or vaginal discharge, elevated erythrocyte sedimentation rate in blood, and positive cultures of *Neisseria gonorrhoeae* or *Chlamydia trachomatis* from the cervix.

1.3.1.3 Adhesions

Adhesions can occur with the development of endometriosis, after abdominal surgery, or as a result of (untreated) pelvic inflammatory disease. It has been proposed that pain from adhesions results from activation of pain receptors by tension and traction of the peritoneum and pelvic organs. However, it is controversial whether adhesions actually cause pelvic pain. (Beard & Reginald, 1992).

Saravelos *et al.* (1995) reviewed the evidence concerning adhesions as a cause of pelvic pain. In 8 studies (5 of which were prospective) of asymptomatic women undergoing laparoscopic sterilisation, adhesions were found in approximately 15% of women (range: 7-34%). This figure compares to a mean of 36% (range: 8-60%) in 18 studies of women with CPP undergoing laparoscopy. Although the authors appear to conclude from these results that adhesions are likely to cause CPP, the data presented do not provide evidence of such a causal link. Firstly, it was unclear what inclusion criteria the different studies used. Furthermore, a number of the studies included in the review were retrospective and therefore may have been subject to investigator bias. In addition, there appear to be very limited data on the severity of pain in relation to the extent of adhesions.

Perhaps more informative are the results of the single, prospective, randomised trial of laparoscopic adhesiolysis by Peters *et al.* (1992). They reported no benefit in terms of pain and quality of life outcomes between 24 women with adhesions who had undergone adhesiolysis compared with 24 who had not, after 9-12 months' follow-up. Only a small subset of women with dense adhesions involving the bowel appeared to benefit from the

procedure, strengthening the generally accepted hypothesis that such severe adhesions can be a cause of CPP (Saravolos *et al.*, 1995; Reiter, 1998).

1.3.1.4 Other gynaecological diagnoses

The other gynaecological diagnoses less commonly associated with CPP include ovarian cysts, uterine fibroids, uterovaginal prolapse, the residual ovary syndrome, the ovarian remnant syndrome, and pelvic congestion. Ovarian cysts have occasionally been associated with pelvic pain, although they are mostly reported to produce acute pain (Howard, 1993). Uterine fibroids have also been associated with pelvic pain, although pelvic heaviness is a more common symptom. Uterovaginal prolapse has been reported to cause a chronic dragging sensation in the vagina that is sometimes perceived as pain.

The residual ovary syndrome (ROS) occurs in an estimated 1-3% of women who have had a hysterectomy with conservation of one or both ovaries (Beard & Reginald, 1992; Siddall-Allum *et al.*, 1994). At laparoscopy, most women with ROS have severe adhesions involving one of both ovaries. It is therefore thought likely that the pain is due to the tension within developing follicles in an ovary covered with adhesions (Beard & Reginald, 1992). Ovarian remnant syndrome (ORS) is defined as the persistence of functioning ovarian tissue following an apparently complete bilateral oophorectomy. The pain mechanism associated with ORS is unclear. Although its prevalence is unknown, the condition is thought to be rare (Steege, 1987).

A condition that has been proposed by some investigators as a major cause of CPP in women without pathology at laparoscopy, is pelvic congestion (Drife, 1993; Beard *et al.*, 1988; Carey & Beard, 1996). First suggested as a cause for pelvic pain in the late 1940s (Taylor, 1949), it is defined as the presence of dilated pelvic veins combined with vascular stasis seen at transcervical venography (a radiological method for displaying the pelvic veins) (Carey & Beard, 1996). It has been mainly Beard's group who have favoured the

hypothesis of pelvic congestion causing pelvic pain. They observed moderate to severe pelvic congestion (dilated veins combined with the slow disappearance of contrast medium during venography) in 41 out of 45 CPP patients without pathology at laparoscopy, compared with 0 out of 10 women with pathology (endometriosis, PID, or adhesions) and 2 out of 8 asymptomatic women who had undergone laparoscopic sterilisation (Beard *et al.*, 1984). In a subsequent study, Beard *et al.* (1988) compared clinical features of 35 women with pelvic congestion to those of 22 women with 'classical pathology' (endometriosis, PID, and fibroids), and suggested that the presence of postcoital ache and ovarian point tenderness could distinguish women with pelvic congestion from those with other causes.

Suggested reasons for the development of dilated pelvic veins include the absence of valves in pelvic veins combined with the effect of gravity, abnormal increases in blood flow through the pelvic region, and relaxation of smooth muscle in the walls of the pelvic veins caused by an unknown vasoactive substance or neurological dysfunction (Beard *et al.*, 1984). Suggested ways in which pelvic congestion could cause pain include the physical distension of the veins and release of pain-producing substances caused by the reduction in blood flow (Beard & Reginald, 1992).

1.3.2 Gastrointestinal diagnoses

Pain of gastrointestinal origin is thought to be derived from intestinal distension, disturbed motility (smooth muscle spasms), inflammation, or ischaemia (Rapkin & Mayer, 1993). Since the cervix, uterus and adnexa share the same visceral innervation with the lower ileum, colon, and rectum, it can be very difficult to distinguish gynaecological from gastrointestinal factors resulting in CPP. In addition, gastrointestinal pain is often poorly localised and may be referred to the same dermatome (the skin area innervated by the fibres in a single spinal nerve) as pain originating from the reproductive organs (Rapkin & Mayer, 1993). The fluctuation of gastrointestinal symptoms with menses (Moore *et al.*, 1998) and

the high prevalence of dyspareunia and urinary symptoms in patients with irritable bowel syndrome (IBS) (Whorwell *et al.*, 1986) add further to this confusion.

IBS is by far the most common gastrointestinal diagnosis associated with CPP. It is classified as a 'functional bowel disorder', which is defined as the presence of gastrointestinal symptoms or dysfunction without detectable structural or biochemical abnormality (Thompson *et al.*, 1992). In the past, IBS was a diagnosis made after exclusion of other conditions. In 1978, however, Manning proposed a set of six criteria to positively identify an IBS patient (abdominal distension, pain relief with bowel movements, more frequent stools with onset of pain, looser stools with onset of pain, passage of mucus, and sensation of incomplete evacuation). These criteria were further developed in 1988 by an international working group, resulting in the 'Rome Criteria' (Thompson *et al.*, 1989), which were altered slightly in 1992 (see below) (Thompson *et al.*, 1992). No complete consensus, however, exists for the diagnosis of IBS, and different definitions are still being used (Kay *et al.*, 1998).

The 'Rome' criteria for diagnosis of IBS

At least three months of continuous or recurrent symptoms of:

1. abdominal pain or discomfort which is:
 - (a) relieved with defaecation, and/or
 - (b) associated with a change in frequency of stool, and/or
 - (c) associated with a change in consistency of stool;
 - and***
 2. two or more of the following, on at least a quarter of occasions or days:
 - (a) altered stool frequency (>3 bowel movements/day or <3 bowel movements/week);
 - (b) altered stool form (lumpy/hard or loose/watery stool);
 - (c) altered stool passage (straining, urgency, or feeling of incomplete evacuation);
 - (d) passage of mucus;
 - (e) bloating or feeling of abdominal distension.
-

High prevalence rates of IBS (50-79%) have been found in women referred to gynaecology for CPP (Prior *et al.*, 1989; Hogston, 1987; Walker *et al.*, 1991). Similarly, in a

study of 60 women referred to a gastroenterological clinic for IBS, 35% were classified as CPP patients (with at least 6 months of ‘medically unexplained’ lower abdominal pain which was attributed to the reproductive system) (Walker *et al.*, 1996).

Other gastrointestinal diagnoses less commonly associated with CPP are diverticular disease/diverticulitis, constipation, and inflammatory bowel disease (although the latter condition is sometimes excluded from CPP definitions). Diverticular disease (or diverticulosis) is a condition in which small pouches are formed in the wall of the colon. Inflammation of these diverticulae is referred to as diverticulitis, and may result in symptoms similar to IBS: lower abdominal pain and disturbed bowel habit (Rapkin & Mayer, 1993). Constipation, defined as persistent symptoms of difficult, infrequent or seemingly incomplete defaecation (Thompson *et al.*, 1992), is sometimes associated with pain. The majority of patients with inflammatory bowel disorders (Crohn’s disease and ulcerative colitis) have lower abdominal pain, but this is usually accompanied by more severe bowel disturbance and/or the passage of blood (Rapkin & Mayer, 1993).

1.3.3 Urological diagnoses

The principal urological diagnoses associated with CPP are interstitial cystitis and the urethral syndrome (Moore & Kennedy, in press). Interstitial cystitis is a chronic inflammatory condition of the bladder wall. Although no consensus exists, its diagnostic criteria include symptoms such as frequency, urgency, nocturia, and suprapubic pain, negative urine culture, and certain features visible at cystoscopy. The cause for inflammation is unknown, but suggested mechanisms have included an autoimmune disorder, excessive permeability of the bladder wall to noxious substances in the urine (Summitt, 1993), and neurogenic inflammation following infection or trauma (Elbadawi, 1997). In a survey of 374 patients who were attending a urology clinic or were members of the Interstitial Cystitis Association, 66% reported CPP and 50% dyspareunia (Koziol *et al.*, 1993).

The urethral syndrome has been described as a condition in which irritative lower urinary tract symptoms are present for which no pathologic cause is found (Summitt, 1993). These symptoms include urinary urgency, frequency, and dysuria, which often lead to a misdiagnosis of urinary tract infection. The causes of the syndrome are unknown, although many have been proposed. One theory has been the presence of chronic urethral infection due to pathogenic bacteria, with a colony count of less than 10^5 /ml (the criterion used for acute cystitis), perhaps in combination with urethral spasm (Summitt, 1993). Others have suggested it may be a variation or earlier form of interstitial cystitis (Moore & Kennedy, in press).

1.3.4 Musculo-skeletal and nerve-related diagnoses

Pelvic pain of musculo-skeletal origin has been reported to be very similar in quality to that associated with gynaecological conditions, and it may also vary with menstruation (Baker, 1993). Several musculo-skeletal diagnoses of CPP have been suggested. Firstly, ‘mechanical’ pelvic pain – i.e. pain arising from the bony structure of the pelvis – may occur. For instance, pregnancy or trauma can result in malalignment of the pelvic bones. Poor posture can cause mechanical strain on joints, ligaments and muscles and act either as a primary factor for CPP or, if secondary to the pain, aggravate or perpetuate it (Moore & Kennedy, in press).

Another type of musculo-skeletal pain is so-called ‘myofascial pain’ (pain associated with muscles or fascia). Myofascial pain was reported by Reiter and Gambone (1991) as ‘the most common diagnosis’ in 122 CPP patients with negative findings at laparoscopy presenting to their tertiary multidisciplinary CPP clinic. This type of pain is thought to be indicated by the presence of ‘trigger points’ (localised areas of hyper-irritability) on the abdominal skin or in the abdominal wall. Diagnosis is made by reproduction of the pelvic pain by pressure on these points. Subsequent injection of a local anaesthetic has been suggested to provide short-

term as well as long-term relief of the pain (Slocumb, 1984). ‘Tension myalgia’ (muscle spasm occurring in the pelvic floor) has also been reported as a cause of pelvic pain (Campbell & Collett, 1994).

Suggested nerve-related causes of CPP include nerve entrapment and neuropathic pain (i.e. pain due to damage of the nerve) (Moore & Kennedy, in press). Nerve entrapment may occur in scar tissue at sites of previous surgical incisions, and can be diagnosed on relief of the pain by local injection of anaesthetics (Beard & Reginald, 1992). Others have suggested that pelvic pain may result from a regional neurological dysfunction (which – as mentioned in section 1.3.1.4 – may be related to the presence of abnormally dilated veins seen in pelvic congestion) (Kamm, 1997).

1.3.5 The broader picture: influence of psychological and socio-environmental factors

The previous sections have illustrated the wide range of somatic conditions that may underlie CPP. The biopsychosocial model of CPP (Reiter, 1998), however, proposes that psychological (e.g. depression, anxiety, illness beliefs) and socio-environmental factors (e.g. social and family support, employment status) are likely to influence pain persistence and perceived severity, and may play a role in its aetiology.

Depression, anxiety, and to some extent neuroticism, have all been studied in relation to CPP. Generally, higher levels of these psychological conditions have been reported amongst CPP patients compared with symptom free controls, but similarly high rates have been reported in other chronic pain populations (Nolan *et al.*, 1992; Collett *et al.*, 1998; Campbell & Collett, 1994; Reiter, 1998). A high prevalence of sleep disturbance (difficulty falling asleep, frequent awakenings, and non-regenerative sleep) has also been reported in CPP patients compared with asymptomatic controls (Nolan *et al.*, 1992), with similar associations found in IBS patients (Whorwell *et al.*, 1986; Goldsmith & Levin, 1993). However, most

studies reporting these findings have tended to be small and used highly selected study groups identified from clinical settings.

A history of abuse is one of the socio-environmental factors that has most frequently been associated with CPP (Reiter, 1998; Campbell & Collett, 1994). Many studies have documented a higher prevalence of childhood and adult physical and sexual abuse in CPP cases compared with pain-free controls (Reiter & Gambone, 1990; Harrop-Griffiths *et al.*, 1988). Others, however, have not found these associations (Fry *et al.*, 1993) or have suggested that abuse rates in CPP cases were not different from other chronic pain patients (Rapkin *et al.*, 1990). These studies were small and principally conducted in secondary or tertiary care settings. One large study in the USA of 581 women approached in waiting areas of primary care clinics noted that both childhood and adult sexual abuse were more prevalent in women who had CPP³ compared to women without this pain (Jamieson & Steege, 1997). However, further analysis revealed that this prevalence was only elevated in women with childhood abuse continuing into adulthood.

Various other socio-environmental factors have been investigated, the most important of which have been the influence of sexual and relationship problems, and the role of 'significant others' (e.g. family). High levels of sexual and relationship problems have been reported in CPP patients as well as in other chronic pain patients, compared with pain-free controls (Savidge & Slade, 1997; Steege *et al.*, 1993). The level and type of support received from significant others has been implicated as potentially influencing pain aetiology and maintenance (Turk *et al.*, 1987; Flor *et al.*, 1989).

Two non-systematic reviews (Fry *et al.*, 1997; Savidge & Slade, 1997) and one meta-analysis (McGowan, in press) have tried to unravel the various conflicting findings of studies that addressed psychological and social factors in relation to CPP. In these articles, the most

³ CPP cases were defined as women who 'currently had pelvic pain always or often at times other than during menstruation or intercourse'.

important problems regarding many of these studies are summarised: inadequate sample sizes, the use of secondary or tertiary care study settings resulting in highly selected study groups, lack of comparability of CPP case definitions used (e.g. with/without pathology at laparoscopy), differences in types of control groups used (pain-free or other chronic pain patients), and lack of matching for duration of pain when comparing CPP cases with other pain patients. The use of traditional psychological assessment tools in CPP patients has also been questioned in that they were designed to measure general psychopathology or personality factors rather than being aimed at chronic pain populations (Steege *et al.*, 1993).

The meta-analysis by McGowan *et al.* (in press) included 22 studies of CPP patients and controls without or with other types of chronic pain. They concluded that CPP cases differed consistently from pain-free controls with regard to their ‘psychological profile’, with increased rates of depression, anxiety, neuroticism, somatisation, disease conviction, and past childhood and adult physical or sexual abuse. However, no such differences were found between CPP and other chronic pain cases, suggesting that these factors are linked to a chronic pain state rather than specifically to CPP. It should be noted that, to date, all studies addressing the potential influence of psychosocial factors on CPP were of cross-sectional design, i.e. both CPP and psychological profiles were investigated at the same point in time. It is unknown, therefore, whether the psychological characteristics preceded CPP symptoms, or whether they were secondary to the pain condition.

1.4 Assessment and treatment of CPP: the ‘integrative model’

It follows from the biopsychosocial model described previously that the assessment and treatment of CPP have to take account of all potential somatic, psychological and socio-environmental factors that may influence the pain. The traditional approach of diagnosing ‘psychogenic’ pain, after pathology that may account for the pain has been ‘excluded’ (mind/body dualism), is not helpful (Grace, 1998). Instead, there has been a call for a more

integrative, multi-disciplinary, approach in which all factors interacting in the multi-factorial pain model are addressed from the outset (Steege *et al.*, 1993; Milburn *et al.*, 1993; Turk & Rudy, 1987). Several studies assessing the effectiveness of this type of approach - including one randomised controlled trial of 106 women - have suggested that it significantly improved outcomes at 6 months – 1 year follow-up compared with the traditional approach (Kames *et al.*, 1990; Peters *et al.*, 1991).

In the following sections, a brief overview is given of the different assessment and treatment strategies for CPP. However, a detailed description with evidence of their effectiveness goes beyond the scope of this thesis.

1.4.1 Assessment

In the assessment of CPP, time should be taken for complete history taking, including assessment of pain severity and its relationship with the menstrual cycle, sexual intercourse, urinary symptoms, bowel pattern, and dietary habits. A standard questionnaire (e.g. based on the Rome criteria described in section 1.3.2) may be used to diagnose IBS. A thorough physical examination may reveal areas of abdominal tenderness specific to a certain type of somatic pathology or trigger points (Reiter, 1998).

Psychosocial evaluation is also part of a multi-disciplinary approach to CPP. A variety of questionnaires can be used to assess the impact of the pain on the life of the patient as well as psychosocial variables that may affect her ability to cope with the pain (Milburn *et al.*, 1993). For example, the West Haven-Yale Multidimensional Pain Inventory (WHYMPI) evaluates the adjustment to pain and its effect on different aspects of a patient's life (Kerns *et al.*, 1985). Various scales can be used for assessment of depression, anxiety, and social factors such as marital adjustment and social support. A detailed sexual history, including past abuse, may also be part of a comprehensive evaluation (Reiter, 1998).

A range of non-invasive investigations are commonly employed to assess the presence of somatic factors possibly associated with CPP. Screening laboratory tests, including blood counts, stool samples, and urine and cervical cultures, can be requested to locate possible infection (Milburn *et al.*, 1993). Imaging techniques such as ultrasonography or MRI may be useful in detecting pathology such as ovarian cysts.

Traditionally, however, laparoscopy has been considered the ‘gold standard’ for evaluating somatic conditions possibly associated with CPP (e.g. endometriosis, PID, adhesions). It is still a frequently used diagnostic tool in multi-disciplinary pain clinics (Milburn *et al.*, 1993), although its routine use has been questioned in view of the lack of correlation between observed pathology and pain described previously (Reiter, 1998). In 1976, over 20,000 diagnostic laparoscopies were performed in the UK, 53% of which were for pelvic pain (Chamberlain & Brown, 1978). In the USA, approximately 10-40% of laparoscopies are for the diagnosis of CPP (Reiter, 1990; Messer, 1992).

Different types of pathology are found at laparoscopy with varying degrees of frequency. In a comprehensive review, Howard *et al.* (1993) noted that in 11 studies of women with CPP the frequency with which no pathology was found at laparoscopy varied from 3-92%. The huge discrepancy in these results – which renders them largely uninterpretable – was likely to be due to the different definitions of CPP used, different inclusion criteria of patients, and the mostly retrospective design of the studies. In such studies, diagnostic results may well have been greatly influenced by investigator bias.

It is increasingly being recognised that optimal communication and understanding between CPP patient and doctor is an important aspect of the whole assessment (and treatment) process, and that this may well influence outcome (Selfe *et al.*, 1998). In a questionnaire survey of 144 women who had sought health care for CPP with GPs or gynaecologists in New Zealand, 44% felt their GP (and 27% their gynaecologist) had not adequately explained the given diagnosis, 42% said there had been occasions when they had

felt their doctor was not taking their pain seriously, and 45% reported the experience of ‘feeling less and less in control’ after numerous trips to a doctor without gaining understanding of why they were in pain (Grace, 1995).

1.4.2 Treatment

The choice of treatments for a CPP patient have tended to flow from the type of pain perception model adhered to (Steege *et al.*, 1993). A gynaecologist may first wish to ‘eliminate’ somatic pathology, choosing laparoscopic surgery as a first-line option. A psychotherapist, however, will obviously use a different approach.

The advantage of a multi-disciplinary setting for the treatment of CPP is that optimal use can be made of a wide range of treatment strategies from different disciplines. Within such a setting, choice of treatment depends on many circumstances. For instance, suspected pelvic infection, type and pattern of the pain, success or failure of previous treatments, the age of the woman, and her wish to conceive are all factors that are taken into account. In a meta-analysis of 65 studies, Flor *et al.* (1992) concluded that multi-disciplinary pain treatment benefited chronic pain patients in general in terms of pain reduction, mood, and interference, increased return to work and decreased use of health care. In relation to CPP, a randomised controlled trial showed that a multi-disciplinary pain strategy significantly improved 3 out of 4 outcomes (pain experience, daily activities, associated symptoms) at 1 year follow-up (Peters *et al.*, 1991). In the next sections, a brief description is given of the medical, surgical, and psychological interventions that a CPP patient can undergo as part of a multi-disciplinary, integrated, treatment strategy. It should be noted, however, that very few randomised controlled trials (RCT) of adequate quality have been performed to assess the effectiveness of these different interventions (Stones & Mountfield, 1998).

1.4.2.1 Medical treatments

Medical treatments that may be given to a CPP patient include 1) analgesics, 2) ovarian cycle suppressants, 3) antibiotics, 4) bulk-forming agents and antispasmodics, and 5) psychotropic agents. The most commonly given analgesics are non-steroidal anti-inflammatory agents (NSAIDs), such as ibuprofen or mefenamic acid. Narcotic drugs are rarely given, in view of the build-up of tolerance levels requiring increasingly higher doses, their obvious addictive properties, and possible exacerbation of bowel symptoms (Reiter, 1998).

Drugs that suppress the ovarian cycle – stopping menstruation and oestrogen production in the process – are commonly used in CPP if a strong cyclic component exists. They include 1) progestagens, 2) androgenic hormones, 3) gonadotrophin-releasing hormone (GnRH) analogues, and 4) the oral contraceptive pill. They all have different side-effects. Both combined oral contraceptives (COCs) and progestagens produce a state of pseudopregnancy. Side-effects of COCs are usually limited, but may include weight gain, headaches, nausea, and depression. The most commonly used progestagen is medroxyprogesterone acetate (MPA). Its side-effects may include irregular bleeding, nausea and bloating, and weight gain (Olive & Schwartz, 1993).

The androgenic hormones danazol and gestrinone act principally by displacing testosterone from sex hormone binding globulin and by inhibiting ovarian steroidogenesis. Their main side-effects (weight gain, hirsutism, acne, and deepening of the voice) are due to their androgenic activity (Shaw, 1997). GnRH analogues (e.g. buserelin, nafarelin) cause a reversible menopause-like state by downregulation of GnRH receptors in the pituitary gland. This inhibits gonadotrophin release resulting in hypo-oestrogenism. The side-effects are those of the menopause (hot flushes, headaches, atrophic vagina, and reduced bone density), which can be reduced with the use of ‘add-back’ hormone replacement therapy (Shaw, 1997).

When a positive cervical culture and preferably a diagnostic laparoscopy indicate PID, CPP patients should be treated with appropriate antibiotics (e.g. metronidazole and doxycycline). Similarly, urine cultures indicating lower urinary tract infections also indicate use of appropriate antibacterial therapy (e.g. trimethoprim).

If CPP patients have associated bowel symptoms, for instance IBS or constipation, bulk-forming agents (i.e. fibre supplementation) are often used in addition to a high-fibre diet. In the case of IBS, pain may be relieved by antispasmodics, which act as smooth muscle relaxants.

The psychotropic agents mainly used for CPP (and other chronic pain) are tricyclic antidepressants (e.g. amitriptyline). Originally, the mechanism of action in chronic pain was thought to be the treatment of depression alone. Studies showing pain reduction at doses much lower than required for depression, however, have suggested that there may be a direct analgesic effect (Milburn *et al.*, 1993).

Other treatments that are often used in patients with abdominal trigger points, include transcutaneous electric nerve stimulation (TENS), acupuncture, and local injection of anaesthetics (Reiter, 1998).

1.4.2.2 Surgical treatments

Surgical treatment of CPP can be conservative (removal of visible disease while leaving the pelvic organs in place) or radical (removal of pelvic organs) (Steege *et al.*, 1993). For obvious reasons, conservative surgery is preferred in the younger woman who still wishes to conceive.

Conservative surgery is usually performed laparoscopically now, and often at the time of a diagnostic laparoscopy (Reiter, 1998). The main procedures carried out laparoscopically are adhesiolysis (cutting of adhesions) and surgical excision or laser ablation of endometriotic deposits. The effectiveness of these treatments remains unclear. A prospective,

randomised, trial questioned the benefit of adhesiolysis in all but severe cases with bowel involvement (Peters *et al.*, 1992), whereas the single randomised trial assessing the effectiveness of ablating endometriotic deposits (Sutton *et al.*, 1994) could not be interpreted because all patients in the treatment arm also received laparoscopic uterosacral nerve ablation (Reiter, 1995). Although based on little evidence, it has been suggested that diagnostic laparoscopy itself (or rather the reassurance following a negative laparoscopy) may have a therapeutic effect: in a study of 60 women with CPP who were monitored after negative laparoscopy, 58% were pain-free after 6 months follow-up (Baker & Symonds, 1992).

Hysterectomy (usually with bilateral salpingo-oophorectomy) is often used as the ultimate treatment in women who have not responded to other interventions, especially in those who do not or no longer wish to have children. In the USA, CPP is listed as the indication for 10-12% of hysterectomies performed (Reiter, 1990). In a large cohort study of women attending family planning clinics in the UK, 7% of hysterectomies were reported to have been performed because of abdominal pain or endometriosis (Vessey *et al.*, 1992). There are, however, no randomised controlled trials on the efficacy of hysterectomy for CPP (Reiter, 1998). One retrospective study of medical records from 99 women with CPP who had undergone a hysterectomy reported a 'success rate' (complete resolution of pain) after one year of follow-up of approximately 75% (Stovall *et al.*, 1990), but this meant that pain persisted in a quarter of women who had undergone this major operation.

1.4.2.3 Psychological treatments

Reiter *et al.* (1998) described the importance of cognitive-behavioural therapy in the multi-disciplinary treatment of CPP patients. As part of this therapy, the patient is taught how to increase her sense of control over the pain, e.g. through relaxation techniques, stress management, pain-coping strategies, and distraction techniques that decrease the focus on

physical signals. Disability due to the pain is reduced by progressive activity programmes and encouragement to return to work. Furthermore, a patient's general health profile (which is often very poor) is targeted by education about nutrition, sleep, and exercise.

Additional psychotherapy can be used to focus on specific problems, such as clinical depression, anxiety, or eating disorders. Women with a past history of sexual or physical abuse may also benefit from additional psychotherapy targeting the trauma of these events. Marital and family counselling may also be offered when appropriate (Milburn *et al.*, 1993).

1.5 What is known about the epidemiology of CPP?

The objective of epidemiological studies is to provide information on the distribution of illnesses in different populations, and to identify factors associated with illness, in an effort to shed light on potential mechanisms of causation. The next few sections describe the current knowledge about prevalence, incidence, and risk-factors for CPP.

1.5.1 Prevalence and incidence of CPP

In a recent population-based study in the USA, the 3-month period prevalence of CPP (pelvic pain of at least six months' duration) was found to be 15% in 5,263 women aged 18-50 (Mathias *et al.*, 1996). These authors stated that their study was the first to report a prevalence estimate for CPP in the general population.

In the UK, the epidemiological characteristics of CPP appear to have received little or no attention. Published UK studies on CPP have mainly focused on the pathology found at laparoscopy (Mahmood *et al.*, 1991; Liu & Hitchcock, 1986), and on possible alternative causes for the condition in those without obvious pathology (Beard *et al.*, 1984; Hogston, 1987; Fry *et al.*, 1993; Low *et al.*, 1993; Hodgkiss *et al.*, 1994; Waller & Shaw, 1995). A

systematic search was therefore carried out to find data that could provide an estimate of the prevalence of CPP in the general population, focusing on the UK (Zondervan *et al.*, 1998).

1.5.1.1 Methods of data searching

Although the main focus of the literature search was CPP, studies on dyspareunia, dysmenorrhoea, and abdominal pain/IBS were also reviewed, because of the possible overlap in symptoms.

The databases MedLine, EMBase, and PsycLit were systematically searched from their starting date until April 1999 (MedLine from January 1966, PsycLit from January 1974, and EMBase from January 1980). The search terms used to retrieve UK studies consisted of 'incidence', 'prevalence' or 'epidemiology' combined with the pain symptoms 'pelvic near pain', 'dyspareunia', 'dysmen*', or 'abdominal pain'. The search also included the terms 'endometriosis', 'adenomyosis', 'pelvic inflammatory disease', 'pelvic adhesions', 'irritable bowel syndrome', 'genitourinary pain', 'genitourinary symptoms', 'gastrointestinal pain', 'gastrointestinal symptoms', 'ovarian cysts', and 'pelvic congestion', to identify studies that might allow the prevalence of the four pain symptoms to be calculated. Searches were limited to papers published in the English language. Reference lists of selected papers were hand-searched back to 1960 for additional citations. To obtain papers for non-UK studies, the search terms of the four pain symptoms only were used, and reference lists of the papers retrieved were hand-searched.

Studies were included in the review (1) if they were community-based and reported the prevalence of any of the four pain symptoms, or (2) if they referred to a clinical population but reported the prevalence of any of the four pain symptoms in a disease-free control group. Furthermore, the results of these studies had to relate to adult populations. An additional criterion for studies reporting abdominal pain in both men and women was that specific prevalence rates for women had to have been calculated.

1.5.1.2 Prevalence of CPP

No community-based studies were found that provided an estimate of the prevalence of CPP (non-cyclical pelvic pain not related to intercourse) in the general UK population. The only study to provide a hospital-based estimate for the prevalence of CPP, defined as ‘recurrent pelvic pain unrelated to menstruation or coitus’, was conducted by Mahmood *et al.* (1991) in Aberdeen (Table 1.1). Their estimated prevalence was 39% in 559 pathology-free women having a laparoscopy for sterilisation or investigation of infertility. The inclusion of infertile women in this group may, however, partly account for this high prevalence rate, and the estimate cannot be assumed to relate to the general population.

Only two studies - both in the USA - appear to have been published on the prevalence of CPP that were community-based to some extent (Jamieson & Steege, 1996; Mathias *et al.*, 1996). In the study by Jamieson & Steege (1996) the prevalence of pelvic pain was assessed in 581 women aged 18-45 who were approached in waiting rooms of obstetrics and gynaecology and family medicine practices. Although one-third of these women were accompanying patients, their results were pooled with those of patients, which made the results only partly community-based and therefore unsuitable for generalisation to the population. Thirty-nine percent of women reported having some degree of pelvic pain, while 20% reported pelvic pain of more than 1 year’s duration. As previously mentioned, Mathias *et al.* (1996) investigated the prevalence of CPP and its relation to functioning and well-being in a telephone survey of 5,263 women aged 18-50 randomly selected from the general US population. CPP (of at least six months’ duration and with pain having occurred in the past three months) was reported by 15% of these women (95% C.I.: 13-17%).

1.5.1.3 Prevalence of dyspareunia

Prevalence rates for non-cyclical pelvic pain related to intercourse were reported in one community-based study and two hospital-based studies in the UK (Table 1.1). In a

Table 1.1. The prevalence of non-cyclical (dyspareunia and chronic pelvic pain not related to intercourse) and cyclical (dysmenorrhoea) pelvic pain as observed in community-based studies and control groups in hospital-based studies in the UK

Reference	Study aim	Methods (type of study, population and setting, method of data collection)	Prevalence rates of non-cyclical pelvic pain (95% confidence intervals)	Prevalence rates of cyclical pelvic pain (95% confidence intervals)
<u>Community-based studies</u>				
Osborn et al., 1988 (1) and Gath et al., 1987 (2)	(1): prevalence of sexual dysfunction in the community (2): prevalence of psychiatric disorders and gynaecological symptoms in the community	(1)+(2): cross-sectional questionnaire survey in 2 selected general practices of 521 randomly selected women aged 35-59; (1): 379 women with partners; (2): 265 pre-menopausal women	(1): 'operational dyspareunia' ² : 8% (5-11) (0% in 35-39 yr to 17% in 55-59 yr)	(2): 'any dysmen. past 6 months': 57% (43-71) 'at least half the periods': 48% (36-60) 'interfering with daily life': 15% (10-20) 'usually taking medication': 36% (27-45)
Kessel & Coppen, 1963	prevalence of common menstrual symptoms	cross-sectional questionnaire survey: 463 women aged 18-45 randomly selected from 10 general practices;	-	'moderate dysmenorrhoea': 33% (27-39) 'severe dysmenorrhoea': 12% (9-15)
Hewison & van den Akker, 1996	prevalence of dysmenorrhoea, menstrual attitude and GP consultation	cross-sectional questionnaire survey: 70 student volunteers aged 18-26;	-	'mild dysmenorrhoea': 30% (15-45) 'moderate dysmenorrhoea': 53% (28-78) 'severe dysmenorrhoea': 14% (4-24)
<u>Hospital-based studies</u>				
Liu et al., 1986	association between endometriosis, retrograde menstruation, and dysmenorrhoea	prospective study: 75 women aged 26-48, admitted for laparoscopic ST; questionnaire	-	'dysmenorrhoea': 55% (30-80)
Whorwell et al., 1986	prevalence of non-colonic symptoms in IBS cases and controls	retrospective case-control study 90 IBS-free women from staff registers of local commerce and industry, aged 18-64; questionnaire	'dyspareunia' (in IBS/-): 5% (0-10)	'dysmenorrhoea' (in IBS/-): 42% (24-60)
Mahmood et al., 1991	prevalence of menstrual symptoms in women with and without pelvic endometriosis	prospective study: 559 control women admitted for laparoscopy for INF/ST without pelvic pathology at laparoscopy; questionnaire	'deep dyspareunia': 16% (7-25) 'pain after intercourse': 4% (3-5) 'recurrent pelvic pain unrelated to menstruation or coitus': 39% (32-46)	'dysmenorrhoea': 41% (34-48)
Shah et al., 1994	prevalence of menstrual symptoms in HIV ¹ -positive women and controls	retrospective case-control study: 55 HIV-negative controls from genitourinary and family planning clinics, aged 21-49; MDS-AM questionnaire ¹ for severity of dysmenorrhoea	-	'dysmenorrhoea' (in HIV/-): 62% (28-92) 'mild' ¹ : 26% (11-41) 'moderate' ¹ : 26% (11-41) 'severe' ¹ : 11% (2-20)

Abbreviations: IBS= irritable bowel syndrome; INF= infertility; HIV=human immunodeficiency virus; ST= sterilization.

¹ MDS-AM questionnaire= multidimensional menstrual pain questionnaire developed by Andersch & Milsom (1982). Dysmenorrhoea defined as 'mild' (painful but seldom inhibits woman's normal activity, analgesics seldom required), 'moderate' (daily activity affected, analgesics required and give relief so that absence from work or school is unusual), and 'severe' (activity clearly inhibited, poor effect of analgesics, vegetative symptoms).

² 'Operational dyspareunia' defined as 'pain or discomfort causing difficulties during intercourse more than half of the time during the previous 3 months'.

community-based study on sexual dysfunction in Oxford, ‘operational dyspareunia’ (pain or discomfort causing difficulties during sexual intercourse more than half the time during the previous 3 months) was found in 8% of 379 women aged 35-59 with partners (Osborn *et al.*, 1988). However, no distinction was made between superficial dyspareunia (felt mainly at the introitus at initial penetration) and deep dyspareunia (felt mainly on deep penetration) (Setchell, 1981). In a small hospital-based study in Manchester, investigating the prevalence of ‘non-colonic symptoms occurring more than once per 2 weeks’ in 90 IBS patients and 90 IBS-free controls, dyspareunia was reported by 5% of controls (Whorwell *et al.*, 1986). The exact definition of dyspareunia used in this study, however, was unclear. In the hospital-based study by Mahmood *et al.* (1991), prevalence rates of ‘deep dyspareunia’ and ‘pain after intercourse’ were 16% and 4%, respectively, in 559 pathology-free women.

Prevalence rates for dyspareunia observed in community-based studies outside the UK were considerably higher than UK rates, but definitions varied greatly. Amongst 313 US women in their 30s, the prevalence of dyspareunia (pain or discomfort in the labial, vaginal, or pelvic area during or after intercourse) was 34%, while 61% reported having had dyspareunia ‘at some point in life’ (Glatt *et al.*, 1990). In the previously quoted study by Jamieson & Steege (1996), 45% of the 18-45 yr old American women approached in clinic waiting areas reported having dyspareunia during or after intercourse (sometimes, often, or always).

1.5.1.4 Prevalence of dysmenorrhoea

Prevalence rates for cyclical pelvic pain in the UK were reported in three community-based and four hospital-based studies (Table 1.1). In a community-based study of 463 women aged 18-45 in the 1960s, randomly selected from 10 general practices in different areas of England, an overall prevalence for dysmenorrhoea of 45% was observed, with 12% reporting ‘severe’ dysmenorrhoea (Kessel & Coppen, 1963). Another community survey of

521 middle-aged women in Oxford found a prevalence of 57% for 'any dysmenorrhoea in the past 6 months' in 265 pre-menopausal women, while 48% reported dysmenorrhoea during at least half their periods (Gath *et al.*, 1987). A survey in Birmingham of 70 nursing undergraduates aged 18-26 found a prevalence rate as high as 97% for any dysmenorrhoea (Hewison & van den Akker, 1996). The results of this study, however, are likely to have been influenced by the use of volunteers.

Prevalence estimates for dysmenorrhoea in control subjects in the four hospital-based studies were similar to those observed in the community studies, and ranged from 41% to 62% (Mahmood *et al.*, 1991; Liu & Hitchcock, 1986; Whorwell *et al.*, 1986; Shah *et al.*, 1994). In three of these studies, however, the definition of dysmenorrhoea was not specified (Mahmood *et al.*, 1991; Liu & Hitchcock, 1986; Whorwell *et al.*, 1986). Only one small hospital-based case-control study, examining the association between menstrual symptoms and HIV-positivity, investigated the severity of dysmenorrhoea using a well-defined multidimensional questionnaire developed by Andersch & Milsom (1982). The observed prevalence of dysmenorrhoea was 62% in 55 HIV/negative women (Shah *et al.*, 1994).

In studies outside the UK, reported rates of dysmenorrhoea were similar. In a Norwegian survey of 234 female industrial workers aged 18-50, 50% reported dysmenorrhoea in the last three months (Bergsjø *et al.*, 1975). In New Zealand, a prevalence of 53% for any dysmenorrhoea was reported in a non-random survey of 1,456 pre-menopausal women aged 16-54 who attended GP clinics. In a random community sample of 415 women aged 15-54 in Singapore, a similar prevalence of 52% was reported for any dysmenorrhoea in the past year (Ng *et al.*, 1992). In a community survey of menstrual symptoms in a random sample of 596 19-year old women in Sweden, using the Andersch & Milsom scoring system, a prevalence rate as high as 72% was observed (Andersch & Milsom, 1982). In the US study by Jamieson & Steege (1996), the reported prevalence of dysmenorrhoea (sometimes, often, or always) was extremely high, at 90%.

1.5.1.5 Prevalence of abdominal pain

Prevalence rates for gastrointestinal symptoms, including both upper and lower chronic abdominal pain, in women were reported in three community-based and one hospital-based study in the UK (Table 1.2). In one community-based study assessing the prevalence of ‘functional gastrointestinal symptoms’ in 164 apparently healthy volunteers, 23% reported having had ‘abdominal pain more than 6 times per year’ (Thompson & Heaton, 1980). Approximately two-thirds of these women reported that the pain was relieved by defaecation, one of the Manning criteria for IBS (Manning *et al.*, 1978). Similar rates were observed in two other large community-based studies, aimed at assessing IBS symptoms defined according to the Manning criteria (Heaton *et al.*, 1992; Jones & Lydeard, 1992): prevalence rates of ‘abdominal pain more than 6 times in the past year’ in these studies were 25% and 29% (with IBS-associated rates of 20% and 24%).

One hospital-based study of 798 women referred to a gynaecology clinic and 321 control women referred to dermatology and ear/nose/throat clinics in Manchester reported a prevalence for ‘abdominal pain more than once a week’ of 21% in all control women (with and without IBS), and 9% in IBS-free controls (Prior *et al.*, 1989). ‘Lower abdominal pain’ (frequency or duration not specified) was reported by 37% of all control women and 18% of IBS-free women referred to the control clinics.

There have been a number of non-UK community-based studies on the prevalence of abdominal pain and IBS, but most of them have not reported results for men and women separately. Prevalence rates for abdominal pain in those studies that did report results for women varied from 17% for ‘IBS or chronic abdominal pain in the last 3 months’ (Drossman *et al.*, 1993) in women aged 15 or older to 27% for ‘lower abdominal pain in the last 3 months’ in 20-49 year olds (Agreus *et al.*, 1994) and 28% for ‘abdominal pain at least once a month’ in 30-60 year olds (Kay *et al.*, 1994).

Table 1.2. The prevalence of abdominal pain in women as observed in community-based studies and control groups in hospital-based studies in the UK

Reference	Study aim	Methods (type of study, population and setting, method of data collection)	Prevalence rates of abdominal pain (95% confidence intervals)
<i><u>Community-based studies</u></i>			
Thompson et al., 1980	prevalence of functional gastrointestinal symptoms in apparently healthy people	cross-sectional survey: volunteers: 1) 49 female nurses, aged 17-27; 2) 52 women in clinic screening/hospital clerical staff aged 45-65; 3) 63 women in elderly accommodation, aged 60-91; questionnaire based on Manning criteria ¹	‘abdominal pain >6 times/year’: 23% (15-31) (35% in 17-27 yr; 10% in 45-65 yr; 16% in 60-91 yr) ‘+ relieved by defaecation’: 16% (9-23) (27% in 17-27 yr; 6% in 45-65 yr; 16% in 60-91 yr) ‘+ not relieved by defaecation’: 7% (3-11) (8% in 17-27 yr; 4% in 45-65 yr; 10% in 60-91 yr)
Heaton et al., 1992	prevalence of IBS ² in the general population	cross-sectional survey: 1058 women randomly selected from GP registers in Bristol, aged 25-69; questionnaire based on Manning criteria ¹	‘abdominal pain >6 times in past year’: 25% (22-28) ‘pain + IBS symptom’: 20% (17-23) ‘pain without IBS symptom’: 5% (4-6)
Jones et al., 1992	prevalence of IBS ² in the general population	cross-sectional survey: 835 women randomly selected from 2 health centres in Southampton and Andover, aged 20-90; questionnaire based on Manning criteria ¹	‘abdominal pain >6 times in past year’: 29% (25-33) ‘IBS’: 24% (20-28) ‘non-IBS’: 5% (3-7)
<i><u>Hospital-based studies</u></i>			
Prior et al., 1989	prevalence of IBS ² in women referred to gynaecological clinic cp. with clinic controls	retrospective case-control study: 321 controls (232 IBS-free) referred to dermatology and ear/nose/throat clinics, aged 18-70; questionnaire for assessment of IBS ²	‘abdominal pain >1/week’ (in all controls): 21% (15-27) (in IBS/-): 9% (5-13) ‘lower abdominal pain’ (duration/frequency not specified): (in all controls): 37% (29-45) (in IBS/-): 18% (12-24)

Abbreviations: IBS= irritable bowel syndrome

¹ Manning criteria: IBS defined as ‘abdominal pain more than 6 times per year plus two or more of the following six symptoms’: relief of abdominal pain by defecation, looser stools with the onset of pain, more frequent stools with the onset of pain, abdominal bloating or distention, feelings of incomplete evacuation, and passage of mucus per rectum (Manning et al., 1978)

² IBS defined as: ‘abdominal pain more than once per month in combination with abdominal distension at times other than menstruation and an abnormal bowel habit (constipation, diarrhoea, or alternating).

1.5.1.6 Conclusions

No published studies were found from which the prevalence of CPP in the UK could be estimated. A community-based study of CPP not associated with menstruation or intercourse has never been performed, and not one of the community-based studies investigating the prevalence of dyspareunia or dysmenorrhoea has provided any information on the prevalence of CPP. The only study providing a prevalence rate for CPP in a group of women truly representative of the general population appeared to be the community-based study by Mathias *et al.* (1996) in the USA.

Studies investigating the prevalence of dyspareunia and dysmenorrhoea in the UK were included in this review, as women with CPP also often have these types of gynaecological pain. Dyspareunia was reported by 8% of women in one community-based study (Osborn *et al.*, 1988), and varied from 5% to 16% in two hospital-based studies (Mahmood *et al.*, 1991; Whorwell *et al.*, 1986), while the prevalence of dysmenorrhoea ranged from 45% to 97% in three community-based studies (Kessel & Coppen, 1963; Gath *et al.*, 1987; Hewison & van den Akker, 1996) and from 41% to 62% in control subjects of four hospital-based studies (Mahmood *et al.*, 1991; Liu & Hitchcock, 1986; Whorwell *et al.*, 1986; Shah *et al.*, 1994). Substantial differences in (or even a complete lack of) definitions of dyspareunia and dysmenorrhoea, together with differences in age ranges of the populations studied, complicate the interpretation and comparison of these rates. The disparate nature of outcome measures also rendered the data unsuitable for formal meta-analysis. Furthermore, the majority of these studies were limited by small sample size and could therefore not estimate prevalence rates precisely.

Studies investigating the UK prevalence of abdominal pain/IBS were included in this review, as there is likely to be a considerable overlap between these symptoms and those of CPP. However, the prevalence rates for abdominal pain cannot easily be used as an indication for the prevalence of CPP, because of differences in pain definition and because

the age ranges were wider in women included in abdominal pain studies. In general, the prevalence rates for abdominal pain were expected to be higher than for CPP, as the former commonly includes upper abdominal pain. Extrapolating the 15% prevalence of CPP found in the US study to the UK population, this expectation was confirmed by the findings of the three community-based British studies examining abdominal symptoms, in which prevalence rates for ‘abdominal pain occurring more than 6 times in the past year’ ranged from 23% to 29% (Thompson & Heaton, 1980; Heaton *et al.*, 1992; Jones & Lydeard, 1992).

Not one of the UK studies provided any information on the possible overlap between symptoms of CPP, dyspareunia, dysmenorrhoea, and abdominal pain/IBS. Similarly, this overlap has hardly been investigated at all in studies outside the UK. In the study by Mathias *et al.* (1996) it was reported that of those CPP patients who were sexually active, 82% also reported dyspareunia or pain after intercourse most or all of the time in the past month, but no figures were given on the possible overlap with symptoms of dysmenorrhoea or IBS. In one hospital-based study of 651 US women aged 18 and over, 43% of women with CPP also reported dyspareunia and 39% ‘excessive’ dysmenorrhoea, while 79% met the diagnostic (Rome) criteria of probable IBS (Walker *et al.*, 1991).

1.5.2 Risk-factors for CPP

Bradford Hill (1965) proposed a set of well-known criteria ⁴ that should – in an ideal situation – be fulfilled before a causal relationship between a certain exposure variable ⁵ and disease appears likely. Often, however, possible exposures related to a disease may be unclear (CPP is a good example, as illustrated in the previous sections) or difficult to

⁴ These criteria include 1) strength of association found between exposure and disease; 2) consistency of results in different populations; 3) specificity of effect; 4) temporality: exposure should precede the disease onset; 5) existence of a dose-response relationship; 6) biological plausibility and coherence; 7) experimental evidence; 8) analogy with other conditions. Many epidemiologists (Rothman & Greenland, 1998a) have since questioned most of these criteria in particular situations. Temporality, however, is still seen as a very important criterion for a causal relationship.

⁵ Exposure is used here in the widest possible context as any exogenous or endogenous/genetic factor that may be causally related to disease.

measure. Risk-factor analysis will therefore also commonly include a range of other variables (e.g. age, social class) that may somehow be related to certain exposures.

Epidemiological studies that can provide information about risk-factors can be classified as prospective (cohort studies), retrospective (case-control studies), and cross-sectional⁶ (Rothman & Greenland, 1998d). In a cohort study, two or more groups of people who are free of the disease of interest, but who differ according to the risk-factor (exposure) of interest, are followed prospectively to investigate who develops the disease. The main advantage of this type of study is the ability to collect unbiased risk-factor information. However, cohort studies are very costly, and may not be feasible when the disease of interest is rare or requires a very long follow-up. In addition, the careful recording of risk-factor information over a long period of time usually requires a clear idea from the outset of the study which factors need to be investigated.

In a case-control study, a group of incident (new) cases with the disease is identified and their risk-factor information pre-dating the onset of disease is collected. This information is compared with that provided by a carefully selected control group that is free of disease. Case-control studies are particularly appropriate when the disease of interest is rare. They also have the advantage that a large selection of potential risk-factors can easily be investigated. However, a disadvantage is that retrospectively collected risk-factor information may be incomplete (if it relies on previously recorded data) or biased (if it relies on recall).

In cross-sectional studies, a representative sample is drawn from a population, and prevalent cases (i.e. those with the disease at the time of data-collection) are identified in this sample. The main objective of such studies is usually to assess the prevalence of a disease in that population. A secondary aim can be to compare retrospective risk-factor information

⁶ Cross-sectional studies are also sometimes described as retrospective if they collect historical information that is likely to predate the onset of disease.

from prevalent cases with that of non-cases in the sample. The advantages and disadvantages of this type of analysis are similar to those of case-control studies. An additional problem, however, is that the inclusion of prevalent cases means that it is often difficult to assess whether or not the exposure preceded the onset of disease. Therefore, even when detailed historical risk-factor information is collected, causal relationships can almost never be inferred.

At best, CPP presents a major challenge for the epidemiologist wishing to investigate potential risk-factors. This is illustrated in Figure 1.1. Suppose one were to use CPP cases identified from the community for an epidemiological study. The first problem is the fact that (if one accepts that CPP has a somatic aetiological component) these CPP cases may suffer from various underlying conditions, which may all have different or even conflicting risk-factors (I). A brief description of the risk-factors associated with the most common diagnoses of CPP (endometriosis, PID, and IBS) is given in the next section.

Furthermore, following the biopsychosocial CPP model, psychological and socio-environmental factors (II) also play a role in pain aetiology or maintenance (see section 1.3.5). CPP risk may therefore be influenced by a variety of these factors, some of which can be difficult to measure. In addition, frequencies of underlying somatic and psychosocial conditions may vary in groups of CPP cases sampled from different communities, so that results from one country may not be comparable to those of another.

The situation becomes even more complex when CPP cases are identified from primary (III) or secondary/tertiary care settings (IV). Associations between CPP and risk-factors emerging may be very different in these settings compared to a community setting, because of differences in health care seeking behaviour and referral patterns. For example, pelvic pain might be very common in young women, but if they are less likely to go to their GP with their symptoms than older women they are less likely to be identified as CPP cases. Consequently, 'risk' of CPP may be seen as low in this group. Similarly, differences in

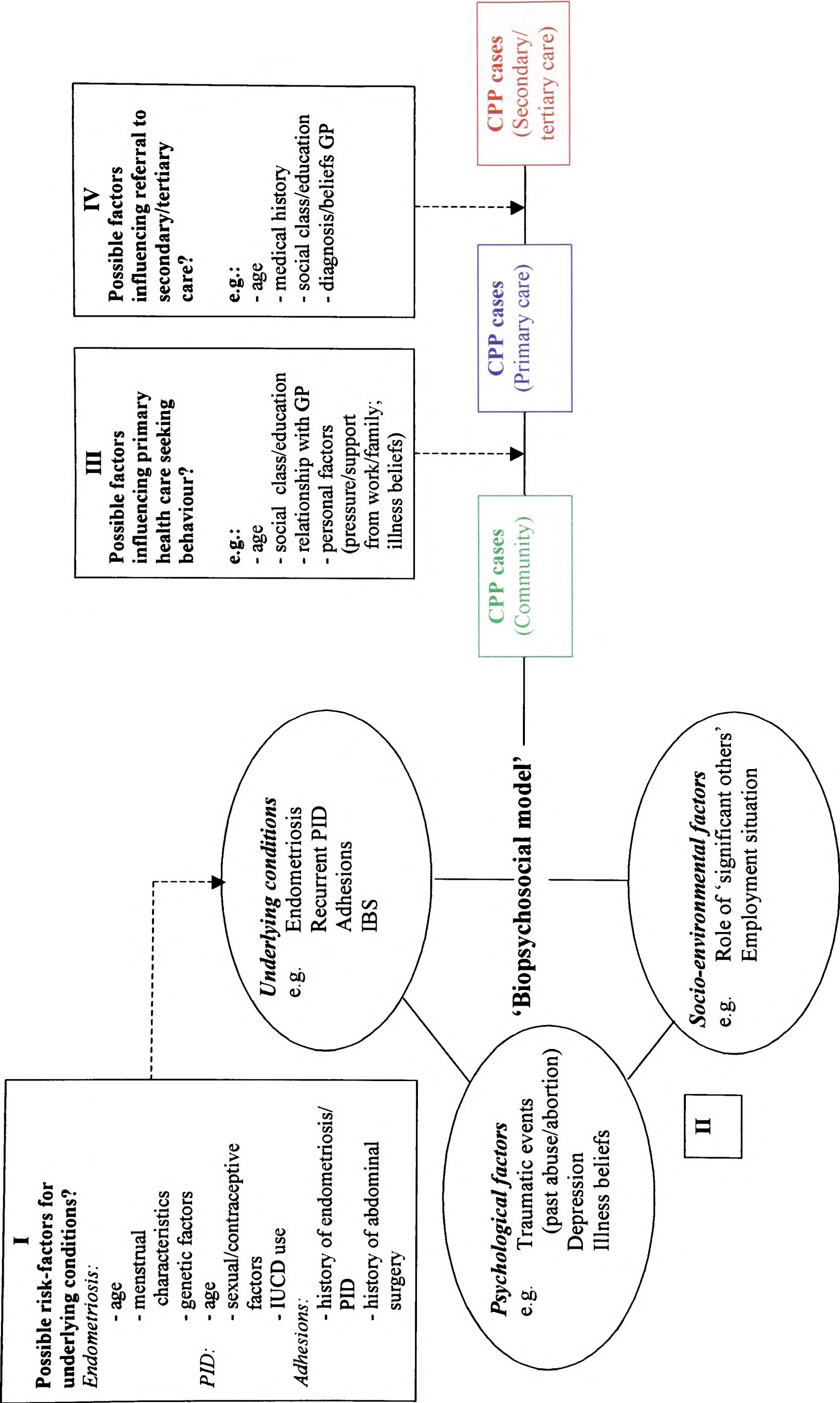


Fig. 1.1. Complexity of investigating 'risk-factors' for CPP

referral patterns from primary to secondary or tertiary care between, for example, age and social class groups may result in an even further distorted picture of CPP risk. Descriptions of ‘clinical profiles’ of CPP patients at secondary or tertiary care level (Reiter, 1990) may therefore be of some use to an individual clinic, but are not suitable for generalisation to the wider population.

To summarise, risk-factor analysis of CPP is at present only of some value using cases identified at community level. Even at community-level, however, the unknown distribution of underlying somatic conditions and multi-causality of CPP pose serious problems, and any relationship found between a certain factor and risk of CPP should be interpreted with great caution. Only the development of non-invasive tools for the diagnosis of underlying conditions such as endometriosis and PID will provide a first step towards a better understanding of risk patterns associated with CPP.

1.5.2.1 Risk-factors for endometriosis, PID, and IBS

The underlying conditions most commonly associated with CPP are endometriosis, PID (and associated adhesion formation) and IBS. Of these, risk-factors for endometriosis and PID have been most extensively studied, but the studies have been greatly limited by the lack of a non-invasive diagnostic tool. The need for laparoscopy or laparotomy to make the diagnoses has meant that studies have inevitably included highly selected case groups identified in secondary or tertiary care. Most studies have attempted to reduce the ascertainment bias likely to result from this case definition by selecting ‘appropriate’ control groups for comparison. These have generally consisted of either asymptomatic women undergoing laparoscopic sterilisation, or women consulting for other conditions in the same care setting, who were not laparoscoped and in whom pathology therefore could not be assessed. Such study designs, however, have compromised the generalisability of the results to a wider population.

As described in section 1.3.1.1, the most popular hypothesis to explain the development of endometriosis is retrograde menstruation. Studies examining the risk-factors for endometriosis have therefore largely focused on differences in menstrual characteristics, contraceptive use, and child birth between cases and controls. Mangtani and Booth (1993) reviewed the risk-factors associated with endometriosis, highlighting the methodological problems with many of these studies. The highest prevalence rates of endometriosis have been found in women around 30-40 years of age, but ascertainment bias has almost certainly played a role in these results. Similarly, the suggested higher prevalence in Caucasian women and women of higher social class (mainly observed in less recent case series) may well be explained by differences in access to health care.

Regular menses, prolonged menstrual flow, and early menarche have all been implicated as increasing the risk of endometriosis, whereas pregnancy and use of oral contraceptives (OCs) have been suggested as protective. Evidence supporting these suggestions, however, has been inconsistent (Mangtani & Booth, 1993). Vercellini *et al.* (1993) reviewed the evidence on the relation between contraceptive use and endometriosis, and found that OCs and intra-uterine contraceptive devices (IUCDs) have both been associated with decreased, increased, or no effect on the risk of endometriosis. A large prospective cohort study found a protective effect of OCs in current users, but no significant differences in past users, suggesting that OCs only mask symptoms associated with endometriosis (Vessey *et al.*, 1993). Other factors suggested to play a role have included exercise, smoking (both decreasing risk) and alcohol use (increasing risk), potentially resulting from effects on endogenous oestrogen levels (Mangtani & Booth, 1993; Thylan, 1995). Genetic factors are also thought to play a role in the development of endometriosis, and research investigating hereditary links is currently underway.

Grodstein and Rothman (1994) have critically reviewed the different risk-factors associated with the development of PID. As with endometriosis, case definition of PID is a

problem in epidemiological studies, since the condition can remain asymptomatic and can only be reliably diagnosed by laparoscopy/laparotomy. The incidence of PID appears to be highest in younger women, whereas it also seems to be higher for non-Caucasian women. This may be partly due to diagnostic bias, though biological mechanisms for increased susceptibility to infection in these groups have also been proposed. As the majority of PID cases are likely to be the result of sexually transmitted diseases, young age at first intercourse, high frequency of intercourse and a large number of partners have all been reported to increase the risk of PID. Barrier methods of contraception and OCs have been reported to be protective (Buchan *et al.*, 1990). IUCD use was initially regarded as a factor strongly increasing the risk of PID, but this association was later suggested to have mainly resulted from comparison with OC and barrier users who are at decreased risk. Subsequent studies have suggested that risk may be associated with particular (non-medicated) devices or that it may only be elevated immediately after insertion of the device (possibly related to the introduction of organisms into the uterine cavity) (Grodstein & Rothman, 1994). Smoking and vaginal douching have also been implicated as increasing risk, but evidence for this has been weak.

Although some recent epidemiological studies have estimated the prevalence of IBS, very few have addressed potential risk-factors for the condition. This is not surprising, since no clear hypotheses exist about its causation and – until recently – it was a diagnosis made after exclusion of all others. As with CPP, psychological (e.g. depression and anxiety) and socio-environmental factors (e.g. abuse history) have been implicated in its aetiology and persistence (Farthing, 1995). Two consecutive cross-sectional surveys of 3,000 Danish men and women found (irrespective of sex) a higher prevalence and incidence of IBS in younger age groups and in those assessed as being psychologically vulnerable or experiencing problems (Kay *et al.*, 1994). No association was found with social class, smoking, body mass index, or alcohol use. A cross-sectional survey of 1,500 women in the USA found a similar

decrease in prevalence of IBS with increasing age, and no association with smoking status, alcohol consumption, marital status, or educational level (Talley *et al.*, 1995).

1.5.2.2 Risk-factors reported in community-based studies of CPP

The cross-sectional community survey in the USA by Mathias *et al.* (1996) and the semi-community study of women and their companions in primary care clinics by Jamieson *et al.* (1996) both described the association between certain demographic factors and CPP. In a logistic regression model adjusted for age, ethnicity, education, and marital status, Mathias *et al.* found a slightly decreased risk of CPP in women older than 35 compared to younger women (OR: 0.7, 95% CI: 0.6-0.8), and in women of African-American origin compared to Caucasian women (OR: 0.7, 95% CI: 0.5-0.95), whereas an increased risk was found in separated/widowed/divorced women compared with single women (OR: 1.5, 95% CI: 1.1-2.0). No association was found between CPP and educational status.

Jamieson *et al.* found that pelvic pain (defined as any current pain not associated with menstruation or intercourse) varied significantly with age, with rates decreasing from 44% in 18-25 year olds and 49% in 26-30 year olds to 28% in 31-35 year olds and 22% in 36-40 year olds, before increasing again to 37% in 41-45 year olds. Contrary to Mathias *et al.*'s findings, a higher prevalence of CPP was observed in African-American vs. Caucasian women (53% vs. 35%), and no associations were found with marital status, income, education, or parity. No adjustment was made for other variables in significance tests.

1.6 The 'burden' of CPP – quality of life and economic implications

1.6.1 Quality of life

Many of those involved in the treatment of CPP patients have commented that – from clinical experience – the condition can have a considerable impact in terms of interference

with daily life and general well-being (Reiter, 1990; Nolan & Elkins, 1993; Beard, 1998; Kennedy, 1995). Reiter *et al.* (1990) illustrated this by stating that ‘patients commonly describe years of disability and suffering, loss of employment, marital discord and divorce, and myriad untoward and unsuccessful medical misadventures’.

There appear to be limited data, however, supporting these statements. This lack of data is particularly apparent in the UK. In a small qualitative study of 21 women interviewed 12 to 18 months after a negative laparoscopy, women stated that the pain affected many aspects of their lives, in particular their sex life, socialising and work activities. They also stated that worrying about the pain affected their mood, sleep, and weight (Savidge *et al.*, 1999). One study among 342 members (including 44 men) of the IBS Network support group in the UK has assessed the impact of IBS on functioning and well-being to a very limited extent: they showed that IBS cases scored ‘significantly lower’ on all items of the Short-Form 36 questionnaire (a generic health status measure) compared with data from a normative population (Hahn *et al.*, 1999).

In the USA, the two previously described community-based studies of CPP both investigated CPP-related quality of life to a limited extent. In the study of women approached in primary care clinics in the USA (Jamieson & Steege, 1996), 10% of 227 women who had non-menstrual, non-coital, pelvic pain reported that it had caused them to miss at least 1 day at work in the last month, whereas 28% reported it had limited them in home activity, and 30% in sexual activity. Mathias *et al.* (1996) assessed functioning and well-being in women with CPP using a well-validated health status measurement tool (the Medical Outcomes Long-form questionnaire). However, most of their data were impossible to interpret, as no information was collected from a control group without CPP. The authors were only able to compare three quality-of-life items with normative data for demographically similar women who had participated in a national health survey, showing that general health scores were significantly lower for CPP patients and that more CPP

patients reported at least one bed-day (26% in the last month vs. 7% in the last 2 weeks) and at least one reduced-activity day (58% in the last month vs. 11% in the last 2 weeks).

1.6.2 Economic implications

Another frequent comment made by investigators is that CPP is a costly condition, resulting in work loss and frequent use of health care resources. To illustrate this, results from the Working Party Report on the Use of Laparoscopy in the UK are often quoted, in which it was estimated that 20% of all general gynaecological referrals in the UK are for CPP and that it is the most common indication for a diagnostic laparoscopy (Chamberlain & Brown, 1978). It has never been possible, however, to calculate the economic cost of CPP in the UK, because of its unknown prevalence. Davies *et al.* (1992) have attempted to estimate the cost of 'the pelvic pain syndrome', i.e. CPP without obvious pathology found at laparoscopy. Their cost figures were based on an estimated annual incidence of 0.98/1000 women (range: 0.56/1000-3.6/1000) and prevalence of 24.4/1000 women (range: 14/1000-90/1000); the source of these estimates is unclear. They estimated the total direct annual costs of the pelvic pain syndrome (resources used in its diagnosis and treatment) at approximately £158 million (range: £90m-£602m). The indirect costs (associated loss of work) were estimated at £24 million (range: £14m-£89m).

In the USA, CPP has similarly been quoted as a condition with substantial resource implications. As an illustration, authors have stated that it is the indication for 2-10% of outpatient gynaecological referrals, 30-50% of diagnostic laparoscopies and approximately 10% of hysterectomies (Reiter, 1990). The first evidence of the high costs associated with CPP was provided by Mathias *et al.* (1996) in their community-based study of CPP. They extrapolated the observed CPP prevalence to the total female population, giving an estimated 9.2 million CPP sufferers in the USA. The total direct costs of CPP (calculated from visits to physicians and mental health professionals plus out-of-pocket expenses) were estimated at

\$2.8 billion, but this excluded the costs of diagnostic procedures or hospitalisation. In addition, the total indirect cost of CPP due to time lost from work was estimated at \$555 million.

1.7 Rationale and aims of thesis

An overview has been given in the previous sections of what constitutes CPP. The large volume of research into the condition has produced many different theories of complex causation mechanisms, and has suggested ideas for the development of appropriate assessment and treatment protocols.

Remarkably, however, the epidemiology of CPP has been virtually ignored as a field of research. Statements made by many investigators that ‘CPP is likely to be a very common condition that greatly affects a woman’s life’ appear to be based on clinical experience in secondary or tertiary care settings alone. In the UK, no studies have been performed that provide information on the prevalence or incidence of CPP in the general population or in primary care. The single community-based study that has provided such evidence was performed in the USA: a high prevalence of CPP (14.7%) was found amongst women aged 18-50. Most of their results regarding CPP-associated quality of life, however, could not be interpreted due to the lack of a control group.

The work described in this thesis aimed to provide the first community-based data on the epidemiology of CPP in the UK. Two studies were designed to investigate the size of the problem in primary care and in the community as a whole:

- (1) a retrospective analysis of a national general practice database (MediPlus)
- (2) a cross-sectional survey of women in the Oxfordshire community

(1) The MediPlus database contains routinely collected clinical and prescribing data from more than 1,700,000 patients in the UK. This database was used to:

- derive estimates of prevalence and incidence of CPP in women aged 12-70 in primary care, stratified by age and region
- investigate duration of symptoms, and patterns of diagnosis and referral in the 3.5 year follow-up of computerised records of a cohort of incident CPP cases

The methods and results of this analysis are described in chapters 2 to 4.

(2) The community survey was carried out in a random sample of women aged 18-50 in Oxfordshire.

Its primary aims were to:

- derive prevalence estimates of CPP
- describe pelvic pain in these women in terms of severity, duration and frequency
- investigate the overlap with dysmenorrhoea, dyspareunia, IBS, and genito-urinary symptoms

Its secondary aims were to:

- describe use of health care arising from CPP
- assess associated functioning and well-being
- investigate some potential factors associated with CPP (for hypothesis-generating purposes only)

The methods and results of the survey are described in chapters 5 to 8.

Chapter 2

The MediPlus UK Primary Care Database - CPP case selection

2.1 Introduction

As mentioned in the previous chapter, the analysis of the MediPlus database aimed to:

- calculate the prevalence and incidence of CPP in primary care, by age and region, and estimating the duration of symptoms. The results of these analyses are described in Chapter 3.
- provide insight into the diagnostic processes involving women with CPP by investigating the patterns of diagnosis and referral for CPP, by age and duration of symptoms. These results are described in Chapter 4.

The present chapter gives a description of the database and the methods used to select CPP cases.

2.2 The MediPlus UK Primary Care Database

2.2.1 Description of the database

MediPlus was chosen rather than the General Practice Research Database (GPRD) for several reasons. Firstly, whereas the MediPlus data were available free of charge (see section 2.4), access to the GPRD data would have been very costly. Secondly, the definition of a CPP episode (described in section 2.3) required the registration of every contact for pelvic pain with general practice. In the GPRD, however, chronic conditions are only coded at first diagnosis and details of separate contacts cannot be obtained.

MediPlus contains anonymised clinical and prescribing data from 1991 onwards on approximately 1,700,000 patients. The data are collected by Intercontinental Medical

Statistics (IMS-UK and Ireland) from general practices in the UK who use AAH Meditel's System 5 software (at the time of this study 140 practices with approximately 500 GPs used the system). Patient data are entered into the practice system by the GP at or shortly after each patient contact, which can be a visit to the practice, a home visit, telephone encounter, or repeat prescription. All clinical data - symptoms, diagnoses, investigations, referrals, procedures, or prescriptions - are entered by selecting the relevant codes from a comprehensive list incorporated in the system. This list includes Read codes (Chisholm, 1990), codes from the International Classification of Diseases - ninth revision (ICD-9), and other codes built in by IMS.

Entry of data in the practice system is based on the concept of 'problem-orientated records'. Linked to the contact date, a GP first enters a 'problem' code identifying the main complaint. Subsequently, more detail can be provided by linking 'note' codes and prescriptions to the problem. All codes indicating symptoms, diagnoses, referrals and procedures can be entered as problem or note codes, but prescriptions are always attached to a problem. In addition to the coded information, GPs can enter comments or personal information as free text. This information is not accessible to IMS and therefore does not appear in MediPlus.

All coded information entered into a practice system is collected daily via a computer network (AT&T Istel). Practice systems dial in each night to transmit their information, which is downloaded each morning by IMS. An encryption key is generated at random to encrypt the patient reference number, so that the number by which IMS knows any patient cannot be related to the number used in the practice system. Non-medical patient information in the database is limited to sex and year of birth.

MediPlus is updated monthly with new patient information. The link between the contact date, problems and notes is retained in the database, thereby providing longitudinal patient records for the period of time they remain within the practice.

2.2.2 Representativeness, validity, and completeness of the data

The practices providing data to MediPlus were recruited to be representative of all practices in the UK regarding geographical distribution (by Regional Health Authority), fundholding status, and dispensing status. At the time of the present study, Scottish practices were slightly under-represented. Age and sex distributions of doctors and patients on the database are similar to national figures (IMS Health, 1998).

Collection of data for MediPlus conforms to the guidelines compiled by the Joint Computing Group of the Royal College of General Practitioners and the General Medical Services Committee of the British Medical Association (1995), and IMS employs an independent medical advisor to monitor adherence to these guidelines.

The quality and completeness of the data entered by practices contributing to MediPlus is monitored by IMS according to 11 criteria, shown in Table 2.1. Points are awarded for the criteria met, with a maximum of 610 points to be gained. Each practice is sent a quarterly validation report that highlights success and deficiency in meeting the standards for the practice and its individual GPs. Practices are required to score a minimum average of 500 points in each quarterly period. Those practices that consistently fail to reach this standard are eliminated from the database. Each practice can redeem the points awarded against items needed, or exchange them for cash (£100/1,000 points). An additional annual bonus is given to those practices achieving much higher targets than required (>99% acute and repeat prescriptions and >80% of notes linked to problems or diagnoses coded at level 3 or 4 of the Read code⁷; >95% of all issued prescriptions entered into the system). Currently, these higher targets are met by 25-30% of practices annually.

⁷ Read codes are organised hierarchically according to level of specificity, with level 1 representing the least specific codes and level 4 the most specific. For example:

.J... Genitourinary system diseases	- level 1
.J5.. Female pelvic inflammatory diseases	- level 2
.J51. Pelvic inflammatory disease	- level 3
.J511 Acute salpingitis/oophoritis	- level 4

Table 2.1 Quality criteria set by IMS, to be met by practices and individual GPs contributing data to *MediPlus*[®] (adapted from IMS Health, 1998)

Criterion	Minimum requirement	Points awarded	Practices meeting requirement in 1997
<i>Patient coverage</i>			
1. Percentage of 'active' ¹ patients reported in any 12 month period	50%	50	100%
2. Percentage of completed demographic data on all registered patients	98%	30	100%
3. Number of items prescribed per week per 1,000 registered patients	40	50	100%
<i>Problem and note records</i>			
4. Percentage of notes linked to a specified problem or diagnosis	70%	50	92%
5. Percentage of notes linked to a problem or diagnosis recorded at the third or fourth Read code level ²	50%	40	90%
<i>Prescription details</i>			
6. Percentage of acute prescription items linked to a problem or diagnosis	80%	100	97%
7. Percentage of repeat prescription items linked to a problem or diagnosis	90%	100	91%
8. Percentage of prescriptions with problem or diagnosis recorded at the third or fourth Read code level ²	60%	40	95%
9. Percentage of detail present on dosage and quantity	85%	20	100%
10. Ratio of repeat to acute prescriptions	<6:1	30	94%
<i>Other parameters</i>			
11. Percentage of prescriptions entered into the computer, compared to the total number dispensed as recorded by the PPA ³	80%	100	98%

¹ 'Active' = alive and permanently registered with the practice

² Read codes are organised hierachically according to level of specificity, with level 1 representing the least specific codes and level 4 the most specific (for details see footnote 7)

³ PPA = Prescription Pricing Authority

In April 1997, an independent questionnaire survey of practices contributing to MediPlus was carried out to investigate generalisability, validity and completeness of the recorded data (Lawrenson *et al.*, 1998). Out of 129 practices, 14% relied equally on written and computerised records and 41% indicated that the computer record was their primary record, while 28% were essentially paperless. This figure is much higher than the 8-10% quoted nationally (Purves, 1996). A policy of encouraging consistent use of Read codes was reported by 88% of the practices, with 75% using specially written protocols - known as SOPHIEs ('Screening Of Patient in an Interactive Environment') - for the coding of common conditions. The majority of practices (70%) indicated that more than 95% of consultations generated a computer record, with only two suggesting that this percentage could be 55% or less.

However, 43% of practices still considered written records as primary, despite recording all key diagnoses and prescriptions on the system. The survey also found that laboratory results and hospital-related information were less well recorded, with 43% of practices indicating that less than 50% of hospital discharge summaries were entered. In addition, not all practices (81%) routinely recorded the date of death of a patient, with 19% usually recording mortality details in free text.

The survey concluded that there was no reason to believe that MediPlus is any more or less reliable as a source of general practice activity than any other UK general practice database. The high proportion of paperless practices was reassuring, as it seems likely that their recorded information most accurately reflected the care of patients. Thus, it was likely that completeness and validity of recorded diagnostic and prescription data were sufficient for epidemiological purposes. However, hospital and death related information (which is less complete) should be used with caution.

2.3 Definitions of a contact, CPP case and episode

The following definitions were used in the selection of CPP cases on the database:

Contact: A date in the medical history of a patient, recorded on the database. This may have been a visit to the surgery, home visit, telephone encounter, or repeat prescription.

From the available data, no distinction could be made between the different types of contact.

CPP: Pain in the lower abdominal region persisting for at least six months. This excluded pain due to 1) malignancy, 2) chronic inflammatory and other defined bowel diseases (e.g. Crohn's, coeliac disease, ulcerative colitis), 3) acute conditions verified by having surgery (e.g. appendicectomy, cholecystectomy) or 4) pregnancy. Patients with pelvic pain occurring only during menstruation (dysmenorrhoea or menstrual symptoms) or sexual intercourse (dyspareunia) were also excluded.

Episode of CPP: Pelvic pain on two or more contacts, with at least six months (≥ 183 days) between the first and the last contact but with no period of more than one year (> 365 days) without a pelvic pain contact. An episode of CPP was defined as starting 6 months after the first contact and finishing at the contact preceding a pain-free one-year interval (if any).

2.4 Selection of the denominator, CPP cases and episodes

Pharmacia & Upjohn Ltd (Milton Keynes) - a licence holder of MediPlus - allowed free and unlimited access to the database for the research goals described above. Although the software built for MediPlus could be used to select the denominator group of women, it proved unsuitable for the selection of CPP cases and episodes according to the definitions described above. This selection was performed using SAS version 6.12 (SAS Institute Inc., 1990). Figure 2.1 shows the complete selection process.

Step I: Denominator selection (Jan 1991 to Dec 1995)

Selection 1: 'active' ¹ women, aged 12-70 in 1991: 385,183
Selection 2: 4 practices with incomplete data excluded: 381,076
Selection 3: women with data in 1991: **284,162** (=denominator)

Step II: Case selection ²

A: 28,184 B: 73,987 C: 3,199 D: 84,217

135,069

Step III: Exclusions of cases and contacts

Exclusion of cases on basis of: -1,135

- Cancer in abdominal region
- Chronic (inflammatory) bowel disorders (e.g. Crohn's/coeliac disease/ulcerative colitis)

Exclusion of A-D contacts because related to: -2,947

- Pregnancy
- Irrelevant abdominal operations

Exclusion of B and D contacts because of: -2,979

- Irrelevant location symptoms
- Irrelevant medication

Exclusion of D contacts:

- Referrals irrelevant to CPP -35,789

133,934

130,987

128,008

92,219

Step IV: Durational criteria - exclusions

Only one contact for CPP in 1991-1995: -41,794

Less than 6 months between first and last contact: -21,970

50,425

28,455 (=30,314 episodes)

Step V: Diagnostic criteria: exclusions

Exclude episodes with D codes only -1,314

27,141 (=28,899 episodes)

Exclude episodes with

- dysmenorrhoea or menstrual symptom codes only -2,949
- dyspareunia codes only - 139

24,053 (=25,543 episodes)

¹ 'Active'= alive and permanently registered on 30 June 1996

² Group A included women with specific pelvic pain codes or diagnoses that implied pelvic pain (e.g. 'lower abdominal pain', 'pelvic inflammatory disease');
Group B included women with less specific abdominal pain/symptom codes (e.g. 'abdominal pain', 'constipation');
Group C included women with codes related to but not necessarily implying pelvic pain (e.g. 'endometriosis', 'ovarian cysts');
Group D included women with the least specific procedure/referral codes that could be related to pelvic pain (e.g. 'laparoscopy', 'gynaecological referral').

Fig. 2.1 Numbers of women selected to estimate the prevalence of CPP in MediPlus UKPCD

2.4.1 The population denominator

Selection of the denominator group on MediPlus was started in July 1996, using patient data that were last updated on 30 June 1996. The study period for analysis was January 1991 to December 1995, five complete years since the start of the database. Firstly, all women who were ‘active’ (i.e. alive and permanently registered with the practice on 30 June 1996) and aged 12-70 in 1991 were selected (n=385,183; Fig. 2.1, Step I). The lower age limit was chosen so as to include adolescent women in our investigation. The upper age limit was chosen because of increased mortality risk in the follow-up of women over 70, which could cause problems since the date of death was not always accurately recorded (see section 2.2.2).

Women had to have complete data for the whole study period, 1991-1995, to apply the durational criteria for CPP. Therefore, four of the 140 practices which had ceased using Meditel System 5 during the study period were excluded. Although all selected women were ‘active’ on 30 June 1996, this did not mean that they had all been registered with the practice from the start of the database in 1991. No record was kept on the database of when patients joined a practice. The only way, therefore, to ensure that all women had complete data was to select those who had had a GP contact in 1991. This resulted in a group of 284,162 women selected as the population denominator (Fig. 2.1), 73.8% of those in the initial selection of active women.

The effect that this selection had on the representativeness of the denominator group in terms of age distribution is shown in Fig. 2.2. Consistent with the information given by IMS, the age distribution of the baseline group of 385,183 ‘active’ women aged 12-70 in 1991 was very similar to the mid-year estimates of the general female population of England and Wales in that year (OPCS, 1993c). The exclusion of women who did not have a GP contact in 1991 resulted in an under-representation of young women: 32.2% of women in the

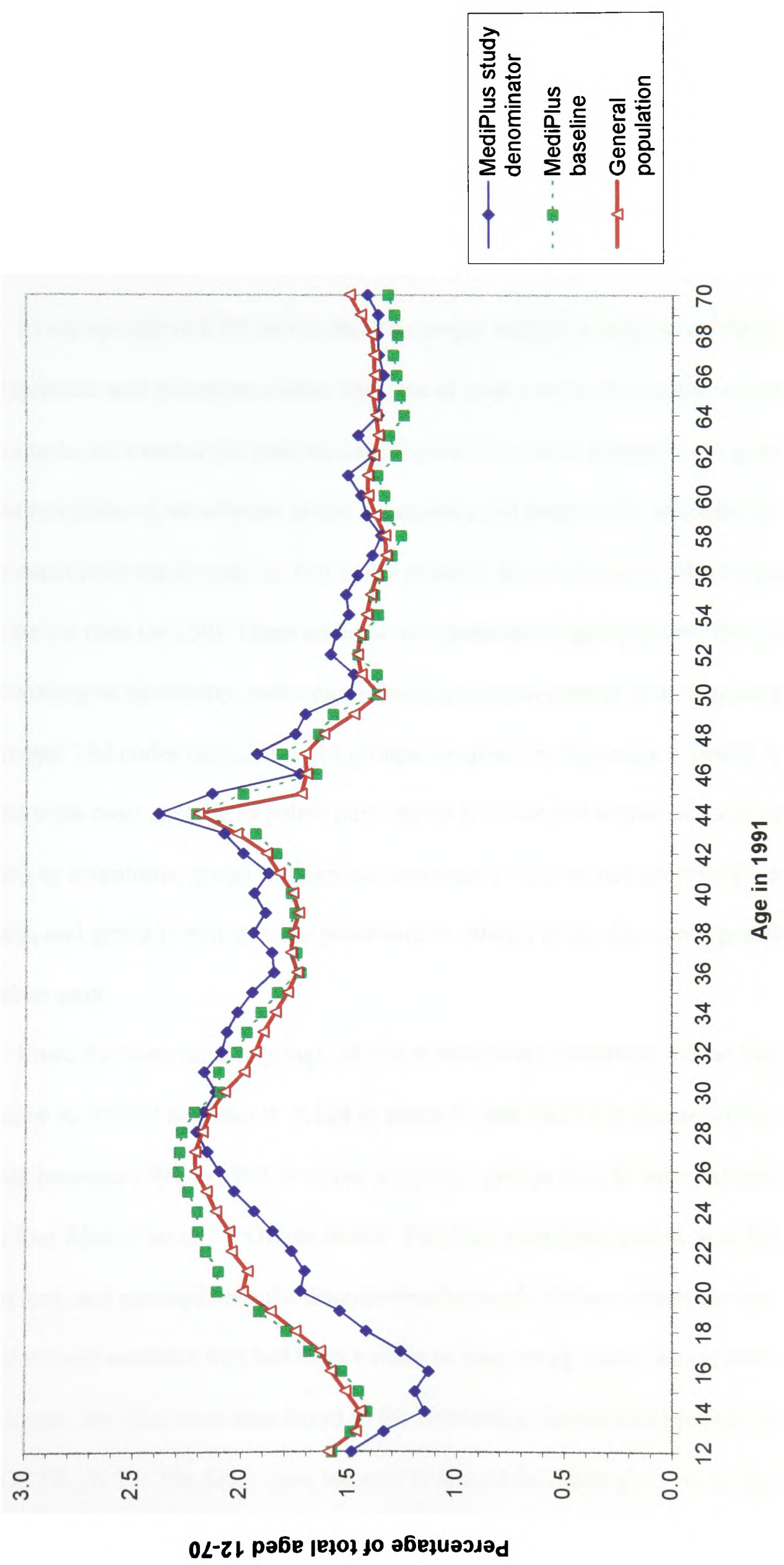


Fig. 2.2. Comparison of the 1991 age distribution of the study denominator (n=278,509), the baseline MediPlus denominator of active women (n=385,183) and the general female population of England and Wales (OPCS, 1993).

denominator group were less than 30 years old compared with 36.1% in the general population.

2.4.2 Selection of CPP cases

Every episode of CPP on the database might include a range of different symptom, diagnostic, and procedure codes. The type of code used at data-entry would depend, for example, on whether the pain was accompanied by other symptoms (e.g. genito-urinary, gastrointestinal), or whether or not a diagnosis had been made. Initially, all codes were selected from the system list that could possibly be relevant, but which varied in specificity to pelvic pain (n=150). These codes were subsequently grouped into four categories (A to D) according to specificity, enabling different exclusion criteria to be applied to the different groups. The codes included in the groups are given in Appendix I. Group A contained codes that were most specific to pelvic pain, group B codes that indicated more general abdominal pain or symptoms, group C diagnoses associated with but not necessarily implying pelvic pain, and group D non-specific procedure or referral codes that could possibly be related to pelvic pain.

From the denominator group, 28,184 women were identified with at least one code in group A, 73,987 in group B, 3,199 in group C, and 84,217 in group D (Fig. 2.1, Step II). All data between 1991 to 1995 from the women in groups A to D were exported from MediPlus as four files of up to 1.5 GByte in size. The files were downloaded onto DAT tapes, taken to Oxford, and restored onto the departmental network. Before importing into SAS, missing values and variables that had been written as long string values had to be recoded. For this purpose, the files were transferred to the University Network and processed using FORTRAN 77. The files - now reduced to almost half their size - were then transferred back onto the departmental network, and imported into SAS. Irrelevant contacts, at which none of

the 150 selected codes were used, were excluded, further reducing the files to 1/10 of their original size.

2.4.3 Exclusion of cases and contacts

The files with data from women in groups A to D were merged, resulting in a selection of 135,069 cases (the number of women in the separate groups did not add up to the total because some women had codes in more than one group). The original classification was kept, so that each contact was coded as an 'A', 'B', 'C', or 'D' contact, or a combination of those (Fig. 2.1, Step III).

At this stage, certain cases and contacts were excluded on the basis of associated codes (Appendix II). All cases with a code indicating cancer in the abdominal region (n=527) or a defined (inflammatory) gastrointestinal disorder (n=608) were completely excluded. Secondly, all contacts with a code indicating pregnancy (n=2,552) or an abdominal operation for an acute condition (n=395) were excluded, leaving 130,987 cases. Next, less specific 'B' and 'D' contacts were excluded if they were combined with codes indicating an irrelevant location of symptoms (n=1,694) or only irrelevant medication (n=1,285), reducing the number of cases to 128,008. Lastly, 'D' contacts with referral codes for conditions unrelated to the abdominal area (e.g. 'general surgical referral' for a breast lump) were excluded (n=35,789), leaving 92,219 cases.

2.4.4 Durational criteria

Having selected the pelvic pain contacts, the next step was to determine for each woman whether the contacts amounted to a CPP episode (Fig. 2.1, Step IV). As described in section 2.3, a CPP episode consisted of at least two pelvic pain contacts covering a period of at least six months (≥ 183 days). However, if a contact-free interval of at least one year (≥ 365 days)

occurred, the contacts preceding and following the interval were considered to be part of separate pelvic pain episodes. Following this definition, a case could have up to 3 CPP episodes from January 1991 to December 1995. Out of the 92,219 women, 28,455 were selected with one or more CPP episodes persisting for at least 6 months (30,314 episodes).

2.4.5 Exclusion of episodes

In the last step of CPP episode selection, the content of each episode was considered (Fig. 2.1, Step V). First, 1,415 episodes (1,314 cases) were excluded that consisted of ‘D’ contacts alone without evidence of CPP (e.g. multiple entries of ‘hysterectomy’), resulting in a selection of 27,141 cases (28,899 episodes). Furthermore, in accordance with the previously described definition of CPP, episodes that only contained codes for ‘dysmenorrhoea’, ‘menstrual symptoms’ or ‘dyspareunia’ were excluded. It should be emphasised that episodes including these codes together with at least one other code were retained. This resulted in a final case selection of 24,053 women (25,543 episodes) from 1991 to 1995.

Chapter 3

Prevalence, incidence and duration of CPP in primary care

3.1 Introduction

In the previous chapter, the method of CPP episode and case selection from MediPlus was described. From 1991 to 1995, 25,543 episodes of CPP were identified. The study described in this chapter investigates the prevalence, incidence and duration of CPP calculated using these episodes.

3.2 Methods

3.2.1 Basic definitions of prevalence and incidence

The prevalence rate of a disease in a population is the proportion of the population that has the disease at a specific point in time (point prevalence) or at some point in a time period (period prevalence) (Kirkwood, 1988).

The incidence rate of a disease is the number of new cases in a given period as a proportion of the ‘person-time’ at risk (i.e. the aggregated time that the members of the population spend at risk in that population over the period). As individuals contract the disease, they are eliminated from the ‘at risk’ population. More intuitively comparable to the prevalence rate, however, is the incidence proportion (or cumulative incidence), which is the number of new cases in a risk period as a proportion of the population at risk at the start of the period. In a ‘closed’ population (i.e. one in which no migration or migration only due to

birth and death occurs), the incidence proportion approximates the incidence rate⁸, if either the incidence rate or the risk period is sufficiently small (Rothman & Greenland, 1998b).

The MediPlus denominator population used in the analyses was closed, with the total number of women observed remaining constant (n=284,162) from 1991 to 1995. Both the risk-period over which incidence was calculated - one month - and the total number of new cases in each month were small. Incidence was therefore calculated as a proportion of the unaffected population at risk at the start of each period.

3.2.2 Initial prevalence and incidence calculations

Using the data from January 1991 to December 1995 and following the basic definitions outlined in the previous section, monthly prevalence was first calculated as the number of existing CPP episodes per thousand in each calendar month in all 284,162 women. Monthly incidence was calculated as the number of new CPP episodes per thousand in all women 'at risk', which - following the definition of a CPP episode - were those who were free of pelvic pain in the year preceding the month for which incidence was calculated.

Figures 3.1 and 3.2 show the monthly prevalence and incidence in all 284,162 women. Because of the definition of CPP used, all incident and prevalent episodes could only be identified between July 1992 and December 1994, as is shown in the figures⁹.

Monthly prevalence steadily increased from 21.8/1,000 in July 1992 to 29.8/1,000 in

$$^8 \text{ Incidence rate } I_R = \frac{\# \text{ new cases in } \Delta t}{\bar{N} * \Delta t} \quad \text{and} \quad \text{Incidence proportion } I_P = \frac{\# \text{ new cases in } \Delta t}{N_{t_0}}$$

Where Δt = fixed risk period = $t_1 - t_0$; # new cases in Δt = $N_{t_0} - N_{t_1}$; and $\bar{N}$ = average population at risk = $(N_{t_1} + N_{t_0})/2$. When Δt or # new cases is small, the population at risk will decline only slightly over the risk period: $\bar{N} \approx N_{t_0}$.

⁹ An episode of CPP was defined as pelvic pain on two or more contacts, with at least six months between the first and last contact but no period of more than one year without a contact. Incident episodes could only be identified if a one-year pain-free period occurred prior to the first contact. With CPP defined as starting 6 months after the first pelvic pain contact, incident episodes could therefore only be identified from July 1992 onwards. Similarly, all prevalent episodes could only be identified from July 1992: prior to July 1992, prevalent episodes with two or more contacts in just under six months and one contact up to 12 months earlier would not be counted if the first had occurred before the start of the database. After December 1994, both prevalent and incident episodes that started with two or more contacts in just under six months with a further contact after December 1995 would not be counted.

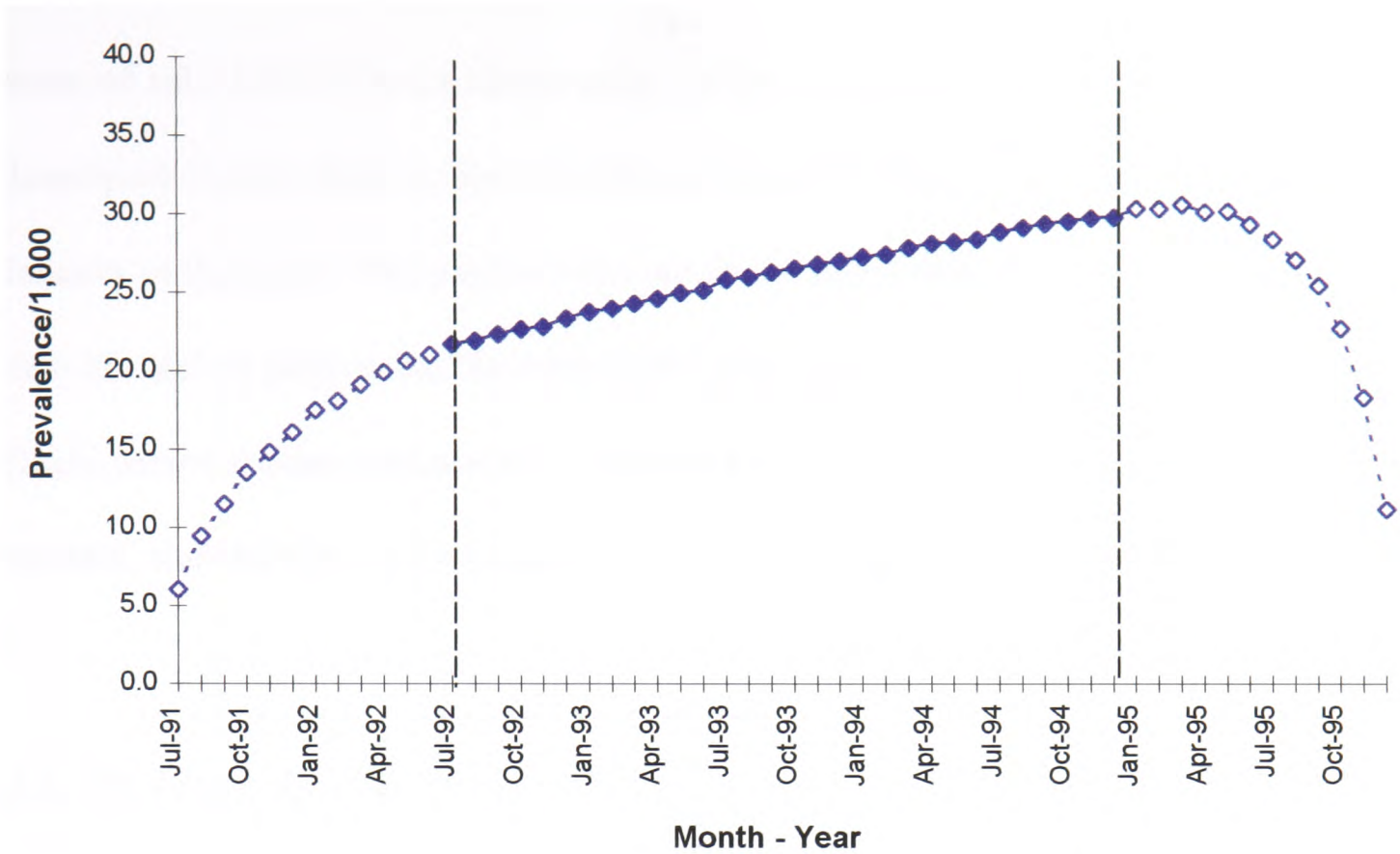


Fig. 3.1 Monthly prevalence of CPP per thousand using data from January 1991 to December 1995
(the definition of a CPP episode only allowed prevalence to be estimated accurately from July 1992 to December 1994).

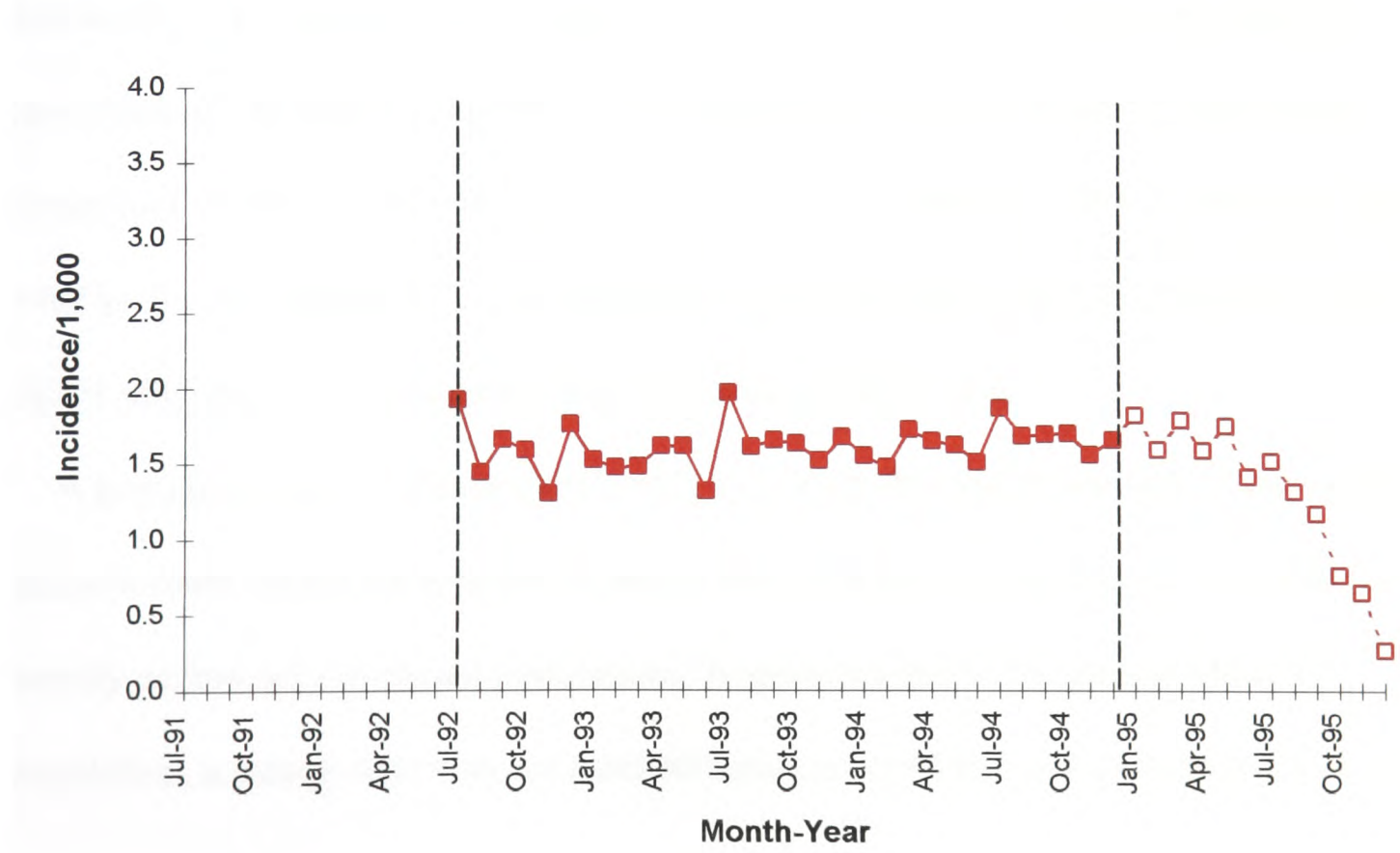


Fig. 3.2 Monthly incidence of CPP per thousand using data from January 1991 to December 1995
(the definition of a CPP episode only allowed incidence to be estimated accurately from July 1992 to Deccmber 1994).

December 1994. The monthly incidence, however, remained reasonably stable around a mean of 1.61/1,000. The incidence peaks in July of each year corresponded to a disproportionately high number of women with their first pelvic pain contact registered on 1 January of that year. This proved to be an oddity in the data, caused by GPs uncertain of the date of a pelvic pain contact in a particular year using 1 January of that year as a default (IMS, personal communication). A linear regression model, fitted using the least squares method, showed that the incidence did not increase significantly over the 30 months ($p=0.4$).

3.2.3 Resolving the issue of rising CPP prevalence

The steady increase in prevalence could not be explained by any changes in the number of new cases presenting to GPs or by improved registration on the database, as this would have resulted in increasing incidence rates over time. A possible explanation for an increase in prevalence over time was the effect of ageing of the cohort, although it seemed unlikely that this would have caused such a steady increase over a relatively short time-period. Nevertheless, the effect of ageing was investigated by standardisation (Rothman & Greenland, 1998b) of the monthly prevalence rate in December 1994 according to age in 1992 in 5-year categories¹⁰. The standardised monthly prevalence in December 1994 was 28.5/1,000, only 1.4/1,000 lower than the unstandardised rate.

A population is in a 'steady state', with a constant disease prevalence, if the number of incident cases equals the number of people who stop having the disease. This condition usually occurs only in closed populations. It appeared that in the closed MediPlus population, a steady state was not reached between July 1992 and December 1994. The

¹⁰ The stratified prevalence rate in December 1994, P_s , was calculated using thirteen 5-year age strata (≤ 15 yr, 16-20, etc):

$$P_s = \frac{\sum_{k=1}^{13} P_k N_k}{284,162} \quad \text{where: } P_k \text{ is the December 1994 prevalence rate in the } k^{\text{th}} \text{ age-stratum, and}$$

$$N_k \text{ is the number of women in the } k^{\text{th}} \text{ age-stratum in 1992}$$

number of incident cases each month was greater than the number who stopped having the disease, so that prevalence continued to rise.

This situation arose because of the way in which the denominator population was identified (see Chapter 2). The study population consisted of the 284,162 women who had a GP contact in 1991; women registered with a practice who had no GP contact in that year were excluded. Thus, the prevalence estimate was flawed in two ways: (1) the estimate was too high and (2) 'long-term' prevalent cases were overrepresented and there was a shortfall of new cases.

Prevalence in July 1992 was overestimated, since all CPP cases (who necessarily contacted their GP in 1991) were included in both the numerator and the denominator, but some women who did not visit their GP in 1991 were excluded from the denominator. For example, if half of the women ($n=48,457$) excluded from the denominator because they did not have a GP contact in 1991 were in fact registered with a practice in that year, the estimated monthly prevalence per thousand in July 1992 would decrease from 21.8 to 18.6¹¹.

There was a shortfall of new cases because cases that would have originated from July 1992 onwards in women with no GP contact in 1991 were missing. As long-term cases stopped having CPP at a slower rate than short-term cases, prevalence continued to rise and a steady state was not observed.

3.2.4 Calculation of prevalence and incidence of CPP

Although the prevalence of CPP could not be directly observed from the data, it was possible to obtain an unbiased prevalence estimate by following the accumulation of new

¹¹ Suppose 48,457 women, excluded from the denominator because they did not have a GP contact in 1991, were in fact registered with a practice in that year. Assuming that this group had a monthly incidence of CPP similar to that of unaffected women who had seen their GP in 1991 ($1.61/1,000$), the new average number of incident cases in July 1992 in the new denominator of 332,619 women would have been $332,619 \times 0.00161 = 536$ cases. Combined with the 5,659 cases who were prevalent in July 1992 and had a seen their GP for CPP in 1991, the new July 1992 prevalence would be $(5,659 + 536) / 332,619 = 18.6/1,000$

cases towards an approximate steady state, in the cohort of women who were free of CPP in 1991. When following such a cohort, a steady state will only be reached after a time-period has passed that equals the maximum duration of the disease (Freeman & Hutchison, 1980). As is shown later in section 3.3.4, the maximum duration of disease was longer than the 2.5 year observation period available (July 1992 to December 1994). The steady state prevalence was therefore not attained by December 1994, but - as will be shown in this section - could be approximated.

The 5,653 women who had a pelvic pain contact in 1991 were excluded from the original denominator of 284,162, leaving 278,509 unaffected women at the start of 1992. Exclusion of these women did not affect the representativeness of the denominator compared to the general population, with women under 30 remaining under-represented by 4% (see Chapter 2).

Using the new denominator, monthly incidence was - as before - estimated as the number of new episodes in a given month as a proportion of the unaffected population at risk. The prevalence of CPP was estimated by following the accumulation of incident cases towards a steady state (Figure 3.3). The monthly increase in prevalence fell steadily over the period, so that the prevalence rate had almost stabilised by December 1994. A least squares regression line relating the monthly change in prevalence to time since July 1992 was used to derive an approximation of the monthly prevalence in the steady state. The resulting equation ($342.38 - 10.39 \times \text{months since July 1992}$, with $R^2=0.83$), used to extrapolate the monthly prevalence beyond December 1994 (Figure 3.3), predicted the steady state to be reached in April 1995 (with the estimated monthly number of prevalent cases=6,000).

To allow comparison with published prevalence figures for other conditions given in the OPCS Morbidity Statistics from General Practice (1995a), the annual prevalence rate in the steady state was estimated on the basis of monthly prevalence and incidence figures (annual

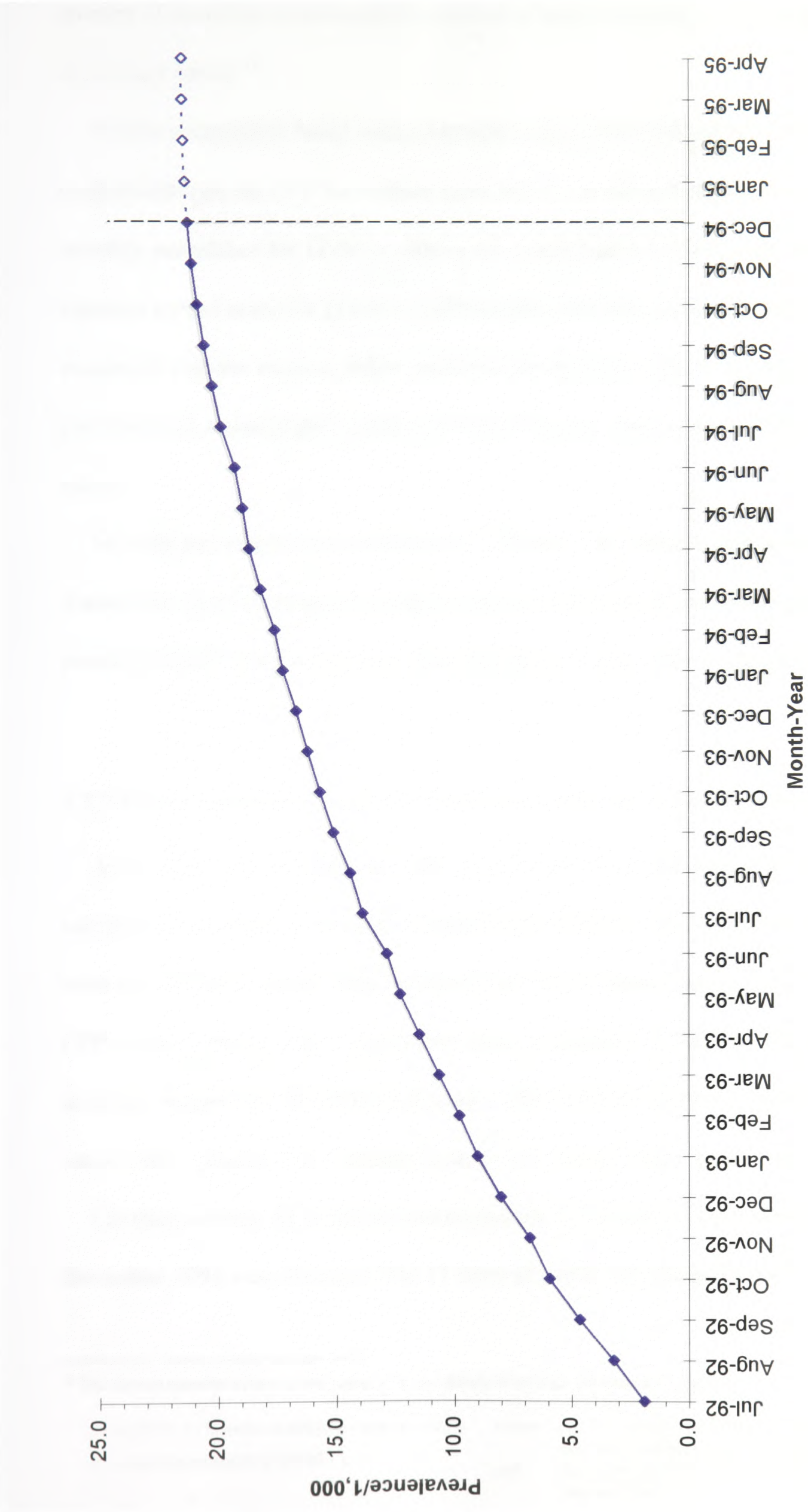


Fig. 3.3 Prevalence of CPP following the accumulation of new cases from July 1992 in 278,509 women aged 12-70 in 1991 who were unaffected at the start of 1992 (*prevalence is predicted from January 1995*).

number of prevalent cases=monthly number of prevalent cases + 11*mean monthly number of incident cases)¹².

In their community-based study, Mathias *et al.* (1996) had reported a three-monthly consultation rate for CPP for women aged 18-50. To allow comparison with their figures, monthly prevalence for 18-50 yr olds in the steady state was first predicted; the appropriate equation turned out to be $215.96 - 7.07 \times \text{months since July 1992}$. The resulting estimate was combined with the mean monthly incidence for 18-50 yr olds, to calculate the three-monthly prevalence (3-monthly prevalent cases= monthly prevalent cases + 2*mean monthly incident cases).

Monthly prevalence and incidence for different age groups and Regional Health Authorities were investigated using December 1994 data, as the observed prevalence in this month was only marginally lower than the predicted prevalence in the steady state.

3.2.5 Minimum prevalence and incidence: symptoms and conditions constituting CPP

As described in Chapter 2, the CPP episodes on which prevalence and incidence calculations were based included a broad range of codes. Although strict exclusion criteria were applied, some codes were included that may not have been specific enough to indicate CPP if they were the only codes constituting an episode. To test the specificity of the selection method, the minimum prevalence and incidence were calculated by only considering episodes that contained codes most strongly associated with CPP.

For this purpose, all symptom and diagnostic codes used in the episodes prevalent in December 1994 were arranged into 17 clinically relevant groups (Table 3.1). Ten of these

¹² The annual number of prevalent cases, x , in the steady state was calculated by solving:

$$x = 6,000 + 11 * [\text{mean monthly incidence rate}] * y \quad \text{where: } y = \# \text{ of unaffected women at risk each month (i.e. those who were not prevalent in the previous 12 months)}$$

$$y = \text{total denominator } 278,509 - x \quad \text{and: } \text{the mean monthly incidence rate} = 1.58/1,000 \text{ (see section 3.3.1)}$$

Table 3.1. Groups of symptoms and diagnoses and frequency of their use in 5,939 CPP episodes prevalent in December 1994.

Symptoms	Number of episodes with a contact in group (%)	Diagnoses	Number of episodes with a contact in group (%)
* 1. (lower) abdominal pain	2,541 (42.8)	* 9. irritable bowel syndrome (IBS)	1,871 (31.5)
2. gastrointestinal symptoms ¹	1,485 (25.0)	* 10. cystitis	1,665 (28.0)
* 3. dysmenorrhoea	612 (10.3)	* 11. other gastrointestinal diagnoses ⁵	580 (9.8)
4. menstrual symptoms ²	488 (8.2)	* 12. pelvic inflammatory disease (PID)	548 (9.2)
5. genitourinary symptoms ³	207 (3.5)	* 13. endometriosis	295 (5.0)
* 6. dyspareunia	190 (3.2)	14. ovarian cysts	169 (2.8)
7. unspecified pelvic symptoms ⁴	86 (1.4)	15. uterine fibroids	159 (2.7)
* 8. ovulation pain	83 (1.4)	16. adhesions	44 (0.7)
		* 17. other gynaecological diagnoses ⁶	25 (0.4)

* Groups used in the estimation of the minimum prevalence rate. Minimum prevalence of CPP was estimated using only those episodes that contained at least one contact in one of these groups. Episodes with dysmenorrhoea or dyspareunia codes always contained at least one more contact in another group (see Methods).

¹ Includes 'psychogenic GIT disorders', 'constipation', 'GIT disorders', 'gastrointestinal symptoms NOS'; ² Includes 'menstruation disorders' and 'menstrual disorders NOS'; ³ includes 'psychogenic GU symptoms' and 'genito-urinary sympt. NOS'; ⁴ includes 'female genital symptoms NOS', 'abdomen/pelvis symptoms NOS', 'abdominal discomfort'; ⁵ includes 'diverticular disease', 'diverticulitis', and 'viral+ill-defined GIT infections'; ⁶ includes 'pelvic congestion syndrome' and 'benign ovarian tumour'.

groups were considered most strongly associated with CPP: (lower) abdominal pain, dysmenorrhoea, dyspareunia, ovulation pain, irritable bowel syndrome, cystitis, other gastrointestinal diagnoses (mainly diverticular disease), pelvic inflammatory disease, endometriosis, and other gynaecological diagnoses (mainly pelvic congestion). The minimum prevalence and incidence rates of CPP in December 1994 were estimated by counting only those episodes that contained at least one contact in one of these groups. As mentioned in Chapter 2, episodes with dysmenorrhoea or dyspareunia always contained at least one further contact in another group.

3.2.6 Duration of pelvic pain symptoms

Duration of symptoms in the database was calculated as the time between the first and the last pelvic pain contact of a CPP episode, and could therefore only be investigated using incident episodes. Following the definition of CPP, the minimum duration of an episode was six months. Since an episode was considered to finish at the start of a one-year pain-free interval (if any), duration of CPP could be calculated only for those incident episodes that finished in 1994 or before.

Because the duration of episodes continuing into 1995 was unknown, the mean duration of symptoms could not be determined. Instead, median duration and inter-quartile ranges were calculated, and duration was also classified into six groups: '6 months - 1 year', '>1 - 1.5 years', '>1.5 - 2 years', '>2 - 2.5 years', '>2.5 years', and 'lasting into 1995'.

Duration of symptoms, and the consistency of these results over time, were investigated in seven consecutive three-month incidence groups from July 1992 to March 1994. For the episodes that were incident after March 1994, the median duration could not be calculated, as more than 50% lasted into 1995. For the episodes incident after September 1992, the upper quartile of duration could not be determined, as more than 25% lasted into 1995.

The association between the age of women and the duration of their symptoms was investigated using the first annual incidence group, from July 1992 to June 1993.

3.2.7 Statistical methods

All analyses were performed using SAS version 6.12 (SAS Institute Inc., 1990) or Excel version 5.0 (Microsoft Corporation, 1993a). Confidence intervals (95% CI) for observed prevalence and incidence rates were calculated using the standard error of the estimates in the population ¹³. Prevalence and incidence rates between age and regional groups were compared using Pearson chi-squared tests and Mantel-Haenszel chi-squared tests for trend. Prevalence rates between regional groups after adjusting for age were compared using a logistic regression model for categorical data, the CATMOD Procedure (SAS Institute Inc., 1989a). As the distribution of duration of symptoms was skewed, the association between median symptom duration and age was assessed by first transforming the values of duration into ranks (RANK Procedure), and using these ranks in a general linear model (GLM Procedure) (SAS Institute Inc., 1989b).

3.3 Results

3.3.1 Prevalence and incidence of CPP

The monthly prevalence of CPP estimated in the steady state for women aged 15-73 was 21.5/1,000 (95% CI: 21.0-22.0), with a last observable monthly prevalence, for December 1994, of 21.3/1,000 (95% CI: 20.8-21.8). The estimated annual prevalence rate of CPP was

¹³ 95% confidence intervals for incidence and prevalence rates were calculated as:

$$\text{lower 95\% confidence limit} = p - 1.96 * \sqrt{\frac{p(1-p)}{n}} \quad \text{and} \quad \text{upper 95\% confidence limit} = p + 1.96 * \sqrt{\frac{p(1-p)}{n}}$$

where: p = prevalence (or incidence) rate and n = number of women in denominator group

NB. Additional variance of the estimation of the steady state prevalence using a linear regression line was negligible compared to overall variance as calculated above.

38.3 (95% CI: 37.5-39.0). This rate was compared with annual prevalence figures of three common chronic conditions - asthma, migraine, and back pain - given in the OPCS Morbidity Statistics from General Practice (1995a) for women aged 16-74. Prevalence of CPP was found to be higher than reported for migraine (21/1000) and comparable to that of asthma (37/1000) and back pain (41/1000).

The estimated annual prevalence in women aged 18-50 was 37.2 (95% CI: 36.3-38.1), with a three-month rate of 23.6/1,000 (95% CI: 22.9-24.4). This prevalence was lower than the consultation rate reported in the community study by Mathias *et al.* (1996). They reported that 37/1,000 American women aged 18-50 had seen a health care provider (gynaecologist, other physician or mental health professional) for CPP in the previous three months.

The monthly incidence of CPP in women aged 12-70 in 1991 remained approximately stable from July 1992 to December 1994, around a mean of 1.58 (95% confidence interval 1.43 to 1.73) with a low of 1.28 and a high of 1.96 per thousand per month.

The minimum prevalence of CPP was estimated from episodes prevalent in December 1994 that contained codes most indicative of CPP (Table 3.1). Minimum monthly prevalence and incidence rates per thousand for December 1994 were 18.5 (95% CI: 18.0-19.0) and 1.36 (95% CI: 1.22-1.50), respectively. The reduction in rates was mainly due to the exclusion of episodes with codes for constipation or uterine fibroids alone.

3.3.2 Adjustment of prevalence and incidence for the under-representation of young women

The prevalence and incidence rates of CPP given in the previous section were derived from the denominator group of women who had a GP contact not related to CPP in 1991. As described in section 2.4, the exclusion of women who did not have a GP contact in 1991 resulted in a 4% under-representation of women younger than 30 in the denominator group compared to the general population. Adjustment of the results for this under-representation

(by assuming that none of these women had a GP contact for pelvic pain in 1991-95) reduced the monthly and annual prevalence rates only slightly, to 20.4/1000 and 36.1/1000 respectively, and the mean monthly incidence rate to 1.49/1000.

3.3.3 Monthly prevalence and incidence by age and region

Figure 3.4 shows the prevalence of CPP for December 1994 by period of incidence, for different age groups. Prevalence rates significantly increased from 18.2/1,000 in 15-20 year olds to 27.6/1,000 in women older than 60 ($\chi^2_{df=1}$: $p<0.001$). However, incidence slightly decreased with age ($\chi^2_{df=1}$: $p=0.04$) from 1.66 in 15-20 year olds to 1.32 in women older than 60. The rise in prevalence with age was caused by CPP lasting longer in older women, as indicated by the increasing proportion of cases with an onset of CPP before December 1994. Duration of CPP in relation to age is discussed further in section 3.3.4.

The monthly prevalence by period of incidence for different Regional Health Authorities is shown, in ascending order, in Figure 3.5. Prevalence rates were significantly different between regions ($\chi^2_{df=16}$: $p<0.001$). The lowest rate per thousand was found in Scotland (16.0, 95% CI: 14.0-18.0) and the highest in Wales (29.4, 95% CI: 26.5-32.3). These differences remained highly significant after adjusting for variations in age distributions ($\chi^2_{df=16}$: $p<0.001$).

When ordering the regions according to increasing prevalence, there was no significant trend in the proportion of cases with onset of CPP before December 1994 ($\chi^2_{df=1}$: $p=0.6$). Therefore, it is likely that the differences in prevalence were attributable to regional differences in incidence rather than duration.

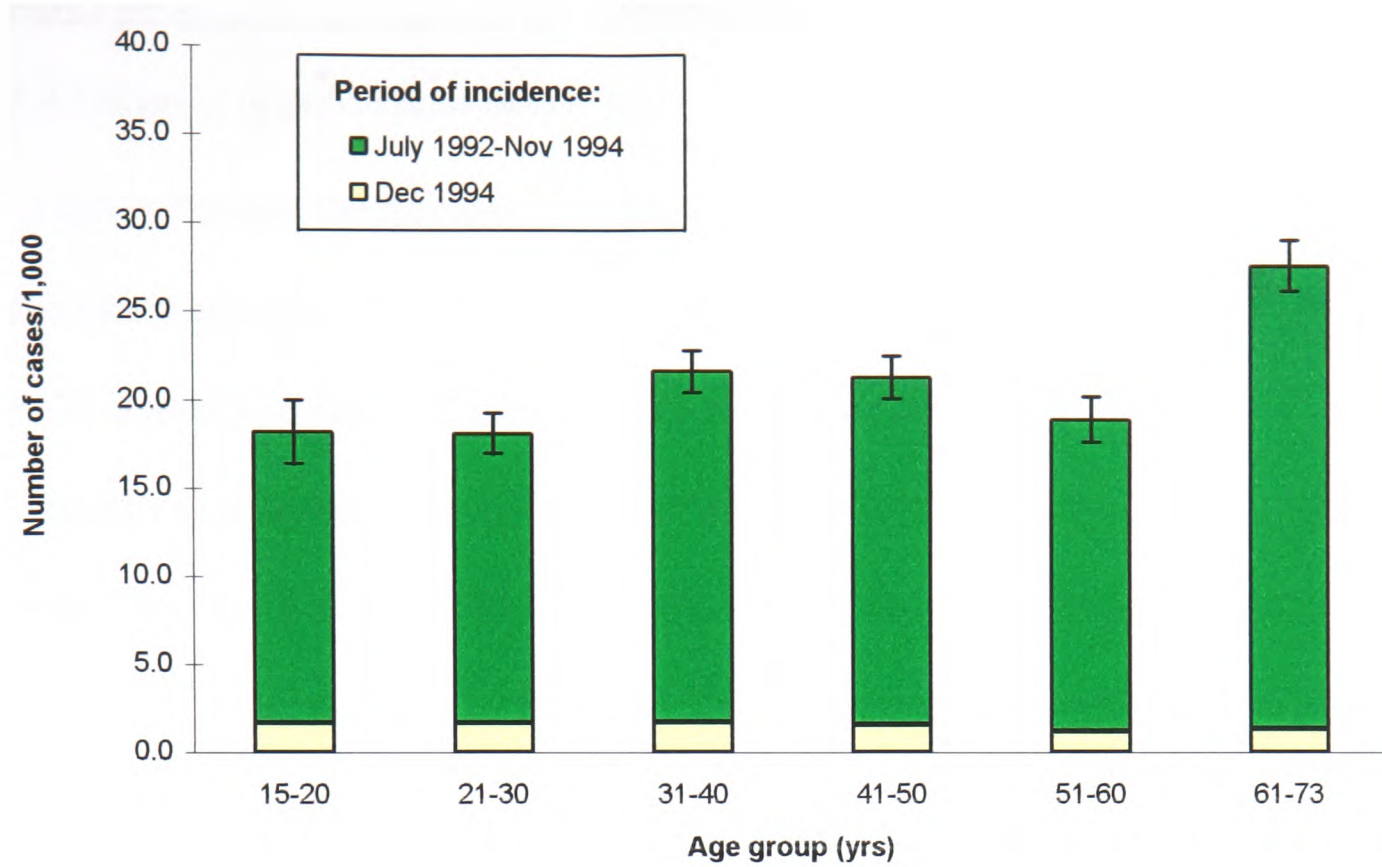


Fig. 3.4. Monthly prevalence rates of CPP for December 1994 by age in 1994 and period of incidence (error bars indicate 95% confidence intervals for total prevalence rates)

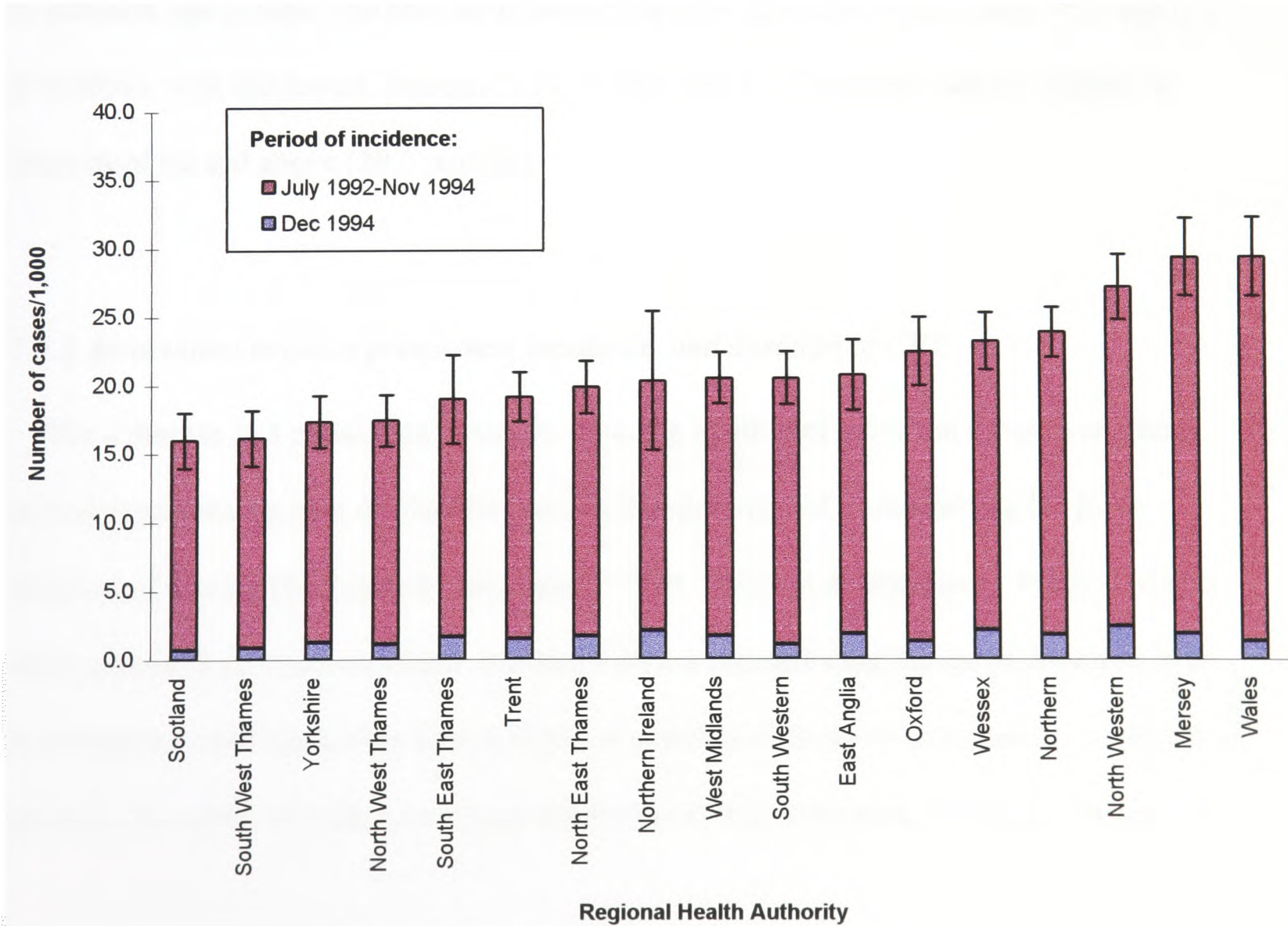


Fig. 3.5. Monthly prevalence rates of CPP for December 1994 by Regional Health Authority and period of incidence (error bars indicate 95% confidence intervals for total prevalence rates).

3.3.4 Duration of pelvic pain symptoms

Table 3.2 shows the duration of symptoms from July 1992 to March 1994 in consecutive three-month groups of incident episodes. The maximum duration that could be determined for all incident episodes in a group is indicated by a dashed line.

Patterns of duration were consistent over the different incidence groups, with a median duration around 15 months. Approximately 40% of incident episodes lasted up to 1 year, 17% >1-1.5 years, and 10% >1.5-2 years. Out of the first incidence group, 23% of women went on to have symptoms until the end of 1995 and 8% returned to their GP with a second episode before the end of 1995.

The association between age and duration of symptoms was investigated using women with episodes in the first annual incidence group (July 1992 to June 1993). Five women were excluded due to missing age, leaving 5,111 women. Figure 3.6 shows duration of symptoms in different age groups. The median symptom duration increased significantly with age ($F_{df=1}$: $p<0.0001$), with the lowest duration in 21-30 year olds (12.7 months) and the highest in those aged 60 and above (20.3 months).

3.3.5 Association between prevalence, incidence, and duration of CPP

For a disease in a population in steady state, the number of prevalent cases over a time-period equals the number of incident cases in that time-period multiplied by the mean duration of disease (Rothman & Greenland, 1998b; Freeman & Hutchison, 1980). A steady state assumes a constant incidence combined with a constant distribution of durations in an incidence series of cases over time, a criterion which is unlikely to be completely fulfilled in practice. However, the data were examined to check their consistency with this theory.

Table 3.2 Duration of symptoms in three-month incidence groups from July 1992 - March 1994.

	Incidence groups						
	July - Sept 1992 (n=1,380)	Oct - Dec 1992 (n=1,272)	Jan - Mar 1993 (n=1,223)	Apr - June 1993 (n=1,241)	July - Sept 1993 (n=1,425)	Oct - Dec 1993 (n=1,312)	Jan - Mar 1994 (n=1,290)
Median duration in months (IQ range)	15.3 (9.7-31.4)	15.5 (10.0- ?) ¹	14.9 (9.7- ?) ¹	14.4 (9.8- ?) ¹	15.6 (9.6- ?) ¹	15.4 (9.8- ?) ¹	15.0 (9.7- ?) ¹
Number (%) with episode duration							
6 months - 1 year	560 (40.6)	486 (38.2)	481 (39.3)	517 (41.7)	547 (38.4)	510 (38.9)	508 (39.4)
>1 - 1.5 years	222 (16.1)	232 (18.2)	218 (17.8)	232 (18.7)	249 (17.5)	221 (16.8)	195 (15.1)
>1.5 - 2 years	140 (10.1)	129 (10.1)	135 (11.0)	106 (8.5)	137 (9.6)	38 (2.9)	-
>2 - 2.5 years	97 (7.0)	78 (6.1)	61 (5.0)	24 (1.9)	-	-	-
>2.5	40 (2.9)	21 (1.7)	-	-	-	-	-
lasting into 1995	321 (23.3)	326 (25.6)	328 (26.8)	362 (29.2)	492 (34.5)	543 (41.4)	587 (45.5)
Number (%) with 2nd episode	113 (8.2)	94 (7.4)	72 (5.9)	52 (4.2)	48 (3.4)	13 (1.0)	5 (0.4)

¹ Upper quartiles could not be determined, as >25% of episodes continued into 1995.

NB. A dashed line indicates the maximum duration that could be determined for all incident episodes in a particular group.

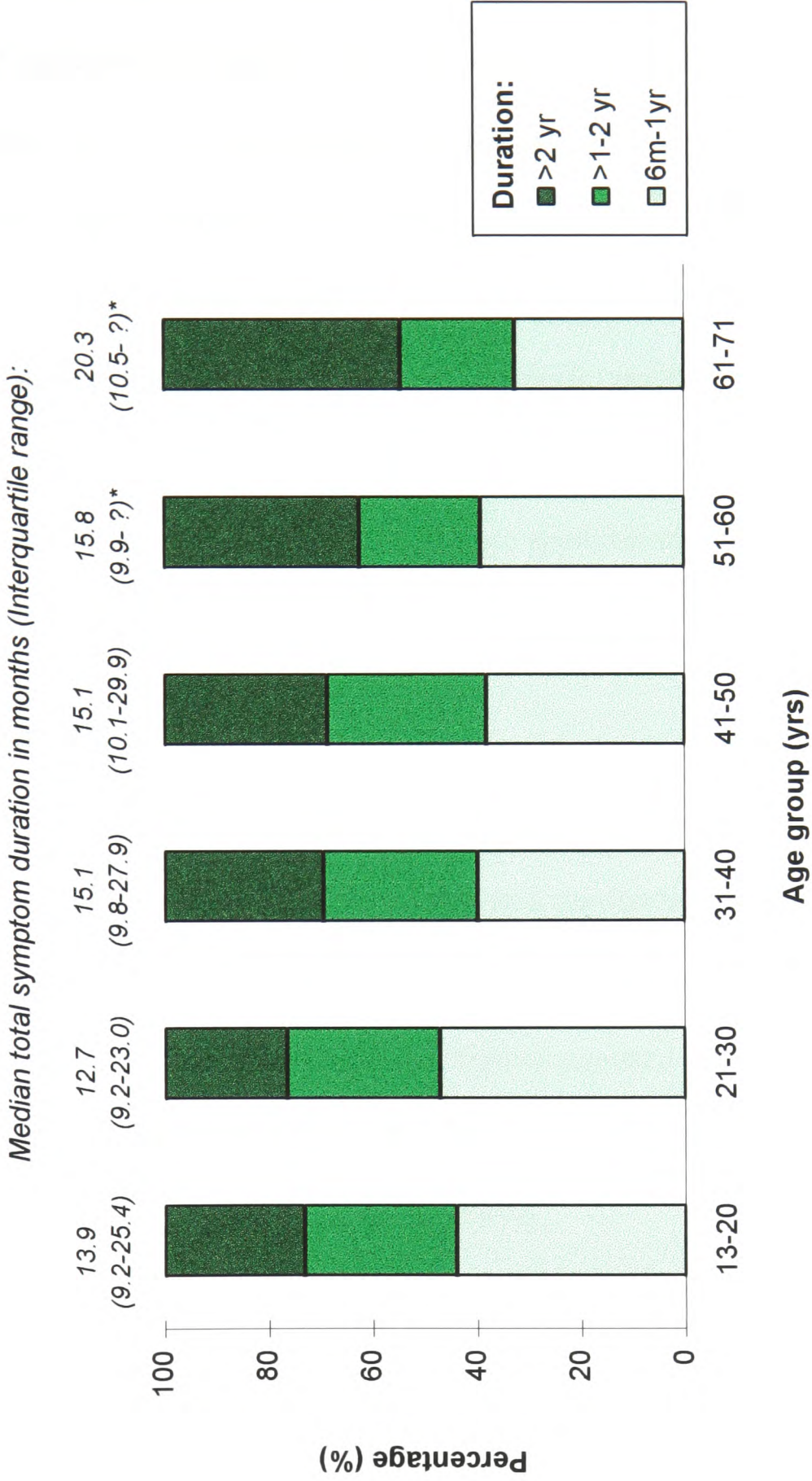


Fig. 3.6. Duration of symptoms by age in 5,111 women with onset of CPP in July 1992 - June 1993.

* Upper quartiles could not be calculated, as >25% of women continued to have symptoms into 1995

From the regression equation, the estimated monthly number of prevalent cases in the steady state was 6,000, with an estimated monthly number of incident cases of 423¹⁴. The expected mean duration of CPP in the study population was therefore 14.2 months from the onset of CPP, equal to 20.2 months when calculated from the first contact.

As described before, the mean duration of disease could not be calculated, since even in the earliest identifiable incidence cohort (July to September 1992) 23% of women still had symptoms in December 1994. When the last known pelvic pain contact in 1995 for these women was taken as the end of their episode, the mean duration of episodes for the incidence group was 20.9 months (95% CI: 20.2-21.6) from the first pelvic pain contact. Thus, the observed incidence, prevalence and duration were approximately in line with expectation.

3.4 Discussion

This study provided the first evidence that the prevalence of CPP in the UK is high. Using the MediPlus database, the monthly prevalence and incidence rates of CPP for women aged 15-73 were estimated to be 21.5/1000 and 1.58/1000, respectively. Comparison of the annual CPP prevalence (38/1000) with primary care figures reported for other 'common' chronic conditions illustrates that CPP has a prevalence comparable to migraine (21/1000), asthma (37/1000), and back pain (41/1000) (OPCS, 1995a).

The estimated three-month prevalence rate of 23.6/1000 for women aged 18-50 was lower than the consultation rate reported in the community study of CPP by Mathias *et al.* (1996). They found that 37/1000 American women aged 18-50 had seen a health care provider

¹⁴ Based on the previously described regression equation (section 3.2.4), the monthly number of prevalent cases in the steady state was estimated to be 6,000. The monthly number of incident cases in the steady state, z , was calculated using the equations given earlier in footnote 12:

$$x = 6,000 + 11 * z$$

$$y = \text{total denominator } 278,509 - x$$

$$z = 1.58/1,000 * y$$

where: x = annual # of prevalent cases

y = # of unaffected women at risk each month (i.e. those who were not prevalent in the previous 12 months)

z = monthly # of incident cases in steady state

(gynaecologist, other physician or mental health professional) for CPP in the previous three months. Their results, however, were based on patient recall and self-report, and are likely to provide higher estimates than those based on medical records. In addition, differences in systems of access to health professionals may also account for some of the variation between figures.

The prevalence of CPP was highest in older women (those above 60), due to a longer duration of symptoms. In their community-based study of 18-50 year old women, Mathias *et al.* (1996) reported the highest prevalence of CPP in 25-34 year olds. In their study of 18-45 year old women approached in clinic waiting rooms, Jamieson & Steege (1996) reported that pelvic pain was most prevalent among 26-30 year olds. Neither of these studies, however, included women older than 50 years. If women older than 50 had similarly been excluded from the MediPlus analysis, a peak prevalence of CPP would have been found in 31-40 year olds.

Prevalence and incidence also varied significantly between regions, after adjusting for differences in age distributions. It should be noted, however, that these results are based on women seeking treatment for pelvic pain. Therefore, differences in age and region-specific rates may not only be due to possible underlying differences in community-based rates, but also to differences in health care seeking behaviour.

Duration of CPP symptoms as calculated from the available data was long, with a median duration of approximately 15 months. Approximately a quarter of women who started having CPP in July-September 1992 had symptoms until the end of 1995. Since these results were based on contacts with general practice, no conclusions can be drawn regarding the true duration of symptoms. It is likely that duration as calculated was not only influenced by the actual duration of women's symptoms, but also by possible other factors, such as patient satisfaction with any treatment offered, interaction with the GP and the sense of being taken

seriously, weariness of repeated visits to the GP, and inclination to 'put up' with seemingly incurable symptoms.

General practice databases such as MediPlus are increasingly being used for research purposes, predominantly in the fields of pharmaco-epidemiology and drug prescription monitoring (Martin *et al.*, 1997; Perez-Gutthan *et al.*, 1997; Jick *et al.*, 1995). They are also potential sources of morbidity data (Hollowell, 1997) and - as this study confirms - can provide valuable information on the epidemiology of clinical problems in primary care (Lawrenson *et al.*, 1998). However, use of routinely collected data for epidemiological purposes has certain limitations. Issues of generalisability and completeness of the data registered in MediPlus were discussed in section 2.2.2. Although the computer record was the primary record for 41% of practices, 43% of practices still considered written records as primary and recorded only key diagnoses and prescriptions in the MediTel system. Theoretically, it is possible that the latter type of use resulted in an underestimate of CPP cases, and that the uneven geographical spread of highly computerised practices may to some extent have accounted for the differences in rates found between regions. The chance of this bias occurring, however, was minimised by using an extensive method for selecting CPP cases, based on a wide range of symptom and diagnostic codes.

A related problem that has been reported is that of diagnostic variability, i.e. varying use of different symptom or diagnostic labels depending on the interpretation of the complaint (Crombie *et al.*, 1992). Again, this problem was avoided to a large extent by the all inclusive method of code selection. Identification of CPP cases, therefore, was not likely to have been greatly influenced by differences in types of code used by GPs.

Since the MediPlus data cannot provide information on the prevalence of CPP in women not seeking health care, it is certain that the results underestimate general population rates. Mathias *et al.* (1996) found that while 147/1000 of women aged 18-50 had CPP in the last three months, only 25% had seen a health care provider in that period. In this respect, CPP

appears to be similar to back pain, which was described by the Clinical Standards Advisory Group (1994) as a condition that many people cope with themselves without seeking health care. In their report, the annual prevalence of back pain in the adult population was found to be 36-37% in recent population surveys, while according to medical records of the last two decades only 6-7% had consulted a GP for their pain. In Chapter 6, the results are discussed of the community-based study in which the prevalence of CPP in the general population was investigated.

Chapter 4

Patterns of diagnosis and referral in primary care

4.1 Introduction

In the previous chapter, the prevalence and incidence of CPP were estimated using cases who were incident from July 1992 onwards. This chapter reports the diagnostic and referral patterns observed in a cohort of 5,051 incident cases from their first contact with a GP for pelvic pain.

4.2 Methods

4.2.1 Selection of the cohort of CPP cases

To be most confident that a contact of a CPP case was the first ever contact for pelvic pain, one would ideally like to select incident cases with the longest possible pain-free time prior to the contact, i.e. those who had their first episode of CPP towards the end of the available data. This approach, however, would have the obvious disadvantage of not allowing much follow-up time. For the present analysis, the annual incidence group with the longest possible follow-up time was chosen. This consisted of 5,111 women with CPP incident between July 1992 and June 1993. Duration of symptoms in this cohort was given previously in section 3.3.4.

The original (computerised) records of the cohort were checked for any diagnoses related to pelvic pain (e.g. endometriosis) that had occurred more than 12 months prior to the first contact of the index episode, but had not counted towards a CPP episode (according to the definition of an episode). Sixty women had such a diagnosis. These women were excluded from the analyses, as it was likely that a previously recorded diagnosis would have

influenced the diagnosis given in the incident CPP episode. The cohort of incident CPP cases used in the analysis therefore consisted of 5,051 women. These women were followed from their first contact in 1992 until the end of the CPP episode or - if symptoms persisted - until the end of 1995, a mean follow-up period of 3.5 years. Second episodes of CPP (n=328) were not included in the analyses presented here, but a separate analysis including these episodes did not affect the results.

4.2.2 Definitions of symptoms, diagnoses and specialist referral

The following definitions were used in the analyses:

Symptom: a symptom code occurring in the follow-up of a CPP case. Symptom codes were grouped into five categories: ‘non-cyclical pelvic pain’ (lower abdominal/pelvic pain and unspecified pelvic symptoms), ‘cyclical pain/symptoms’ (dysmenorrhoea, menstrual pain/symptoms, and ovulation pain), ‘dyspareunia’, ‘gastrointestinal symptoms’, and ‘genito-urinary symptoms’.

Diagnosis: a diagnostic code occurring in the follow-up of a CPP case. Diagnostic codes were grouped into nine categories: ‘cystitis’, ‘irritable bowel syndrome’, ‘other gastrointestinal diagnoses’ (diverticular disease, diverticulitis, GIT infections), ‘pelvic inflammatory disease’, ‘endometriosis’, ‘ovarian cysts’, ‘uterine fibroids’, ‘adhesions’, and ‘pelvic congestion syndrome’¹⁵. For the analyses by age and diagnostic group, the latter four labels were grouped into ‘other gynaecological diagnoses’.

The final diagnosis was defined as the diagnosis registered as the last pelvic pain contact of the episode. For those women who had two diagnoses registered at the last contact (n=25), the second diagnosis was arbitrarily taken as the final diagnosis.

¹⁵ None of the 5,051 women received a diagnosis of ‘benign ovarian tumour’ in their follow up, which had previously been grouped with pelvic congestion syndrome into ‘other gynaecological diagnoses’ in the analysis of minimum prevalence. (See section 3.2.5: *Minimum prevalence and incidence: symptoms and diagnoses constituting CPP*)

Duration of symptoms: as in the previous chapter, the duration of symptoms was calculated as the time between the first and the last pelvic pain contact of an episode. Median duration and inter-quartile ranges were calculated where possible. In addition, duration was categorised into: '6 months - 1 year', '>1 - 2 years', and '>2 years'.

Specialist referral: a code indicating a referral to a hospital specialist for CPP occurring in the follow-up of a CPP case. Firstly, all codes initially selected as part of group D (see section 2.4) were counted as evidence of referral. As described previously in Chapter 2, these comprised specific procedure codes such as laparoscopy or hysterectomy (counted as separate contacts without the requirement of a linked symptom or diagnostic code that was relevant to CPP) and specific referral codes (as long as they were linked to a code relevant to the abdominal area). In addition, all codes linked to the CPP contacts of the cohort were screened for any indicating a specialist referral. The list of all codes selected is given in Appendix III. For the analyses, codes were grouped into: 'gynaecological referral', 'gastroenterological referral', 'urology referral', 'general surgical referral', 'general medical referral', and 'other/unspecified referrals'.

4.2.3 Validation of symptoms and diagnoses

It was impossible to judge from the database whether or not a given diagnosis was confirmed by an investigation. However, it was possible to validate to some extent the use of symptom and diagnostic codes, by investigating whether or not prescribed medication attached to the codes was appropriate. For this purpose, medication linked to the CPP contacts of the cohort was investigated.

Symptoms and diagnoses constituting CPP at these contacts were arranged into seven indication groups, for which different medication classes were deemed appropriate: 'pelvic pain' (non-cyclical pelvic pain and dyspareunia), 'cyclical pain/symptoms', 'gastrointestinal complaints' (gastrointestinal symptoms, IBS, other gastrointestinal diagnoses), 'genito-

urinary complaints' (genito-urinary symptoms and cystitis), 'PID', 'endometriosis', and 'other gynaecological diagnoses'. Medication was classified into eight classes (Table 4.1): 'analgesics', 'lower gastro-intestinal specific', 'genito-urinary specific antibiotics', 'other antibiotics & anti-fungals', 'hormonal contraceptives & hormone replacement therapy (HRT)', 'other hormonal products & gonadotrophin releasing hormone (GnRH) analogues', 'antidepressants', and 'other (irrelevant)'.

Medication could only be attached to problem codes (see section 2.2 for a description of problem vs. note codes). In Table 4.2, the frequency with which symptoms and diagnoses in different indication groups appeared as notes and problems is given, showing that the majority (83-96%) were entered as problems. However, the frequency of prescribed medication attached to problems varied from 31% in 'other gynaecological diagnoses' to 82% in 'gastrointestinal complaints'.

Also in Table 4.2, the frequency of different prescribed medication classes is given for each indication group, as a percentage of the total number of prescriptions in that group. Medication considered appropriate for the group is marked (*). The high percentage of appropriately prescribed medication in each indication group (varying from 72% in other gynaecological diagnoses to 94% in non-cyclical pain/dyspareunia) is reassuring in that diagnostic codes entered were at least suspected diagnoses. The use of symptom and diagnostic codes as problems without medication attached, however, could not be evaluated.

4.2.4 Statistical methods

All analyses were performed using SAS version 6.12 (SAS Institute Inc., 1990). Comparisons between proportions were made using the Pearson chi-squared test. Trends in proportions were assessed using the Mantel-Haenszel chi-squared test for trend. Differences in proportions after adjusting for age and/or symptom duration in categories were assessed

Table 4.1. Classification of medication prescribed for CPP

Medication class	Includes:
1. Analgesics	- non-narcotic/narcotic analgesics; NSAIDs
2. Lower gastrointestinal (GI) specific	- anti-spasmodics; laxatives
3. Genito-urinary (GU) specific antibiotics	- urinary quinolones; trimethoprim combinations; other urological products
4. Other antibiotics & anti-fungal preps	- penicillins; cephalosporins; tetracyclines; macrolides; metronidazole; anti-fungal preps
5. Hormonal contraceptives & HRT	- combined mono/tri-phasic/progestagen only OCs; topical hormones; HRT products
6. Other hormonal products & GnRH analogues	- progestagen & combinations; other sex hormones; GnRH analogues
7. Antidepressants	- antidepressants
8. Other (irrelevant)	- all other medication

Table 4.2. Frequency with which codes in indication groups were registered as notes or problems, and frequency of prescribed medication classes.

	Indication group					Other gynaecological diagnoses (n=1,053)
	Non-cyclical pelvic pain/dyspareunia (n=10,800)	Cyclical pain/symptoms (n=4,173)	Gastrointestinal complaints (n=22,628)	Genito-urinary complaints (n=7,108)	PID (n=2,165)	Endometriosis (n=1,803)
Number of codes (%) entered as a note	1,693 (15.7)	422 (10.1)	878 (3.9)	659 (9.3)	335 (15.5)	105 (5.8)
Number of codes (%) entered as a problem	9,107 (84.3)	3,751 (89.9)	21,750 (96.1)	6,449 (90.7)	1,830 (84.5)	1,698 (94.2)
- no medication attached	4,472 (41.4)	1,336 (32.0)	3,172 (14.0)	1,785 (25.1)	663 (30.6)	791 (43.9)
- medication attached	4,635 (42.9)	2,415 (57.9)	18,578 (82.1)	4,664 (65.6)	1,167 (53.9)	907 (50.3)
Total number of prescriptions ¹	5,265	2,619	21,527	4,845	1,705	998
						361
Medication class prescribed						
(% of total number of prescriptions)						
1. Analgesics	1,241 (23.6)*	972 (37.1)*	1,002 (4.7)	140 (2.9)	293 (17.2)*	140 (14.0)*
2. Lower GI specific	2,676 (50.8)*	47 (1.8)	19,817 (92.1)*	76 (1.6)	50 (2.9)	26 (2.6)
3. GU specific antibiotics	148 (2.8)*	10 (0.4)	35 (0.2)	2,813 (58.1)*	22 (1.3)	7 (0.7)
4. Other antibiotics & anti-fungals	640 (12.2)*	134 (5.1)	358 (1.7)	1,611 (33.3)*	1,160 (68.0)*	45 (4.5)
5. Hormonal contraceptives & HRT	151 (2.9)*	631 (24.1)*	31 (0.1)	148 (3.1)	28 (1.6)	130 (13.0)*
6. Other hormonal prods & GnRH analog.	93 (1.8)*	698 (26.7)*	1 (0.0)	12 (0.2)	45 (2.6)	564 (56.5)*
7. Anti-depressants	108 (2.1)	24 (0.9)	197 (0.9)	21 (0.4)	5 (0.3)	23 (2.3)
8. Other (irrelevant)	208 (4.0)	103 (3.9)	86 (0.4)	24 (0.5)	102 (6.0)	63 (6.3)
Percentage with 'appropriate' medication	94.0	87.9	92.1	91.3	85.2	83.6
						72.0

¹ The number of prescriptions exceeds the number of problem codes with medication attached in each indication group, due to multiple prescriptions per problem.

* Medication considered to be appropriate for indication group.

using a logistic regression model for categorical variables (CATMOD Procedure) (SAS Institute Inc., 1989a).

Differences in median duration of symptoms between groups were assessed by transforming the skewed durational data into ranks (RANK Procedure) and entering them in a general linear model (GLM Procedure) (SAS Institute Inc., 1989b). Differences in the number of pelvic pain contacts between groups were assessed similarly.

4.3 Results

4.3.1 Frequency of symptoms and diagnoses

Table 4.3 shows the frequency with which symptoms and diagnoses occurred in the 3-4 year follow-up of the cohort of 5,051 incident CPP cases. Overall, the most common symptoms were non-cyclical pelvic pain (42%), gastrointestinal symptoms (21%), and cyclical pain/symptoms (17%). Figure 4.1 shows the frequency of symptoms in different age groups. Non-cyclical pelvic pain decreased from 63% in 12-20 year olds to 29% in women over 60, whereas gastrointestinal symptoms increased from 15% to 34% in these age groups. Cyclical pain/symptoms were recorded for 42% of 12-20 year olds, approximately 23% of 21-40 year olds, and decreased to 4% of 51-60 year olds. Dyspareunia was most commonly reported in younger women, with the highest frequency found in 21-30 year olds (7%).

The most common diagnoses given to women with CPP were cystitis (31%), IBS (29%), and PID (10%) (Table 4.3). Cystitis and IBS were the most common labels at all ages (Fig. 4.2). PID was a diagnosis most commonly given to younger women (with a maximum frequency of 24% in 21-30 year olds), whereas endometriosis and other gynaecological diagnoses were more common between the ages of 30 and 50. Other gastrointestinal diagnoses (mainly diverticular disease and diverticulitis) were uncommon before the age of 50, but were recorded in 23% of women aged over 60, a rate similar to IBS.

Table 4.3. Symptoms and diagnoses occurring in the follow-up of 5,051 women.

Symptoms	Number (%) of women with label	Diagnoses	Number (%) of women with label
Non-cyclical pelvic pain	2,103 (41.6)	Cystitis	1,556 (30.8)
Gastrointestinal symptoms	1,057 (20.9)	Irritable bowel syndrome (IBS)	1,468 (29.1)
Cyclical pain/symptoms	864 (17.1)	Pelvic inflammatory disease (PID)	525 (10.4)
Dyspareunia	140 (2.8)	Other gastrointestinal diagnoses	434 (8.6)
Genito-urinary symptoms	121 (2.4)	Endometriosis	209 (4.1)
		Ovarian cysts *	127 (2.5)
		Uterine fibroids *	119 (2.4)
		Adhesions *	29 (0.6)
		Pelvic congestion syndrome *	8 (0.2)

* In the remainder of the chapter, the labels ovarian cysts, uterine fibroids, adhesions and pelvic congestion syndrome were grouped into ‘*other gynaecological diagnoses*’

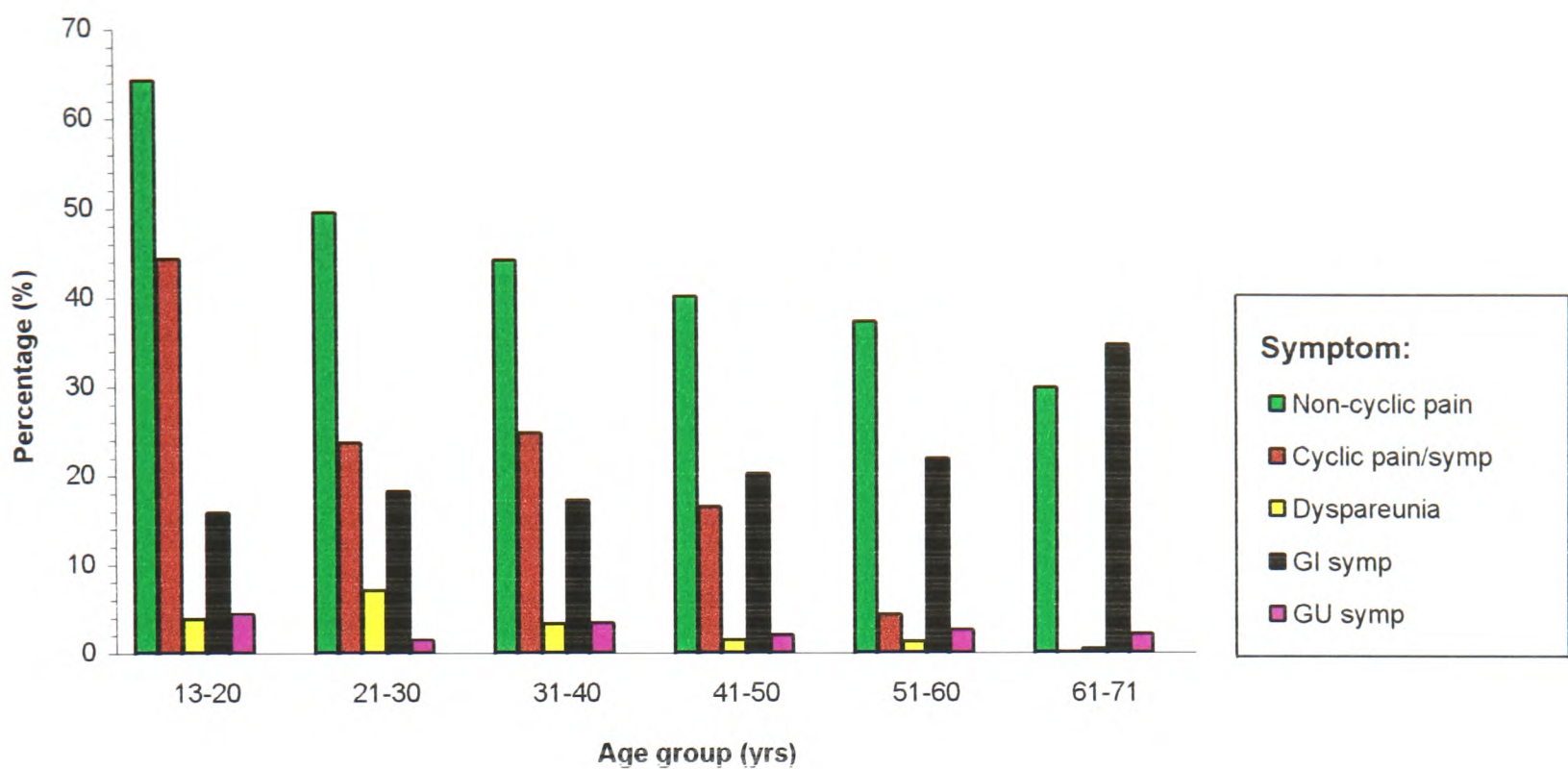


Fig. 4.1. Symptom frequencies (ever in follow-up) by age in 1992

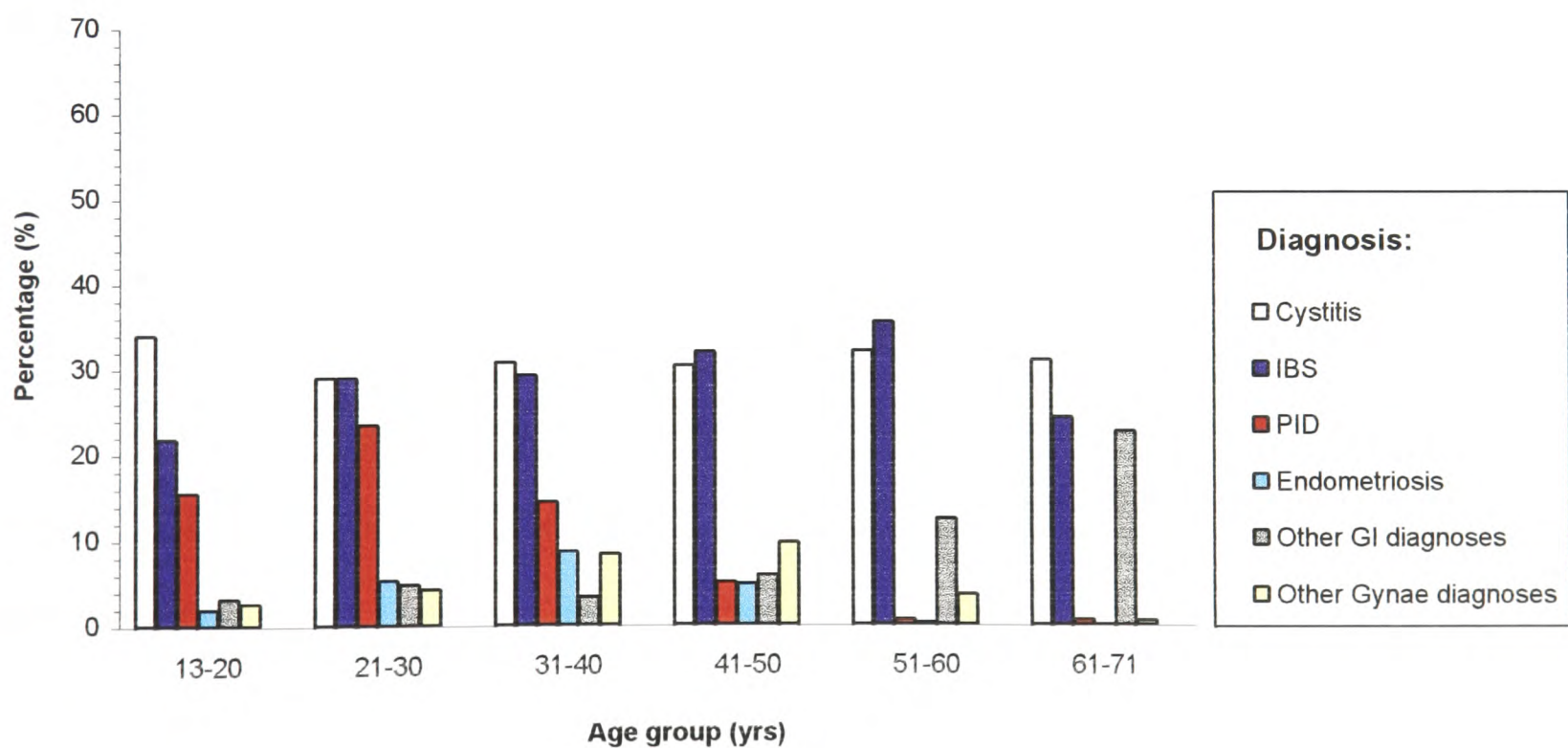


Fig. 4.2. Diagnosis frequencies (ever in follow-up) by age in 1992

4.3.2 Duration of symptoms

In section 3.3.4, duration of symptoms and its association with age in 1992 was briefly described for the 5,111 women who were incident in July 1992 - June 1993, before the exclusion of 60 cases with a prior diagnosis. Exclusion of these cases did not alter these results. Of the 5,051 women, 40% had symptoms lasting for 6 to 11 months, 28% for 1-2 years, and 32% for more than two years, with 26% continuing to have symptoms into 1995. The median duration of symptoms increased with age ($F_{df=1}: p<0.001$) (Table 4.4), as did the number of contacts for pelvic pain ($F_{df=1}: p<0.001$).

Table 4.5 shows the duration of symptoms in women grouped according to the final diagnosis received during the follow-up period. Median duration of symptoms varied significantly between diagnostic groups, from 13.6 months in women with no diagnosis or cystitis as the final diagnosis to 22.9 months in women whose final diagnosis was endometriosis ($F_{df=6}: p<0.001$, after adjustment of age). As expected, the number of pelvic pain contacts was also significantly different between diagnostic groups after adjusting for age ($F_{df=6}: p<0.001$).

4.3.3 Number and combinations of diagnoses

Of the 5,051 women, 28% ($n=1,428$) did not receive any diagnosis for the whole duration of their symptoms, 57% received one diagnosis, 13% received two, and 2% received more than two. Of those women with a diagnosis, 73% received a diagnosis at their first pelvic pain contact.

The longer symptoms persisted, the more likely women were to receive a diagnosis ($\chi^2_{df=1}: p<0.001$). However, even after two years or more of persistent symptoms, 26% of women remained without a diagnosis (Fig 4.3). The number of diagnoses also varied significantly

Table 4.4. Duration of symptoms and number of diagnoses in 5,051 women by age in 1992.

		Age group ¹					TOTAL (n=5,051)
		13-20 (n=409)	21-30 (n=1,021)	31-40 (n=1,101)	41-50 (n=1,031)	51-60 (n=611)	
Median symptom duration in months (IQ) ²		13.8 (9.2-25.2)	12.7 (9.2-23.0)	15.1 (9.8-28.5)	15.1 (10.0-29.9)	15.7 (9.9-?) ³	15.0 (9.8-?) ³
Symptom duration [% (n)]:	6 months -1 yr	44.5 (182)	47.3 (483)	39.9 (439)	38.1 (393)	39.6 (242)	40.1 (2,026)
	>1 - 2 yrs	29.3 (120)	29.3 (299)	29.4 (324)	30.7 (316)	23.2 (142)	27.6 (1,394)
	>2 yrs	26.2 (107)	23.4 (239)	30.7 (338)	31.2 (322)	37.2 (227)	32.3 (1,631)
Median number of contacts (IQ) ²		5 (3-11)	6 (3-11)	7 (4-13)	7 (4-15)	8 (4-17)	7 (3-14)
Number of diagnoses [% (n)]:	no diagnosis	37.2 (152)	26.4 (270)	24.5 (270)	27.5 (283)	27.8 (170)	28.3 (1,428)
	1	47.9 (196)	54.6 (557)	58.8 (647)	58.9 (604)	60.7 (371)	56.9 (2,876)
	2	13.5 (55)	16.3 (166)	14.3 (157)	12.7 (131)	10.5 (64)	13.0 (659)
		1.5 (6)	2.7 (28)	2.5 (27)	1.3 (13)	1.0 (6)	1.7 (88)

¹ Age at onset of symptoms (1992)

² IQ= Interquartile range

³ Upper quartiles could not be determined, as >25% of women had symptoms continuing into 1995.

Table 4.5. Age, duration of symptoms, number of diagnoses, and type of other diagnoses and symptoms in 5,051 women by final diagnosis received

Final diagnosis							
	None (n=1,428)	Cystitis (n=1,299)	IBS (n=1,252)	Other GI diagn. (n=347)	PID (n=364)	Endometriosis (n=174)	Other Gyn. diagn. (n=187)
Mean age (SD) ¹	42.0 (16.5)	42.1 (15.6)	42.3 (14.8)	54.5 (15.7)	29.7 (8.7)	34.9 (7.9)	40.0 (9.2)
Median symptom duration in months (IQ) ²	13.6 (9.3-30.2)	13.6 (9.5-25.5)	17.0 (10.3-?) ³	17.4 (10.4-?) ³	15.2 (9.5-26.7)	22.9 (13.1-?) ³	14.3 (9.7-27.4)
Symptom duration [% (n)]:							
6 months -1 yr	44.0 (628)	44.3 (576)	35.6 (446)	32.9 (114)	39.8 (145)	21.3 (37)	42.8 (80)
>1 - 2 yrs	26.9 (384)	28.7 (372)	26.0 (325)	26.2 (91)	30.5 (111)	31.6 (55)	30.0 (56)
>2 yrs	29.1 (416)	27.0 (351)	38.4 (481)	40.9 (142)	29.7 (108)	47.1 (82)	27.3 (51)
Median number of contacts (IQ) ²	6 (3-13)	5 (3-9)	8 (4-16)	8 (4-20)	7 (4-14)	15 (8-25)	10 (5-19)
Total number of diagnoses [% (n)]:							
1	-	84.6 (1,099)	77.5 (970)	78.4 (272)	75.8 (276)	63.8 (111)	79.1 (148)
2	-	13.8 (179)	20.4 (255)	19.3 (67)	20.1 (73)	29.9 (52)	17.7 (33)
>2	-	1.6 (21)	2.1 (27)	2.3 (8)	4.1 (15)	6.3 (11)	3.2 (6)
Type of other diagnoses given [% (n)]:							
Cystitis	-	-	12.3 (154)	12.1 (42)	11.3 (41)	6.3 (11)	4.8 (9)
IBS	-	8.7 (113)	-	7.8 (27)	10.4 (38)	13.2 (23)	8.0 (15)
other GI diagnoses	-	2.8 (36)	3.2 (40)	-	1.2 (6)	1.1 (2)	1.6 (3)
PID	-	3.9 (51)	5.5 (69)	2.3 (8)	-	10.3 (18)	8.0 (15)
Endometriosis	-	0.8 (11)	1.0 (13)	0.6 (2)	1.2 (6)	-	1.6 (3)
other Gynae. diagnoses	-	0.9 (12)	2.9 (36)	1.2 (4)	3.8 (14)	12.6 (22)	-
Type of coded symptoms [% (n)]:							
none	-	56.0 (727)	50.4 (631)	48.7 (169)	31.6 (115)	34.5 (60)	43.9 (82)
non-cyclic pelvic pain	64.0 (914)	25.6 (332)	32.4 (406)	37.5 (130)	49.5 (180)	39.1 (68)	39.0 (73)
cyclic pelvic pain	22.8 (326)	13.3 (173)	12.9 (161)	7.8 (27)	20.3 (74)	37.4 (65)	20.3 (38)
dyspareunia	3.5 (50)	2.0 (26)	2.5 (31)	1.2 (4)	4.4 (16)	5.7 (10)	1.6 (3)
GI symptoms	43.1 (616)	11.2 (146)	13.2 (165)	13.3 (46)	14.0 (51)	8.0 (14)	10.2 (19)
GU symptoms	5.0 (72)	1.5 (19)	1.1 (14)	1.7 (6)	2.7 (10)	- (0)	- (0)

¹ Age at onset of symptoms (1992)

² IQ= Interquartile range

³ Upper quartiles could not be determined, as >25% of women had symptoms continuing into 1995.

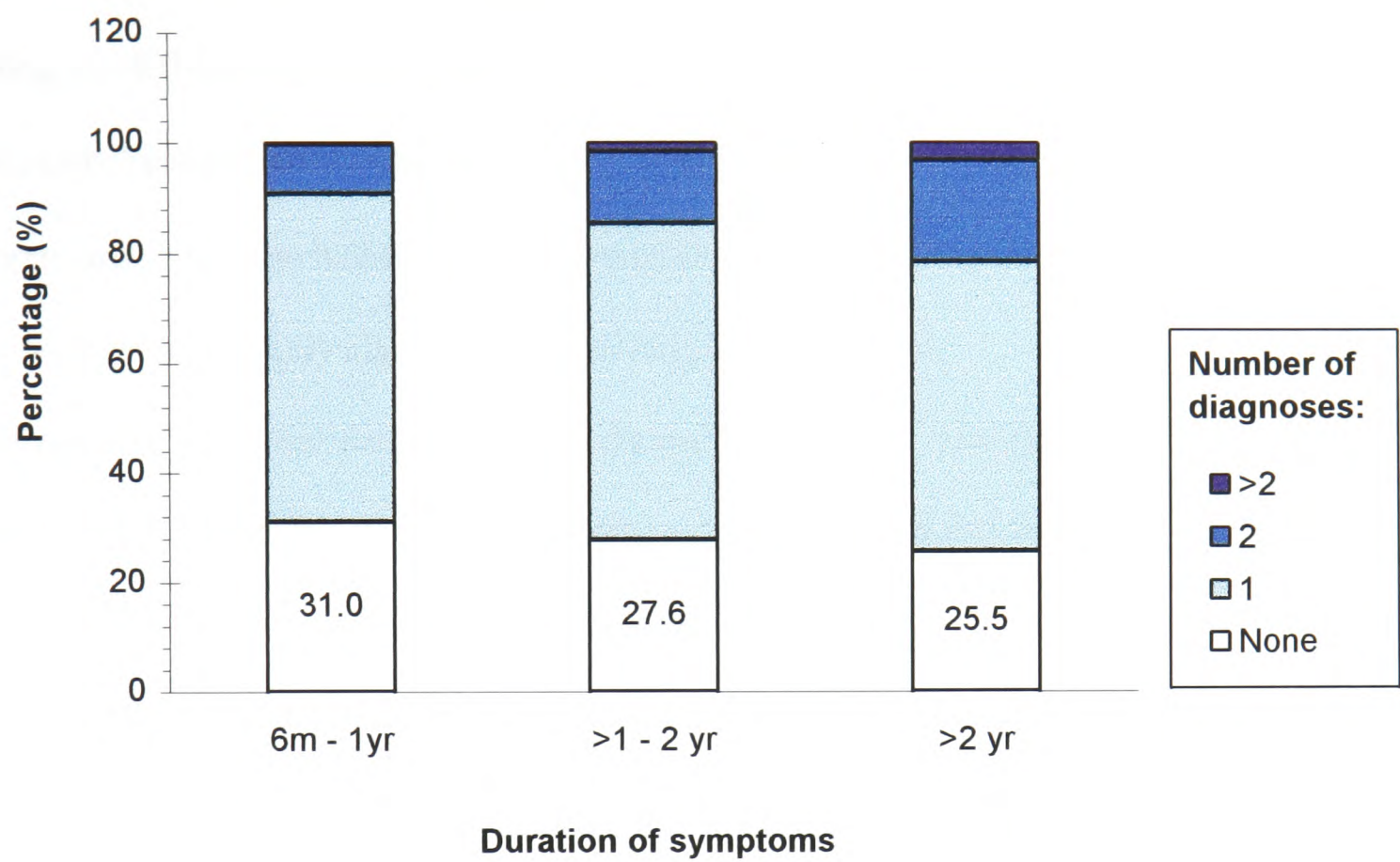


Fig 4.3. Number of diagnoses in follow-up of all 5,051 women by duration of symptoms

with age (Table 4.4), after adjusting for symptom duration ($\chi^2_{df=15}$: $p<0.001$): women under 21 and over 60 were least likely to have received a diagnosis.

Table 4.5 shows the number of diagnoses according to the final diagnosis received. After adjusting for differences in age and duration of symptoms, the number of diagnoses varied significantly between diagnostic groups ($\chi^2_{df=10}$: $p<0.001$). Women whose final diagnosis was endometriosis (who also had the longest symptom duration and the largest number of contacts) were most likely also to have received other diagnoses.

The frequency of other diagnoses given during follow-up in relation to the final diagnosis is also shown in Table 4.5. For most final diagnoses, common preceding diagnoses were IBS and cystitis. Endometriosis and other gynaecological diagnoses were also commonly preceded by PID, and endometriosis by other gynaecological diagnoses. It was unusual for endometriosis to precede other diagnoses, which corresponds to the earlier finding that endometriosis cases have a long symptom duration.

Diagnoses - especially cystitis, IBS and other GI diagnoses - were often coded without additional symptom codes (Table 4.5). The symptom of non-cyclic pelvic pain was most commonly coded with all final diagnoses, whereas cyclic pelvic pain was also common in younger women with final diagnoses of PID, endometriosis, or other gynaecological diagnoses.

4.3.4 Specialist referral and procedures

Overall, 40% of women had a specialist referral during their follow-up, increasing from 29% in women with symptoms lasting 6 months - 1 year to 50% in women having symptoms for more than two years ($\chi^2_{df=1}$: $p<0.001$). Of the 1,317 women who continued to have symptoms into 1995, 51% had evidence of a specialist referral.

Referral rates differed significantly between age groups (Table 4.6), even after adjusting for differences in symptom duration ($\chi^2_{df=5}$: $p < 0.001$). Half of the women aged 31-40 were referred, whereas only 25% of women over the age of 60 had any evidence of referral. The most common type of referral by far for women under 60 was to a gynaecologist. Women older than 60 were most commonly referred to a general surgeon. Few women had more than one type of referral coded in their whole follow-up.

As expected, the peaks in the proportions of women with a code indicating a laparoscopy/laparotomy (15% in 21-30 yr olds) or a hysterectomy/oophorectomy/salpingectomy (18% in 41-50 yr olds) corresponded to the peak in referral to gynaecology.

Table 4.7 shows the proportions of women ever having had a specialist referral in the different diagnostic groups. The lowest referral rate was found in women with cystitis as their final diagnosis. The referral rate was highest in women with endometriosis or other gynaecological diagnoses (81% in both), suggesting that these diagnoses were likely to have been made or confirmed by a specialist. Indeed, 76% with a diagnosis of endometriosis had been referred to a gynaecologist (75% had a gynaecological referral preceding the diagnosis). The proportion of women with more than one type of referral was also highest in women with endometriosis (12%), with the most common combination being referral to gynaecology and general surgery services.

As expected, the number of women with a coded laparoscopy/laparotomy was highest in women with gynaecological conditions as their final diagnoses, with the highest rate found in women with endometriosis (38%). Hysterectomy/oophorectomy/salpingectomy was most frequently found in the follow-up of women with endometriosis (29%) or other gynaecological diagnoses (37%) as their final diagnoses.

Table 4.6. Specialist referral rates and procedures coded ever in follow-up of 5,051 women by age in 1992.

	Age group					TOTAL (n=5,051)
	13-20 (n=409)	21-30 (n=1,021)	31-40 (n=1,101)	41-50 (n=1,031)	51-60 (n=611)	61-71 (n=878)
Any specialist referral [% (n)]	29.1 (119)	41.6 (425)	49.8 (548)	47.0 (485)	35.7 (218)	24.9 (219)
Type of referral [% (n)]						
Gynaecology	15.9 (65)	28.6 (292)	36.0 (396)	32.6 (336)	12.6 (77)	5.0 (44)
General Surgery	6.4 (26)	6.6 (67)	7.9 (87)	8.0 (82)	11.6 (71)	10.9 (96)
Gastroenterology	2.4 (10)	2.7 (28)	2.5 (28)	4.8 (50)	6.7 (41)	5.2 (46)
General Medicine	2.2 (9)	3.6 (37)	2.9 (32)	3.6 (37)	4.3 (26)	2.8 (25)
Urology	1.7 (7)	1.7 (17)	2.7 (30)	2.6 (27)	3.9 (24)	2.8 (25)
Other/unspecified	13.4 (55)	16.5 (168)	20.7 (229)	16.7 (172)	16.9 (103)	9.3 (82)
With >1 type of referral ¹ [% (n)]	2.9 (12)	5.6 (57)	5.6 (62)	6.5 (67)	5.9 (36)	4.4 (39)
With procedure [% (n)]:						
Laparoscopy/laparotomy	6.1 (25)	14.6 (149)	12.2 (134)	7.0 (72)	2.0 (12)	0.6 (5)
Hysterectomy/oophorectomy/ salpingectomy	0.2 (1)	3.3 (34)	11.2 (123)	17.8 (183)	6.6 (40)	2.6 (23)

¹ Counting only specific type of referrals (i.e. gynaecology, general surgery, general medicine, gastroenterology, and urology)

Table 4.7. Specialist referral rates and procedures coded ever in follow-up of 5,051 women by final diagnosis received

	Final diagnosis					Other Gyn. diagn. (n=187)
	None (n=1,428)	Cystitis (n=1,299)	IBS (n=1,252)	Other GI diagnosis (n=347)	PID (n=364)	Endometriosis (n=174)
Any specialist referral [% (n)]	40.5 (578)	27.5 (357)	36.7 (459)	38.9 (135)	53.3 (194)	80.5 (140)
Type of referral [% (n)]						
Gynaecology	22.3 (319)	15.9 (207)	16.3 (204)	13.0 (45)	45.3 (165)	76.4 (133)
General Surgery	10.3 (147)	4.5 (59)	8.6 (108)	18.4 (64)	6.9 (25)	7.5 (13)
General Medicine	3.6 (51)	1.7 (22)	5.0 (62)	3.7 (13)	2.5 (9)	4.0 (7)
Gastroenterology	3.4 (49)	1.2 (16)	8.5 (106)	6.3 (22)	1.1 (4)	1.7 (3)
Urology	1.6 (23)	5.7 (74)	1.4 (18)	1.2 (4)	1.4 (5)	1.1 (2)
Other/unspecified	17.8 (254)	9.3 (121)	14.5 (181)	16.4 (57)	21.2 (77)	30.5 (53)
With >1 type of referral ¹ [%, (n)]	5.2 (74)	3.5 (46)	5.5 (69)	7.8 (27)	6.3 (23)	11.5 (20)
With procedure [% (n)]:						
Laparoscopy/laparotomy	6.4 (92)	3.9 (51)	5.4 (68)	3.2 (11)	18.1 (66)	37.9 (66)
Hysterectomy/oophorectomy/ salpingectomy	6.9 (98)	5.2 (67)	5.8 (73)	6.3 (22)	6.9 (25)	28.7 (50)

¹ Counting only specific type of referrals (i.e. gynaecology, general surgery, general medicine, gastroenterology, and urology)

4.4 Discussion

In this chapter, patterns of diagnosis and referral in a cohort of 5,051 women aged 13-71 in 1992 were investigated. The women were followed for a maximum of 3-4 years, from their first pelvic pain contact in 1992 until the end of their CPP episode or the end of 1995. The duration of pelvic pain symptoms in this group was long, with a median duration of 15 months. A quarter of women continued to have symptoms until the end of the available data (for at least two years). However, 28% of all women and 26% of those who had symptoms lasting for more than two years did not receive a diagnosis within the 3-4 years observed.

The most common diagnoses ever given to women of all ages were cystitis and IBS. PID was a common diagnosis in women up to 40, and other gastrointestinal diagnoses (mainly diverticular disease and diverticulitis) were common in women above 50. Endometriosis was a relatively rare diagnosis, with only 4% of women ever having been labelled with it. Its frequency was highest in women aged 31-40 (9%).

Only 40% of all women (50% of those with symptoms for more than two years) had evidence of ever having been referred to a specialist for their symptoms. Women in the 31-40 age group were approximately twice as likely to have been referred as the youngest or oldest women in the cohort, due to higher rates of referral to a gynaecologist. It was striking that women over 60, despite having the longest duration of symptoms, had the lowest referral rate. In general, referral rates in women with no diagnosis or with common final diagnoses such as cystitis, IBS, and other gastrointestinal diagnoses were lowest, indicating that these diagnoses were more commonly managed within primary care.

It is possible that extension of the follow-up of the cohort might reveal that some of the women without a diagnostic label subsequently received one. In line with the findings, it might be expected that the number of women diagnosed with endometriosis would increase, possibly after referral for specialist assessment.

The detail of analysis possible in this study and the interpretation of the results were limited to some extent by aspects of validity and completeness of the database, as discussed in section 2.2.2. One can be most confident about the completeness of the diagnostic data, since even the 43% of practices that were least computerised (i.e. still considered written records as their primary data source) stated that they coded all key diagnoses and prescriptions on the MediTel system (Lawrenson *et al.*, 1998). It was not possible to judge from the data whether or not a given diagnosis was confirmed by an investigation. Use of a certain diagnostic label, however, did mean that the diagnosis was at least suspected, with more than 90% of prescriptions being consistent with the diagnosis to which they were linked. It should be borne in mind, though, that a confirmed diagnosis may not necessarily represent a definite explanation of the pain, as identifying the cause of CPP in women can be very difficult.

It is possible that symptoms were coded less consistently, as these would depend much more on the coding accuracy of the GP and his/her familiarity with the system. The exact frequency of different symptom types presented here should therefore be interpreted with some caution. Similarly, the completeness of hospital related codes may be questioned, as 43% of practices indicated that not all details of hospital discharge summaries were entered (though events deemed significant by the GP were entered more consistently). It was therefore not feasible to investigate referral patterns in relation to the time of diagnosis in any detail. However, on the assumption that a GP would record at least one hospital-related code for any woman ever referred to hospital for pelvic pain, it was considered possible to investigate whether or not a specialist referral had ever occurred.

In summary, this study showed that CPP symptoms often persist for years without being resolved. It also showed that the numbers and types of diagnosis given depend on the age of the woman as well as on the duration of her symptoms, as does her likelihood of being referred to a specialist.

Since the prevalence of CPP in the general population is likely to be substantially higher than its prevalence in primary care (Mathias *et al.*, 1996) and 50-75% of women consulting in primary care for CPP appear not to be referred for the duration of their symptoms, women seen in secondary care for CPP are a highly selected group and are likely to represent only the tip of the iceberg.

Chapter 5

The Oxfordshire Women's Health Study - design, data-collection and response

5.1 Introduction

The studies described in the previous chapters only considered women who had sought medical advice for their symptoms in primary care. In the remaining chapters, the results of the Oxfordshire Women's Health Study are described, in which epidemiological aspects of CPP were investigated in a community sample of women.

The primary aims of this study were to:

- estimate the prevalence of CPP, dysmenorrhoea, and dyspareunia
- describe the duration, frequency and severity of CPP symptoms
- investigate the overlap between CPP and dysmenorrhoea, dyspareunia, IBS, and genito-urinary symptoms;

The secondary aims (given the constraints of the methodology) were to:

- describe the use of health care arising from CPP, such as use of medication, GP and specialist consultation, investigations and diagnoses
- assess the effect of CPP on the lives of women
- investigate associations between CPP and factors such as menstrual characteristics, child bearing history, and contraceptive use

The study consisted of two parts: 1) a pilot study, to test methods of recruitment and data collection and investigate the adequacy of the sample size, and 2) the main survey. In this chapter, the study design is described together with the pilot results and the response to the main survey. Approval for the study was given by the Central Oxford Research Ethics Committee (COREC Project No 97.079).

5.2 Study design

The most important aim of the study - to estimate the community-based prevalence of CPP accurately - could only be achieved by obtaining information from a large group of women representative of the general population. The study design chosen was therefore a cross-sectional postal questionnaire survey. The target population for the study consisted of women aged 18-49, living in the area covered by the Oxfordshire Health Authority (OHA). The lower age limit was chosen because of the anticipated complications in obtaining parental consent for recruitment of girls under 18 years of age. The upper limit was lower than the 70 years used in the MediPlus analysis. This was because, in the design stage of the survey, women of reproductive age were considered by the steering group to be the most relevant target group for an investigation of CPP prevalence.

In designing any epidemiological study, an important issue is to ensure precision and validity of the results (Rothman & Greenland, 1998c). Precision relates to random error in estimation and can be improved by increasing the study size (see section 5.2.1). Validity relates to systematic error in estimation and can be separated into internal and external validity. Internal validity represents the validity of inference of results to the source population (i.e. are the survey results valid for all women aged 18-49 on the OHA register?), whereas external validity represents the validity of inferences to people outside the source population (i.e. can the survey results be extrapolated to women aged 18-49 in the UK population as a whole?).

Various biases can influence the internal validity of a cross-sectional study, with selection bias an important one to avoid. Selection bias occurs if participants in a study are unrepresentative of the source population: it can arise from the method of sample selection and from non-response. In the survey, the chance of selection bias due to sampling was minimised by using a sampling frame that included as large a part of the general Oxfordshire population as possible, i.e. the OHA register. The method of sampling used is described in

section 5.2.2. Maximum efforts were made to reduce the chance of selection bias due to non-response in designing the questionnaire format (section 5.3.2) and in the recruitment process (section 5.4.1). Post-hoc, the occurrence of a selection bias due to non-response was investigated by comparing age and social class distributions of study participants with the original OHA sample and the general Oxfordshire population (section 5.6.3).

Another potential bias affecting the internal validity of a study is recall bias. This might occur, for example, if women with CPP failed to remember details of their symptoms or if women with and without CPP differed in the accuracy of recalling risk-factor information. To reduce the chance of recall bias, questions were framed to draw informative conclusions without relying too much on accurate or distant recall (section 5.3.1).

Although no measures could be taken in the design stage of the survey that would influence external validity, it could be investigated post-hoc to some extent. For this purpose, age and social class distributions of the study sample were compared with general population figures for England and Wales (section 5.6.3), and the observed prevalence of CPP was compared with the results of the national MediPlus analysis (section 6.3.2.5).

5.2.1 Determination of study size

The survey had to be large enough to 1) estimate the prevalence of CPP with adequate precision, and 2) enable reasonable effect sizes to be detected for risk-factors that varied in prevalence in the community. The sample size required to obtain adequate precision was calculated by estimating the 95% confidence interval for the prevalence estimate based on the standard error ¹⁶. Minimum effect sizes (odds ratios) for putative risk factors, detectable

¹⁶ A study sample of n women will, with 95% confidence, allow the true CPP prevalence p to be estimated within $1.96 * \text{s.e.}$,

where s.e. = the standard error of $p = \sqrt{\frac{p(1-p)}{n}}$

with a power of 90% and at a significance level α of 0.05¹⁷, were calculated using the software package Epi-info (version 6.04b).

Assuming a true CPP prevalence of 15% - as reported by Mathias *et al.* (1996) - a study sample of 2,150 women would be required to estimate the prevalence, with 95% confidence, to within 1.5%. However, allowance had to be made for the uncertainty of the actual prevalence rate and non-response. Table 5.1 shows the expected 95% confidence intervals if 4,000 women were approached for the study, assuming prevalence rates of 10% and 20%, and response rates of 50% and 75%. The lowest detectable odds ratios (OR) are given for risk-factors with a community prevalence of 10% and 60%. Based on these calculations, a sample size of 4,000 women was considered sufficient for the survey.

5.2.2 *The study sample*

The sampling frame used for the study was the OHA register. This register is representative of the general population in that it includes all people registered with a GP in the area covered by the OHA. People living in the area but missing from the register would include those who recently moved into the area and have not (yet) registered with a local GP. At the same time, those who have recently moved away but have failed to notify their GP would still be on the register. The accuracy of Health Authority registers has been investigated in the past, by comparing information on the register with the electoral roll¹⁸. Percentages of inaccurate Health Authority addresses in inner-city areas of London and

¹⁷ The cut-off level for statistical significance, α , is commonly set at 0.05. It represents the probability of detecting an association between a risk-factor and the outcome of interest while in truth there is no such association ('false positive'). It is also referred to as a Type I error. The probability of failing to detect an association between a risk-factor and the outcome while in truth there is one ('false negative'), β , is called a Type II error. The value of β depends on the effect size of the risk-factor and the sample size of the study. The *power* of a study to detect a certain effect size is $100(1-\beta)\%$. In sample size calculations, the required power of a study is usually set at 90%.

¹⁸ The electoral roll was rejected as a possible sampling frame for this study. Apart from its unknown accuracy, it was only accessible in hard-copy format. Selection of a random sample of 4,000 women in a certain age-group without the aid of a computer would not have been feasible.

Table 5.1 Sample size calculations using a sample of 4,000 women: effect of varying response rates and prevalence rates of CPP on the 95% confidence interval (CI) of the prevalence estimate, and on the lowest detectable odds ratio (OR) of a risk-factor with a community prevalence of 10% and 60%.

	CPP prevalence			
	10%		20%	
95% CI (%)				
Response rate=50% (N=2,000)	±1.3		±1.8	
Response rate=75% (N=3,000)	±1.1		±1.4	
Lowest detectable OR of risk-factor ¹	Risk-factor prevalence	Risk-factor prevalence	Risk-factor prevalence	Risk-factor prevalence
	10%	60%	10%	60%
	Response rate=50% (N=2,000)	2.0	1.7	1.7
Response rate=75% (N=3,000)	1.8	1.5	1.6	1.4

¹ Calculations were carried out with power=90% and the significance level α=0.05 (see footnote 17)

Stockport were found to be 27% and 22%, respectively (Bickler & Sutton, 1993; Pope & Croft, 1999).

For the survey, 4,000 women were randomly selected by the OHA, out of approximately 140,000 women aged 18-49 on the register (a 3% sample). For the pilot study, 200 women were selected similarly. The sampling method employed by the OHA for a sample size n is to select every n^{th} person from the register, after having randomly picked a starting point. This method, known as systematic or quasi-random sampling, is widely used for sample selection (Moser & Kalton, 1996c). Systematic sampling differs from simple random sampling in that the selection of one member is dependent on the selection of a previous one. Strictly speaking, systematic sampling can only be seen as simple random sampling if the register is organised randomly (Bland, 1987). Although not random, the OHA register is organised alphabetically, which was unlikely to have a great effect on the representativeness of the sample selected.

5.3 The questionnaire

The semi-quantitative questionnaire used in the study was developed over a time-span of six months. Careful consideration was given to important issues such as its content, the wording of the questions, question format, and the question order (Moser & Kalton, 1996b). All major decisions regarding the design were made in meetings of the collaborative steering group supporting the study. A copy of the final version of the questionnaire is given in Appendix IV.

5.3.1 Content

5.3.1.1 Pelvic pain

Pelvic pain was described in the questionnaire as 'any type of pain in the lower part of your belly (the area from your navel down) that you may have had in the last 12 months'. A diagram was given to indicate the relevant part of the abdomen. Dysmenorrhoea was described as 'pelvic pain with periods, including irregular bleeding or bleeding while on the Pill or Hormone Replacement Therapy'; dyspareunia/pain after intercourse as 'pelvic pain during or in the 24 hours after sexual intercourse'; and other pelvic pain as 'pelvic pain not occurring with periods or intercourse, either *on and off* or *constantly*'.

For each of the three pelvic pain types, questions were asked regarding pain frequency, the occurrence of the most recent episode, and time since the first episode. Women with dyspareunia or pain after intercourse were asked additional questions regarding the location of the pain (superficial or deep), and its effect on frequency of intercourse. Women with pelvic pain at times other than with periods or intercourse (from whom CPP cases were later identified, see section 6.2.2) were asked about the number and typical duration of pain episodes, and their occurrence in relation to the menstrual cycle.

To enable investigation of the overlap between CPP and IBS, women with pelvic pain unrelated to periods or intercourse were asked questions regarding gastrointestinal symptoms. The questions used to establish the diagnosis of IBS were based on the internationally agreed Rome criteria (Thompson *et al.*, 1992). In addition, these women were asked about genitourinary symptoms that may be associated with pelvic pain (Summitt, 1993).

Following advice from the Pain Relief Unit in Oxford, severity of dysmenorrhoea, dyspareunia/pain after intercourse and other pelvic pain was assessed in several ways. For all three types of pelvic pain, typical pain severity in the preceding 12 months was assessed using a four-item verbal rating scale (none/mild/moderate/severe) and a 10 cm visual

analogue scale, going from 'least possible pain' to 'worst possible pain'. Both instruments have been described and validated extensively in the past (Ohnhaus & Adler, 1975; Huskisson, 1982; Wallenstein *et al.*, 1980). In addition, women with pelvic pain unrelated to periods or intercourse were asked to rate their typical pain in the preceding 12 months using the multi-dimensional Pain Rating Index of the Short-Form McGill pain questionnaire. This scale has been used and validated in various groups of pain patients (Melzack, 1987). More details about the pain measurement instruments are given in Chapter 6.

5.3.1.2 Health care-related items

Women with any pelvic pain were asked about pelvic pain-related health care use in the preceding 12 months (visits to a GP, a specialist or an alternative therapist; prescribed and 'over-the counter' (OTC) medication; other treatments). General rather than detailed information was sought, since the validity of these data relied on accuracy of recall. Information collected on medication prescribed in the last 12 months was limited to prescriptions issued by specialists, since it was thought that recall of medication prescribed by a GP might not be sufficiently accurate ¹⁹.

Questions regarding diagnoses received and major investigations for pelvic pain were asked in relation to whole life-time, as this information was likely to be more accurately remembered. A checklist of possible diagnoses was provided, with the opportunity to add diagnoses that were not listed. In plain language, a checklist was also given of the major investigations for pelvic pain (ultrasound scan; x-ray; laparoscopy; sigmoidoscopy; colonoscopy). All women completing the questionnaire were asked about past medical history possibly relevant to pelvic pain, i.e. any major procedures undergone in the lower abdominal area (hysterectomy; oophorectomy; salpingectomy; other procedures).

¹⁹ Many women described prescriptions issued by their GP in an open question in which information could be given about any other type of treatment used for the pain.

5.3.1.3 Items relating to functioning and well-being

The questionnaire contained several items to assess the functioning and well-being of women with CPP compared to women with other or no pelvic pain. Firstly, all women participating in the study completed the UK version of the Short-Form 36 (SF-36) Health Survey. This is a well-validated, generic, health status measure, which has been used extensively in the past in postal surveys (Brazier *et al.*, 1992; Jenkinson *et al.*, 1993). The instrument contains eight multi-item dimensions relating to health status in the last four weeks (physical functioning, role limitations due to physical problems, role limitations due to emotional problems, social functioning, mental health, energy/vitality, bodily pain, and general health perception) and a single item relating to change in health over the past year. Use of the SF-36 is described in more detail in Chapter 7.

In addition, all women completed questions about their sleeping pattern in the last 4 weeks. Women who were employed were asked if they had taken time off work due to any illness or due specifically to pelvic pain, in the last 12 months. If so, they were asked to indicate how many days they had missed approximately, in broadly defined categories.

Women reporting any pelvic pain in the previous 12 months were asked two open-ended questions relating to their pain experience. Firstly, they were asked if they experienced any limitations in their daily life due to their pelvic pain. Secondly, they were asked to describe what troubled them most about their pelvic pain.

5.3.1.4 Other factors

All women surveyed were asked questions about physical, life-style and demographic factors possibly related to pelvic pain. Information collected on menstrual history consisted of age at menarche and - for the last 12 months - the presence or absence of menstruation, regularity of menstruation (with 'irregular' defined as less or more frequent than every 3-5 weeks), and typical duration of bleeding. Questions were formulated following World Health

Organisation guidelines for the assessment of menstrual bleeding patterns (Belsey *et al.*, 1986).

Information collected on life-time pregnancies and childbirth included age at first pregnancy, time since last pregnancy, parity, and frequency of miscarriages, terminations, or ectopic pregnancies. In addition, women were asked if they had ever had any episodes of sub-fertility (defined as having tried to conceive for more than 12 months without succeeding). If so, they were asked if they had had any investigations for sub-fertility, and to indicate on a checklist whether any diagnosis was given.

Information on life-time contraceptive use and HRT use was also collected. Women were asked if and when they had been sterilised. They were asked to indicate in a checklist whether they had ever used certain contraceptive methods, and if so, the time since they last used a particular method. Information collected on use of HRT – likely to be more accurately remembered than contraceptive use - consisted of ever use, age at first use, time since last use and total duration of use, and most recent type of HRT.

Other life-style information collected was limited to smoking history and alcohol consumption. Initial plans to include questions on exercise and diet - the effect of which would also have been interesting to investigate in relation to pelvic pain - were rejected due to lack of space. Questions were asked to identify women as current, ex-, and never smokers, and to obtain a limited measure of tobacco exposure by asking current smokers about the average daily number of cigarettes smoked in the last 12 months. Typical alcohol consumption was assessed in units during an average week.

Demographic information collected consisted of date of birth, height, weight, present marital status, current employment status, woman's and partner's (if any) most recent occupation, and ethnicity.

5.3.2 Design considerations

As shown in the previous section, the amount of information to be collected in the questionnaire was extensive. In an initial plan, it was proposed to carry out the study in two stages: a screening questionnaire would be sent out first to identify CPP cases and appropriate controls, followed by a second questionnaire in which more detailed information would be collected. This plan was rejected for practical reasons: during the time between completing the first and the second questionnaire, both the pain status of women and factors influencing the pain (e.g. treatment) might well have changed. It was therefore important for all information to be collected at one point in time, which meant that all information had to be collected in a single questionnaire.

The questionnaire was designed using the wordprocessor package Microsoft Word version 6.0 (Microsoft Corporation, 1993b). In designing the questionnaire format, two considerations were important:

- it had to be user-friendly and attractive, so as to obtain a high response rate, and
- it had to limit the chance of selection bias, resulting from a higher response from women with pelvic pain than those without.

To reduce the chance of selective response, the study title was chosen to reflect women's health in general: 'The Oxfordshire Women's Health Study'. The front page of the questionnaire stated the topic of study - 'women's health in general and some pain symptoms specific to women' - and stressed the confidentiality with which collected information would be treated. A recognisable logo (adapted from the picture gallery of the software package CorelDraw) was used in conjunction with the study title and appeared on the questionnaire and all correspondence.

Great care was taken that the questionnaire - despite its length - would interest as many women as possible and be user-friendly. The questionnaire was divided into two differently coloured sections, separating questions applicable to all women (blue) from those only to be

answered by women with pelvic pain (yellow). The questionnaire started with a blue section containing general health items likely to interest most women: the SF-36, sleep, menstrual patterns, parity, and infertility. This was followed by the yellow section collecting all pelvic pain-related questions. The final blue section contained the remaining general items: past medical history, employment, and life-style and demographic factors.

For ease of completion, most questions were asked in pre-defined, categorical, format. However, space was allowed for women to provide additional information if they wished to do so. Within items, questions were ordered following a 'funnel sequence' (Moser & Kalton, 1996b), i.e. from general to more specific. Most items started with a 'screening question', allowing women to skip the subsequent specific questions if they were not applicable. For example, women who had not had any type of pelvic pain in the previous 12 months (asked on the first page of the yellow section) could move directly on to the last blue section.

Women were offered the option of not answering questions relating to sexual intercourse if they preferred ²⁰. Finally, respondents were asked their opinion about the survey in an open-ended question on the last page.

5.3.3 Preliminary testing

Prior to the pilot study, the questionnaire was tested extensively in different groups of women in the 18-49 age range. The aims of these tests were to:

- identify any problems with the content of the questionnaire (e.g. inconsistency, confusing items)
- assess the time needed to complete the questionnaire
- receive any feedback that might help improve the questionnaire
- get a feel for the general interest in the study and willingness of women to participate

²⁰ Of the 1,511 women with any type of pelvic pain who were asked questions about sexual intercourse, only 48 (3.2%) objected to answering these questions.

The first three versions were tested in 15 female volunteers in the Department of Public Health, who remained anonymous. They were asked to indicate on an evaluation form: 1) the time taken to complete the questionnaire; 2) specific sections they had problems with or were unable/unwilling to complete; 3) whether they would have returned the questionnaire if they had been sent it; 4) any further suggestions or comments. Eleven women returned the questionnaire completed, with time needed for completion ranging from 10 to 30 minutes. Seven women said they would have returned the questionnaire if it had been sent to them through the post. All problems and suggestions - mostly relating to the wording of questions and instructions - were discussed in a meeting of the working group, and the questionnaire was adjusted where necessary.

The fourth version of the questionnaire was tested in 1) 30 women with pelvic pain attending a pelvic pain clinic of two working group members (Stephen Kennedy and David Barlow) at The Women's Centre, John Radcliffe Hospital, Oxford, and 2) 30 women without pelvic pain attending the general practice of one working group member (Martin Dawes). Women were handed the questionnaire and asked to complete it together with the evaluation form, and to return both in a pre-paid envelope. Nine women from the pelvic pain clinic (30%) and seven from the general practice (23%) returned the questionnaire. The time needed for completion varied from 10 minutes to 1 hour. Following the test, some additional changes were made to the questionnaire, mainly involving correction of inconsistencies and simplification of instructions.

Using the fifth version, a last test was carried out in 29 women arbitrarily selected from records of Martin Dawes' general practice in Oxford. They were mailed the questionnaire without an evaluation form, and asked to return it in a pre-paid envelope. Eleven women (38%) returned a completed questionnaire (no reminders were sent out). A few final changes relating to wording were made after this mailing.

5.4 Methods of data collection

5.4.1 The recruitment process

The Local Medical Committee was informed of the study, and asked to publish details about the study in their newsletter to GPs. Before recruitment of women for the pilot and the survey, GPs of the women to be approached were sent a letter with a detailed description of the study, and were offered a copy of the questionnaire on request. They were not told in the first instance which women in their practice would be approached, but they were offered the opportunity to object in general to women in their practice participating. GPs who wished to know which women were to be recruited were sent a list, and offered the opportunity to object to any of them being approached.

Four weeks after the GPs were notified, women were sent the questionnaire with a covering letter (Appendix V) informing them in detail about the study and asking them to participate by returning the questionnaire. Three weeks after the first mailing, non-responders were sent a reminder card. A third mailing was sent to non-responders after another four weeks had elapsed, containing a reminder letter together with a copy of the original covering letter and the questionnaire. In the pilot study only, women who had still not responded after the third mailing were contacted by telephone (if possible) to encourage participation.

Prior to the main survey, a press-release was sent to the local media via the Oxford University Press Office (Appendix VI). The object of the release was to raise regional awareness of the study, and hopefully increase the response rate. Following the release, a radio interview was given by myself (KZ) on the local radio station Thames Valley FM. In addition, a piece describing the study appeared in the Oxford University Gazette.

5.4.2 Data-entry systems

Two data-entry systems were developed, one for the day-to-day administration of the study, and another for entry of the questionnaire data. The software package most useful for the daily administration proved to be Microsoft Access (Microsoft Corporation, 1994). It allowed design of a highly customised data-entry system, with the ability to print-out summary information at the press of a button. In addition, its mail-merge facility in combination with Microsoft Word 6.0 enabled easy printing of personalised letters for any required subset of women.

The database was built from the information provided by the OHA in Excel 5 format. It was designed so that, on opening, a form appeared showing a woman's administration record consisting of her ID number, first and last name, date of birth, GP's ID number, and the current 'administration status' (e.g. not yet received/returned after 1st mailing/returned undelivered). Command buttons were added to the form, which - with a mouse click - allowed a search on a woman's ID number or surname, her GP's name and practice, and an up-to-date summary of the total mailing administration (number of questionnaires returned after each mailing, returned undelivered, declined to participate, etc). This design allowed the administration to be updated on a daily basis, and enabled a quick response to telephone calls with questions from women or GPs.

A different system was set up for the entry of questionnaire data, using SPSS II (1987). The reason for using this system was that it allowed double data-entry and application of 'skip and fill rules' (e.g. on the basis of the answer to a screening question, subsequent questions that were not applicable were automatically coded as missing), which greatly reduced time needed for data-entry. The data-entry system was compatible with SPSS 8.0 (1998), the package used for subsequent data-analysis.

5.4.3 Confidentiality

Names and addresses of women were held in the Access database, which was password-protected. The password was only known to KZ. Questionnaires were labelled with the identification numbers only. Thus, women returning the questionnaire could be identified if necessary, but only by KZ. In cases where questionnaires were returned with names or addresses added, this information was made illegible before data-entry and storage of the questionnaires.

5.5 Pilot study

Prior to the main survey, a pilot study was carried out in an OHA sample of 200 women.

The aims of the pilot were to:

- test the feasibility of the survey and adjust the sample size if necessary, by estimating the likely response rate and the prevalence of CPP
- identify any final problems with the questionnaire
- test the data-entry systems to be used

5.5.1 Response

The 200 women in the pilot were registered with 62 different practices (153 GPs). Only one practice (2 GPs) objected to their patients being approached. These women (n=3) were not sent a questionnaire, leaving 197 in the study.

The three mailings of the pilot study were sent out in May to July 1997. Table 5.2 shows the response after each mailing. Eleven questionnaires (5.5%) were returned undelivered. After three mailings, 107 women (53.5% of 200 or 57.5% of 186) had returned the completed questionnaire. Nine women returned the questionnaire uncompleted, leaving 70/186 (37.6%) non-repliers. Their addresses were checked against the electoral roll (last

Table 5.2 Details of response to the pilot study and the main survey after three mailings.

	Pilot n (%)	Survey n (%)
Non-receivers	14 (7.0)	402 (10.1)
Not approached (participated in pilot)	n/a	5 (0.1)
Not approached (GP objected)	3 (1.5)	76 (1.9)
Returned undelivered	11 (5.5)	318 (8.0)
Mentally unable to participate	-	3 (0.1)
Possible receivers	186 (93.0)	3,598 (89.9)
Responders	112 (56.0)	2,304 (57.6)
Responded to 1 st mailing	66 (33.0)	1,519 (38.0)
Responded to 2 nd mailing	14 (7.0)	327 (8.2)
Responded to 3 rd mailing	27 (13.5)	458 (11.5)
Responded to phone call	5 (2.5)	n/a
Non-responders	74 (37.0)	1,294 (32.4)
Refused to participate	9 (4.5)	93 (2.3)
Non-repliers	65 (32.5)	1,201 (30.0)
Total	200 (100)	4,000 (100)

Table 5.3 Non-repliers after three mailings: comparison between women’s names and information on the electoral roll, in the telephone directory, or provided by colleges.

Electoral roll/telephone directory/college	Pilot n (%)	Survey n (%)
Match	42 (60.0)	709 (59.0)
First name and surname matched	42 (60.0)	698 (58.1)
First name matched, but surname did not ¹	-	11 (0.9)
No match	28 (43.1)	492 (41.0)
Surname matched, but first name did not	2 (3.1)	85 (7.1)
No such surname at address	20 (30.8)	288 (24.0)
Unable to find address	6 (9.2)	119 (9.9)
Total	70 (100)	1,201 (100)

¹ Women counted in this category had unusual first names: the assumption was made that these were in fact the women identified from the OHA register.

Table 5.4 Crude and adjusted reponse rates

Response rate	Pilot		Survey	
	n/N	%	n/N	%
Crude ¹	112/186	60.2	2,304/3,598	64.0
Adjusted ²	112/158	70.9	2,304/3,106	74.2

¹ Crude response rates were calculated as a percentage of ‘possible receivers’: i.e. all responders and non-responders (see Table 5.2)

² Adjusted response rates were calculated as a percentage of ‘probable questionnaire receivers’: i.e. responders and non-responders, whose address matched the electoral roll/telephone directory/college information (see Table 5.3)

update: October 1996), the telephone directory (last update: July 1996), and information from colleges if appropriate (Table 5.3). Based on these sources, 42 out of the 70 (60%) non-repliers appeared to be living at their OHA address, but 22 women were not. For 6 women - even after checking the postcode book - their OHA address could not be found at all.

In the pilot study, the telephone numbers of women whose OHA address matched that on the electoral roll or in the telephone directory were checked with Directory Enquiries. Out of the 42 women, 9 were not listed, 9 were ex-directory, and 24 were listed. Three attempts were made to contact these 24 women by telephone at different times of the day. No contact could be established with 5 women, 1 claimed to have returned the questionnaire, 13 promised to return it, and 5 declined to participate. Five women returned the questionnaire as promised, raising the final number of respondents to 112 (56% of 200).

Table 5.4 shows the response rates to the pilot study, after taking into account those women who did not receive a questionnaire. The crude response rate, calculated by excluding the 14 non-receivers (Table 5.2) from the denominator, was 60%. However, when taking into account the additional 28 women whose OHA address did not match the electoral roll/telephone directory/college information, the adjusted response rate as a percentage of the 158 'probable questionnaire receivers' was 70%.

5.5.2 Feasibility of the survey and adequacy of sample size

The response rate in the pilot study, which was likely to lie between 60% (the crude response rate) and 70% (the adjusted response rate), was considered sufficient to proceed with the survey using the questionnaire in its present format. The power calculations given in section 5.2.1 assumed a response (calculated as a percentage of the original sample size) between 50-75%. The response to the three mailings of the pilot (107/200: 53.5%) was within this range.

The other assumption used in the power calculations was a prevalence of CPP (not related to pregnancy) between 10 and 20%. Out of the 112 responders in the pilot study, 13 (11.6%) were excluded because they had been pregnant in the preceding 12 months. Of the remaining 99 women, 20 (20.2%) reported pelvic pain unrelated to menstruation or intercourse in the last 3 months, that had lasted for at least 6 months.

Based on these results, the sample size of 4,000 women was judged to be sufficient for the survey. It would provide a study group of 1,980 women who were not pregnant in the previous 12 months. A group this size would, with 95% confidence, allow a prevalence of 20% to be estimated within 1.8%. The lowest detectable ORs for risk-factors with 10% and 60% prevalence would be 1.7 and 1.5, respectively.

5.6 The survey

5.6.1 Response

The 4,000 women were registered with 85 practices (404 GPs). Five women who had already participated in the pilot study were excluded from the survey. No attempt was made to approach the practice that had objected to women participating in the pilot study, and the 73 women registered with it were also excluded from the survey. After notification, eight GPs requested more information about the study and a list of women to be recruited. One of these objected to three women participating on medical grounds. They were therefore not sent a questionnaire either. The total number of questionnaires sent out was therefore 3,919.

The three mailings were sent out between September and November 1997. The mailing system used was Mailsort 3 (Royal Mail), as it reduced the price of postage by 30% compared to the standard second class mail. It required each mailing to be sorted on postcode, which was easily achieved by sorting the Access database before printing out

letters and labels. Each sorted mailing had to be bundled for collection, which was done two days in advance with the aid of 5 temporary workers.

During the study, approximately 150 women rang the Department of Public Health to ask for more information. The questions asked most frequently were how their address had been obtained, what the collected information was going to be used for, and whether their answers would remain 'anonymous'. Ten women had removed the identification number before returning the questionnaire, but nine could be identified by comparing the date of birth on the questionnaire with the information in the Access database.

Response to the three mailings is given in Table 5.2. Out of the 3,919 questionnaires, 3 were returned with a letter stating that the woman in question was mentally unable to participate in the study. These women were counted as non-receivers. In addition, 318 questionnaires were returned undelivered.

A completed questionnaire was returned by 2,304 women (57.6% of 4,000). Out of the 1,294 non-responders, 93 women replied saying they did not wish to participate, leaving 1,201 non-repliers. The addresses of these non-repliers were checked on the electoral roll and through colleges (if appropriate). Since the electoral roll was updated in October 1997 - just before the start of the study - the telephone directory (last updated in July 1996) was only used in situations where the address could not be found on the electoral roll. In total, 709 women (59%) had a matching OHA address (Table 5.3). The response rate in the survey was higher than in the pilot, with a crude rate of 64%, and an adjusted rate (calculated as a percentage of 'probable receivers' ²¹) of 74% (Table 5.4).

The percentage of 'probable receivers' ($3,106/3,916=79\%$) corresponded well to figures of 73% and 78% previously reported in other studies that compared Health Authority (HA)

²¹ Probable questionnaire receivers consisted of responders and non-responders whose address matched the electoral roll, telephone directory, or college information (see section 5.6.1 and Table 5.4).

registers in London and Stockport with the electoral roll (Bickler & Sutton, 1993; Pope & Croft, 1999). In Stockport, the combined use of the HA register and the electoral roll to identify probable receivers was found to be particularly effective: of 1,000 persons whose HA address matched that of the electoral roll, 92% were found to be living at this address when a home visit was made, whereas of the 200 persons whose HA address did not match that on the electoral roll, only 12% lived at the HA address (Bickler & Sutton, 1993). Interestingly, this study also reported that out of all wrongly addressed mail, only 34% was returned undelivered by the Post Office: in the survey, this percentage was very similar, with 39% (318/810) of questionnaires returned undelivered that were likely to be wrongly addressed.

5.6.2 Quality of entered data

Questionnaire data for the 2,304 women who responded were entered once in the SPSS II system. To check the accuracy of single data-entry, the data from a 10% sample (225 women) were entered a second time. Possible data-entry errors were separated into 'correctable' (i.e. wrongly coded data that would be noticed in frequency tabulations and consistency checks) and 'uncorrectable' (i.e. wrongly coded data that would go unnoticed unless entered a second time). Following common practice, the maximum accepted uncorrectable error rate was set at 1 error per 100 questions.

The frequency of uncorrectable errors was calculated relative to the minimum number of 75 questions answered by all women (ignoring those questions that may not have been applicable) and the maximum number of 200. In 225 women, the frequencies of uncorrectable errors were 1 per 270 and 1 per 710, respectively. Since this was well below the maximum accepted error rate, data for the remaining 2,079 women were not entered a second time.

Variables were checked for impossible values by looking at frequency distributions and consistency checks were run between answers to related questions. Impossible, unlikely, or conflicting information was always checked by going back to the questionnaires. Thus, all correctable errors were rectified. Information given in three questionnaires was inconsistent to such an extent that it rendered the information uninterpretable: these women were excluded from all data analyses.

5.6.3 Internal and external validity: age and social class distributions

As explained in section 5.2, an important problem that may compromise the internal and external validity of study results is selection bias. To investigate to what extent non-response might have caused bias in the survey, age and social class distributions of the study sample were compared with the source population and general population figures.

Table 5.5 shows the age distribution of the study participants compared with probable questionnaire receivers, the original OHA sample of 4,000 women, and mid-1997 estimates of women aged 18-49 living in Oxfordshire, and England and Wales (Population Estimates Unit, Office for National Statistics, personal communication). Compared with the original OHA sample and general population figures, women under 25 were under-represented in the study sample. However, the study sample was very similar in age distribution to probable questionnaire receivers. The difference in age distribution between study participants and the source population, therefore, did not appear to be due to age-specific differences in response but to a higher frequency of inaccurate OHA addresses amongst young women. This is further shown in Table 5.6. Basic response rates (calculated as a percentage of the original OHA sample) varied from 42% in women under 25 to 68% in women aged 41-45. However, adjusted response rates (calculated as a percentage of probable questionnaire receivers) varied to a much lesser extent, from 71% in women under 25 to 77% in women aged 41-45.

Table 5.5. Age distribution of study participants compared with probable questionnaire receivers¹, the original OHA sample, and mid-1997 estimates of the general population of Oxfordshire and England and Wales ².

Study participants		Probable questionnaire receivers ¹	Original OHA sample	Oxfordshire ²	England and Wales ²
Age in yrs [% (n)]					
18-25	18.1 (417)	18.9 (588)	24.6 (983)	23.6 (33,300)	21.7 (2,504,700)
26-30	18.0 (414)	17.1 (532)	17.6 (703)	17.1 (24,100)	17.2 (1,982,700)
31-35	18.1 (417)	18.4 (570)	17.8 (711)	17.8 (25,200)	18.2 (2,107,300)
36-40	16.8 (388)	17.1 (533)	15.2 (606)	15.9 (22,500)	16.2 (1,870,200)
41-45	16.0 (369)	15.5 (482)	13.6 (542)	13.9 (19,600)	14.5 (1,675,400)
46-49	13.0 (299)	12.9 (401)	11.4 (455)	11.8 (16,700)	12.3 (1,419,000)
Total	100 (2,304)	100 (3,106)	100 (4,000)	100 (141,400)	100 (11,559,300)

¹ Probable questionnaire receivers consisted of responders and non-responders whose address matched the electoral roll, telephone directory, or college information (see paragraph 5.6.1 and Table 5.4).

² Mid-1997 age distributions in Oxfordshire and England and Wales (rounded to the nearest hundred) were obtained through the Office for National Statistics (Population Estimates Unit, personal communication).

Table 5.6. Basic and adjusted response rates, stratified by age.

Age category (yr)	Response rate	
	Basic (% of original OHA sample)	Adjusted (% of probable receivers)
18-25	42.4	70.9
26-30	58.9	77.8
31-35	58.6	73.2
36-40	64.0	72.8
41-45	68.1	76.6
46-49	65.7	74.6
Total	57.6	74.2

Tables 5.7a and 5.7b show the social class distributions of the study participants, based on the Registrar General's classification (OPCS, 1995b), compared with a 10% sample of the 1991 Census (age 16-64, excluding retired people) for Oxfordshire (OPCS, 1993a) and England and Wales (OPCS, 1993b). Social class of women participating in the survey was grouped in two ways: based on partner's class and on woman's class²². Partner's class allowed comparison with the Census social class data based on the occupation of the 'head of household'²³, whereas woman's class could be compared with Census data on woman's occupation.

Among study participants grouped according to partner's class, social classes I to III-manual were slightly over-represented and classes IV and V slightly under-represented compared with Oxfordshire figures. When considering women's class only, classes I to III-non-manual were again over-represented. The lower percentage of 'economically inactive' was partly attributable to a shortfall of students, consistent with the relative lack of young women observed previously among study participants. As expected, the differences were somewhat more pronounced when using the England and Wales Census data for comparison: in general, the Oxfordshire population has a greater percentage of residents in the higher social classes and fewer unemployed compared to national figures.

From these results, there appears to be no evidence of a significant selection bias when comparing the age and social class distributions in the study sample with the Oxfordshire population. The relative lack of young women among study participants appeared to be due more to a higher number of inaccurate addresses than to selective non-response. There is no reason to believe that young responders would differ from young non-responders who did not receive their questionnaire with regard to the study outcomes. Although women participating in the survey tended to be of somewhat higher social class than the general

²² 'Partner's class was defined as the partner's full-time or part-time occupation; if a woman had no partner, the woman's occupation was taken. Woman's class did not take a partner's occupation into account.

²³ The Census defines a head of household as any person who is aged 16 years or over and is usually resident at the address of enumeration. The 'head of household' is asked to complete the first column of the form and is thus identified.

Table 5.7a. Social class distribution of study participants, grouped according to partner’s class, compared with a 10% sample of the 1991 Census ¹ grouped according to ‘head of household’ ².

Social class	Study participants	10% Census sample: head of household	
	Partner’s class ³ % (n)	Oxfordshire %	England and Wales %
I	10.2 (235)	9.0	5.6
II	32.9 (758)	30.4	25.9
IIINm	13.6 (313)	10.0	11.4
IIIIm	22.0 (507)	20.0	22.4
IV	9.4 (217)	11.1	11.5
V	2.4 (56)	3.8	4.0
Armed Forces	1.8 (41)	2.9	0.8
Rest of economically active (missing)	0.5 (11)	1.3	1.4
Economically inactive ⁴	7.2 (166)	11.6	17.0
Total	100 (2,304)	100	100

Table 5.7b. Social class distribution of study participants grouped according to their own class, compared with women in a 10% sample of the 1991 Census ¹ grouped according to woman’s occupation.

Social class	Study participants	10% Census sample: woman’s occupation	
	Woman’s class % (n)	Oxfordshire %	England and Wales %
I	4.3 (98)	2.0	1.2
II	26.1 (602)	20.5	16.9
IIINm	29.3 (676)	24.6	23.9
IIIIm	4.4 (101)	4.3	4.4
IV	10.9 (250)	9.0	10.3
V	2.8 (65)	4.6	4.5
Armed Forces	0	0.2	0.1
Rest of economically active (missing)	0.7 (16)	1.1	1.3
Economically inactive ⁴	21.5 (496)	33.8	37.4
Total	100 (2,304)	100	100

¹ 10% sample of the general population, aged 16-64, excluding retired.

² In the Census, the ‘head of household’ was a self-appointed person aged 16 years or over and usually resident at the address of enumeration.

³ Partner’s full-time or part-time occupation. If a woman has no partner, then social class is based on woman’s occupation.

⁴ ‘Economically inactive’ included students, housewives, unemployed, disabled.

Oxfordshire population, differences were not great, and were unlikely to have caused any significant bias.

These results provide reasonably strong evidence of the internal validity of the survey. The external validity – extrapolation of the results to the population of women outside Oxfordshire - might be compromised to some extent by differences in social class distributions.

Chapter 6

Community prevalence of CPP, pain severity and use of health care

6.1 Introduction

In this chapter, the following results of the Oxfordshire Women's Health Study are described:

- the community prevalence of CPP, dysmenorrhoea, and dyspareunia
- the overlap between CPP and other types of pelvic pain and associated symptoms
- the duration, frequency and severity of CPP symptoms
- health care use related to CPP, such as use of medication, GP and specialist consultations, investigations and diagnoses

6.2 Methods

6.2.1 *The study group*

As described in the previous chapter, the total study sample consisted of 2,304 women who returned a completed questionnaire. Three women were excluded because the pelvic pain section of the questionnaire was completed inconsistently and the data could not be interpreted. Since the definition of CPP excluded pain related to pregnancy, 259 women (11%) were excluded because they had been pregnant in the last 12 months. Thus, the study group consisted of 2,042 women ²⁴.

Table 6.1 shows the demographic characteristics of the study group compared with the original 2,304 responders. No substantial differences were observed, although the exclusion

²⁴ In some definitions of CPP, pelvic pain related to inflammatory bowel disorders is excluded (as was done in the MediPlus analysis). Amongst 483 women with CPP in the survey, 10 reported having received a diagnosis of inflammatory bowel disease (see Table 6.9). However, 7 out of these also reported having received other diagnoses, such as IBS, stress, constipation, ovarian cysts, and endometriosis. Since it could not be established whether the inflammatory bowel diagnoses were confirmed, the 10 women were not excluded from the study group.

Table 6.1. Demographic data: comparison of the study group (n=2,042) with the total group of responders (n=2,304), after exclusion of 3 unreliable questionnaires and 259 women pregnant in the last 12 months ¹

Variable	Study group (n=2,042)		All responders (n=2,304)	
Mean age (SD)	35.0 (8.9)		34.4 (8.7)	
Age [% (n)]				
18-25	17.8	(364)	18.1	(417)
26-30	15.9	(324)	18.0	(414)
31-35	16.5	(336)	18.1	(417)
36-40	17.6	(359)	16.8	(388)
41-45	17.6	(360)	16.0	(369)
46-49	14.6	(299)	13.0	(299)
Social class ² [% (n)]				
I/II	42.9	(872)	43.3	(993)
IIINm	14.2	(289)	13.7	(313)
IIIIm	21.6	(439)	22.1	(507)
IV/V	11.9	(242)	11.9	(273)
Other	9.4	(190)	9.0	(207)
Marital status [% (n)]				
Single	21.5	(437)	19.6	(450)
Cohabiting/married	68.9	(1,401)	71.3	(1,638)
Divorced/separated/widowed	9.6	(196)	9.1	(208)
Employment status woman [% (n)]				
full-time	49.3	(1,005)	47.0	(1,081)
part-time	27.0	(550)	27.2	(626)
caring home/family	12.7	(260)	15.8	(363)
unemployed/ill/disabled	3.6	(74)	3.4	(78)
student	7.3	(149)	6.6	(152)
Ethnicity [% (n)]				
Bangladeshi/Indian/Pakistani	1.0	(20)	1.0	(23)
Chinese/other Asian	1.0	(20)	0.9	(21)
Black African/Caribbean/other	0.7	(15)	0.7	(15)
White	96.0	(1,959)	96.2	(2,215)
Mixed	1.3	(27)	1.3	(29)

¹ Numbers do not always add up to the total due to small numbers of missing values.

² Based on social class of partner (if any). For definition see section 5.6.3.

of pregnant women caused the study group to be slightly older and include relatively more single and full-time working women.

6.2.2 Definitions of pelvic pain and other symptoms

The following definitions were used in the analyses:

Dysmenorrhoea: pelvic pain during or shortly before/after periods.

Dyspareunia: pelvic pain during or in the 24 hours after sexual intercourse ²⁵.

CPP: constant or intermittent pelvic pain that started at least 6 months previously, not exclusively associated with periods or intercourse.

IBS: at least 3 months of continuous or recurrent symptoms of:

1. lower abdominal pain ²⁶ which was relieved with defaecation and/or associated with a change in frequency of stool and/or associated with a change in consistency of stool, and
2. two or more of the following, on at least a quarter of occasions or days:
altered stool frequency; altered stool form (hard/loose); altered stool passage (straining/urgency/incomplete evacuation); passage of mucus; bloating or feeling of abdominal distension

Genito-urinary symptoms: frequency and/or urgency and/or stinging on passing urine that is associated with CPP, on at least a quarter of occasions.

6.2.3 Calculation of prevalence rates

Prevalence rates of the different types of pelvic pain and associated symptoms were calculated as follows:

²⁵ Strictly speaking, the term 'dyspareunia' refers to pain during intercourse only. To aid the reader, however, 'dyspareunia' here also includes pain after intercourse. Where appropriate, results are shown separately for pain during and after intercourse.

²⁶ The internationally agreed Rome criteria (Thompson *et al.*, 1992), on which the definition of IBS was based, includes upper as well as lower abdominal pain. As the questionnaire did not specifically ask about upper abdominal pain, the prevalence of IBS could only be determined in women with CPP (i.e. lower abdominal pain).

Dysmenorrhoea: the number of women reporting dysmenorrhoea in the last 3 or 12 months, as a proportion of women with periods in the last 12 months in the total study group or in sub-groups of CPP cases and controls (see next section).

Dyspareunia: the number of women reporting pain during or after intercourse in the last 3 or 12 months, as a proportion of the *estimated* number of sexually active women in the last 12 months in the total study group or in sub-groups of CPP cases and controls (see next section). The number of sexually active women had to be estimated, because only those women with any type of pelvic pain in the last 12 months (n=1,511) were asked whether they had sexual intercourse in the last 12 months. Of these, 48 had objected to answering the question, leaving 1,463 women with and 531 without information on sexual intercourse. Apart from the 531 women being older, no substantial differences in demographic characteristics were observed between the two groups. Age-specific rates of intercourse found in the 1,463 women were therefore applied to the 531 women. Out of the 1,463 women, 1,325 (90.6%) had intercourse: 84.8% of 18-25 yr. olds; 94.4% of 26-30 yr. olds; 90.2% of 31-35 yr. olds; 92.7% of 36-40 yr. olds; 92.6% of 41-45 yr. olds; 89.3% of 46-49 yr. olds. This produced an estimated number of 482 women who had intercourse amongst the 531 women. Adding the 1,325 women who reported having had sexual intercourse in the last 12 months gave an estimated number of 1,807 sexually active women.

CPP: the number of women reporting CPP in the last 3 months²⁷ as a proportion of women in the total study group.

IBS: the number of women reporting IBS in the last 12 months, as a proportion of CPP cases.

²⁷ The prevalence of CPP was not calculated for the last 12 months, since the questions on which the definition of CPP was based were likely to require a more accurate recall than for dysmenorrhoea or dyspareunia.

Genito-urinary symptoms: the number of women reporting genito-urinary symptoms in the last 12 months, as a proportion of CPP cases.

6.2.4 Analyses of CPP cases and controls

6.2.4.1 Classification of case and control groups

A CPP case was defined as a woman with CPP in the last 3 months. Out of the 2,042 women, 26 women could not be classified as a CPP case or a control due to missing values. Of the remaining 2,016 women, 483 were classified as CPP cases and 1,533 as controls without CPP (control group I). Two additional nested control groups were formed from control group I, consisting of 660 women who had dysmenorrhoea only in the last 3 months (control group II) and 186 women who had dyspareunia with or without dysmenorrhoea ²⁸ in the last 3 months (control group III).

An important objective of the present chapter was to describe pain experienced by CPP cases in detail, according to its severity, chronicity, and associated use of health care. The steering group chose pain severity and health care use – both assessed using a range of measures (see sections 6.2.4.2 and 6.2.4.3) – as the main factors of interest. The 483 CPP cases were classified according to the remaining variable – chronicity – defined in terms of cumulative duration of pelvic pain in the last 12 months ('disease burden'), thus allowing exploration and comparison of mean pain scores and use of health care between CPP cases of different pain duration. This chronicity measure – although itself not standardised and validated – was significantly correlated with the standardised measures of pain severity and those of health care use (shown in section 6.3.2.4 and Table 6.6).

Cumulative CPP duration was calculated by multiplying the approximate duration of a typical episode in the last 12 months by the number of episodes reported in that time period.

²⁸ Out of the 186 women with dyspareunia, 149 (80%) also had dysmenorrhoea.

Since information on both duration and number of episodes was recorded in categories, the mid-points of each category were used in the calculations. Categories of cumulative duration were formed according to approximate tertiles: up to 24 hours ('short': n=174); 25-168 hours²⁹ ('intermediate': n=173); >168 hours ('long': n=133). Three CPP cases had missing values for duration and could not be classified.

6.2.4.2 Pain measurement

For CPP cases and pelvic pain controls, the typical severity of pain in the last 12 months was assessed. In view of the possible inaccuracy of recalling the severity of pain over time, it was important to note that the majority of cases and controls (approximately 60%) had pain in the last month (Erskine *et al.*, 1990). For all types of pelvic pain, severity was measured on a verbal rating scale (VRS) and a visual analogue scale (VAS). In addition, severity of CPP was measured using the Pain Rating Index (PRI) of the multi-dimensional Short-Form (SF) McGill pain questionnaire.

On the VRS, pain intensity is measured using verbal descriptors of increasing severity. It is a much used and validated pain measurement instrument, that is easy to complete. However, it lacks the sensitivity of a VAS or a multi-dimensional instrument (Macclaverty & Shaw, 1995). An additional complication is that it measures pain on an ordinal, not an interval scale (i.e. the increase in pain severity from 'mild' to 'moderate' cannot be assumed the same as from 'moderate' to 'severe'). Non-parametric methods of analysis are therefore required if the VRS is analysed as a continuous variable (as is common practice).

The VAS assesses pain intensity on a continuous line, with definitive end-points representing the extremes of experience. It has been shown to be a sensitive and reproducible method of measuring pain severity, and results correlate well with other methods of

²⁹ 168 hours=1 week

measuring pain, including the VRS (Huskisson, 1982). Although the distribution of pain severity on a VAS is continuous, it is not normal and requires non-parametric methods of analysis when small groups of study subjects are compared. The VAS used here was a 10 cm horizontal line going from ‘least possible pain’ to ‘worst possible pain’ (Wallenstein *et al.*, 1980).

The SF-McGill questionnaire (Melzack, 1987) is the abbreviated version of the long-form McGill pain questionnaire (Melzack, 1975). It is a multi-dimensional pain measurement instrument, that is based on the Gate Control Theory of pain (see section 1.1). Rather than regarding pain solely on the basis of intensity (as is done when using the VRS and VAS), it is measured in terms of its characteristics. The severity of pain is assessed using 15 descriptive words indicating the quality of the pain. The descriptors are grouped in 2 classes: *sensory* (11 descriptors with temporal, spatial, pressure and thermal properties: e.g. throbbing, stabbing, hot-burning) and *affective* (4 descriptors with tension, fear and autonomic properties: e.g. tiring-exhausting, fearful, sickening). For each descriptor, patients are asked to indicate the intensity of that particular pain quality from ‘none’ to ‘severe’, scored from 0 to 3. PRIs are calculated by summing the pain intensity scores for each class and for the total.

6.2.4.3 Health care use, investigations, diagnoses and major procedures

Pelvic pain related use of health care in the last 12 months (visits to a GP/specialist/alternative therapist, use of medication and other treatments) was assessed in CPP cases and pelvic pain controls. Information on GP or specialist consultations was collected for each of the three pelvic pain types separately. Information about alternative therapy, use of medication and other treatments was collected for all types of pelvic pain combined.

Medication use was analysed for all prescribed and ‘Over The Counter’ (OTC) drugs combined and for OTC drugs separately ³⁰.

Life-time investigations undergone and diagnoses received from a GP or specialist ³¹ were investigated in CPP cases only. The investigations regarded as ‘appropriate’ for pelvic pain were: ultrasound scan; MRI scan; laparoscopy; laparotomy; sigmoidoscopy or colonoscopy; x-ray; or cystoscopy. Frequency of hysterectomy was investigated in both CPP cases and controls (frequencies of oophorectomy and salpingectomy could not be reliably established due to large numbers of missing values).

6.2.5 Statistical methods

6.2.5.1 Missing values

In general, missing values for a variable were excluded from analyses involving that variable. For the majority of variables, the frequency of missing values was only 1-2%; if the frequency of missing values for a variable exceeded 5%, this was noted in the tables. In a few instances, missing values were imputed:

- 1) The McGill pain scale: 17% of women had indicated the severity of pain for some but not all of the 15 descriptors. In these cases, missing values were scored as ‘none’.
- 2) Genito-urinary and bowel symptoms: 3% of women had a missing value for one or more genito-urinary symptoms, and 9% for one or more gastrointestinal symptoms. Missing values were treated as negative answers.
- 3) Specific alternative therapists and investigations for pelvic pain: frequencies of missing values for the different alternative therapists were approximately 2%, and varied between 8-16% for the different investigations. Missing values were treated as negative answers.

³⁰ Prescribed medication was not analysed separately: few women had used medication prescribed by a specialist and data on medication prescribed by a GP was not specifically collected (see section 5.3.1.2).

³¹ This information was not validated by external sources such as medical records.

6.2.5.2 Methods of analysis

Comparisons between proportions were made using the Pearson chi-squared test. Trends in proportions were assessed for statistical significance using the Mantel-Haenszel chi-squared test for trend. Differences in means between two groups were assessed using the t-test; differences between means of more than two groups were assessed using analysis of variance (ANOVA). Correlations between pain severity scores and cumulative CPP duration were investigated by calculating Pearson correlation coefficients.

Rather than using the VRS as a continuous variable by assigning scores to the four pain categories³², comparisons were made between the proportions of women reporting moderate/severe pain. Although pain severity on the VAS, and PRI of the SF-McGill were not normally distributed (they were positively skewed), group sizes were sufficiently large to allow for parametric testing of differences in scores between groups. To check this, analyses were repeated using non-parametric tests, which produced virtually identical results.

The odds of receiving a diagnosis, investigation, or procedure associated with increasing CPP duration, after adjusting for age, were estimated using logistic regression models.

All analyses were performed using SPSS version 8.0 (1998) and Epi-Info version 6.04b (Centres for Disease Control and Prevention, 1997).

6.3 Results

6.3.1 Prevalence of CPP, dysmenorrhoea, and dyspareunia

Table 6.2 shows the prevalence rates for CPP, dysmenorrhoea, and dyspareunia. The prevalence of CPP was high, with a 3-month rate of 24.0% (95% CI: 22.1-25.8). The

³² The categories from 'none' to 'severe' pain on the VRS are usually scored from 0 to 3. The mean scores (or – more often – mean changes in scores after an intervention) are then compared between groups. Since very few women with pelvic pain reported the severity of their pain to be equal to 'none' on the VRS (because they were asked to rate their 'typical' rather than 'present' pain intensity), it was effectively reduced to a 3-point scale in our study. Mean scores were therefore considered not to be very informative.

Table 6.2. Prevalence rates of CPP, dysmenorrhoea and dyspareunia/pain after intercourse.

Symptom	Definition ¹	n/N ²	Prevalence rates (%) (95% CI)
CPP	In the last 3 months	483/2,016	24.0 (22.1-25.8)
Dysmenorrhoea	In the last 12 months	1,390/1,884	73.8 (71.8-75.8)
	In the last 3 months	1,199/1,877	63.9 (61.7-66.1)
Dyspareunia	In the last 12 months	480/1,807	26.6 (24.6-28.6)
	In the last 3 months	374/1,800	20.8 (18.9-22.7)
	- during intercourse only	111/1,800	6.2 (5.1-7.3)
	- after intercourse only	59/1,800	3.3 (2.4-4.0)
	- during and after intercourse	204/1,800	11.3 (9.8-12.8)
	- superficial only	27/1,799	1.5 (0.9-2.1)
	- deep only	282/1,799	15.7 (14.0-17.4)
	- superficial + deep	64/1,799	3.6 (2.7-4.4)

¹ Details of definitions are given in section 6.2.2.

² The following denominators were used (numbers shown are after exclusion of missing values for variables on which prevalence estimates were based): *CPP*: all women in study; *dysmenorrhoea*: women with periods in the last 12 months; *dyspareunia*: estimated number of women who had intercourse in the last 12 months. For details see section 6.2.4

prevalence of dysmenorrhoea in women with periods in the last 12 months was very high, with a 12-month rate of 73.8% (95% CI: 71.8-75.8), and a three-month rate of 63.9% (95% CI: 61.7-66.1). Of women with dysmenorrhoea in the last 3 months, approximately 30% reported that it occurred occasionally, 20% often, and 50% usually or always with their periods.

In women who were sexually active in the last 12 months, the 12-month prevalence of dyspareunia was 26.6%, with a 3-month rate of 20.8% (95% CI: 18.9-22.7). Three-month rates for pain during and after intercourse separately were 17.5% (95% CI: 15.7-19.3) and 14.6% (95% CI: 13.0-16.2), respectively. Most women with dyspareunia reported deep pain alone (75%) or combined with superficial pain (17%). Most women (70%) reported that they had the pain occasionally, 15% often, and 15% usually or always with intercourse.

Table 6.3 shows the prevalence of CPP by demographic characteristics. Prevalence varied significantly with age ($p=0.02$), with the lowest rate found in 18-25 year olds (19.6%) and the highest in 36-40 year olds (28.4%). Caucasian women had a higher CPP prevalence (24.5%) than women of other ethnicity (10.0%; $p=0.003$), but numbers in the latter group were small. Prevalence of CPP did not vary significantly with social class, marital status, or employment status.

6.3.2 Analyses of CPP cases and controls

6.3.2.1 Demographic characteristics of CPP cases and controls

The demographic characteristics of CPP cases were compared with the three control groups: all women without CPP in the last 3 months (group I), women with dysmenorrhoea only (group II) and women with dyspareunia (group III) (results not shown). The mean age of CPP cases (35.4 yrs, SD: 8.6) was not significantly different from that of group I controls

Table 6.3. Prevalence of CPP by demographic characteristics.

Variable	n/N ¹	Prevalence of CPP (%) (95% CI) ²
Age		
18-25	71/362	19.6 (15.5-23.7)
26-30	83/321	25.9 (21.1-30.6)
31-35	67/329	20.4 (16.0-24.7)
36-40	100/352	28.4 (23.7-33.1)
41-45	97/356	27.2 (22.6-31.9)
46-49	65/296	22.0 (17.2-26.7)
		p=0.02
Social class ³		
I+II	228/862	26.5 (23.5-29.4)
IIINm	63/285	22.1 (17.3-26.9)
IIIm	108/432	25.0 (20.9-29.1)
IV/V	49/240	20.4 (15.3-25.5)
Other	34/188	18.1 (12.6-23.6)
		p=0.06
Marital status		
Single	91/434	21.0 (17.1-24.8)
Cohabiting/married	334/1378	24.2 (22.0-26.5)
Divorced/separated/widowed	57/196	29.1 (22.7-35.4)
		p=0.08
Employment status woman		
full-time	247/997	24.8 (22.1-27.5)
part-time	130/539	24.1 (20.5-27.7)
caring home/family	53/255	20.8 (15.8-25.8)
other (students/unemployed)	53/222	23.9 (18.3-29.5)
		p=0.6
Ethnicity		
Caucasian	475/1935	24.5 (22.6-26.5)
Other	8/80	10.0 (3.4-16.6)
		p=0.003

¹ Numbers do not always add up to the total due to missing values.
² P-values refer to differences in prevalence rates between categories of demographic variables
³ Based on partner's social class (if any).

(34.8 yrs, SD: 9.0; $F_{df=1}$: $p=0.1$)³³. However, it was greater than that of both dysmenorrhoea controls (33.7 yrs, SD: 8.6; $F_{df=1}$: $p=0.001$) and dyspareunia controls (30.5 yrs, SD: 8.2; $F_{df=1}$: $p<0.001$). Furthermore, CPP cases included a slightly higher proportion of Caucasian women (98.3%) than all three control groups (95.3% in group I; 95.8% in group II; 93.5% in group III; $p<0.01$), but numbers of non-Caucasian women were small. Less markedly, CPP cases tended to be of somewhat higher social class and were less likely to be single, but differences were small and may partly have been due to differences in age distributions.

Amongst CPP cases, the mean age of ‘short’ duration cases was younger (33.4 yrs, SD: 8.9) compared with cases of ‘intermediate’ duration (36.2 yrs, SD: 8.2) and of ‘long’ duration (36.9 yrs, SD: 8.3) ($F_{df=1}$: $p=0.001$). They were also more likely to be single (28% compared with 15% in cases of ‘intermediate’ and 14% in cases of ‘long’ duration; $F_{df=1}$: $p=0.001$).

These results were unadjusted for any confounding factors, as they were intended only to provide background information needed to interpret the results presented in this chapter. In chapter 8, the effect of demographic characteristics and other factors on risk of CPP is investigated in more detail, adjusting for potential confounders.

6.3.2.2 Overlap of CPP with other pelvic pain, IBS, and genito-urinary symptoms

In Table 6.4, the prevalence is shown of dysmenorrhoea, dyspareunia, IBS, and genito-urinary symptoms in CPP cases, compared with control group I. Dysmenorrhoea and dyspareunia were reported by large proportions of CPP cases: 90% of those having periods reported dysmenorrhoea in the last 12 months and 50% of those having intercourse reported dyspareunia. These rates were significantly higher than among control group I: the risk ratio (RR) for dysmenorrhoea in the last 12 months for CPP cases compared with controls was 1.3

³³ The distribution of age in categories was somewhat different between CPP cases and controls without CPP (which follows from the results described in the previous section and shown in Table 6.3).

Table 6.4. Prevalence rates of dysmenorrhoea, dyspareunia, IBS, and genito-urinary symptoms in 483 women reporting CPP in the last 3 months vs. 1,533 women without CPP (Control Group I).

Symptom type ¹	Control Group I: No CPP (n=1,533)		CPP (in last 3 months) ²						Test for trend (short-long)	
			All cases (n=483)		'short' (n=174)		'intermediate' (n=173)		'long' (n=133)	
	n/N ³	%	n/N ³	%	n/N ³	%	n/N ³	%	n/N ³	%
Dysmenorrhoea - last 12 months - last 3 months	946/1,410	67.1	405/451	89.8	142/166	85.5	150/163	92.0	111/120	92.5
	817/1,409	58.0	364/451	80.7	126/166	75.9	128/163	78.5	108/120	90.0
Dyspareunia - last 12 months - last 3 months	252/1,349	18.7	216/434	49.8	71/155	45.8	67/157	42.7	76/119	63.9
	186/1,346	13.8	178/432	41.2	60/155	38.7	54/157	34.4	62/117	53.0
IBS (last 12 months)	-	-	186/483	38.5	57/174	32.8	65/173	37.6	62/133	46.6
Genito-urinary symptoms (last 12 months)	-	-	116/479	24.2	25/173	14.5	42/170	24.7	47/133	35.3

¹ Details of definitions are given in section 6.2.2.

² Numbers in the cumulative duration groups do not add up to the total number of CPP cases, since three cases had missing values for cumulative duration of pain in the last 12 months.

³ Denominators (numbers shown are after exclusion of missing values for variables on which prevalence estimates were based): *dysmenorrhoea*: women who had periods in the last 12 months; *dyspareunia*: women who had intercourse in the last 12 months; *IBS/genito-urinary symptoms*: all women in study. For details see section 6.2.4.

(95% CI: 1.3-1.4; $\chi^2_{df=1}$: $p<0.001$), with a RR of 2.7 (95% CI: 2.3-3.1; $\chi^2_{df=1}$: $p<0.001$) for dyspareunia. In addition, 39% of CPP cases had IBS and 24% had genito-urinary symptoms associated with their pelvic pain³⁴.

As shown in the table, prevalence rates of these symptoms all increased significantly with cumulative duration of CPP. However, these trends were mostly due to an elevated risk of symptoms in the 'long' duration group alone. Comparing symptoms of 'long' duration cases with those of 'short' duration, the RR for dysmenorrhoea (in the last 12 months) was 1.1 (95% CI: 1.0-1.2), with RRs of 1.4 (95% CI: 1.1-1.7) for dyspareunia, 1.4 (1.1-1.9) for IBS, and 2.5 (95% CI: 1.6-3.8) for genito-urinary symptoms. Comparing the 'intermediate' duration group with 'short' duration cases, the only significantly elevated RR was that for genito-urinary symptoms (1.7, 95% CI: 1.1-2.7).

Figure 6.1 shows the combined overlap between CPP, dysmenorrhoea, and dyspareunia in the last three months in women who had periods and who were sexually active. Most women with CPP (347/403=86%) also had another type of pelvic pain.

6.3.2.3 Basic pelvic pain characteristics of CPP cases

Basic characteristics of CPP cases in terms of pelvic pain frequency and duration are given in Table 6.5. Most women with CPP reported intermittent pain (96%). Of CPP cases, 39% reported pain that was not related to the menstrual cycle, whereas 29% reported mid-cycle pain. However, a third of women indicated they could not tell if the pain was related to their cycle.

Two-thirds of women with CPP reported pain in the last month, and the majority (81%) had their first pelvic pain episode more than one year previously (with 33% of women reporting pain that started >5 years ago). Overall, 77% of women reported that a typical

³⁴ Amongst the 116 CPP cases with genito-urinary symptoms, the most frequently reported symptoms were urgency (81%) and frequency (80%), with only 27% reporting dysuria.

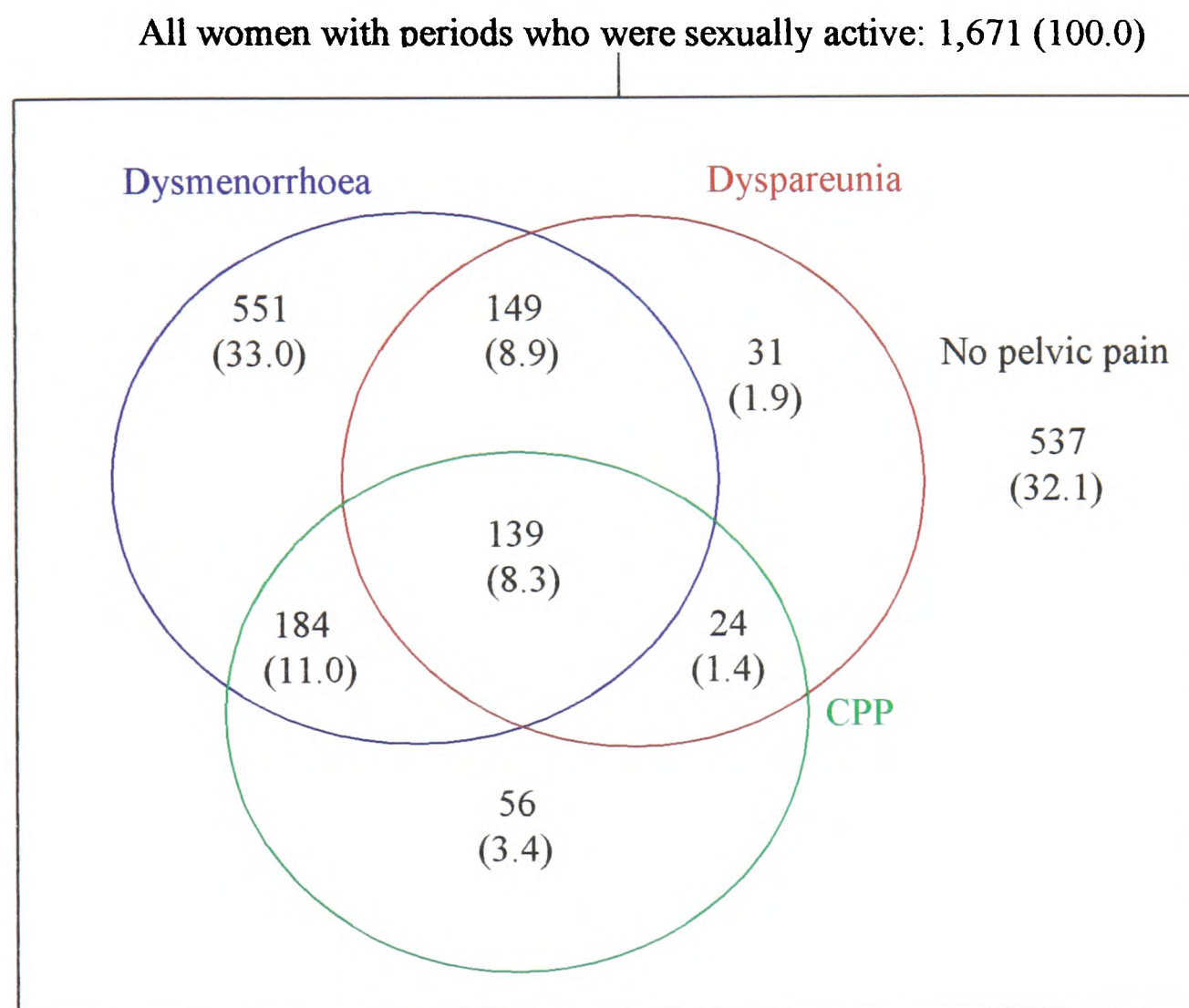


Fig 6.1. Numbers of women (%) with and without pelvic pain in the last three months among 1,671 women who had periods and who were sexually active: overlap between CPP, dysmenorrhoea, and dyspareunia.

Table 6.5. Reported characteristics of CPP by cumulative duration of CPP ¹.

	All CPP cases (n=483) % (n)	CPP: 'short' (n=174) % (n)	CPP: 'intermediate' (n=173) % (n)	CPP: 'long' (n=133) % (n)
Frequency of pain in the last 12 months				
intermittent	95.9 (463)	100 (174)	100 (173)	85.0 (113)
constant	4.1 (20)	-	-	15.0 (20)
Relation to cycle				
no	38.9 (188)	35.6 (62)	32.9 (57)	42.5 (48)
yes: mid-cycle	29.4 (142)	19.5 (34)	43.4 (75)	29.2 (33)
don't know	31.7 (153)	44.8 (78)	23.7 (41)	28.3 (32)
Most recent pain				
last month	65.6 (317)	54.6 (95)	64.2 (111)	81.2 (108)
1-3 months ago	34.4 (166)	45.4 (79)	35.8 (62)	18.8 (25)
Time since first pain				
6 months - 1 year	19.0 (92)	17.2 (30)	20.2 (35)	20.3 (27)
>1 year:	81.0 (391)	82.8 (144)	79.8 (138)	79.7 (106)
>1-5 yrs	31.3 (151)	32.2 (56)	28.3 (49)	33.8 (45)
>5-10 yrs	19.7 (95)	20.1 (35)	20.2 (35)	17.3 (23)
>10 yrs	13.3 (64)	9.2 (16)	16.8 (29)	14.3 (19)
exact duration unknown ²	16.8 (81)	21.3 (37)	14.5 (25)	14.3 (19)
Duration of a typical pain episode in the last 12 months				
one hour or less	34.9 (168)	95.6 (166)	0.6 (1)	0.8 (1)
few hrs - 1 day	41.6 (200)	4.6 (8)	97.1 (168)	17.3 (23)
2-5 days	15.2 (73)	-	2.3 (4)	51.9 (69)
6-10 days	2.3 (11)	-	-	8.3 (11)
>10 days	1.9 (9)	-	-	6.8 (9)
constant pain	4.1 (20)	-	-	15.0 (20)
Number of episodes in the last 12 months				
1-2	7.1 (34)	15.5 (27)	2.3 (4)	2.3 (4)
3-5	32.2 (155)	37.4 (65)	38.2 (66)	18.0 (24)
6-10	36.7 (177)	32.8 (57)	49.7 (86)	25.6 (34)
>10	19.9 (96)	14.4 (25)	9.8 (17)	39.1 (52)
constant pain	4.1 (20)	-	-	15.0 (20)

¹ Numbers do not always add up to the totals due to missing values.

² These CPP cases indicated that their pain started >1 year ago, but had missing values for the actual number of years since first pain.

pelvic pain episode lasted up to 1 day, and 69% reported they had 3-10 pain episodes in the last 12 months.

CPP cases grouped according to cumulative duration of pain in the last year resulted in 'short' duration cases mainly consisting of women with 3-10 episodes lasting one hour or less, 'intermediate' duration cases mainly of women with 3-10 episodes lasting a few hours to 1 day, and 'long' duration cases mainly of women with >6 episodes that lasted at least 2 days. It was notable that the case groups did not differ materially with regard to the time since they first experienced the pain.

6.3.2.4 Severity of pelvic pain

Table 6.6 shows the typical severity of different types of pelvic pain in CPP cases who reported having these types of pelvic pain in the last 3 months. All three measures of CPP severity were significantly correlated with cumulative duration of CPP ($p < 0.001$), although correlation coefficients were small: $r = 0.24$ for the VAS; $r = 0.18$ for the VRS, and $r = 0.30$ for the total McGill PRI (not shown). From 'short' to 'long' duration, the proportion of women reporting moderate/severe pain rose from 40% to 65% and the mean score on the VAS from 3.5 to 5.0. Mean total PRIs increased from 8.0 to 13.4, with sensory PRIs rising from 7.0 to 10.8 and affective PRIs from 1.0 to 2.7.

The severity of dysmenorrhoea reported by CPP cases was somewhat greater than that reported by dysmenorrhoea controls (not shown): the proportion reporting moderate/severe pain was 62% in dysmenorrhoea controls vs. 72% in CPP cases ($\chi^2_{df=1}$: $p = 0.001$), with mean VAS scores of 4.5 (SD: 2.5) and 5.1 (SD: 2.5), respectively ($F_{df=1}$: $p < 0.001$). Severity of dysmenorrhoea increased significantly from the 'short' CPP duration group to the 'long' duration group in terms of VAS scores (from 4.7 to 5.6), although the differences in scores were modest. Dysmenorrhoea pain scores in the 'short' duration group (mean VAS: 4.7; SD: 2.7) were similar to those in the dysmenorrhoea control group (mean VAS: 4.5; SD: 2.5).

Table 6.6. Severity of different pelvic pain types in CPP cases who reported having these types of pain in the last 3 months, by cumulative duration of CPP.

Pelvic pain measurement ¹	All CPP cases (n=483)	CPP: ‘short’ (n=174)	CPP: ‘intermediate’ (n=173)	CPP: ‘long’ (n=133)	Test for trend (short-long)
<i>CPP</i>					
% moderate/severe on VRS	50.9	40.2	50.9	65.4	p<0.001
Mean severity on VAS (SD)	4.2 (2.6)	3.5 (2.5)	4.2 (2.3)	5.0 (2.7)	p<0.001
Mean PRI in SF-McGill (SD)					
sensory	8.6 (5.4)	7.0 (4.3)	8.6 (5.1)	10.8 (6.3)	p<0.001
affective	1.8 (2.6)	1.0 (1.8)	1.8 (2.4)	2.7 (3.1)	p<0.001
total	10.4 (7.4)	8.0 (5.5)	10.4 (6.9)	13.4 (8.8)	p<0.001
<i>Dysmenorrhoea</i>					
	(n=364)	(n=126)	(n=128)	(n=108)	
% moderate/severe on VRS	71.7	65.1	78.0	74.5	p=0.06
Mean severity on VAS (SD)	5.1 (2.5)	4.7 (2.7)	5.3 (2.2)	5.6 (2.5)	p=0.005
<i>Pain during intercourse</i>					
	(n=156)	(n=53)	(n=47)	(n=54)	
% moderate/severe on VRS	50.6	49.1	48.9	53.7	p=0.9
Mean severity on VAS (SD)	4.0 (2.3)	4.1 (2.7)	3.5 (2.0)	4.2 (2.0)	p=0.3
<i>Pain after intercourse:</i>					
	(n=127)	(n=34)	(n=39)	(n=53)	
% moderate/severe on VRS	40.9	41.2	30.8	47.2	p=0.3
Mean severity on VAS (SD)	3.8 (2.3)	3.7 (2.5)	3.2 (2.1)	4.1 (2.2)	p=0.2

¹ VRS= Verbal rating scale; VAS= Visual analogue scale; PRI in SF-McGill= Pain Rating Index in Short-Form McGill pain questionnaire for total, sensory, and affective domains (see section 6.2.5).

The reported severities of pain during and after intercourse did not differ materially between CPP cases and dyspareunia controls (not shown): moderate/severe pain during intercourse was reported by 45% of dyspareunia controls and 51% of CPP cases ($\chi^2_{df=1}$: $p=0.3$), and mean VAS scores were 3.9 (SD: 2.4) and 4.0 (SD: 2.3), respectively ($F_{df=1}$: $p=0.8$). With regard to pain after intercourse, 34% of dyspareunia controls and 41% of CPP cases reported moderate/severe pain ($\chi^2_{df=1}$: $p=0.2$). Mean VAS scores were 3.4 (SD: 2.0) and 3.8 (SD: 2.3), respectively ($F_{df=1}$: $p=0.04$). There was no trend in pain severity either during or after intercourse with increasing cumulative duration of CPP.

6.3.2.5 Pelvic pain related use of health care

Table 6.7 shows reported health care use for pelvic pain in the last 12 months, for CPP cases and dysmenorrhoea and dyspareunia control groups. Overall, 31% of CPP cases had seen a GP and 12% had seen a specialist for any type of pelvic pain. When considering visits specifically for CPP (not shown in table), these rates were 23% and 9%, respectively (24% for GP/specialist combined). CPP cases who had consulted a GP or specialist for CPP differed substantially from non-consulters in terms of reported typical CPP severity. Moderate/severe pain was reported by 76.5% of consulters vs. 43.1% of non-consulters ($\chi^2_{df=1}$: $p<0.001$), with mean VAS scores of 3.7 (SD: 2.4) vs. 5.7 (SD: 2.5) ($F_{df=1}$: $p<0.001$).

Consultation rates for any pelvic pain were significantly higher in women with CPP compared with dysmenorrhoea controls (12% of whom consulted a GP and 4% a specialist) but not compared with dyspareunia controls (of whom 34% had consulted a GP and 13% a specialist). It should be noted that 80% of the dyspareunia controls also had dysmenorrhoea, and the majority reported having seen a GP or specialist for dysmenorrhoea, not for intercourse-related pelvic pain.

Table 6.7. Pelvic pain related use of health care in the last 12 months in women reporting CPP in the last 3 months compared to control women with only other types of pelvic pain.

In last 12 months [% (n)]	No CPP (in last 3 months)		CPP (in last 3 months)				Test for trend (short-long)
	Group II: Dysmenorrhoea only (n=660)	Group III: Dyspareunia (+/- dysmenorrhoea) (n=186)	All cases (n=483)	‘short’ (n=174)	‘intermediate’ (n=173)	‘long’ (n=133)	
Seen a GP for <u>any</u> pelvic pain	12.2 (80) [‡]	33.9 (63)	30.9 (148)	17.4 (30)	28.5 (49)	50.8 (67)	p<0.001
Seen a specialist for <u>any</u> pelvic pain	3.8 (25) [‡]	12.9 (24)	11.7 (56)	6.3 (11)	11.0 (19)	19.1 (25)	p=0.002
Seen alternative therapist for <u>any</u> pelvic pain	1.8 (12) [‡]	4.3 (8)	7.9 (38)	2.3 (4)	5.8 (10)	18.3 (24)	p<0.001
Used medication for <u>any</u> pelvic pain	73.3 (483)	70.4 (131)	75.5 (364)	60.3 (105)	82.1 (142)	87.1 (115)	p<0.001
Used OTC analgesics frequency:	71.5 (471)	67.2 (125)	71.0 (342)	56.9 (99)	78.0 (135)	80.3 (106)	p<0.001
	occasionally	29.6 (55)	34.6 (167)	31.6 (55)	37.0 (64)	34.8 (46)	
	often	13.5 (89)	13.5 (65)	9.8 (17)	18.5 (32)	12.1 (16)	
	usually	13.8 (91)	11.8 (57)	9.8 (17)	11.0 (19)	15.9 (21)	
	always	12.4 (82)	11.0 (53)	5.7 (10)	11.6 (20)	17.4 (23)	p=0.02
Used other treatments for <u>any</u> pelvic pain	10.0 (66) [‡]	11.4 (21)	16.7 (80)	11.5 (20)	18.7 (32)	21.4 (28)	p=0.02

Comparison of CPP cases with control groups:

[‡] p<0.001

GP and specialist consultation rates rose significantly with increasing cumulative duration of CPP: comparing the 'short' with the 'long' duration group, the proportion of women who saw a GP for any pelvic pain increased from 17% to 51% and the proportion who saw a specialist from 6% to 19%. The consultation rates found in the 'short' duration group were most similar to those found in the dysmenorrhoea control group.

Out of all CPP cases, 8% had seen an alternative therapist for any pelvic pain, compared with 2% of dysmenorrhoea controls and 4% of dyspareunia controls. Among the CPP cases, the proportion increased significantly from 2% in the 'short' duration group to 18% in the 'long' duration group, with the rate in the 'short' duration group again similar to that found in dysmenorrhoea controls. Amongst all CPP cases, the most commonly visited alternative therapist was a homeopath (3%), followed by acupuncturists, osteopaths, or herbalists (2%).

The majority of CPP cases and controls (approximately 3/4) had used medication for pelvic pain in the last 12 months. Use of any medication was not different between CPP cases and controls, but did increase significantly from 60% to 87% with cumulative duration of CPP. Similarly, frequency of OTC use was not different between CPP cases and controls, but rose significantly from 57% to 80% with increasing cumulative duration of CPP.

CPP cases were somewhat more likely to have used treatments other than medication (17%) compared with dysmenorrhoea controls (10%) but not compared with dyspareunia controls (11%). The proportion of women with CPP using other treatments rose from 12% in the 'short' duration group to 21% in the 'long' duration group, with use in the 'short' duration group again similar to that in controls. The most frequently used non-medical treatment for both cases and controls was heat (e.g. hot water bottle/hot bath), which was reported by 6-9% of CPP cases and controls. CPP cases appeared to use a somewhat wider variety of other treatments, which included exercise, reflexology/massage, and use of aloe vera/primrose oils and aromatherapy (all reported by approximately 2% of cases).

6.3.2.6 Investigations and diagnoses

Out of all 483 CPP cases, 34% reported that they had undergone at least one investigation (Table 6.8), increasing significantly from 23% in the ‘short’ duration group to 48% in the ‘long’ duration group. Considering ‘appropriate’ investigations only, these percentages were 30%, and 18% to 46%, respectively. The results remained highly significant ($p < 0.001$) after adjusting for the differences in age distributions between the case groups (see section 6.3.2.1). The most frequently reported investigation was an ultrasound scan.

Table 6.9 shows the diagnoses received in women with CPP by a GP or a specialist. Half of all women with CPP reported ever being given a diagnosis, increasing from 36% of women with a ‘short’ CPP duration to 73% of women with a ‘long’ duration. The number of diagnoses received also increased significantly between the groups. Again, these results remained highly significant after adjusting for age differences between the groups ($p < 0.001$).

In all CPP cases, IBS was by far the most common diagnosis received (20%)³⁵, followed by stress (10%). The frequency of the different types of diagnosis varied depending on whether a woman had undergone an investigation or not (Table 6.10). Among the 319 women who stated that they had never had an investigation, most frequently reported diagnoses were IBS (9%), constipation (6%), stress (5%) and cystitis (4%). Among the 162 women had at least one investigation, IBS (40%) and stress (17%) were also common diagnoses, but so were diagnoses that would have required a more thorough investigation: ovarian cysts (22%), endometriosis (18%), and PID (15%)³⁶.

When considering the different diagnoses, the percentage of women ever having undergone an investigation varied from 90% in those diagnosed with ovarian cysts to 48% in those diagnosed with constipation (Table 6.11). Women reporting diagnoses that could only

³⁵ Out of the 96 women who reported a diagnosis of IBS, 62 (65%) had IBS according to the Rome criteria in the questionnaire.

³⁶ It should be stressed that this information does *not* imply that these diagnoses were ‘validated’ by an appropriate investigation, since no information was collected on whether a certain diagnosis was received before or after an investigation.

Table 6.8. Investigations ever undergone for pelvic pain in women with CPP ¹.

	All CPP cases (n=483)	'short' (n=174)	'intermediate' (n=173)	'long' (n=133)	Test for trend
Ever undergone any investigation [% (n)]	33.7 (162)	22.5 (39)	33.7 (58)	48.1 (64)	p<0.001
Ever undergone an appropriate investigation ² [% (n)]	29.7 (143)	17.9 (31)	29.1 (50)	45.9 (61)	p<0.001
<i>Type:</i>					
Ultrasound scan	21.2 (102)	12.7 (22)	19.8 (34)	34.6 (46)	
Laparoscopy	10.8 (52)	4.6 (8)	12.2 (21)	16.5 (22)	
Sigmoid/colonoscopy	9.6 (46)	5.2 (9)	8.1 (14)	16.5 (22)	
X-ray	7.1 (34)	2.3 (4)	7.6 (13)	12.8 (17)	
Other ³	1.4 (7)	1.2 (2)	1.2 (2)	2.3 (3)	

¹ Only women with missing values for ever having undergone an investigation were excluded from frequency tabulations (for details see section 6.2.7.1)

² Investigations considered appropriate for CPP: ultrasound scan, x-ray, laparoscopy, laparotomy, MRI scan, sigmoidoscopy/colonoscopy, and cystoscopy. The most commonly reported investigations that were considered less appropriate were blood tests, urine samples, and cervical smear tests.

³ 'Other' appropriate investigations included MRI scan, laparotomy, and cystoscopy

Table 6.9. Diagnoses of pelvic pain received by women with CPP from a GP or a specialist. ¹

	All CPP cases (n=483)	'short' (n=174)	'intermediate' (n=173)	'long' (n=133)	Test for trend
Ever received diagnosis [% (n)]	50.1 (239)	36.4 (63)	45.9 (78)	73.3 (96)	p<0.001
<i>Type:</i>					
IBS	20.1 (96)	9.8 (17)	17.6 (30)	28.2 (48)	
Stress	9.6 (46)	6.4 (11)	6.5 (11)	14.1 (24)	
Ovarian cysts	8.4 (40)	5.8 (10)	9.4 (16)	8.2 (14)	
Endometriosis	7.3 (35)	4.6 (8)	8.2 (14)	7.1 (12)	
Cystitis	7.1 (34)	6.4 (11)	5.3 (9)	8.2 (14)	
PID	6.5 (31)	3.5 (6)	4.7 (8)	10.0 (17)	
Constipation	6.5 (31)	2.9 (5)	6.5 (11)	8.8 (15)	
Back pain/problems	5.7 (27)	4.0 (7)	3.5 (6)	8.2 (14)	
Uterine fibroids	5.0 (24)	2.3 (4)	4.7 (8)	7.1 (12)	
Adhesions	4.6 (22)	1.7 (3)	4.7 (8)	5.9 (10)	
Appendicitis	2.5 (12)	1.2 (2)	4.7 (8)	1.2 (2)	
Inflammatory bowel dis.	2.1 (10)	1.2 (2)	1.8 (3)	2.9 (5)	
Other ²	12.8 (61)	6.4 (11)	10.0 (17)	19.4 (33)	
Number received [% (n)]					
0	49.9 (238)	63.6 (110)	54.1 (92)	26.7 (35)	p<0.001
1	23.5 (112)	22.5 (39)	20.6 (35)	28.2 (37)	
2	12.8 (61)	8.7 (15)	12.4 (21)	18.3 (24)	
3	8.0 (38)	2.9 (5)	8.7 (15)	13.7 (18)	
>3	5.9 (28)	2.3 (4)	4.1 (7)	13.0 (17)	

¹ Women with missing values for ever having received a diagnosis were excluded from frequency tabulations.

² Most common 'other' diagnoses were ovulation (n=15), uterine/vaginal prolapse (n=7), pelvic congestion (n=3), and retroverted uterus (n=2).

Table 6.10. Diagnoses received by whether or not an investigation had been made: all CPP cases.

	Ever had any investigation	
	no (n=319)	yes (n=162)
Ever received diagnosis [% (n)]	30.6 (96)	87.6 (141)
Type: IBS	9.2 (29)	40.4 (65)
Stress	5.4 (17)	17.4 (28)
Ovarian cysts	1.3 (4)	22.4 (36)
Endometriosis	1.9 (6)	18.0 (29)
Cystitis	4.1 (13)	13.0 (21)
PID	2.2 (7)	14.9 (24)
Constipation	5.7 (18)	8.1 (13)
Back pain/problems	1.9 (6)	13.0 (21)
Uterine fibroids	1.6 (5)	11.8 (19)
Adhesions	1.3 (4)	11.2 (18)
Appendicitis	1.3 (4)	5.0 (8)
Inflammatory bowel dis.	0.6 (2)	5.0 (8)
Other	10.2 (32)	17.9 (29)
Number of diagnoses received		
[% (n)]		
0	69.4 (218)	12.4 (20)
1	18.5 (58)	32.9 (53)
2	8.0 (25)	21.7 (35)
3	2.5 (8)	18.6 (30)
>3	1.6 (5)	14.3 (23)

Table 6.11. Different types of investigation by diagnosis received: all CPP cases.

	number of CPP cases	% (n) reporting any investigation	% (n) reporting ‘appropriate’ ¹ investigation	% (n) reporting laparoscopy/ laparotomy
Type of diagnosis received				
Ovarian cysts	40	90.0 (36)	87.5 (35)	45.0 (18)
Endometriosis	35	82.9 (29)	80.0 (28)	57.1 (20)
Adhesions	22	81.8 (18)	77.3 (17)	63.6 (14)
Inflammatory bowel dis.	10	80.0 (8)	80.0 (8)	20.0 (2) ²
Uterine fibroids	24	79.2 (19)	79.2 (19)	25.0 (6)
Back pain/problems	27	77.8 (21)	74.1 (20)	29.6 (8)
PID	31	77.4 (24)	67.7 (21)	29.0 (9)
IBS	96	69.1 (65)	62.8 (59)	21.9 (21)
Appendicitis	12	66.7 (8)	50.0 (6)	16.9 (2)
Cystitis	34	61.8 (21)	50.0 (17)	14.7 (5)
Stress	46	62.2 (28)	51.1 (23)	15.2 (7)
Constipation	31	41.9 (13)	38.7 (12)	12.9 (4)
Other	61	47.5 (29)	42.6 (26)	18.0 (11)

¹ Investigations considered appropriate for CPP: ultrasound scan, x-ray, laparoscopy, laparotomy, MRI scan, sigmoidoscopy/colonoscopy, and cystoscopy.

² Out of the 10 women with an inflammatory bowel diagnosis, 5 had had a sigmoidoscopy/colonoscopy (the appropriate type of investigation for inflammatory bowel conditions).

reliably be established through laparoscopy or laparotomy, i.e. endometriosis and adhesions, indeed had the highest frequency of these investigations (57% and 64%, respectively).

6.3.2.7 Hysterectomy

Out of all CPP cases, 25 (5.3%) reported having had a hysterectomy, a proportion that was virtually identical to that reported by controls without CPP (5.2%: $\chi^2_{df=1}$: $p=0.9$). The percentage of women who had undergone hysterectomy increased significantly from 2.3% in the 'short' duration CPP group to 5.3% in the 'intermediate' group, and 9.2% in the 'long' duration group ($\chi^2_{df=1}$: $p=0.03$). However, numbers were small: after adjusting for age, the trend became non-significant ($\chi^2_{df=1}$: $p=0.06$).

6.4 Discussion

In this study, the suggestion of a high prevalence of CPP in the community was confirmed. Defined according to standard clinical practice as pelvic pain not related to periods or intercourse, lasting for at least six months, the prevalence of CPP in the last 3 months was 24.0% (95% CI: 22.1-25.8). This figure is substantially higher than the single community-based estimate of 14.7% (95% CI: 13.7-15.7) reported previously by Mathias *et al.* (1996) in the USA. This can be explained by the fact that they excluded women with ovulation pain only from the CPP cases. In our study, such an exclusion would have reduced the estimated prevalence to a more similar figure of 16.9% (95% CI: 15.3-18.6), which might have been reduced still further, had not a third of CPP cases been unable to say whether or not their pain was related to ovulation.

If the pelvic pain contacts of the CPP cases seeking medical advice in the last 12 months (24%) had been recorded on a GP database, this would have translated into a 'primary care prevalence' of 5.7% (95% CI: 4.7-6.7). This figure was higher than the annual prevalence of

3.7% (95% CI: 3.6-3.8) found in MediPlus for women aged 18-50 (see section 3.3.1).

However, this would be expected, because of the differences in CPP definition (the MediPlus definition was more restricted in requiring at least 2 contacts with general practice in a year).

The prevalence rate found for dysmenorrhoea (74% in the last 12 months and 64% in the last 3 months) was high, with 50% of women with dysmenorrhoea reporting having it usually or always with their periods. Direct comparisons with other studies investigating the prevalence of dysmenorrhoea are difficult due to differences in definitions used, but the prevalence was consistent with the high rates varying from 45-96% reported in studies within and outside the UK (see chapter 1).

The prevalence of dyspareunia in sexually active women was 27% for the last 12 months and 21% for the last 3 months. The majority of women with dyspareunia (70%) reported having had the pain occasionally with intercourse. Again, comparison with other studies is difficult due to differences in definitions used (Meana & Binik, 1994). The only community-based study in the UK (Osborn *et al.*, 1988) reported a much lower dyspareunia prevalence of 8%, but their definition of 'operational dyspareunia' was much more restricted than the one used here ³⁷. Considerably higher prevalence rates of dyspareunia have been found in community-based studies outside the UK. Amongst 313 US women in their 30s, the prevalence of dyspareunia (pain or discomfort in the labial, vaginal, or pelvic area during or after intercourse) was 34% (76% of whom reported occasional pain) (Glatt *et al.*, 1990). Jamieson & Steege (1996) reported a dyspareunia prevalence of 45% (sometimes, often, or always) in 18-45 yr old American women approached in clinic waiting areas.

Prevalence rates of dysmenorrhoea and dyspareunia in the last 12 months were substantially higher amongst CPP cases (90% and 50%, respectively) than amongst women without CPP (67% and 19%, respectively). In addition, 39% of CPP cases had IBS according

³⁷ 'Operational dyspareunia' was defined as pain or discomfort causing difficulties during sexual intercourse more than half the time during the previous three months (see Chapter 1).

to the Rome criteria (Thompson *et al.*, 1992) and 24% had genito-urinary symptoms associated with their pain. As described in Chapter 1, there are no data in the UK on the overlap of CPP with other symptoms that can be used for comparison. In the USA, Mathias *et al.* (1996) reported a very high prevalence of dyspareunia in the last month (82%) amongst women with CPP. Another, hospital based, study in the USA of 651 women with CPP reported that 43% of women with CPP had also experienced dyspareunia, 39% 'excessive' dysmenorrhoea, and 79% met the criteria of probable IBS (Walker *et al.*, 1991).

The total duration of CPP, measured as time since first occurrence of symptoms, was long. The majority of CPP cases (80%) reported that their pain started more than one year ago, with a third of cases stating that their pain started more than 5 years ago.

In general, CPP cases had higher levels of pain severity and pelvic pain-related health care use compared with dysmenorrhoea controls, but not compared with dyspareunia controls³⁸. Severity of dysmenorrhoea was somewhat greater in CPP cases than controls with dysmenorrhoea alone, while no difference was observed in severity of dyspareunia compared with dyspareunia controls. Higher proportions of CPP cases had consulted a GP (31%), specialist (12%) or alternative therapist (8%) for pelvic pain in the last year compared with dysmenorrhoea controls (12%, 4%, and 2%, respectively) but not compared with dyspareunia controls (34%, 13%, and 4%, respectively). These results suggest that the dyspareunia controls (most of whom also had dysmenorrhoea) were affected by pelvic pain to a greater extent than the dysmenorrhoea controls.

The use of medication (OTC drugs in particular) was common in all women with any type of pelvic pain: 76% of CPP cases used medication for pelvic pain, as did 73% of dysmenorrhoea and 70% of dyspareunia controls. Non-medical treatments (most commonly

³⁸ It was not possible to make a useful comparison between absolute pain scores of CPP cases with those reported elsewhere for other conditions: studies that used the same pain assessment instruments differed widely in terms of the point in time at which pain was assessed (measuring e.g. 'present' rather than 'typical' intensity) and the extent of recall.

the application of heat to the abdominal area) were used by 17% of CPP cases, a frequency that did not differ greatly from the dysmenorrhoea (10%) and dyspareunia controls (11%).

Half of the women with CPP reported having received a diagnosis from a GP or a specialist (with a quarter reporting more than 1 diagnosis), but only 1/3 reported ever undergoing an investigation. IBS was by far the most commonly reported diagnosis, with 20% of cases having received it. Strikingly, the second most common diagnosis was stress (10%). In addition, for women who reported having had an investigation, the most common other diagnoses were ovarian cysts, endometriosis and PID, whereas for those who had not had an investigation, the most common other diagnoses were constipation and cystitis. It should be noted that these diagnoses were not validated by information from GPs or specialists, and that they were based only on the woman's recall. Comparison between these results of 'life-time' recalled diagnoses and diagnoses recorded in the 3.5 year follow-up of incident CPP cases in MediPlus is difficult. Both analyses, however, are consistent in that the most frequently recorded diagnosis in women aged 18-50 was IBS.

Differences in pain severity and health care use were investigated between CPP cases grouped according to their 'pelvic pain burden', in terms of cumulative duration of symptoms in the last year. This classification of cumulative duration - 'short' (<24 hours), 'intermediate' (25 hrs – 1 week), and 'long' duration (>1 week) - was an arbitrary distinction based on approximate tertiles of duration and should not be interpreted as having a particular clinical relevance. Women in the 'short' duration group mainly reported CPP episodes lasting an hour or less, whereas the women in the 'long' duration group mainly reported episodes lasting more than one day. However, the groups did not differ in their total CPP duration in terms of time since first occurrence of symptoms.

Pain severity rose significantly from 'short' to 'long' duration cases. A strong trend was also found in health care use in the previous year: the percentage of women consulting a GP rose from 17% to 51%, a specialist from 6% to 19%, and an alternative therapist from 2% to

18%. Medication use rose from 60% to 87% and use of other treatments from 12% to 21%. On the whole, the severity of pelvic pain and use of health care in women in the 'short' duration category was very similar to that reported by women in the dysmenorrhoea control group.

Consistent with the results of health care use, frequencies of life-time investigations, diagnoses and procedures varied greatly between CPP cases. Women in the 'long' duration group were twice as likely, compared with the 'short' duration group, to have undergone an investigation (48% vs. 23%) or to have received a diagnosis (73% vs. 36%). They were also more likely to have received more than one diagnosis (45% vs. 14%). Furthermore, they were four times more likely to have had a laparoscopy (17% vs. 5%) or a hysterectomy (9% vs. 2%).

These results suggest that there is a wide variation in the extent to which women are affected by their CPP symptoms, in terms of relative duration, severity, and need for treatment, starting from 'base-line values' similar to women with dysmenorrhoea alone. This does not mean to say that the effect that dysmenorrhoea may have on women should be regarded as 'acceptable' or 'normal', only that a substantial number of CPP cases may perceive their CPP symptoms as no greater a burden than having dysmenorrhoea.

In summary, it was shown in this chapter that the prevalence of CPP in women aged 18-50 in the community is high. However, there appear to be large variations in pain severity and associated health care use within CPP cases. This could suggest either that some women with CPP are much more affected than others, or that some are better able to cope with their pain, or both. These issues are further explored in the next chapter, by comparing measures of functioning and well-being between CPP cases and controls.

Chapter 7

CPP and associated functioning and well-being

7.1 Introduction

In the previous chapter, it was shown that CPP is highly prevalent amongst women aged 18-50 in the community. However, large variations in pain severity and associated use of health care were observed when CPP cases were grouped according to their relative ‘disease burden’ in terms of cumulative duration of pelvic pain in the past year. In this chapter, women with CPP are investigated with regard to various aspects of their functioning and well-being, and differences between case groups are further explored.

7.2 Methods

7.2.1 The study group, CPP cases and controls

The study group used for the analyses has been described in detail in the previous chapter (section 6.2.1). It consisted of 2,042 women who were not pregnant in the last 12 months and who completed the questionnaire adequately.

As before, a CPP case was defined as a woman with CPP in the last 3 months (see section 6.2.4.1). Of all women in the study group, 483 were CPP cases. The remaining women were grouped into three control groups: group I, consisting of 673 women who had no pelvic pain in the last 3 months ³⁹; group II, consisting of 660 women who had dysmenorrhoea only; and group III, consisting of 186 women who had dyspareunia with or without dysmenorrhoea ⁴⁰. A total of 40 women could not be classified as CPP cases or controls due to missing values.

³⁹ Note that control group I is defined differently here from control group I in Chapter 6, which included all women without CPP irrespective of whether or not they had dysmenorrhoea or dyspareunia in the last 3 months. Control groups II and III are the same as in Chapter 6.

⁴⁰ As described before, 149 (80%) of women with dyspareunia also had dysmenorrhoea.

CPP cases were grouped according to level of ‘disease burden’, in terms of cumulative duration of pelvic pain in the last 12 months (see section 6.2.4.1). Categories of cumulative duration were formed according to approximate tertiles: up to 24 hours (‘short’: n=174); 25-168 hours (‘intermediate’: n=173); >168 hours (‘long’: n=133). Three CPP cases had missing values for duration of pelvic pain and could not be classified.

7.2.2 Comorbidity assessment

Comorbidity (i.e. the percentage of women suffering from any chronic condition unrelated to pelvic pain) was compared between CPP cases and controls using information given by women in response to the question: *‘In the last 12 months, have you suffered from any serious or long-standing illnesses or disabilities? (either physical or psychological, e.g. diabetes, cancer, heart disease, depression)’*. Reported conditions were grouped into ‘physical’ (e.g. cancer, diabetes, asthma), ‘psychological’ (e.g. depression, psychological problems), and ‘psychiatric’ (e.g. schizophrenia, manic depression). Since psychological problems such as depression may be related to CPP (see Chapter 1), comorbidity was assessed including all reported conditions, and physical/psychiatric conditions only.

7.2.3 Outcomes of functioning and well-being

7.2.3.1 The Short-Form 36 Health Survey (SF-36)

The SF-36 is a generic health status measure, originally developed in the USA from long-form questionnaires used in the RAND Health Insurance Experiment and Medical Outcomes Study (Jenkinson *et al.*, 1996a; Ware & Sherbourne, 1992). The anglicised version used here has been well-validated and shown to have high levels of reliability and validity (Brazier *et al.*, 1992; Jenkinson *et al.*, 1993). The instrument contains 36 items, together comprising eight multi-item dimensions of health status relating to the previous four weeks (physical

functioning, role limitations due to physical problems, role limitations due to emotional problems, social functioning, mental health, energy/vitality, bodily pain, and general health perception), and a single item relating to change in health over the past year. For each dimension, items are scored, summed, and transformed onto a scale from 0 (worst health) to 100 (best health) (Jenkinson *et al.*, 1996a).

Two summary scores can be derived from the eight dimensions: the Physical Component Summary (PCS) score and the Mental Component Summary (MCS) score. In calculating the PCS and MCS scores, they are standardised to a general population sample (thus facilitating comparison of results across studies). Firstly, the dimension scores for each individual are standardised into z-scores, using means and standard deviations (SD) from the normative population ⁴¹. These z-scores are multiplied by the factor score coefficient for each dimension (which are derived from a higher order factor analysis for the 8 domains of the SF-36 of the normative data), and summed to derive aggregate z-scores for the MCS and PCS separately ⁴². Lastly - for ease of interpretation - these aggregate scores are standardised to T-scores ⁴³, relative to a normative population mean of 50 and an SD of 10 (Jenkinson *et al.*, 1996a). The normative population used to calculate PCS and MCS scores consisted of 9,332 men and women aged 18-64 who participated in the Oxfordshire Healthy Life Survey (OHLS). The sample used in the OHLS had been randomly selected from the Health Authority registers of Berkshire, Buckinghamshire, Northamptonshire, and Oxfordshire.

⁴¹ Calculation of individual z-scores for each dimension i :

$$z_i = \frac{x_i - \bar{x}_i}{SD_i} \quad \text{where } \begin{array}{ll} x_i & = \text{dimension score for an individual,} \\ \bar{x}_i & = \text{mean dimension score in the normative population, and} \\ SD_i & = \text{the standard deviation of the score in the normative population} \end{array}$$

⁴² Calculation of individual aggregate z-scores for the PCS and MCS:

$$z_{ag} = \sum_{i=8} (z_i * f_{ci}) \quad \text{where } \begin{array}{ll} z_i & = \text{individual z-score for dimension } i, \\ f_{ci} & = \text{factor score coefficient for dimension } i, \end{array}$$

⁴³ Calculation of individual T-scores for the PCS and MCS:

$$T = \bar{x}' + SD' * z_{ag} \quad \text{where } \begin{array}{ll} \bar{x}' & = \text{the new mean for the normative population, i.e. 50} \\ SD' & = \text{the new standard deviation for the normative population, i.e. 10} \\ z_{ag} & = \text{the aggregate z-score for the PCS or MCS} \end{array}$$

To determine comparability between the study group and the OHLS data, mean dimension and summary scores for the study group (n=2,042) were first compared with those of women aged 18-50 in the OHLS (n=3,980) (C. Jenkinson, personal communication). Subsequently, health status of CPP cases in the study was assessed by comparing 1) mean dimension and summary scores with those of controls, 2) mean dimension and summary scores with those of other patient groups identified in the OHLS, and 3) the distribution of scores with that of the normative OHLS data.

The patient groups used for comparison with CPP cases consisted of women reporting a chronic bowel condition (n=62) or back pain (n=171) in the OHLS ⁴⁴. To avoid potential bias due to differences in comorbidity, women reporting any additional chronic illness were excluded from CPP cases and the OHLS patient groups. This resulted in the exclusion of 102 CPP cases (21% of 483). Two-thirds of these women had reported depression or other 'psychological problems' as a chronic illness, problems that may be related to CPP itself. Exclusion limited to women reporting physical or psychiatric problems only (n=36), however, did not materially alter the results.

Although comparison of mean SF-36 scores provides a useful impression of differences in average health status, it does not allow for detection of differences that may exist between groups in score distributions (which are not normal). The distribution of summary scores, in terms of median values with interquartile (IQ) ranges and the proportion of women scoring less than 50, was therefore compared between CPP cases and published normative OHLS data for women aged 18-64 (Jenkinson, 1998).

⁴⁴ Women were identified in the OHLS through the question '*do you have any longstanding or chronic illness?*'. Chronic bowel conditions included inflammatory bowel disorders (e.g. Crohn's disease) and IBS.

7.2.3.2 Sleep and work characteristics

The SF-36 does not contain a dimension that taps sleep. Sleep characteristics relating to the last 4 weeks were therefore assessed separately, comparing CPP cases with the three control groups. For each woman, the 'lack of sleep' in number of hours each night was calculated by subtracting the reported average number of hours sleep *received* each night from the reported number of hours sleep *required*. The other sleep characteristics investigated were: 1) difficulty falling asleep, 2) waking up more than once at night, and 3) waking up feeling tired or not rested (non-regenerative sleep). These variables have also been used by others as indicators of sleep quality (Nolan *et al.*, 1992; David *et al.*, 1994).

For women who had been employed in the previous 12 months, absence from work was compared between CPP cases and controls. General and pelvic pain-specific absence was assessed as the number of days taken off work in the last year (in broadly defined categories).

7.2.3.3 Additional information

Women with any type of pelvic pain were asked two open-ended questions relating to their pain experience: 1) '*Does your pelvic pain affect what you can or cannot do?*', and 2) '*What troubles you most about the pelvic pain?*'. General themes derived from the given answers were compared between CPP cases and control groups II and III.

Theme derivation was performed following recommended methods for qualitative data analysis (Moser & Kalton, 1996a). This involved detailed coding of individual items mentioned in response to the questions, followed by grouping of these codes into common themes. The themes indicating limitations due to pelvic pain were: 1) inability to do anything unless taking rest or analgesics; 2) general lack of energy/feeling lethargic or tired; 3) work activities (including house work); 4) exercise; 5) general mobility (moving around/walking); 6) posture (standing/sitting); 7) concentration; 8) sleep; 9) social activities; 10) sexual

intercourse; and 11) cannot have certain foods or drinks. Limitations that could not be grouped under these themes, and that occurred with a frequency of less than 0.5%, were grouped under 'other limitations'.

The themes indicating aspects of pelvic pain that women reported they were most troubled by, were: 1) the pain itself (e.g. its nature and severity); 2) associated symptoms (e.g. gastrointestinal or genitourinary symptoms) 3) limitations caused by the pain; 4) lack of control over the pain (e.g. its inevitability, inability to predict its occurrence); 5) worries about it (e.g. its cause, long-term damage or infertility, possible future procedures); 6) its effect on mood (e.g. irritability, feelings of depression); and 7) interaction with environment (e.g. feelings of guilt/embarrassment towards others, lack of understanding from significant others and GP). Aspects that could not be grouped under these themes, and that occurred with a frequency of less than 0.5%, were grouped under 'other aspects'.

7.2.4 Statistical methods

7.2.4.1 Missing values

Missing values for a variable were excluded from analyses involving that variable. For the majority of variables, the frequency of missing values was only 1-2%; if the frequency of missing values exceeded 5%, this was noted in the tables. Frequencies of missing values for the individual dimensions of the SF-36 never exceeded 5%. However, 11.6% of all women had one or more missing values for any dimension ⁴⁵, which resulted in missing values for the PCS and MCS. Following recommendations (Jenkinson *et al.*, 1996a), missing values were not imputed for these women.

⁴⁵ Most of these women (7.6% in total) only had missing values for one or two items.

7.2.4.2 Methods of analysis

Comparisons between proportions were made using the Pearson chi-squared test. Trends in proportions were assessed for statistical significance using the Mantel-Haenszel chi-squared test for trend. Differences in means between two groups were assessed using the t-test; differences between means of more than two groups were assessed using analysis of variance (ANOVA).

Although SF-36 scores were not normally distributed (they were negatively skewed), group sizes were sufficiently large to allow for parametric testing of differences in scores between groups. To check this, analyses were repeated using non-parametric tests, which produced virtually identical results.

As an indication of the size of the observed differences in mean SF-36 scores, 'effect sizes' were calculated comparing CPP cases with control group I (the 'healthiest' controls: women without pelvic pain in the last 3 months). Effect sizes are most commonly used as measures of change in health status after an intervention. Here, however, an effect size should be interpreted as the improvement in health status that could be achieved if an intervention were able to bring CPP cases to the level of the most healthy controls. This procedure has been adopted elsewhere (Ziebland, 1995; Jenkinson *et al.*, 1996b). For each dimension and summary score, effect sizes were calculated by dividing the difference in mean scores between cases and controls by the SD of the score for cases. An effect size of 1.0 corresponded to a difference of 1 SD. Effect sizes of 0.20 are commonly regarded as small, 0.50 as moderate, and 0.80 as large (Cohen, 1977; Jenkinson *et al.*, 1994).

All analyses were performed using SPSS version 8.0 (1998).

7.3 Results

7.3.1 Demographic characteristics of CPP cases and controls

In section 6.3.2.1 of the previous chapter, the demographic characteristics of CPP cases were compared with dysmenorrhoea (group II) and dyspareunia controls (group III). Cases were significantly older (mean age: 35.4 yrs) compared with group II (33.7 yrs) and group III (30.5 yrs). Compared with the control group of women without any pelvic pain introduced here, however, they were somewhat younger (group I: 36.9 yrs; $p < 0.01$).

CPP cases included a higher proportion of Caucasian women (98.3%) compared with group I (95.5%), group II (95.3%) and group III (93.5%), but numbers of non-Caucasian women were small. No differences were observed between cases and controls in terms of social class distribution, employment status, or marital status.

Differences between CPP cases according to cumulative duration were also described previously: those of 'short' cumulative duration were younger (mean age: 33.4 yrs) compared with cases of 'intermediate' duration (36.2 yrs) and of 'long' duration (36.9 yrs); they were also more likely to be single.

7.3.2 Comorbidity

A significantly higher proportion of CPP cases reported having another chronic illness (21%) compared with pelvic pain-free (group I) controls (13%; $p < 0.001$), and with dysmenorrhoea (group II) controls (13%; $p < 0.001$), but not compared with dyspareunia (group III) controls (18%; $p = 0.6$). Women with 'short', 'intermediate', and 'long' CPP duration had equally high comorbidity rates (20%, 19%, and 25% respectively; $p = 0.4$). The high rates for CPP cases and dyspareunia controls were mainly due to women in these groups reporting depression or 'other psychological problems' as an additional chronic illness. When limited to physical or psychiatric conditions only, comorbidity rates were

reduced to 8% in CPP cases, compared with 5% in pain-free controls ($p=0.03$), 4% in dysmenorrhoea controls ($p=0.009$), and 7% in dyspareunia controls ($p=0.4$). The rates were again similar in the three CPP case groups (8%, 8%, and 6%; $p=0.8$).

7.3.3 The SF-36

7.3.3.1 SF-36 scores in the study group compared with normative data

Table 7.1 shows the mean scores on the eight dimensions of the SF-36 for the whole study group, together with the PCS and MCS scores. In general, scores were very similar to the OHLS data for women aged 18-50, suggesting that the study group was representative of the general population not only in terms of age and social class distribution (as shown in Chapter 5).

7.3.3.2 SF-36 scores in CPP cases compared with controls

The SF-36 dimension and summary scores for CPP cases compared with the three control groups are shown in Table 7.2. It should be noted that the results presented here are not influenced by variations in comorbidity between the groups described previously: exclusion of women reporting any other chronic illness from the analyses slightly increased absolute scores, but did not alter the differences observed between the groups.

CPP cases scored significantly lower on all dimensions compared with controls without pelvic pain (group I) and dysmenorrhoea controls (group II). However, differences were only small to moderate on most dimensions. Comparing CPP cases with the 'healthiest' controls (group I), the only large effect size found was for pain (0.76). Moderate effect sizes were observed for energy (0.52), mental health (0.49), general health perception (0.47), and role limitations due to emotional problems (0.43), whereas effect sizes for physical function, role limitations due to physical function, and social function were small (<0.40).

Table 7.1. Mean (SD) dimension and summary scores of the SF-36 in the total study group of 2,042 women compared with normative data for women aged 18-50 from the Oxfordshire Healthy Lifestyle Survey (OHLS).

Dimension	Study group (n=2,042)		OHLS normative data for women aged 18-50 (n=3,980)	
	n (%)	Mean (SD)	n (%)	Mean (SD)
Physical functioning	1,954 (95.7)	91.0 (15.3)	3,768 (94.7)	90.2 (15.7)
Role limitations due to physical problems	1,998 (97.8)	86.6 (28.6)	3,842 (96.5)	85.6 (29.9)
Role limitations due to emotional problems	1,997 (97.8)	77.6 (34.4)	3,843 (96.6)	80.1 (33.7)
Social functioning	1,986 (97.3)	85.6 (20.1)	3,849 (96.7)	86.6 (19.8)
Mental health	1,999 (97.9)	69.8 (17.2)	3,792 (95.3)	71.4 (17.7)
Energy	2,001 (98.0)	56.7 (19.9)	3,803 (95.6)	58.6 (19.8)
Pain	2,013 (98.6)	77.6 (21.7)	3,803 (95.6)	80.5 (21.6)
Health Perception	1,974 (96.7)	73.2 (18.8)	3,802 (95.5)	74.6 (19.7)
Physical component summary (PCS)	1,806 (88.4)	50.5 (9.6)	3,500 (87.9)	50.5 (9.7)
Mental component summary (MCS)	1,806 (88.4)	47.3 (10.7)	3,500 (87.9)	48.5 (10.6)

Table 7.2. Mean (SD) dimension and summary scores of the SF-36: CPP cases compared with control groups I, II, and III ¹.

Dimension	No CPP (in last 3 months) ²					CPP (in last 3 months)				Test for trend (short-long)
	Group I: No pelvic pain (n=673)	Group II: Dysmenorrhoea only (n=660)	Group III: Dyspareunia (+/- dysmenorrhoea) (n=186)	All cases (n=483)		'short' (n=174)	'intermediate' (n=173)	'long' (n=133)		
Physical functioning	91.8 (15.3) [‡]	92.4 (14.2) [‡]	91.3 (15.1) *	88.4 (16.3)		89.0 (16.0)	90.7 (13.5)	84.8 (19.1)		p=0.03
Role limitations due to physical problems	89.6 (25.9) [‡]	88.9 (26.5) [‡]	82.4 (30.4)	81.8 (32.4)		87.4 (27.8)	83.8 (30.3)	72.5 (37.6)		p<0.001
Role limitations due to emotional problems	84.7 (30.2) [‡]	78.6 (34.1) [‡]	72.9 (36.6)	68.9 (37.0)		71.4 (35.8)	71.0 (36.8)	63.6 (38.4)		p=0.07
Social functioning	89.2 (18.3) [‡]	87.2 (17.7) [‡]	82.1 (21.6)	80.5 (22.7)		84.0 (19.7)	82.5 (22.3)	74.0 (25.0)		p<0.001
Mental health	74.1 (16.5) [‡]	70.3 (16.5) [‡]	66.7 (16.7)	65.3 (17.8)		66.4 (17.0)	67.7 (17.7)	61.2 (18.1)		p=0.01
Energy	60.9 (19.9) [‡]	58.5 (18.3) [‡]	53.2 (18.8)	50.3 (20.3)		52.3 (18.8)	53.0 (19.7)	44.5 (21.6)		p=0.001
Pain	84.5 (19.9) [‡]	78.6 (20.2) [‡]	73.2 (21.7) *	69.4 (22.4)		74.6 (21.9)	69.8 (21.0)	62.1 (22.6)		p<0.001
Health Perception	77.3 (17.3) [‡]	75.3 (17.1) [‡]	69.1 (19.8)	67.8 (20.2)		69.4 (19.2)	71.7 (16.8)	61.4 (23.4)		p<0.001
Number with complete data	n=584	n=589	n=166	n=434		n=154	n=158	n=119		
PCS	51.8 (8.9) [‡]	51.3 (8.5) [‡]	49.5 (9.6)	48.2 (11.0)		50.0 (10.3)	49.3 (9.5)	44.7 (12.8)		p<0.001
MCS	49.8 (9.7) [‡]	47.7 (10.1) [‡]	45.5 (11.0)	44.4 (11.5)		45.3 (10.9)	45.4 (12.1)	42.3 (11.2)		p=0.03

¹ The number of women used for the calculation of the mean dimension scores varied due to missing values, but the percentage of missing values never exceeded 5%.

² Comparisons of CPP cases with control groups: * p<0.05; [‡] p<0.01; [‡] p<0.001

CPP cases were similar to dyspareunia controls (group III) in terms of health status: those scores that were lower in CPP cases (physical functioning and pain) translated into small effect sizes only (<0.20). No differences were found between CPP cases and any of the control groups for the separate (unscored) item asking for change in health over the past year. The majority of cases and controls (69-75%) reported that their health was much the same as one year ago.

Consistent with the results for the dimension scores, analysis of the PCS and MCS only showed significant differences for CPP cases compared with pelvic pain-free (group I) or dysmenorrhoea (group II) controls, but not compared with dyspareunia controls (group III). Effect sizes calculated for CPP cases compared with control group I were small for the PCS (0.33) and moderate for the MCS (0.47).

Although the differences in scores between CPP cases and controls were not large, greater differences were observed when comparing CPP cases of increasing cumulative duration. All dimension and summary scores decreased significantly with increasing cumulative duration of CPP, with the exception of role limitations due to emotional problems. These trends were mainly caused by lower scores in the 'long' duration group. Effect sizes in this group, compared with control group I, were all moderate to large: 0.99 for pain; 0.76 for energy; 0.71 for mental health; 0.68 for general health perception; 0.61 for social function; 0.55 for role limitations due to emotional health; 0.45 for role limitations due to physical problems; 0.37 for physical function; 0.55 for the PCS; and 0.67 for the MCS. Effect sizes for the 'short' duration group compared with control group I were, however, small for all dimensions apart from mental health (0.45), energy (0.46), pain (0.45), and general health perception (0.41), resulting in a small effect size for the PCS (0.17) but a moderate effect size for the MCS (0.41).

Health status was also compared between CPP cases who visited a GP or a specialist in the last 12 months compared with those who did not (not shown). In Chapter 6, it was found

that typical CPP severity differed substantially between these two groups, with moderate/severe pain reported by 76.5% in consulters vs. 43.1% in non-consulters.

Consistent with these findings, consulters scored significantly lower on all dimensions of the SF-36, with the largest effect sizes (compared with control group I) found for pain (0.72) and general health perception (0.66), and the lowest for mental health (0.28) and role limitations due to emotional problems (0.23). The mean PCS score was significantly lower ($p<0.001$) in consulters compared with non-consulters (42.4 vs. 50.1), but there was no significant difference between mean MCS scores (42.7 vs. 44.9).

Lastly, mean dimension and summary scores of the 380 CPP cases who reported no other chronic illness (see section 7.2.2.1) were compared with OHLS data for women with a chronic bowel condition ($n=62$) or back pain ($n=171$) (not shown). CPP cases had a mean PCS score (49.5) that was higher (i.e. better) compared to women with back pain (44.8; $p<0.001$). Their mean MCS score (45.7), however, was much lower than in women with back pain (52.1; $p<0.001$). Compared with women with a bowel condition, CPP cases had a similar PCS score (49.5 vs. 48.6; $p=0.4$), but also a slightly lower MCS score (44.8 vs. 49.0; $p=0.03$).

7.3.3.3 Distribution of scores in CPP cases

In the previous section, the mean summary scores of CPP cases were compared with those of other women. Table 7.3 provides a better insight in the distribution of these scores, by showing the median PCS and MCS scores and IQ ranges, and the proportions scoring less than 50, for the total study group and CPP cases.

The distribution of scores for the study group corresponded well to the normative OHLS distribution for women aged 18-64 (not shown), although MCS scores were slightly lower

Table 7.3. Median PCS and MSC scores (IQ ranges) and percentages scoring less than 50 for women in the total study group and CPP cases, compared with OHLS normative data for 18-64 yr old women.

		CPP cases (in last 3 months)					
		OHLS normative data (n=5,103)	Total study group (n=2,042)	All cases (n=483)	‘short’ (n=174)	‘intermediate’ (n=173)	‘long’ (n=133)
Number of women with complete SF-36 data		n=4,448	n=1,806	n=434	n=154	n=158	n=119
Median (IQ range)							
	PCS	52.7 (45.9-56.1)	53.2 (47.6-56.4)	51.4 (44.0-55.5)	52.9 (46.8-56.8)	51.4 (45.3-55.3)	49.5 (37.1-54.4)
	MCS	52.6 (44.3-56.7)	50.8 (40.8-55.4)	47.6 (34.9-54.2)	49.1 (36.6-54.2)	50.1 (37.0-54.7)	43.1 (32.5-52.3)
% scoring <50							
	PCS	36.7	32.9	43.5	35.1	42.4	56.3
	MCS	39.3	47.1	56.7	54.5	49.4	68.1

than expected ⁴⁶. CPP cases had median, lower quartile, and upper quartile PCS scores that were also similar to normative values, cutting off the bottom 21%, 45%, and 70%, respectively, of the normative distribution. However, their MCS scores were lower than the norm: the lower quartile cut off the bottom 13%, the median the bottom 30%, and the upper quartile the bottom 60% of the normative distribution.

The 'long' duration CPP cases showed the greatest difference in distribution compared with the normative data: their lower quartile PCS score cut off the bottom 12% of the normative distribution, the median the bottom 35%, and the upper quartile the bottom 60%. Even more strikingly, the lower quartile MCS score of the 'long' duration group cut off the bottom 10% of the normative distribution, the median the bottom 23%, and the upper quartile the bottom 50%.

7.3.4 Sleep characteristics

In Table 7.4, sleep characteristics in the last 4 weeks are shown for CPP cases and controls. The mean lack of sleep per night was significantly higher in CPP cases (1.2 hrs) compared with pelvic pain-free controls (0.8 hrs) and dysmenorrhoea controls (1.0 hrs), but not compared with dyspareunia controls (1.2 hrs). This difference was due to a lower *received* number of hours of sleep reported by women with CPP and dyspareunia controls: the number of hours of sleep said to be *required* each night did not differ between cases and controls (with a mean of 8.0 hrs for all groups).

Higher proportions of CPP cases than pelvic pain-free and dysmenorrhoea controls reported difficulty in falling asleep often, usually, or always (24% vs. 12% and 15%); waking up more than once at night (54% vs. 36% and 42%); or waking up tired/not rested

⁴⁶ This result is not due to comparison with a slightly older normative population of 18-64 yr old women: a somewhat lower mean MCS score for the study group was also found when compared with OHLS data for women aged 18-50 (see Table 7.1). Indeed, women aged 50-64 tend to score equally high on the MCS compared to younger women (Jenkinson, 1998).

Table 7.4. Sleep characteristics in the last four weeks: CPP cases compared with control groups I, II, and III.

	No CPP (in last 3 months)			CPP (in last 3 months)			
	Group I: No pelvic pain (n=673)	Group II: Dysmenorrhoea only (n=660)	Group III: Dyspareunia (+/- dysmenorrhoea) (n=186)	All cases (n=483)	'short' (n=174)	'intermediate' (n=173)	'long' (n=133)
In the last 4 weeks							Test for trend (short-long)
Mean lack of sleep in hours (SD)	0.8 (1.1) [†]	1.0 (1.2) [†]	1.2 (1.3)	1.2 (1.2)	1.2 (1.1)	1.1 (1.1)	1.5 (1.4) p=0.02
Difficulty falling asleep [% (n)]							
never/occasionally often	87.7 (586) [†] 7.0 (47)	84.9 (558) [†] 9.0 (60)	74.1 (137) 15.1 (28)	76.0 (364) 13.8 (66)	82.7 (143) 11.6 (20)	76.2 (131) 15.7 (27)	67.2 (88) 13.7 (18)
usually/always	5.2 (35)	5.9 (39)	10.8 (20)	10.2 (49)	5.8 (10)	8.1 (14)	19.1 (25) p<0.001
Woken up more than once at night [% (n)]							
never/occasionally often	64.0 (427) [†] 14.4 (96)	58.4 (384) [†] 20.8 (137)	51.4 (95) 21.1 (39)	46.6 (223) 23.2 (111)	51.7 (89) 21.5 (37)	52.9 (91) 22.1 (38)	31.8 (42) 27.3 (36)
usually/always	21.6 (144)	20.8 (137)	27.6 (51)	30.3 (145)	26.7 (46)	25.0 (43)	40.9 (54) p=0.001
Woken up feeling tired/not rested [% (n)]							
never/occasionally often	62.9 (418) [†] 17.9 (119)	53.2 (349) [†] 25.5 (167)	38.7 (72) 27.4 (51)	38.1 (183) 27.3 (131)	41.6 (72) 28.3 (49)	41.9 (72) 27.3 (47)	29.5 (39) 25.0 (33)
usually/always	19.2 (128)	21.3 (140)	33.9 (63)	34.6 (166)	30.1 (52)	30.8 (53)	45.5 (60) p=0.008

Comparisons of CPP cases with control groups:

* p<0.05; [†] p<0.01; [‡] p<0.001

(62% vs. 37% and 47%). No such differences were observed between CPP cases and dyspareunia controls.

Amongst CPP cases, sleep quality worsened significantly with increasing cumulative CPP duration. In the ‘long’ duration group, the mean lack of sleep increased to 1.5 hrs (SD: 1.4), while a third reporting difficulty falling asleep often, usually, or always, and the majority (70%) reporting waking up at night or woken up tired/not rested. Sleep patterns in the ‘short’ duration group – although the least affected of CPP cases – tended to be more similar to dyspareunia controls than to pelvic pain-free or dysmenorrhoea controls.

7.3.5 Absence from work

Characteristics of absence from work in the previous 12 months for CPP cases and controls are summarised in Table 7.5. A slightly higher proportion of CPP cases than pelvic pain-free controls had been employed in that time period, but no difference was observed compared with the other control groups. Amongst employed women, there were no differences in mean number of hours worked between cases and controls.

CPP cases reported having taken more time off work due to any illness than pelvic pain-free and dysmenorrhoea controls (at least 3 days absence: 40% vs. 28% and 35%), but not compared with dyspareunia controls (44%). At least 1 day of pelvic pain-related absence was reported by 18% of CPP cases, a proportion greater than that reported by dysmenorrhoea controls (10%), but similar to dyspareunia controls (22%).

Absence due to any illness was equally common in the different CPP groups. However, rates of pelvic pain-related absence increased steeply with CPP duration, with women in the ‘long’ duration group again most affected: loss of at least one working day was reported by 9% of women in the ‘short’ duration group, 15% of those in the ‘intermediate’ group, but 33% of those in the ‘long’ duration group.

Table 7.5. Work characteristics in the last 12 months: CPP cases compared with control groups I, II, and III.

	No CPP (in last 3 months)			CPP (in last 3 months)				Test for trend (short-long)
	Group I: No pelvic pain (n=673)	Group II: Dysmenorrhoea only (n=660)	Group III: Dyspareunia (+/- dysmenorrhoea) (n=186)	All cases (n=483)	‘short’ (n=174)	‘intermediate’ (n=173)	‘long’ (n=133)	
In the last 12 months								
Employed [% (n)]	81.3 (547) [†]	84.5 (557)	85.5 (159)	86.7 (419)	89.7 (156)	89.0 (154)	79.7 (106)	p=0.02
<i>In employed women:</i>								
Mean number of hrs worked (SD)	31.9 (13.4)	33.0 (13.0)	32.4 (15.3)	33.0 (13.4)	33.5 (13.3)	32.9 (14.5)	32.5 (11.8)	p=0.5
Taken time off due to illness [% (n)]								
none/<1 day	50.7 (259) [‡]	43.6 (230) [*]	34.2 (51)	33.9 (131)	31.9 (46)	41.0 (57)	27.0 (27)	p=0.5
1-2 days	21.1 (108)	21.4 (113)	22.1 (33)	25.9 (100)	25.7 (37)	25.9 (36)	26.0 (26)	
3-5 days	15.3 (78)	19.7 (104)	22.8 (34)	19.9 (77)	21.5 (31)	18.0 (25)	21.0 (21)	
>5 days	12.9 (66)	15.2 (80)	20.8 (31)	20.2 (78)	20.8 (30)	15.1 (21)	26.0 (26)	
Taken time off due to pelvic pain [% (n)]								
none/<1 day	-	89.9 (488) [†]	77.8 (119)	82.3 (331)	91.3 (136)	84.8 (123)	66.7 (70)	p<0.001
1-2 days	-	5.0 (27)	13.1 (20)	9.5 (38)	4.0 (6)	11.0 (16)	15.2 (16)	
3-5 days	-	3.1 (17)	5.9 (9)	4.2 (17)	2.7 (4)	4.1 (6)	6.7 (7)	
>5 days	-	2.0 (11)	3.3 (5)	4.0 (16)	2.0 (3)	-	11.4 (12)	

Comparisons of CPP cases with control groups:

* p<0.05; [†] p<0.01; [‡] p<0.001

7.3.6 Limitations due to pelvic pain and most troublesome aspects of pelvic pain

Table 7.6 shows the proportion of CPP cases and dysmenorrhoea and dyspareunia controls who reported any limitations caused by their pelvic pain. Of all CPP cases, 42% reported that they were limited in some way by their pain. This proportion was significantly greater ($p<0.001$) than the 32% reporting limitations in women with dysmenorrhoea only, but identical to that found in women with dyspareunia. The most common limitations in cases as well as controls were of a general nature: inability to do anything without taking analgesics or rest, or a general lack of energy (both reported by approximately 9%). In addition, limitations in work activities, posture, general mobility, and sexual intercourse were each reported by approximately 6% of all CPP cases.

In the three CPP groups, the percentage of women reporting limitations varied greatly, from 29% in the 'short' duration group (similar to dysmenorrhoea controls) to 56% in the 'long' duration group. CPP cases of 'long' duration commonly reported inability to carry out normal activities without painkillers or rest (12%), limitations in work activities (11%), limitations in general mobility (9%), limitations in taking exercise (9%), and lack of energy (8%).

Table 7.7 shows the most troubling aspects of pelvic pain reported by women. Of all CPP cases, 73% reported at least one troubling aspect of their pain. This proportion was similar to that in dyspareunia controls (65%), but higher ($p<0.001$) than in dysmenorrhoea controls (48%). In both cases and controls, a similar proportion of women mentioned being troubled by the pain itself (19%), limitations caused by it (13-17%), and a feeling of lack of control over their pain (10-14%). However, CPP cases differed strikingly in that almost a third mentioned the worrying aspect of the pain (mainly its cause, as mentioned by 27%) compared with only 7% in dysmenorrhoea controls. A similarly high percentage of dyspareunia controls (23%) reported to be worried to some extent about the pain.

Table 7.6 Limitations due to pelvic pain: CPP cases and control groups II and III.

	No CPP (in last 3 months)		CPP (in last 3 months)				Test for trend (short-long)
	Group II: Dysmenorrhoea only (n=660)	Group III: Dyspareunia (+/- dysmenorrhoea) (n=186)	All cases (n=483)	‘short’ (n=174)	‘intermediate’ (n=173)	‘long’ (n=133)	
Reporting any limitation [% (n)]	31.7 (209) [‡]	41.9 (78)	42.2 (204)	29.3 (51)	43.9 (76)	56.4 (75)	p<0.001
Type of limitations [% (n)]							
Has less energy: feels lethargic/tired	8.6 (57)	4.8 (9)	8.1 (39)	4.6 (8)	11.0 (19)	8.3 (11)	
Cannot do anything: needs rest/painkillers	8.5 (56)	7.0 (13)	8.7 (42)	6.3 (11)	8.1 (14)	12.0 (16)	
Work activities (including housework)	6.2 (41)	8.1 (15)	6.6 (32)	2.3 (4)	7.5 (13)	11.3 (15)	
Exercise	4.5 (30)	5.4 (10)	4.8 (23)	1.7 (3)	4.6 (8)	9.0 (12)	
Posture: standing/sitting	3.3 (22)	5.4 (10)	6.8 (33)	8.6 (15)	5.2 (9)	6.8 (9)	
Concentration	2.6 (17)	3.2 (6)	1.9 (9)	1.1 (2)	2.9 (5)	1.5 (2)	
General mobility: moving/walking	2.4 (16)	5.4 (10)	6.4 (31)	5.2 (9)	5.2 (9)	9.0 (12)	
Sleep	2.0 (13)	2.7 (5)	1.7 (8)	-	2.3 (4)	3.0 (4)	
Social activities	1.5 (10)	1.6 (3)	1.9 (9)	0.6 (1)	2.9 (5)	2.3 (3)	
Sexual intercourse	0.2 (1)	8.1 (15)	6.2 (30)	6.3 (11)	5.8 (10)	6.8 (9)	
Cannot have certain foods/drinks	0.2 (1)	1.6 (3)	1.2 (6)	-	1.7 (3)	2.3 (3)	
Other	2.6 (17)	3.8 (7)	4.3 (21)	3.4 (6)	2.9 (5)	7.5 (10)	

Comparisons of CPP cases with control groups:

* p<0.05; [†] p<0.01; [‡] p<0.001

Table 7.7. Most troubling aspects of pelvic pain: CPP cases and control groups II and III.

	No CPP (in last 3 months)		CPP (in last 3 months)				Test for trend (short-long)
	Group II: Dysmenorrhoea only (n=660)	Group III: Dyspareunia (+/- dysmenorrhoea) (n=186)	All cases (n=483)	'short' (n=174)	'intermediate' (n=173)	'long' (n=133)	
Reporting any troubling aspect [% (n)]	48.5 (320) [‡]	65.1 (121)	72.7 (351)	66.7 (116)	68.8 (119)	85.0 (113)	p<0.001
Type [% (n)]							
The pain itself	19.2 (127)	19.4 (36)	19.5 (94)	24.7 (43)	15.6 (27)	18.0 (24)	
Limitations caused by it	12.7 (84)	16.7 (31)	13.0 (63)	6.9 (12)	13.3 (23)	21.1 (28)	
Lack of control over it	10.0 (66)	9.7 (18)	14.1 (68)	12.1 (21)	16.2 (28)	14.3 (19)	
Worries about it	6.5 (43)	22.6 (42)	30.8 (149)	29.9 (52)	25.4 (44)	37.6 (50)	
Associated symptoms	6.5 (43)	6.5 (12)	6.2 (30)	2.3 (4)	6.9 (12)	9.8 (13)	
Effect on mood	3.5 (23)	3.8 (7)	4.3 (21)	2.3 (4)	5.2 (9)	6.0 (8)	
Interaction with environment	0.9 (6)	1.6 (3)	3.3 (16)	2.9 (5)	2.9 (5)	3.8 (5)	
Other	2.0 (13)	1.1 (2)	1.7 (8)	0.6 (1)	1.2 (2)	3.8 (5)	

Comparisons of CPP cases with control groups:

* p<0.05; [†] p<0.01; [‡] p<0.001

Amongst CPP cases of different cumulative duration, the pain itself and lack of control over the pain were commonly mentioned, with women of longer duration more likely also to report the limitations imposed by the pain. Worries about the pain were very common in all three CPP groups, but the highest percentage reporting this aspect was found in the 'long' duration group (38%).

7.4 Discussion

This study assessed, for the first time, the functioning and well-being of women with CPP in the community. Using a generic health status measure, the SF-36, the health status of CPP cases was shown to be worse than that of women without pelvic pain or with dysmenorrhoea only, but similar to that of women with dyspareunia (most of whom also had dysmenorrhoea).

Overall, women with CPP were more characterised by lower mental component scores than by lower physical component scores. Indeed, while their median PCS score cut off the bottom 45% of the norm, their median MCS score cut off the bottom 30%. The lower mental scores for women with CPP were also notable when compared to women reporting chronic back pain in another community-based study, the OHLS. Whereas women with back pain appeared more affected in terms of their physical function scores than CPP cases, mental component scores were lower in CPP cases.

Health status as measured by the SF-36 varied substantially between CPP cases grouped according to their 'pelvic pain burden' in the last year. Those with a 'short' cumulative CPP duration were characterised by lower mental scores, but had physical scores similar to controls. Those in the 'long' duration group, however, were most affected, and scored low on physical as well as mental scales. Effect sizes for this group compared with pain-free controls were 0.55 for the PCS and 0.67 for the MCS, with median PCS and MCS values cutting off the bottom 35% and 25% of the norm, respectively.

The SF-36 results corresponded well to the qualitative information provided by women on limitations imposed by their pelvic pain and the most troubling aspects of that pain. The proportion of CPP cases reporting a pain-related limitation (42%) was only slightly higher than in women with dysmenorrhoea (32%), but increased from 29% in 'short' duration cases to 56% in 'long' duration cases. As many as 73% of CPP cases reported a troubling aspect of their pain, compared with 49% of women with dysmenorrhoea and 65% of women with dyspareunia. By far the most common aspect reported by CPP cases was worrying about the pain (31%), in particular its cause. The percentage reporting such anxiety was high in all three CPP groups (30%-38%).

It should be noted that the qualitative information obtained through the questionnaire was unprompted. Different frequencies of limitations and troubling aspects might have been found, had women been given a checklist of possible answers or had they been interviewed. Nevertheless, the results were similar to those of a qualitative study of 21 women with CPP, who were interviewed 12-18 months after a negative laparoscopy (Savidge *et al.*, 1999). Women in this study stated that their pain negatively affected many aspects of their lives, in particular their sex life, exercise, socialising, and (house)work activities. In addition, most women reported that they were worried about the pain (mainly its cause and possible long-term effects), and that this anxiety affected their mood, sleep, and weight.

An association between CPP and the occurrence of sleep disorders has been suggested by one small study in the USA of 72 CPP cases in a gynaecology clinic compared with 26 asymptomatic women undergoing laparoscopic sterilisation (Nolan *et al.*, 1992). A small prospective study of 23 IBS patients also reported a 'link' between self-reported IBS symptoms and sleep quality during the previous night (Goldsmith & Levin, 1993). The results presented here support an association between CPP and quality of sleep: compared with pain-free and dysmenorrhoea controls, women with CPP reported more 'lack of sleep' each night and were more likely to have experienced recent difficulty falling asleep, frequent

awakenings, and non-regenerative sleep. However, no difference in sleep quality was observed between CPP cases and dyspareunia controls.

The information collected in this study on work absence was limited. Women with CPP reported having taken more time off work due to illness in general and due to pelvic pain than women with dysmenorrhoea, but not compared to women with dyspareunia. While absence due to illness in general was not different between CPP groups, pelvic pain-related absence increased steeply with increasing cumulative CPP duration. At least 1 day off work due to pelvic pain was reported by 9% of women with a 'short' CPP duration (a percentage similar to that in dysmenorrhoea controls), 15% of women with an 'intermediate' duration, and 33% of women with a 'long' duration.

The results described above are consistent with those presented in the previous chapter. There, it was shown that CPP cases had higher levels of pain severity and pelvic pain-related use of health care compared with women with dysmenorrhoea only, but not compared with women with dyspareunia. The general lack of difference observed between CPP cases and dyspareunia controls in terms of pain severity, health care use, and functioning and well-being, raises the question of who constitutes the latter group. An interesting observation is that they are the youngest group in the study (with a mean age of 30.5 yrs compared with 35.4 yrs in CPP cases). One theory might be, therefore, that the group contains women who may develop CPP in the future⁴⁷. If this were so, their relatively low mental component scores on the SF-36, and high levels of anxiety about their pain (also seen in CPP cases) might indicate a 'negative' psychological state – suggested by the biopsychosocial model of CPP to play a role in CPP development and persistence as described in Chapter 1.

It is possible that information bias has played some role in the results found for the 'short' duration group. Most of these women had very infrequent, short, pelvic pain episodes in the

⁴⁷ Indeed, 25 out of the 186 dyspareunia controls (13.4%) reported they had pelvic pain at times other than with periods or intercourse: they were not counted as CPP cases mainly because their pain started less than 6 months ago. Out of the 660 dysmenorrhoea controls, 45 (6.8%) reported such pain.

previous year, and reported pain severity, associated health care use, and physical impairment that was similar to dysmenorrhoea controls. However, they had relatively low mental component scores and a high proportion reported being worried about the symptoms. In addition, they had a comorbidity frequency that was similar to other CPP cases but twice as high as pain-free or dysmenorrhoea controls. These characteristics may have made them more likely to report their symptoms.

In this study, functioning and well-being was assessed using several different outcomes: the SF-36, sleep quality, absence from work, and limitations due to the pain and troubling aspects of the pain. It should be noted that the SF-36 is a generic (i.e. not illness-specific) health status measure, designed to tap dimensions of health in different groups in the population. Although shown to be sensitive to detect differences in health status between various patient groups and the community (Jenkinson *et al.*, 1996a), it may not have tapped all dimensions of health that are affected in CPP cases. For instance, sleep is not measured in the SF-36 (although related items of energy and vitality are), whereas the results described above showed that this may be an important dimension to consider in women with CPP. Similarly, a study in the USA of 250 IBS cases and 120 community controls stated that - although the SF-36 was sensitive enough to detect differences between IBS patients, non-consulters, and healthy controls - sleep was a common area of concern to IBS cases that was not covered by the SF-36 (Whitehead *et al.*, 1996). A CPP-specific health status measure, which may be used in combination with a generic tool such as the SF-36, will become particularly important in the evaluation of outcomes following new treatment strategies for CPP in the future. Plans for the development of such an instrument are currently underway.

In the previous chapter, it was shown that there were large variations among CPP cases in terms of pelvic pain severity and associated use of health care. It was argued that this could suggest that some women with CPP are more affected than others in terms of associated functioning, or that some might be better able to cope with their symptoms, or both. The

results presented here support both hypotheses: substantial variations were found among CPP cases in the degree to which they were affected by their pain from a physical point of view. Nevertheless, those women with a relatively small pelvic pain ‘burden’ indicated that they were as affected in terms of anxiety about their symptoms as those who were more physically impaired. It is likely that more clarity about CPP and its possible causes could help in reassuring these women. Qualitative research into such information needs of women is currently underway.

Chapter 8

Factors associated with CPP

8.1 Introduction

In Chapter 1, the difficulties involved in assessing risk-factors for CPP were discussed in detail. The different conditions underlying CPP (all of which may have different associated risk patterns), combined with the possible influence of psychosocial variables as proposed by the biopsychosocial model of CPP, pose serious problems for risk-factor analysis. The cross-sectional design of a study imposes additional constraints: it is often impossible to determine whether the occurrence of a suspected risk-factor preceded or followed the onset of the pain.

In the present chapter, the results are described of an investigation into a range of factors that may be associated with CPP, using data from the Oxfordshire Women's Health Study. The study was performed for hypothesis-generating purposes only. In interpreting its results, the limitations described above should be borne in mind.

8.2 Methods

8.2.1 Definitions of CPP cases and controls

CPP cases and controls were defined as in Chapter 6: CPP cases were women reporting CPP in the last 3 months (n=483) and controls were all women without CPP in that time period (n=1,533). Women who had dysmenorrhoea only or who had dyspareunia with or without dysmenorrhoea were included in the control group. This decision was made because the objective of the analyses was to investigate factors specifically associated with CPP. Most CPP cases also had dysmenorrhoea or dyspareunia, and exclusion of women with these symptoms from the control group might have produced risk-factor results that were associated with dysmenorrhoea or dyspareunia rather than with CPP. Cases were grouped

according to ‘level of disease burden’ in terms of cumulative pain duration in the last 12 months: ‘short’ (n=174); ‘intermediate’ (n=173); ‘long’ (n=133); 3 cases had an unknown duration.

8.2.2 Potential factors associated with CPP

A range of factors was investigated: demographic characteristics, contraceptive and HRT use, smoking, alcohol consumption, height, weight, menstrual characteristics, and pregnancy and childbirth. Some of these variables could be regarded as ‘exposure’ variables (or proxies for unknown exposures), i.e. they could not have resulted from CPP, or were unlikely to have done so. These variables included age, social class, ethnicity, height, IUCD use, condom use, diaphragm use, sterilisation, termination, and HRT use ⁴⁸. As described in Chapter 1, there were a priori hypotheses for associations between some of these exposures and risk of CPP, namely: age, social class, IUCD use (potentially increasing risk of PID), condom and diaphragm use (barrier methods protective of PID), sterilisation (potentially increasing risk of pelvic pain), and termination (potentially increasing risk of PID).

The other factors for which information was collected were regarded as ‘associative variables’: factors that could contribute to or modify the risk of CPP but could also be the result of CPP or an underlying condition. These included marital and employment status, smoking, alcohol consumption, OC use, weight, Body Mass Index (BMI), regularity of menstrual cycle (with ‘irregular’ defined as periods more or less frequent than every 3-5 weeks), typical length of a period, age at first pregnancy, parity, miscarriage, ectopic pregnancy, and sub-fertility ⁴⁹.

⁴⁸ HRT use could also be the result of CPP if it followed a hysterectomy or bilateral oophorectomy for pain. Here, HRT use is regarded as an exposure variable after adjusting for hysterectomy/bilateral oophorectomy.

⁴⁹ Sub-fertility was defined as ever having tried to conceive for at least 12 months without success (see section 5.3.1.4).

8.2.3 Statistical methods

8.2.3.1 Missing values

Missing values for a variable were excluded from analyses involving that variable. For the majority of individual variables, the frequency of missing values was only 1-2%; the frequency never exceeded 5%. In the multiple logistic regression models described in the next section, cases and controls were excluded from analyses if they had a missing value for any of the variables in the model. The maximum frequency of missing values in these models was 7%.

8.2.3.2 Methods of analysis

The unadjusted risk of having CPP according to the different exposure and associative variables - expressed in terms of odds ratios (OR) with 95% confidence intervals (CI) - was assessed using logistic regression models. Separate unadjusted analyses were performed for risks of 'short', 'intermediate', and 'long' duration CPP.

The OR is calculated as the odds of exposure in cases divided by the odds of exposure in controls. The risk ratio (RR) is the proportion of diseased in the exposed divided by the proportion in the unexposed, and is the true estimate of relative risk associated with an exposure in a prevalence study. When a disease is rare, the OR closely approximates the RR (Greenland & Rothman, 1998). When a disease is more prevalent, however, ORs are inflated and overestimate relative risk. Since the prevalence of all CPP combined was high (24%), RRs were calculated for the purpose of comparison with the unadjusted ORs. In the remainder of this chapter, however, the terms 'risk' and 'odds' are used interchangeably.

Since age was an important potential confounder in the risk estimation for many factors, ORs of CPP were first adjusted for age alone, using logistic regression. Effects of exposure and associative variables that remained significant after adjusting for age were further

adjusted for a range of other possible confounding factors. These factors included: 1) all exposure variables that were a priori considered to be important *and* were found to be at least borderline significantly ($p < 0.1$) associated with CPP or one of the CPP sub-groups in the age-adjusted analyses (age, social class, ethnicity, IUCD use, condom use, diaphragm use, and sterilisation); 2) those additionally found to be associated with risk of CPP (height and HRT use); and 3) the associative variable OC use (since this variable was likely to be associated with use of other, non-hormonal, contraceptives).

The overall significance of a variable in a model after adjustment for other variables was calculated using Wald chi-squared tests for heterogeneity. Since the objective of the logistic regression models was merely to adjust the effects of factors for possible confounders (and not to provide a predictive model for CPP), their goodness-of-fit was not assessed. All analyses were performed using SPSS version 8.0 (SPSS Inc., 1998).

8.3 Results

8.3.1 Unadjusted risk of CPP and effect of age adjustment

8.3.1.1 Demographic characteristics

Differences in prevalence of CPP according to demographic characteristics were described previously in section 6.3.1 (Table 6.3). Table 8.1 shows the unadjusted risk of CPP expressed as RRs and ORs for different demographic categories. Risk of any CPP varied significantly with age: compared with the reference group of 18-25 yr olds, the OR was 1.63 (95% CI: 1.15-2.30) for 36-40 yr olds and 1.53 (95% CI: 1.08-2.18) for 41-45 yr olds. The respective RRs for these groups were somewhat lower, at 1.45 and 1.39. Similar differences in risk between age groups were observed for 'intermediate' and 'long' duration CPP, but not for that of 'short' duration.

Table 8.1. Unadjusted risk of CPP by demographic characteristics.

Variable	CPP			‘short’			‘intermediate’			‘long’		
	n/N ¹	RR ²	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	
Age												
18-25	71/362	1	1	18	1	17	1	15	1.08 (0.53-2.20)	1		
26-30	83/321	1.32	1.43 (0.99-2.05)	32	1.19 (0.72-1.95)	35	2.17 (1.19-3.97)	15	1.11 (0.56-2.22)			
31-35	67/329	1.04	1.05 (0.72-1.52)	22	0.86 (0.51-1.46)	28	1.36 (0.71-2.59)	17	2.10 (1.14-3.89)			
36-40	100/352	1.45	1.63 (1.15-2.30)	43	0.83 (0.49-1.42)	26	2.76 (1.55-4.90)	31	1.98 (1.07-3.68)			
41-45	97/356	1.39	1.53 (1.08-2.18)	32	1.03 (0.62-1.70)	33	2.00 (1.09-3.64)	30	1.70 (0.89-3.26)			
46-49	65/296	1.12	1.15 (0.79-1.68)	26	0.56 (0.30-1.03)	16	1.82 (0.97-3.40)	23				
Social class												
I/II	228/862	1	1	88	1	63	1	16	0.73 (0.41-1.28)	1		
IIINm	63/285	0.84	0.79 (0.57-1.08)	20	1.01 (0.64-1.62)	27	0.65 (0.39-1.08)	16	0.90 (0.57-1.43)			
IIIm	108/432	0.95	0.93 (0.71-1.21)	40	0.93 (0.61-1.41)	36	0.91 (0.61-1.35)	29	0.84 (0.48-1.49)			
IV/V	49/240	0.77	0.71 (0.50-1.01)	12	0.92 (0.55-1.53)	21	0.45 (0.24-0.85)	16	0.52 (0.25-1.12)			
Other	34/188	0.68	0.61 (0.41-0.92)	12	0.76 (0.42-1.38)	14	0.56 (0.30-1.05)	8				
Marital status												
Single	91/434	1	1	25	1	18	1	90	1.64 (0.97-2.76)	1		
Cohabiting/married	334/1,378	1.16	1.21 (0.93-1.57)	132	0.75 (0.53-1.08)	110	1.73 (1.11-2.71)	90	3.29 (1.73-6.24)			
Divorced/sep./ widow	57/196	1.39	1.55 (1.05-2.27)	16	0.82 (0.45-1.50)	16	1.58 (0.82-3.05)	24				
Employment status												
Full-time	247/997	1	1	95	1	60	1	38	1.16 (0.76-1.77)	1		
Part-time	130/539	0.97	0.97 (0.76-1.23)	48	0.88 (0.60-1.28)	43	0.93 (0.64-1.34)	38	1.30 (0.77-2.19)			
Caring home/family	53/255	0.84	0.80 (0.57-1.11)	16	0.66 (0.38-1.15)	16	0.63 (0.36-1.09)	21	1.04 (0.57-1.90)			
Other	53/222	0.96	0.95 (0.68-1.34)	14	1.23 (0.77-1.98)	25	0.65 (0.36-1.17)	14				
Ethnicity												
Caucasian	475/1,935	1	1	172	1	129	1	1	0.63 (0.22-1.75)	1		
Other	8/80	0.41	0.34 (0.16-0.72)	1	0.36 (0.11-1.14)	3	0.12 (0.02-0.85)	4				

¹ n= number of CPP cases in category; N= population denominator in category

² RR= Risk ratio

Non-Caucasian women appeared to be at much lower risk of CPP than Caucasian women (OR=0.34; 95% CI: 0.16-0.72), though numbers of non-Caucasian women were very small. Adjustment for age did not affect this result (OR=0.33). Risk of having any CPP was higher in divorced/separated/widowed compared to single women (OR=1.55; 95% CI: 1.05-2.27), but adjustment for age reduced this OR to 1.35 (95% CI: 0.88-2.07). The largest risk associated with being divorced/separated/widowed was observed for 'long' CPP duration (OR=3.29): adjustment for age reduced the OR only slightly to 2.58 (95% CI: 1.24-5.37) compared to single women. The higher risk of 'intermediate' CPP in the cohabiting/married group compared to single women (OR=1.73) became non-significant after adjusting for differences in age (OR=1.37; 95% CI: 0.83-2.26).

Women of lower social class (IV/V) and grouped in the 'other' category (mainly consisting of students) appeared at a somewhat lower risk than those of class I/II (ORs 0.71 and 0.61, respectively), whereas no association was found with employment status. These results were not affected by adjustment for age.

8.3.1.2 Contraceptive and HRT use

In unadjusted analyses, ever use of OCs compared with never use (OR=1.33; 95% CI: 0.99-1.79) was associated with increased risk of CPP; this was also the case for IUCDs (OR=1.41; 95% CI: 1.10-1.82), and condoms (OR=1.43; 95% CI: 1.13-1.80) (not shown). The increased risks, however, were all limited to use more than 12 months ago (Table 8.2). In addition, an increased risk associated with ever use of a diaphragm was found for 'intermediate' CPP only (OR=2.08; 95% CI: 1.40-3.09), but the numbers of women who had used a diaphragm were relatively small. Adjustment for age did not affect these results.

Although no significant association was found with all CPP, women who had been sterilised appeared to be at a higher risk of 'long' duration CPP (OR=2.32; 95% CI: 1.50-3.59). Adjustment for age reduced this OR only slightly, to 1.97 (95% CI: 1.26-3.17).

Table 8.2 Unadjusted risk of CPP by contraceptive and HRT use.

Variable	CPP			‘short’			‘intermediate’			‘long’		
	n/N ¹	RR ²	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	
OCs												
never used	63/315	1	1	23	1	19	1	1	1	1	1	
in last 12 months	138/638	1.08	1.10 (0.79-1.54)	44	0.96 (0.57-1.63)	26	0.96 (0.57-1.63)	26	0.69 (0.37-1.27)	26	0.69 (0.37-1.27)	
> 12 months ago	280/1,036	1.35	1.48 (1.09-2.02)	104	1.51 (0.94-2.42)	88	1.51 (0.94-2.42)	88	1.54 (0.92-2.59)	88	1.54 (0.92-2.59)	
IUCD												
never used	374/1,628	1	1	129	1	93	1	1	1	1	1	
in last 12 months	31/113	1.19	1.27 (0.83-1.95)	10	1.19 (0.60-2.34)	10	1.19 (0.60-2.34)	10	1.64 (0.83-3.28)	10	1.64 (0.83-3.28)	
>12 months ago	76/248	1.33	1.48 (1.10-1.99)	32	1.81 (1.19-2.75)	30	1.81 (1.19-2.75)	30	2.35 (1.51-3.66)	30	2.35 (1.51-3.66)	
Condom												
never used	123/619	1	1	43	1	37	1	1	1	1	1	
in last 12 months	163/719	1.14	1.18 (0.91-1.54)	62	1.29 (0.86-1.93)	36	1.29 (0.86-1.93)	36	0.87 (0.54-1.40)	36	0.87 (0.54-1.40)	
>12 months ago	195/651	1.51	1.72 (1.33-2.23)	66	1.67 (1.11-2.50)	60	1.67 (1.11-2.50)	60	1.76 (1.15-2.71)	60	1.76 (1.15-2.71)	
Diaphragm												
never used	412/1,743	1	1	134	1	117	1	1	1	1	1	
ever used	69/246	1.19	1.26 (0.93-1.70)	37	2.08 (1.40-3.09)	16	2.08 (1.40-3.09)	16	1.03 (0.60-1.77)	16	1.03 (0.60-1.77)	
Sterilised												
no	415/1,762	1	1	153	1	103	1	1	1	1	1	
yes	66/235	1.19	1.27 (0.93-1.72)	19	0.99 (0.60-1.64)	30	0.99 (0.60-1.64)	30	2.32 (1.50-3.59)	30	2.32 (1.50-3.59)	
HRT												
never used	440/1,860	1	1	157	1	117	1	1	1	1	1	
ever used	40/140	1.21	1.29 (0.88-1.89)	16	1.45 (0.83-2.52)	14	1.45 (0.83-2.52)	14	1.70 (0.94-3.07)	14	1.70 (0.94-3.07)	

¹ n= number of CPP cases in category; N= population denominator in category

² RR= Risk ratio

There was no association between ever use of HRT and all CPP: after adjustment for age and ever having had a hysterectomy or bilateral oophorectomy, the OR was 1.44 (95% CI: 0.93-2.23). For 'long' duration CPP, the unadjusted OR was 1.70 (CI: 0.94-3.07), but adjustment reduced this figure to 1.49 (95% CI: 0.77-2.88). Long-term users of HRT (use for at least 12 months) appeared to be at highest risk of CPP (not shown: adjusted OR=1.64; 95% CI: 0.94-2.87), but numbers of women in this category were too small (n/N=23/75) to interpret this result.

8.3.1.3 Smoking, alcohol use, and anthropometric measures

Women who had ever smoked appeared at a slightly higher risk of CPP compared to never smokers (OR=1.22; 95% CI: 0.99-1.50) (Table 8.3). This increased risk, however, was confined to ex-smokers, who had an OR of 1.41 (95% CI: 1.09-1.82) for any CPP and an OR of 1.91 (1.26-2.90) for 'long' duration CPP. Moderate alcohol use (8-14 units/week) was associated with a higher risk of CPP (OR=1.43; 95% CI: 1.04-1.98), but this appeared to be largely confined to 'short' duration CPP (OR=1.71; 95% CI: 1.04-2.82). Adjustment for age did not affect these results.

Tall women (≥ 1.70 m.) were at increased risk of CPP compared to women measuring 1.60 m. or less (OR=1.41; 95% CI: 1.05-1.91); the association remained after adjusting for age (OR=1.48; 95% CI: 1.09-2.00). No associations were observed between risk of CPP and weight or BMI.

8.3.1.4 Menstrual characteristics

Table 8.4 shows the association between CPP and menstrual characteristics in the last 12 months. Risk of 'long' duration CPP was significantly higher in women reporting irregular menstruation (less or more frequent than every 3-5 weeks) than those with regular

Table 8.3. Unadjusted risk of CPP by smoking, alcohol use, and anthropometric measures

Variable	CPP						‘short’			‘intermediate’			‘long’		
	n/N ¹	RR ²	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)
Ever smoked															
no	233/1,047	1	1												
yes	249/963	1.16	1.22 (0.99-1.50)					85	1		1	59	1		
								88	1.14 (0.83-1.56)		1.18 (0.86-1.62)	73	1.41 (0.99-2.02)		
Current smoking status															
never smoker	233/1,047	1	1												
ex-smoker	125/435	1.29	1.41 (1.09-1.82)					85	1		1	59	1		
current: <15 cigs/day	64/267	1.08	1.10 (0.80-1.51)					49	0.97 (0.65-1.52)		1.51 (1.04-2.20)	43	1.91 (1.26-2.90)		
current: ≥15 cigs/day	58/252	1.03	1.04 (0.75-1.45)					18	1.52 (0.99-2.34)		0.85 (0.50-1.44)	12	0.82 (0.43-1.55)		
								20	1.01 (0.61-1.67)		0.99 (0.59-1.65)	17	1.21 (0.69-2.12)		
Alcohol consumption (units per week)															
none/<1	85/394	1	1												
1-7	230/997	1.07	1.09 (0.82-1.44)					32	1		1	25	1		
8-14	112/396	1.31	1.43 (1.04-1.98)					82	1.18 (0.75-1.85)		1.03 (0.67-1.59)	64	1.03 (0.64-1.67)		
>14	55/216	1.18	1.24 (0.84-1.83)					38	1.71 (1.04-2.82)		1.29 (0.79-2.12)	29	1.26 (0.72-2.21)		
								21	1.37 (0.75-2.51)		1.26 (0.70-2.26)	14	1.07 (0.54-2.12)		
Height (metres)															
≤ 1.60	96/442	1	1												
1.61-1.69	242/1,221	1.06	1.08 (0.83-1.41)					34	1		1	29	1		
≥ 1.70	140/497	1.30	1.41 (1.05-1.91)					90	1.21 (0.79-1.84)		1.13 (0.75-1.72)	61	0.90 (0.57-1.43)		
								48	1.51 (0.95-2.42)		1.37 (0.86-2.18)	41	1.37 (0.83-2.25)		
BMI (kg/m ²)															
<20	98/404	1	1												
20- <25	253/1,049	0.99	0.99 (0.76-1.30)					35	1		1	29	1		
25- <30	88/336	1.08	1.11 (0.79-1.55)					91	1.06 (0.70-1.61)		1.00 (0.66-1.51)	66	0.87 (0.55-1.38)		
≥ 30	39/179	0.90	0.87 (0.57-1.33)					36	1.05 (0.62-1.78)		1.27 (0.77-2.08)	22	0.94 (0.52-1.67)		
								9	1.03 (0.55-1.93)		0.56 (0.26-1.20)	14	1.05 (0.54-2.06)		

¹ n= number of CPP cases in category; N= population denominator in category

² RR= Risk ratio

Table 8.4. Unadjusted risk of CPP by menstrual characteristics in the last 12 months.

Variable (last 12 months)	CPP			'short'			'intermediate'			'long'		
	n/N ¹	RR ²	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	
Periods												
yes	451/1,861	1	1	166	1	163	1	120	1	1	1	
no	31/151	0.85	0.81 (0.54-1.22)	7	0.50 (0.23-1.07)	10	0.72 (0.37-1.40)	13	0.72 (0.37-1.40)	13	1.27 (0.70-2.32)	
Cycle pattern												
regular (every 3-5 wks)	364/1,544	1	1	140	1	133	1	90	1	1	1	
irregular	84/302	1.18	1.24 (0.94-1.64)	26	1.00 (0.65-1.56)	28	1.14 (0.74-1.75)	30	1.14 (0.74-1.75)	30	1.80 (1.16-2.79)	
no periods	31/151	0.87	0.83 (0.55-1.26)	7	0.49 (0.23-1.07)	10	0.74 (0.38-1.44)	13	0.74 (0.38-1.44)	13	1.42 (0.77-2.61)	
Typical length of period												
1-4 days	139/606	1	1	49	1	53	1	36	1	1	1	
5-6 days	179/790	0.99	0.98 (0.76-1.27)	74	1.15 (0.79-1.69)	62	0.89 (0.61-1.32)	42	0.89 (0.61-1.32)	42	0.89 (0.56-1.41)	
7+ days	129/427	1.32	1.45 (1.10-1.92)	42	1.34 (0.87-2.08)	45	1.33 (0.87-2.03)	42	1.33 (0.87-2.03)	42	1.83 (1.14-2.92)	
no periods	31/151	0.90	0.87 (0.56-1.34)	7	0.56 (0.25-1.26)	10	0.73 (0.36-1.49)	13	0.73 (0.36-1.49)	13	1.41 (0.72-2.73)	

¹ n= number of CPP cases in category; N= population denominator in category

² RR= Risk ratio

menstruation (OR=1.80; 95% CI: 1.16-2.79). Women who had long periods (lasting 7 days or more) were at a higher risk of having CPP than women with short periods (4 days or less), with ORs of 1.45 for all CPP (95% CI: 1.10-1.92) and 1.83 (95% CI: 1.14-2.92) for 'long' duration CPP. These results were unaffected by adjustment for age.

8.3.1.5 Pregnancy, childbirth, and sub-fertility

The unadjusted risks of CPP associated with pregnancy, childbirth, and sub-fertility are given in Table 8.5. Ever compared to never having been pregnant was not associated with risk of CPP (not shown: OR=1.10; 95% CI: 0.89-1.37). The increased risk of 'short' CPP duration in those who had never been pregnant compared with those with a first pregnancy at age 20 or younger (OR=1.66; 95% CI: 1.02-2.71) was reduced to 1.58 (95% CI: 0.93-2.69) after adjusting for age.

Parity appeared to be associated with increased risk of 'intermediate' and 'long' duration CPP in the crude analyses; these results became non-significant, however, after adjusting for age. For example, the OR for 'long' duration CPP associated with having >2 children was reduced from 2.08 to 1.60 (95% CI: 0.88-2.90). Similarly, the increased risk of 'long' duration CPP associated with ever having had a miscarriage (OR=1.57; 95% CI: 1.01-2.42) was reduced to 1.33 (95% CI: 0.85-2.08) after adjusting for age. Risk of CPP was not associated with previous termination. Only 39 women in the whole study group (8 CPP cases) had had an ectopic pregnancy, and its association with risk of CPP could therefore not be investigated.

Of all the pregnancy-related variables, only sub-fertility was independently associated with the risk of CPP. The unadjusted OR of ever compared with never having been sub-fertile was 1.44 (95% CI: 1.06-1.96), and this result was not affected by adjustment for age.

Table 8.5. Unadjusted risk of CPP by pregnancy, childbirth, and infertility.

Variable	CPP			‘short’		‘intermediate’		‘long’	
	n/N ¹	RR ²	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)	n	OR (95% CI)
Age at first pregnancy									
≤ 20 yrs	92/362	1	1	34	1	35	1	1	
21-25	107/447	0.94	0.92 (0.67-1.27)	43	1.04 (0.59-1.82)	33	1.00 (0.62-1.62)	0.75 (0.45-1.24)	
≥ 26	123/495	0.98	0.97 (0.71-1.33)	47	1.39 (0.82-2.35)	31	1.00 (0.63-1.61)	0.64 (0.39-1.07)	
never pregnant	157/687	0.90	0.87 (0.65-1.17)	48	1.66 (1.02-2.71)	33	0.72 (0.45-1.14)	0.48 (0.29-0.79)	
Parity									
0	179/780	1	1	58	1	37	1	1	
1	48/239	0.88	0.84 (0.59-1.21)	14	0.73 (0.43-1.23)	15	0.76 (0.41-1.39)	1.28 (0.68-2.37)	
2	157/608	1.13	1.17 (0.91-1.50)	64	0.75 (0.51-1.09)	46	1.47 (1.01-2.14)	1.65 (1.06-2.60)	
>2	94/351	1.16	1.23 (0.92-1.64)	36	0.71 (0.45-1.14)	33	1.45 (0.93-2.26)	2.08 (1.27-3.41)	
Ever miscarriage									
no	400/1,690	1	1	138	1	103	1	1	
yes	81/313	1.09	1.13 (0.85-1.48)	34	0.64 (0.39-1.07)	29	1.37 (0.92-2.05)	1.57 (1.01-2.42)	
Ever termination									
no	403/1,664	1	1	144	1	105	1	1	
yes	79/333	0.98	0.97 (0.74-1.28)	29	0.72 (0.45-1.15)	29	1.00 (0.66-1.52)	1.28 (0.82-1.99)	
Ever sub-fertile									
no	410/1,780	1	1	145	1	111	1	1	
yes	67/222	1.31	1.44 (1.06-1.96)	25	1.22 (0.75-1.98)	20	1.52 (0.97-2.40)	1.59 (0.96-2.64)	

¹ n= number of CPP cases in category; N= population denominator in category

² RR= Risk ratio

8.3.2 Further adjusted risk of CPP

8.3.2.1 Exposure variables

Table 8.6 shows the further adjusted risk of CPP for the exposure variables which were significant in the preliminary analysis, or which were – a priori – thought to be potentially important. Although risk of CPP still varied significantly with age ($p=0.03$), ORs in the 36-40 and 41-45 yr age groups were reduced to 1.23 (95% CI: 0.81-1.88) and 1.16 (95% CI: 0.76-1.78), respectively. Non-Caucasian ethnicity remained associated with a decreased risk of CPP (OR=0.35; 95% CI: 0.16-0.78), and tall height (≥ 1.70 meters) with an increased risk (OR=1.37; 95% CI: 1.00-1.88).

Of the different contraceptive methods, the increased risk associated with IUCD use more than 12 months ago was no longer significant (OR=1.32; 95% CI: 0.95-1.83). Condom use more than 12 months ago, however, remained associated with a higher risk of CPP (OR=1.55; 95% CI: 1.17-2.05). After adjustment, diaphragm use, sterilisation, and HRT use did not affect the risk of CPP.

8.3.2.2 Associative variables

Table 8.7 shows the adjusted risk of CPP for the associative variables of interest. Risk of CPP associated with being divorced/separated/widowed was reduced from 1.35 in the age-adjusted analysis to 1.17 (95% CI: 0.74-1.83) in the full model. The increased odds associated with OC use more than 12 months ago also fell, after adjustment, to an OR of 1.10 (95% CI: 0.78-1.55).

The elevated risks in ex-smokers and moderate drinkers became non-significant after adjustment. For ex-smokers, the OR was reduced to 1.26 (95% CI: 0.97-1.64), and for moderate drinkers, to 1.26 (95% CI: 0.89-1.78).

Table 8.6. Adjusted risk of CPP by different exposure variables.

Variable	CPP	
	n/N ¹	Adjusted ² OR (95% CI)
Age		
18-25	71/362	1
26-30	83/321	1.30 (0.88-1.90)
31-35	67/329	0.88 (0.58-1.32)
36-40	100/352	1.23 (0.81-1.88)
41-45	97/356	1.16 (0.76-1.78)
46-49	65/296	0.72 (0.44-1.18)
$\chi^2_{df=5}$		p=0.03
Social class		
I/II	228/862	1
IINm	63/285	0.83 (0.59-1.16)
IIIm	108/432	0.95 (0.72-1.26)
IV/V	49/240	0.85 (0.58-1.22)
Other	34/188	0.66 (0.43-1.04)
$\chi^2_{df=4}$		p=0.4
Ethnicity		
Caucasian	475/1,935	1
Other	8/80	0.35 (0.16-0.78)
$\chi^2_{df=1}$		p=0.01
Height (meters)		
≤ 1.60	96/442	1
1.61-1.69	242/1,221	1.05 (0.70-1.38)
≥ 1.70	10/497	1.37 (1.00-1.88)
$\chi^2_{df=2}$		p=0.07
IUCD		
never used	374/1,628	1
in last 12 months	31/113	1.10 (0.69-1.74)
>12 months ago	76/248	1.32 (0.95-1.83)
$\chi^2_{df=2}$		p=0.3
Condom		
never used	123/619	1
in last 12 months	163/719	1.14 (0.85-1.52)
>12 months ago	195/651	1.55 (1.17-2.05)
$\chi^2_{df=2}$		p=0.005
Diaphragm		
never used	412/1,743	1
ever used	69/246	1.02 (0.74-1.41)
$\chi^2_{df=1}$		p=0.9
Sterilised		
no	415/1,762	1
yes	66/235	1.15 (0.82-1.62)
$\chi^2_{df=1}$		p=0.4
HRT		
never used	440/1,860	1
ever used	40/140	1.41 (0.91-2.18)
$\chi^2_{df=1}$		p=0.1

¹ n= number of CPP cases in category; N= population denominator in category
² Adjustments were made for all variables in the table plus OC use.

Table 8.7. Adjusted risk of CPP by different associative variables.

Variable	CPP	
	n/N ¹	Adjusted ² OR (95% CI)
Marital status		
Single	91/434	1
Cohabiting/married	334/1,378	0.90 (0.65-1.24)
Divorced/sep./ widow	57/196	1.17 (0.74-1.83)
$\chi^2_{df=2}$		p=0.3
OCs		
never used	63/315	1
in last 12 months	138/638	0.96 (0.67-1.39)
> 12 months ago	280/1,036	1.10 (0.78-1.55)
$\chi^2_{df=2}$		p=0.6
Current smoking status		
never smoker	233/1,047	1
ex-smoker	125/435	1.26 (0.97-1.64)
current: <15 cigs/day	64/267	1.16 (0.83-1.62)
current: ≥15 cigs/day	58/252	1.00 (0.71-1.42)
$\chi^2_{df=3}$		p=0.3
Alcohol consumption (units per week)		
none/<1	85/394	1
1-7	230/997	0.97 (0.72-1.30)
8-14	112/396	1.26 (0.89-1.78)
>14	55/216	1.13 (0.75-1.70)
$\chi^2_{df=3}$		p=0.8
Cycle pattern		
regular (every 3-5 wks)	364/1,544	1
irregular	84/302	1.29 (0.96-1.73)
no periods	31/151	0.69 (0.43-1.11)
$\chi^2_{df=2}$		p=0.05
Typical length of period		
1-4 days	139/606	1
5-6 days	179/790	0.96 (0.74-1.25)
7+ days	129/427	1.34 (1.00-1.80)
no periods	31/151	0.69 (0.42-1.13)
$\chi^2_{df=3}$		p=0.02
Ever subfertile		
no	410/1,780	1
yes	67/222	1.50 (1.08-2.07)
$\chi^2_{df=1}$		p=0.02

¹ n= number of CPP cases in category; N= population denominator in category
² Adjustments were made for all exposure variables in Table 8.6 (age, social class, ethnicity, height, IUCD use, condom use, diaphragm use, sterilisation, and HRT use) plus OC use.

Women who had a menstrual flow lasting 7 days or more remained at marginally elevated risk of CPP (OR=1.34; 95% CI: 1.00-1.80), independent of the regularity of cycle. In addition, women who had ever experienced episodes of sub-fertility remained at an increased risk of CPP, with an OR of 1.50 (95% CI: 1.08-2.07).

8.4 Discussion

This chapter investigated the associations between a range of factors and the risk of CPP. In this assessment, ‘exposure variables’ (those that could not have resulted from CPP, or were unlikely to have done so) were distinguished from ‘associative variables’ (those that could have preceded the pain but might also have been a result of the pain or an underlying condition). However, the observed associations of exposure variables with risk of CPP do *not* imply a causal relationship. Several other criteria should be fulfilled before a causal relationship is suggested (see footnote 4). In addition, since so little is known about the aetiology of CPP in general, uncontrolled confounding may well play a role in some of the associations observed.

With regard to exposure variables, associations with risk of CPP were found for age, ethnicity, height, condom use, and to some extent IUCD use. Risk of CPP varied with age, but no clear pattern of association emerged. Compared with 18-25 yr olds, the largest unadjusted ORs for CPP were found in women aged 26-30 yrs (OR=1.43), 36-40 yrs (OR=1.63), and 41-45 yrs (OR=1.53), with RRs of 1.32, 1.45, and 1.39, respectively. These effects, however, were reduced when adjusted for other exposure variables such as contraceptive use.

Slightly less variation of CPP prevalence with age was observed in the MediPlus analysis of women aged 15-50 seeking health care for their symptoms (Fig. 3.4): compared to women aged 15-20 yrs, the results corresponded to RRs of 1.00 for 21-30 yrs olds, 1.19 for 31-40 yr olds, and 1.17 for 41-50 yr olds. This suggested that differences may exist in health care

seeking behaviour for CPP between age groups. However, the small numbers of women with CPP seeking health care in this community study did not allow a reliable investigation of this hypothesis.

An inconsistent pattern of risk with age has also been observed in other studies: Jamieson *et al.* (1996) found that CPP prevalence in women aged 18-45 in primary care clinics decreased from 44-49% in 18-30 yr olds to 22-28% in 31-40 yr olds, and increased again to 37% in 41-45 yr olds⁵⁰. An explanation for these findings could be the presence of different underlying conditions contributing to the pain, which may have different profiles of risk with age. For example, risk of PID is highest in young women (Grodstein & Rothman, 1994), whereas endometriosis is thought to be most prevalent in women around 30-40 (although ascertainment bias could play a role in this observation) (Mangtani & Booth, 1993).

Risk of CPP appeared much lower in non-Caucasian than Caucasian women (adjusted OR=0.35; 95% CI: 0.16-0.78). However, this finding was based on only 80 non-Caucasian women participating in the study, and generalisability to the larger population may therefore be compromised. Interestingly, Mathias *et al.* (1996) reported a reduced risk of CPP in women of African-American origin compared to Caucasian women (OR=0.7; 95% CI: 0.5-0.95), whereas Jamieson *et al.* (1996) reported a higher CPP prevalence in the former group (53%) compared to the latter (35%).

Another association difficult to explain was that of height and increased risk of CPP, even after adjusting for potential confounders such as age and social class (adjusted OR=1.37; 95% CI: 1.00-1.88). In two case-control studies, a similar positive association has been reported between height and risk of endometriosis (Cramer *et al.*, 1986; Signorello *et al.*, 1997). They were also unable to explain their results other than by suggesting residual confounding by unknown factors.

⁵⁰ CPP was defined as any pelvic pain other than with periods or intercourse. The lack of a minimum duration in this definition resulted in the very high prevalence rates.

Condom use was associated with an increased risk of CPP, but this effect was limited to use more than 12 months ago only (adjusted OR=1.55; 95% CI: 1.17-2.05). This elevated risk was surprising, as an a priori hypothesis was that the protective effect of barrier methods against PID may result in a lower risk of CPP. An explanation – though tentative – could be that condom users were different from women using other contraceptives in that they did not consistently use this method, and had more frequent unprotected intercourse. It is also possible that condom users were less likely to have been long-term users of OCs (which may be protective against endometriosis), and that OC use was thus inadequately controlled for.

In the age-adjusted analyses, IUCD use more than 12 months ago was associated with an increased risk of CPP. Although this effect became non-significant after further adjustment (OR=1.32; 95% CI: 0.95-1.83), the association was interesting because of the role of IUCDs in the aetiology of PID (Grodstein & Rothman, 1994). After adjustment, ever use of HRT was not associated with CPP (OR: 1.44; 95% CI: 0.93-2.23). The numbers of women who had used HRT, however, were small: larger numbers would be required to further investigate an association.

It should be noted that the information collected on contraceptive and HRT use in this study was limited. For contraceptive methods, no data were collected on total duration of use, which could have elucidated the observed associations. For both contraceptives and HRT, the longest assessed time since first use was ‘more than 12 months ago’. This did not allow an investigation of whether or not the use preceded the onset of CPP, since the majority of women with CPP (81%) reported that their pain had first started more than a year ago (see Table 6.5).

With regard to associative variables and risk of CPP, interesting results were observed for marital status, smoking status, menstrual patterns and sub-fertility. The association between CPP and marital status was of interest in view of the – largely anecdotal – evidence suggesting that CPP can result in marital discord and divorce (Reiter, 1990). The unadjusted

OR of CPP in women who were divorced/separated/widowed compared to single women was 1.55 (1.05-2.27), but after adjusting for possible confounders including age, the OR became non-significant, at 1.17 (95% CI: 0.74-1.83). For 'long' duration CPP, however, the risk remained significantly increased (OR=2.58; 95% CI: 1.24-5.37) after age adjustment (further adjustment was not possible due to small numbers). Mathias *et al.* (1996) previously found an OR (adjusted for age and ethnicity) of 1.5 (95% CI: 1.1-2.0), whereas Jamieson *et al.* (1996) found no association between marital status and risk of CPP.

The marginally elevated risk of CPP found in ex-smokers compared to never-smokers – that was most apparent in 'long' duration CPP – is difficult to interpret. Since no association was found with current smoking, the result suggested that women with CPP are more likely to give up smoking (perhaps due to concern about their symptoms).

With regard to menstrual characteristics, both irregular periods (OR=1.29; 95% CI: 0.96-1.73) and long periods of bleeding (OR=1.34; 95% CI: 1.00-1.80) were associated with a slightly increased risk of CPP. Similar associations have been reported for endometriosis (Cramer *et al.*, 1986; Signorello *et al.*, 1997), but it is unknown whether these menstrual characteristics preceded or were secondary to the disease (Mangtani & Booth, 1993). The increased risk of CPP in women who ever had an episode of sub-fertility (OR=1.50, 95% CI: 1.08-2.07) probably reflected the presence of an underlying gynaecological condition contributing to both infertility and pain.

In interpreting the results described above, it is important to address the limitations of the analyses. The difficulties in assessing risk-factors for CPP have been described in detail in section 1.5.2. The main problem results from the multi-factorial (biopsychosocial) model of CPP aetiology. This model proposes that a range of conditions can potentially underlie CPP, all of which may have different associated risk-factors. In addition, pain perception and persistence may well be influenced by different psychological and socio-environmental factors.

The range of factors investigated in this study was not comprehensive: information on some factors that may have been relevant to certain underlying conditions (exercise and diet, for example) was not collected. More importantly, psychological and socio-environmental factors were not addressed. The constraints on the number and type of factors investigated, however, were imposed by the study design (a postal questionnaire survey), the main purpose of which was to assess the prevalence of CPP in the general female population.

A step forward in unravelling patterns of CPP risk will be the development of non-invasive diagnostic tools for certain underlying conditions, allowing an investigation of their relative contribution to CPP. The role of psychological and socio-environmental factors in the aetiology of CPP is also an important area requiring further investigation. The influence of these factors, however, can only be adequately investigated in a prospective study.

Chapter 9

Summary and conclusions

9.1 Main results and conclusions

Chronic pelvic pain (CPP) is most commonly defined as constant or recurrent pain in the lower abdominal region lasting for at least 6 months, excluding pain related to pregnancy or malignancy, or pain that occurs *only* with menstruation or intercourse. The aim of this thesis was to investigate the epidemiology of CPP in women in the UK, most importantly its prevalence. This investigation was long overdue: whereas many studies have been performed investigating pathology that could account for CPP and possible alternative causes, the systematic review described in Chapter 1 showed a complete lack of epidemiological information on the condition.

The analysis of the national general practice database MediPlus, based on contacts for pelvic pain with primary care, provided the first evidence of a high prevalence of CPP in women (Chapter 3). The annual prevalence of 38/1,000 in women aged 15-73 was higher than OPCS figures reported for migraine (21/1,000), and comparable to those for asthma (37/1,000) and back pain (41/1,000). CPP prevalence varied with age, from 18/1,000 in 15-20 year olds to 28/1,000 in women older than 60. Regional variations were also found, with prevalence lowest in Scotland (16/1,000) and highest in Wales (29/1,000). These differences in age and region-specific rates could have been due to underlying differences in community-based rates, but also to differences in health care seeking behaviour. In addition, an uneven spread of highly computerised practices may have accounted to some extent for the differences in regional rates, although the painstaking method of case selection (described in Chapter 2) minimised the chance of this bias occurring.

The high community prevalence of CPP suggested by the MediPlus analysis was confirmed by the results of the Oxfordshire Women's Health Study, a cross-sectional postal questionnaire survey of a random sample of 4,000 women aged 18-50 in Oxfordshire

(Chapter 6). In the group of 2,042 respondents who had not been pregnant recently, a 3-month period prevalence of 24% (95% CI: 22.1-25.8) was found. This figure was higher than the 15% reported in the single community-based study by Mathias *et al.* (1996) in the USA, but the difference was largely accounted for by their exclusion of women with ovulation pain only. Only a quarter of women with CPP in the survey had sought medical advice in the preceding 12 months, which would have translated to a 'primary care prevalence' of 5.7% (95% CI: 4.7-6.7). This figure was somewhat higher than the annual prevalence of 3.7% found in MediPlus for women aged 18-50, but this difference would be expected because of the more restricted CPP definition in the latter analysis.

The MediPlus analysis also showed that the high prevalence of CPP was not so much explained by a high incidence (a monthly rate of 1.6/1,000), as by a long duration of symptoms. Follow-up of a cohort of 5,051 incident cases from their first GP contact for pelvic pain showed a median duration of 15 months, with a third of women having persistent symptoms after 2 years (Chapter 4). These results were influenced not only by the actual duration of symptoms, but also by health care seeking behaviour (which, in turn, was probably influenced by factors such as patient satisfaction with the care offered, interaction with the GP, and inclination to 'put up' with symptoms). Results of the community survey confirmed the long duration of CPP (Chapter 6): 81% of women with CPP had had symptoms for at least one year, and a third stated that the pain first started at least 5 years ago.

The survey presented the first evidence of overlap between CPP and other pelvic, gastrointestinal, and genito-urinary symptoms in the community (Chapter 6). Prevalence rates of dysmenorrhoea and dyspareunia in the last 12 months were substantially higher amongst CPP cases (90% and 50%, respectively) than amongst women without CPP (67% and 19%). In addition, 39% of CPP cases had IBS and 24% had genito-urinary symptoms.

These results underlined the range of symptoms a doctor may encounter when assessing a CPP patient.

Diagnostic patterns for CPP were investigated in MediPlus (Chapter 4), and – to a limited extent – in the community survey (Chapter 6). The 3.5 year follow-up of incident CPP cases in MediPlus revealed that a quarter of women received no diagnostic label, and that only 40% had evidence of referral to a specialist (mainly a gynaecologist). The majority of women received one diagnosis only, with IBS and cystitis being the most common diagnoses given in all age groups. In addition, PID was common in women aged up to 40, and other gastrointestinal diagnoses in women above 50. The likelihood of receiving a diagnosis varied with age, even after adjusting for differences in symptom duration: women under 20 and older than 60 were less likely than others to receive a diagnosis. The referral rate varied similarly with age: women in the 31-40 age group were twice as likely to have been referred as the youngest or oldest women in the cohort.

In the community survey, half of the women with CPP reported ever having received a diagnosis, with a quarter reporting more than one diagnosis. The most common diagnosis was IBS (20%), followed by stress (10%). The frequency of other diagnoses depended on whether or not a woman had been investigated: those who had had an investigation also reported diagnoses of ovarian cysts, endometriosis and PID, whereas those who had not had an investigation reported diagnoses of constipation and cystitis. Comparison between these data and the MediPlus results is difficult: the survey data reflected ‘life-time’ diagnoses compared to 3.5 years of follow-up in MediPlus, and information from the survey was based on self-report and could not be validated against medical records. IBS, however, was the most common diagnosis in both studies.

The survey also provided information on use of health care related to pelvic pain in the last 12 months (Chapter 6). Approximately one third of women with CPP reported seeking medical advice from a GP for any type of pelvic pain, 12% from a specialist, and 8% from an

alternative therapist (most commonly a homeopath). These rates were 2 to 3 times higher than reported by women with dysmenorrhoea alone, but they were similar to women with dyspareunia (most of whom also had dysmenorrhoea). Like women with dysmenorrhoea or dyspareunia, the majority of women with CPP reported using self-medication for their pain, mostly in the form of OTC analgesics (71%).

The findings from the survey, supported by a comparison with the MediPlus results, showed that the majority of women do not seek medical advice for their symptoms. Of those who seek advice in primary care, most are not referred to a specialist. Women seen in secondary and tertiary care can therefore be regarded as the 'tip of the iceberg'. However, not all women with CPP may suffer to the same extent from their symptoms. Indeed, the survey results presented in Chapters 6 and 7 showed large differences between CPP cases in terms of associated symptoms, pain severity, use of health care, and functioning and well-being.

For the purpose of the study, CPP cases were grouped (as objectively as possible) according to their relative 'pelvic pain burden' in terms of cumulative pain duration in the last 12 months: 'short', 'intermediate', and 'long'. Based on approximate tertiles, this grouping was arbitrary and had no particular clinical relevance. Women with CPP of 'short' duration typically had 3-10 episodes lasting an hour or less, those with 'intermediate' duration had 3-10 episodes lasting a few hours to 1 day, and those with 'long' duration had more than 6 episodes that lasted at least 2 days.

Comparing CPP cases of 'short' vs. 'long' duration, prevalence rates of associated symptoms in the last 12 months increased from 86% to 93% for dysmenorrhoea, from 46% to 64% for dyspareunia, from 33% to 47% for IBS, and from 15% to 35% for genito-urinary symptoms. Measured using a VRS, VAS, and the multidimensional SF-McGill pain questionnaire, the severity of pain experienced in CPP and associated dysmenorrhoea (but not dyspareunia) also increased with cumulative CPP duration.

These differences in associated symptoms and pain severity were reflected in the use of health care related to pelvic pain. From ‘short’ to ‘long’ CPP duration, the percentage consulting a GP in the last 12 months rose from 17% to 51%, consulting a specialist from 6% to 19%, and consulting an alternative therapist from 2% to 18%. Medication use rose from 60% to 87%, and use of other treatments from 12% to 21%. Furthermore, compared to women with ‘short’ CPP duration, women in the ‘long’ duration group were twice as likely to have ever undergone an investigation (48% vs. 23%) or to have received a diagnosis (73% vs. 36%), and four times as likely to have had a laparoscopy (17% vs. 5%) or a hysterectomy (9% vs. 2%).

All these observations suggested that some women with CPP would be much more affected than others in terms of associated functioning, or that some would be better able to cope with their symptoms, or both. CPP-associated functioning and well-being were therefore investigated in Chapter 7, through the assessment of general health status, sleep quality, absence from work, limitations due to pelvic pain, and most troubling aspects of pelvic pain.

The health status of women with CPP (as measured on the SF-36) was worse than that of women with dysmenorrhoea or without any pelvic pain, but differences were greater in terms of mental component scores than physical component scores. Women with CPP also reported a worse quality of sleep and more absence from work both in general and for pelvic pain, and more frequently reported a limitation due to pelvic pain or a troubling aspect of pelvic pain. In general, no such differences were observed in a comparison between women with CPP and those with dyspareunia.

Interesting differences in functioning and well-being emerged, however, between different CPP cases. Women with ‘long’ CPP duration were most affected in terms of all physical and mental health status outcomes described above. However, women with ‘short’ CPP duration did not appear more physically impaired than women with dysmenorrhoea

alone: their physical component scores on the SF-36, frequency of pelvic pain-related absence from work, and reported limitations due to pelvic pain were very similar in both groups. This was consistent with the lack of difference in pain severity and use of health care found previously. At the same time, however, women with ‘short’ duration CPP were characterised by lower mental component scores on the SF-36, a higher frequency of comorbidity and general absence from work, and a somewhat worse quality of sleep than dysmenorrhoea controls. Furthermore, a high percentage reported worrying about the pain (mainly its cause) as its most troubling aspect.

In short, the results of Chapter 6 and 7 showed that there was substantial variation between CPP cases in the degree to which they were affected by their pain in physical terms, but that women with a relatively small CPP burden were as anxious about their condition as those more seriously affected. This emphasises the need for better information about CPP, and – perhaps most importantly – reassurance as to its possible causes. Qualitative research into the information needs of women is currently underway in Oxford.

The final chapter of this thesis described an investigation into possible factors associated with the risk of CPP, using the survey data. In view of the difficulties in assessing risk-factors for CPP in general (due to its likely multifactorial aetiology) and the constraints imposed by the cross-sectional design of the study, this investigation was performed for hypothesis-generating purposes only.

Interesting associations with risk of CPP (after adjustment for potential confounders) were found for the exposure variables: age, ethnicity, height, condom use, and to some extent IUCD use. No simple pattern with age emerged, with the largest risks of CPP found for women aged 26-30, 36-40, and 41-45. Risk of CPP was approximately 3 times lower in non-Caucasian compared to Caucasian women; however, this result should be interpreted with caution in view of the small numbers of non-Caucasian women in the study. Tall height (≥ 1.70 meters) was associated with an increased risk, an association that might have been

due to uncontrolled confounding but otherwise remained unexplained. Past condom use compared to never use was associated with an increased risk. Speculative explanations for this result could be the inconsistent use of this method combined with a higher frequency of unprotected intercourse, or inadequate control for OC use. Past IUCD use vs. never use was associated with a marginally elevated risk, which was an interesting result in view of its potential role in PID aetiology.

Other variables associated with risk of CPP (which could either be regarded as exposures affecting CPP risk or the result of CPP or an underlying condition) were smoking status, menstrual patterns, and sub-fertility. The marginally elevated risk of CPP in smokers was limited to ex-smokers alone, suggesting that women with CPP were more likely to give up smoking. Irregular periods (more or less frequent than every 3-5 weeks), long periods of bleeding (7 days or more), and ever having had an episode of sub-fertility were associated with increased risk of CPP. These results may have reflected the presence of underlying conditions contributing to abnormal menstrual characteristics, reduced fertility, and pelvic pain.

9.2 Recommendations for further research

The work described in this thesis has answered some important questions regarding the epidemiology of CPP. However, it has also highlighted various areas of research that remain to be explored.

For the MediPlus analysis, a cohort of 5,051 incident CPP cases was identified who were followed from their first pelvic pain contact with a GP. At the time of analysis, the data available for follow-up covered 3.5 years on average. While a quarter of women continued to have symptoms until the end of the available data, a substantial proportion had not received a diagnostic label and the majority had not been referred. Continued follow-up of these women

would provide detail of diagnostic and referral patterns in the longer term. Currently, such an analysis would increase the follow-up time two-fold.

The information collected in the community survey on pelvic pain-related use of health care did not allow an economic analysis of associated cost. Using MediPlus, cost of prescriptions for CPP could be calculated, but the less complete hospital-related information may not allow an accurate calculation of cost associated with procedures and hospitalisation. Economic cost of CPP should therefore be investigated in a separate survey, assessing the use of health care in more detail and validating the information against medical records.

CPP-related functioning and well-being were investigated using the SF-36. As this is a generic health status measure, it may not have been sufficiently sensitive to tap all relevant areas of health status affected by CPP. The development of a CPP-specific measure is currently being planned. This will be particularly important in the evaluation of outcomes following new treatment strategies for CPP in the future.

Another area of research that is currently underway is the needs assessment of women at different stages in the diagnostic process of CPP. The community survey showed a high level of anxiety regarding symptoms in all women with CPP, in particular about its cause. Improved information giving, therefore, is an important aim, the implementation of which should not be limited to secondary or tertiary care but extended to primary care.

A final area of research is the furthering of knowledge regarding causation mechanisms of CPP. As outlined in Chapter 1, this is highly complicated. The development of non-invasive diagnostic tools for conditions such as endometriosis and PID will be an important step forward. This will allow a better investigation of the relative importance of these conditions in women with CPP and of the individual risk-factors associated with these conditions. The influence of psychosocial variables on CPP should, however, not be ignored, and remains to be appropriately investigated in a prospective study.

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Appendix I. The MediPlus analysis: codes included in groups A to D for the selection of CPP cases

<u>Group A: Specific codes indicating pelvic pain</u>		<i>(group B continued)</i>	<i>(group B continued)</i>	<i>(group D continued)</i>	
.R909	Suprapubic pain	.I5Z.	Non-infective GIT inflam. NOS	.79U2	Laparotomy: peritoneal drainage
.R90A	Pain in right iliac fossa	.I62.	Diverticular disease	.79U3	Laparotomy: FB removal
.R90B	Pain in left iliac fossa	.I621	Diverticulitis	.79U4	Laparotomy: perit. adhesions divide
.J691	Dyspareunia - non psychogenic	.I622	Diverticulosis	.79U5	Laparotomy: site re-opened
.J693	Mittelschmerz - ovulation pain	.I62Z	Diverticular disease NOS	.79UZ	Laparotomy NOS
.J694	Dysmenorrhoea - non psychogenic	.I63.	Constipation - functional	.7C2.	Oophorectomy/ovarian excision
.J696	Pelvic congestion syndrome	.I64.	Irritable bowel syndrome - IBS	.7C21	Ovarian cystectomy
.J5..	Female pelvic inflammatory diseases	.I65.	Functional GIT disorder NOS	.7C23	Partial oophorectomy
.J51.	Pelvic inflammatory disease (PID)	.I65Z.	Functional GIT disorder NOS	.7C24	Partial oophorectomy
.J511	Acute salpingitis/oophoritis	.I6Z.	GIT disorders NOS	.7C25	Unilateral oophorectomy
.J512	Chronic salpingitis/oophoritis	.I6ZZ	GIT disorders NOS	.7C26	Bilateral oophorectomy
.J513	Salpingitis/oophoritis NOS	.J26.	Cystitis	.7C27	Unilateral salpingo-oophorectomy
.J515	Acute pelvic inflammatory disease NOS	.J261	Acute cystitis	.7C28	Bilateral salpingo-oophorectomy
.J51Z	Pelvic inflamm. disease NOS	.J262	Chronic cystitis	.7C29	Remaining ovary + tube removed
.J5Z.	Female pelvic inflamm. dis. NOS	.J26Z	Cystitis NOS	.7C2Z	Oophorectomy NOS
.1977	Right iliac fossa pain	.J6..	Other female genital disorders	.7C36	Ovarian adhesions freed
.1978	Left iliac fossa pain	.J69.	Female genital symptoms NOS	.7C4.	Salpingectomy
.1979	Suprapubic pain	.J69Z	Female genital symptoms NOS	.7C41	Fallopian tube lesion excision
.197C	Lower abdominal pain	.J6Z	Female genital disorders NOS	.7C42	Fallopian tube lesion destruct
.1A59	C/O pelvic pain	.JZ..	Genitourinary disease NOS	.7C45	Total unilateral salpingectomy
.25C8	O/E abdominal pain - R. Iliac	.J7..	Menstruation disorders	.7C46	Total bilateral salpingectomy
.25C9	O/E adominal pain - hypogastrium	.J74.	Menstrual disorders NOS	.7C47	Remaining fallopian tube removed
.25CA	O/E abdominal pain - L. Iliac	.J74Z	Menstrual disorders NOS	.7C4Z	Salpingectomy NOS
.25D8	O/E guarding - R. Iliac	.J7Z.	Menstruation disorders NOS	.7CB.	Hysterectomy
.25D9	O/E guarding - hypogastrium	.R90.	Abdominal pain	.7CB2	Total abdominal hysterectomy
.25DA	O/E guarding - L. Iliac	.R900	Acute abdomen	.7CB3	Vaginal hysterectomy
.25E8	O/E rebound - R. Iliac	.R901	Abdominal tenderness	.7CB4	Radical abdominal hysterectomy
.25E9	O/E rebound - hypogastrium	.R902	Abdominal - colic	.7CB5	Radical vaginal hysterectomy
.25EA	O/E rebound - L.Iliac	.R903	Colic	.7CB7	Total hysterectomy & B.S.O.
.2689	Cervical excitation present	.R905	Cramps, abdominal	.7CBZ	Hysterectomy NOS
<u>Group B: Less specific abdominal pain/ symptom codes</u>		.R90Z	Abdominal pain NOS	.8H48	Gastroenterological referral
.A1..	Intestinal infectious diseases	.R9Z.	Abdomen/pelvis sympt. NOS	.8H49	Psychiatric referral
.A12.	Viral + ill-defined GIT infections	.R9ZZ	Abdom./pelvic symptoms NOS	.8H51	General surgical referral
.B28.	Uterine fibroids	.R9...	Other sympt. abdomen/pelvis	.8H58	Gynaecological referral
.B29.	Benign ovarian tumour	.19..	Gastrointestinal symptoms	.8H5B	Referred to urologist
.E483	Psychogenic GIT symptoms	.1962	Colicky abdominal pain	.8H69	Refer to pain clinic
.E484	Psychogenic GU symptoms	.1963	Non-colicky abdominal pain	.8HJ6	Gynaecological self-referral
		.1967	Abdominal migraine - symptom	.8HJ2	General surgical self-referral
		.1968	Abdominal discomfort	.8HJF	Urology self-referral
		.1969	Abdominal pain		
		<u>Group C: Diagnoses potentially related to pelvic pain</u>			
		.I6Z1	Peritoneal adhesions	.7C4Z	Salpingectomy NOS
		.J516	Female peritoneal adhesions	.7CB.	Hysterectomy
		.J61.	Endometriosis	.7CB2	Total abdominal hysterectomy
		.J63.	Ovarian cysts	.7CB3	Vaginal hysterectomy
		.J631	Follicular cyst of ovary	.7CB4	Radical abdominal hysterectomy
		.J632	Corpus luteum cyst	.7CB5	Radical vaginal hysterectomy
		.J63Z	Ovarian cyst NOS	.7CB7	Total hysterectomy & B.S.O.
		<u>Group D: Procedures/referrals possibly related to pelvic pain:</u>			
		.365.	Endoscopy: female genital tract	.7CBZ	Hysterectomy NOS
		.365Z	Endoscopy: female genital tract NOS	.8H48	Gastroenterological referral
		.366.	Endoscopy + puncture/incision	.8H49	Psychiatric referral
		.3667	Laparoscopy/peritoneoscopy	.8H51	General surgical referral
		.3668	Operative enteroscopy	.8H58	Gynaecological referral
		.366Z	Operative endoscopy NOS	.8H5B	Referred to urologist
		.79U	Laparotomy	.8H69	Refer to pain clinic
		.79U1	Laparotomy: exploratory	.8HJ6	Gynaecological self-referral

Appendix II. The MediPlus analysis: exclusion criteria for cases and contacts on the basis of associated codes

Exclusion	Condition: if....	Relevant codes	
1. All cases	a code at any contact indicated: 1. a malignancy in abdominal region, or 2. a defined (inflammatory) disorder of the gastrointestinal tract (GIT)	Malignancies .B12. - .B12Z .B13. - .B13Z .B14. - .B14Z .B15. - .B15Z .B17. - .B17Z	Inflammatory bowel disease/GIT disorders .I2 (etc) Oesophag/stomach/duoden disease .I5 (etc) Non-infective enteritis/colitis .I7 (etc) Liver/biliary/pancreas+GIT NOS
2. any contact (A-D)	a code was registered at the contact indicated: 1. pregnancy 2. abdominal operation for acute condition	Pregnancy .1514 .27...-27Z. .584.-.584Z .6166 .6174 .62.. - 63Z. .67A.-.67AZ .6776 .K.(etc)	Abdominal operations .79F. - .79FZ .79M. - .79MZ .79O. - 79OZ Appendix operations Cholecystotomy - GB incision Biliary tract excision/repair
3. a 'B' or 'D' contact	a code was registered at the contact indicated: 1. irrelevant location of symptoms 2. only irrelevant medication (for codes see next page).	Irrelevant location of symptoms Endoscopic oesophagus biopsy Endoscopic stomach biopsy Surgical biopsy - stomach Surgical biopsy - small intest. Direct oesophagoscopy Direct gastroscopy Gastroscopy via stoma Duodenoscopy Upper GI endoscopy Indigestion symptoms Biliary colic Central abdominal pain Epigastric pain Upper abdominal pain Renal colic Lumbar ache - renal	25C2 25C3 25C4 25C5 25C6 25C7 25D2 25D4 25D7 25E2 25E7 .R71.-Z .R906 .R907 .R908 .R90C O/E - abd. pain - R. hypochondrium O/E - abd. pain - epigastrium O/E - abd. pain - L. hypochondrium O/E - abd. pain - R. lumbar O/E - abd. pain - umbilical O/E - abd. pain - L. lumbar O/E - guarding - R. hypochondrium O/E - guarding - L. hypochondrium O/E - guarding - L. lumbar O/E - rebound - R. hypochondrium O/E - rebound - L. Lumbar Heartburn Epigastric pain Umbilical pain Hypochoondrial pain Loin pain
4. a 'D' contact	a referral code was registered for a condition unrelated to the abdominal area	.8H51	Example of referral for unrelated condition General surgical referral for Breast lump

Appendix II (continued)

Irrelevant medication

A01A0	Stomatologicals	A15A0	Appetite stimulants	D03A0	Wound healing agents	K05A3	Citrates
A02A1	Plain antacids	B01A0	Anticoagulants non inject	D04A0	Topical antipruritics	K05A9	Oth irrigating solutions
A02A3	Antacids+antispasmodics	B01B2	Fractionated heparins	D05A0	Top A-psoriasis+sim prds	L02B1	Cyto anti-oestrogens
A02A4	Antacids+antiflatulents	B01C0	Platelet aggreg inhibitors	D06A0	Top antibiotic/sulpha plain	L04A0	Immunosuppressive agents
A02A5	A-Acid + A-Flat + A-Spasm	B02A1	Synthetic antifibrinolytc	D06D0	Topical antivirals	M01C0	Spec antirheumatic agent
A02A6	Antacids+other drugs	B02G0	Haemostyptics	D07A0	Top. corticosteroids plain	M02A0	Antirheumatics topical
A02B1	H2 antagonists	B03A1	Iron plain	D07B1	Top ster+antibacterials	M03A0	Muscle relaxants, peripher
A02B2	Acid pump inhibitors	B03A2	Iron combination products	D07B2	Top steroids+anti-fung	M03B0	Muscle relaxants, central
A02B3	Prostaglandin A-ulcerants	B03X0	Oth anti-anaem+folic acid	D07B3	Top ster+antibact+antifung	M04A0	Anti-gout preparations
A02B4	Bismuth antiulcerants	B04A2	Fibrates	D07B4	Oth corticosteroid comb	M05B0	Bone calcium regulators
A02B9	All other antiulcerants	B04A3	Ion-exchange resins	D08A0	Antiseptics+disinfectants	N01B0	Anaesthetics local
A03F0	Gastroprokinetics	B04B0	Anti-atheroma nat origin	D10A0	Topical anti-acne preps	N02C0	Anti-migraine preps
A04A9	Other antiemet&antiaus	C01A1	Cardiac glycosides plain	D10B0	Oral anti-acne preps	N03A0	Anti-epileptics
A05A2	Bile stone therapy	C01B0	Antiarrhythmics	D11A0	Other dermatological prep	N04A0	Anti-parkinson preps
A07A0	Anti-infective antiidiarr	C01C1	Cardiac stm ex dopam agts	G01D0	Gynaecolog. antiseptics	N05A0	Neuroleptics
A07B0	Intest. absorbant antiidiar	C01E0	Nitrites and nitrates	G02B0	Topical contraceptives	N06C0	Psycholeptic-anti-depress
A07E0	Intestinal anti-inflamm	C02A1	Antihypert pl mainly cent	G03A9	Schering PC4	N07A0	All other CNS drugs
A07G0	Oral electrolyte replacer	C02A2	Antihypert pl mainly peri	G03G0	Gonadotrophins	N07B0	Antismoking products
A07H0	Motility inhibitors	C03A1	Pot sparing agents plain	H02A1	Inj corticosteroids plain	N07C0	Antivertigo products
A08A0	Antiobesity preparations	C03A2	Loop diuretics plain	H02A2	Oral corticosteroid plain	P01B0	Anthelmintics
A09A0	Digestives inc enzymes	C03A3	Thiazides+analogues plain	H02A3	Oth sys corticostero pln	P01D0	Anti-malarials
A10A1	Insulins human	C03A4	Pot sparing+loop diur com	H03A0	Thyroid preparations	P01E0	Scabicides & ectoparasit.
A10B0	Oral antidiabetics	C03A5	Pot sparing+thiaz combs	H03B0	Anti-thyroid preparations	R01A1	Nasal cortic W/O anti-inf
A11A1	Mvit+min prenatal	C04A1	Cereb/periph vasotheraps	H04D0	Anti-diuretic hormones	R01A3	Nasal cortic W anti-inf
A11A4	Mvit+min others	C04A2	Ca antag W cerebral activ	J04A0	Drugs for tuberculosis	R01A4	Anti-infectives nasal
A11B2	Mvit W/O min paediatric	C05A1	A-haemorrhoid + corticoid	J05A0	Systemic antivirals	R01A6	Nasal a-allergic agents
A11B4	Mvit W/O min others	C05A2	A-haemorrhoid W/O cortic	J07A1	Grippe (influenza)	R01B0	Systemic nasal preps
A11D1	Vit B1 pln or with B6,B12	C05B0	Varicose therapy, topical	J07A2	Tetanus	R02A0	Pharyngeal preparations
A11E1	Vitamin B complex plain	C05C0	Varicose therapy, systemic	J07A3	Hepatitis	R03A1	B2-stimulants inhalants
A11E2	Vitamin B complex + vit C	C06A0	Oth cardiovascular prods	J07A4	Typhoid and paratyphoid	R03A2	B2-stimulants, systemic
A11F0	Vitamin B12 plain	C07A0	Beta blocking agent plain	J07A7	Pneumonia	R03B2	Xanthines, systemic
A11G1	Vitamin C Plain	C07B1	Hypotensive/diuretic comb	J07A9	Other single comp. vaccin.	R03C1	N-S resp a-inflamm inhal
A11H2	Vitamin B6	C08A0	Calcium antagonist plain	K02C0	Gelatin solutions	R03D1	Corticoids inhalants
A12A0	Calcium	C09A0	Ace inhibitors plain	K04B1	Standard solns (<=20 ml)	R03H2	Oth bronchodil systemic
A12B0	Potassium	D01A1	Topical dermat antifungal	K04D0	Oth inj sol/inf ad<=100 ml	R05C0	Expectorants
A13A2	All other tonics	D02A0	Emollients & protectives	K05A2	Saline	R05D1	Antitussives plain

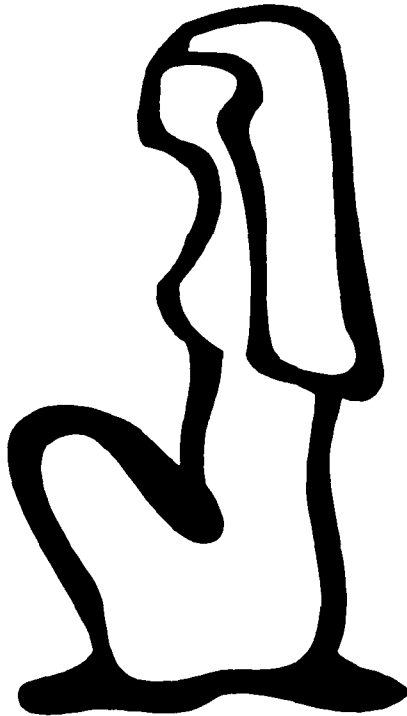
Appendix II (continued)

<i>Irrelevant medication</i>			
R05D2	Other cough sedatives	Y03A2	Non drainable pouches
R06A0	Antihistamines systemic	Y03A3	Urostomy pouches
S01A0	Anti-infectives-eye	Y03C1	Creams/gels/deod
S01B0	Corticosteroids eye	Y03C3	Night drainage bags
S01E2	Miotics+antiglaucoma top	Y03C4	Appliance covers
S01G0	No.specific conjunctivit.	Y03C5	Other accessories
S01K0	Artif. tears+ocular lubric	Y03D0	Protective dressings
S02C0	Steroid anti-infect ear	Y04A0	Intra uterine devices
S02D0	Other ear preparations	Y04B0	Diaphragms
S03C0	Steroid /A-infect eye/ear	Y05A0	Incontinence products
T02A2	Diabetes tests	Y05B4	Silicone elastom/hydrogel
T02A9	Other urine tests	Y05B5	Silicon
T02B1	Blood glucose tests	Y05B6	Others
V05A0	Surgical antiseptics	Y05C1	Leg/calf bags
Y03A1	Drainable pouches	Y05C2	Night bags
Y05E0	Accessories incontinence		
Y10A1	Liquids		
Y10A5	Peptides/amino acids		
Y10B1	Proteins		
Y10B3	Carbohydrates		
Y10B5	Triglycerides		
Y10C1	Soya products		
Y10C2	Non soya products		
Y11A1	Gluten free solids		
Y14A1	Hypoallergic tapes		
Y14A2	Non-hypoallergic tapes		
Y14B1	Sterile swabs		
Y14B2	Non-sterile swabs		
Y14B3	Swabs unspecified		
Y14C0	Sterile dressing packs		
Y14D1	Conforming bandages plain		
Y14E0	Dry non adhesive dressings		
Y14F0	S/permeable adh film drss		
Y14G0	Non medicated tulle gras		
Y14H0	Miscellaneous		
Y15A0	Adhesive bandages		
Y16A1	Closure strips		
Y17C1	Hydrocolloid dressings		
Y17D0	Alginate dressings		
Y18A1	Compression hosiery		
Y18A2	Tubular stockinettes		
Y19A0	Spacers		
Y20A0	SDA only products		
Y21A1	Dispos syringes & needles		
Y25A0	Dispos gloves		

Appendix III. The MediPlus analysis: codes indicating a specialist referral

INITIALLY SELECTED AS PART OF D GROUP		NEWLY SELECTED CODES	
Counted as separate contact	Counted only if attached to abdominal code	Counted only if attached to selected CPP contact	
.365. Endoscopy: female genital tract	.8H48 Gastroenterological referral	.5855 U-S abdominal scan	
.365Z Endoscopy: female genital tract NOS	.8H49 Psychiatric referral	.5856 U-S pelvic scan	
.366. Endoscopy + puncture/incision	.8H51 General surgical referral	.363. Endoscopy: gastrointestinal	
.3667 Laparoscopy/peritoneoscopy	.8H58 Gynaecological referral	.3637 Colonoscopy	
.3668 Operative enteroscopy	.8H5B Referred to urologist	.3638 Sigmoidoscopy	
.366Z Operative endoscopy NOS	.8H69 Refer to pain clinic	.3643 Cystoscopy	
.79U Laparotomy	.8HJ6 Gynaecological self-referral	.3651 Hysteroscopy	
.79U1 Laparotomy: exploratory	.8HJ2 General surgical self-referral	.66AF Attends out-patients	
.79U2 Laparotomy: peritoneal drainage	.8HJF Urology self-referral	.8H.. Referral for further care	
.79U3 Laparotomy: FB removal		.8H2. Emergency hospital admission	
.79U4 Laparotomy: perit. adhesions divide		.8H21 Admit medical emergency unsp.	
.79U5 Laparotomy: site re-opened		.8H22 Admit surgical emergency unsp.	
.79UZ Laparotomy NOS		.8H26. Admit gynaecological emergency	
.7C2. Oophorectomy/ovarian excision		.8H3. Non-urgent hospital admission	
.7C21 Ovarian cystectomy		.8H36 Non-urgent medical admission	
.7C23 Partial oophorectomy		.8H37 Non-urgent surgical admission	
.7C24 Partial oophorectomy		.8H3B Non-urgent gynaecological admission	
.7C25 Unilateral oophorectomy		.8H3K Non-urgent urology admission	
.7C26 Bilateral oophorectomy		.8H41 General medical referral	
.7C27 Unilateral salpingo-oophorectomy		.8H5. Referral to surgeon	
.7C28 Bilateral salpingo-oophorectomy		.8HD. Refer to hospital OPD	
.7C29 Remaining ovary + tube removed		.8HE. Discharged from hospital	
.7C2Z Oophorectomy NOS		.8HE1 Discharged from outpatients	
.7C36 Ovarian adhesions freed		.8HE2 Discharged from inpatients	
.7C4. Salpingectomy		.8HJ. Self-referral to hospital	
.7C41 Fallopian tube lesion excision		.8HQ1 Refer for X-ray	
.7C42 Fallopian tube lesion destruct		.8HQ2 Refer for ultrasound investign	
.7C45 Total unilateral salpingectomy		.8HT. Referral to clinic	
.7C46 Total bilateral salpingectomy		.9N1A Seen in hospital outpatients	
.7C47 Remaining fallopian tube removed		.9ND4 X-ray report received	
.7C4Z Salpingectomy NOS		.9ND5 Consultant letter from:	
.7CB. Hysterectomy		.9ND8 I/pat discharge summary received	
.7CB2 Total abdominal hysterectomy			
.7CB3 Vaginal hysterectomy			
.7CB4 Radical abdominal hysterectomy			
.7CB5 Radical vaginal hysterectomy			
.7CB7 Total hysterectomy & B.S.O.			
.7CBZ Hysterectomy NOS			

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THE OXFORDSHIRE WOMEN'S HEALTH STUDY

CONFIDENTIAL QUESTIONNAIRE

We would like you to help with this survey by completing this questionnaire about women's health and some pain symptoms that are specific to women. This information is needed to improve the understanding of women's health issues which will allow better services to be provided to women in the long-term.

**All the information collected in this questionnaire will remain
ENTIRELY CONFIDENTIAL**

The questionnaire is divided into two sections:

- **blue:** asking general information that applies to all women, about general health, periods, childbirth, contraception and life-style and
- **yellow:** asking more specific questions about pain you might have had. If you have not been troubled much by this pain you will find yourself completing this section very quickly.

We think you will find the questionnaire interesting and easy to complete. Just tick ✓ the appropriate answers in the boxes ☐ provided.

Even if you consider yourself very healthy and have never had any of the pain symptoms we ask about, your answers are still very important to us



GENERAL HEALTH

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions please give the best answer you can and make any of your own comments if you like

1. In general, would you say your health is: (Please tick ✓ one box)
- Excellent ☐_0

Very good ☐_1

Good ☐_2

Fair ☐_3

Poor ☐_4

2. Compared to one year ago, how would you rate your health in general now? (Please tick ✓ one box)
- Much better than one year ago ☐_0

Somewhat better than one year ago ☐_1

About the same ☐_2

Somewhat worse now than one year ago ☐_3

Much worse than one year ago ☐_4

The following questions are about activities you might do during a typical day

3. Does your health limit you in the following activities?
If so, how much? (Please tick ✓ one box on each line)
- | | 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 | ☐ _0 | ☐ _1 | ☐ _2 |
| b. Moderate activities, such as moving a table, pushing a vacuum-cleaner, bowling or playing golf | ☐ _0 | ☐ _1 | ☐ _2 |
| c. Lifting or carrying groceries | ☐ _0 | ☐ _1 | ☐ _2 |
| d. Climbing several flights of stairs | ☐ _0 | ☐ _1 | ☐ _2 |
| e. Climbing one flight of stairs | ☐ _0 | ☐ _1 | ☐ _2 |
| f. Bending, kneeling or stooping | ☐ _0 | ☐ _1 | ☐ _2 |
| g. Walking more than a mile | ☐ _0 | ☐ _1 | ☐ _2 |
| h. Walking half a mile | ☐ _0 | ☐ _1 | ☐ _2 |
| i. Walking 100 yards | ☐ _0 | ☐ _1 | ☐ _2 |
| j. Bathing and dressing yourself | ☐ _0 | ☐ _1 | ☐ _2 |



4. 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 your physical health?

(please answer **Yes** or **No** to each question)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities	☐ _0	☐ _1
b. Accomplished less than you would like	☐ _0	☐ _1
c. Were limited in the kind of work or other activities	☐ _0	☐ _1
d. Had difficulty performing the work or other activities (e.g. it took more effort)	☐ _0	☐ _1

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)?

(please answer **Yes** or **No** to each question)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities	☐ _0	☐ _1
b. Accomplished less than you would like	☐ _0	☐ _1
c. Didn't do work or other activities as carefully as usual	☐ _0	☐ _1

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

(Please tick ✓ **one** box)

- Not at all ☐_0
- Slightly ☐_1
- Moderately ☐_2
- Quite a bit ☐_3
- Extremely ☐_4

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

(Please tick ✓ **one** box)

- None ☐_0
- Very mild ☐_1
- Mild ☐_2
- Moderate ☐_3
- Severe ☐_4
- Very severe ☐_5



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

(Please tick ✓ one box)

- Not at all ☐₀
A little bit ☐₁
Moderately ☐₂
Quite a bit ☐₃
Extremely ☐₄

The following questions are about how you feel and how things have been with you during the past month. For each question, please indicate the one answer that comes closest to the way you have been feeling.

(Please tick ✓ one box on each line)

9. How much time during the last month:	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?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
b. Have you been a very nervous person?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
c. Have you felt so down in the dumps that nothing could cheer you up?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
d. Have you felt calm and peaceful?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
e. Did you have a lot of energy?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
f. Have you felt downhearted and low?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
g. Did you feel worn-out?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
h. Have you been a happy person?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
i. Did you feel tired?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅
j. Has your health limited your social activities (like visiting friends or close relatives)?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅

10. Please choose the answer that best describes how true or false each of the following statements is for you.

(Please tick ✓ one box on each line)

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
a. I seem to get ill more easily than other people	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
b. I am as healthy as anybody I know	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
c. I expect my health to get worse	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
d. My health is excellent	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄



SLEEP

11. How many hours of sleep each night do you feel you personally need? hours

12. In the last 4 weeks, how many hours of sleep each night have you had on average? hours

13. How often during the last 4 weeks:

	Never	Occasionally (Less than a quarter of the nights)	Often (A quarter to half of the nights)	Usually (More than half of the nights)	Always
a. Have you had <u>difficulty falling asleep</u> ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
b. Have you <u>woken up more than once</u> in the middle of the night?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
c. Have you woken up in the morning <u>feeling tired or not rested</u> ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄

PERIODS

If you have never had periods in your whole life, please tick this box → ☐₁ and go to question 21

14. How old were you when you had your first period? years old

15. Have you had periods in the last 12 months? (*including bleeding on the Pill or Hormone Replacement Therapy*)

No ☐₀ → GO TO QUESTION 19

Yes ☐₁ → CONTINUE WITH QUESTION 16

16. In the last 12 months, how regular have your periods usually been? I had a period:

More often than every 3 weeks ☐₀

Every 3 to 5 weeks ☐₁

Less often than every 5 weeks ☐₂

I cannot say, my periods have been too irregular ☐₃

17. In the last 12 months, have you had any 'spotting' before or after a period? (*by 'spotting' we mean bleeding for which you do not need protection or which does not fill a tampon or sanitary towel*)

No ☐₀

Yes ☐₁ → If Yes: for how many days with each period? days

18. In the last 12 months, how many days have you usually bled for during a period (not including spotting)? days

5 / Please turn over →



PREGNANCY AND CHILDREN

19. Have you ever been pregnant? No ☐₀ → GO TO QUESTION 20

Yes ☐₁ → Please answer questions a to e:

- a. Have you been pregnant in the last 12 months? No ☐₀
Yes ☐₁
- b. Have you been breast-feeding in the last 12 months? No ☐₀
Yes ☐₁
- c. How old were you when you first became pregnant? years old
- d. Have you ever had an ectopic pregnancy? No ☐₀
Yes ☐₁ → How many times? times
- e. Have you ever had a miscarriage (not counting ectopic pregnancies)? No ☐₀
Yes ☐₁ → How many times? times
- f. Have you ever had a termination of pregnancy ('abortion')? *(We would like to remind you that all the information you give will remain entirely confidential)* No ☐₀
Yes ☐₁ → How many times? times
- g. How many children have you given birth to? children → IF NONE:
GO TO QUESTION 20
- h. How old were you when you gave birth to your first child? years old

20. Have you ever tried to get pregnant for more than 12 months in a row without succeeding?

No ☐₀ → GO TO QUESTION 21

Yes ☐₁ → Have you or your partner ever had any tests/investigations to find out why you were not getting pregnant?

No ☐₀ → GO TO QUESTION 21

Yes ☐₁ → What were the results of these tests?

(You can tick ✓ more than one box)

- | | |
|---|--|
| Endometriosis ☐ ₀ | Poor sperm count/quality ☐ ₅ |
| Adhesions ☐ ₁ | No cause was found ☐ ₆ |
| Pelvic inflammatory disease ☐ ₂ | I can't remember ☐ ₇ |
| Blocked tubes ☐ ₃ | Other : |
| No or irregular ovulation ☐ ₄ | <i>(please describe)</i> |

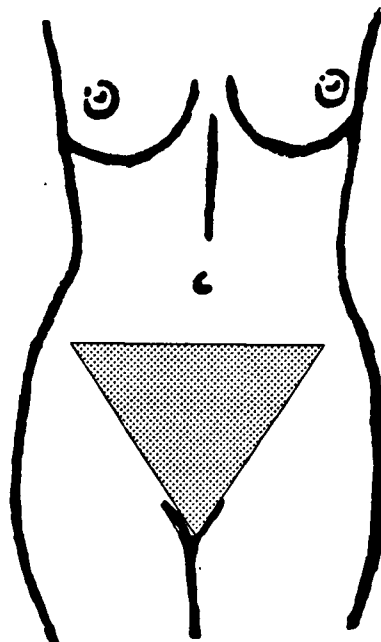


PELVIC PAIN

Even if you have never had pelvic pain please continue with the following questions and tick ✓ the answers that apply to your situation.

What is pelvic pain?

We mean any type of pain (cramping, shooting, stabbing, etc.) in the lower part of your belly (the area from your navel down) that you may have had in the last 12 months. The area is shown shaded in the following picture:



We would like to know about pelvic pain which you have had:

- with your periods (including irregular bleeding and bleeding while on the Pill or on Hormone Replacement Therapy)
- during or in the 24 hours after sexual intercourse
- at times NOT with periods or sexual intercourse (pain that you had 'on and off' or constantly in the last year)

21. In the last 12 months, have you had:

(Please tick ✓ **No** or **Yes** to each question)

- | | No | Yes |
|---|---------------------------------------|---------------------------------------|
| a. pelvic pain with your <u>periods</u> ?
(including irregular bleeding or bleeding while on the Pill or Hormone Replacement Therapy) | ☐ ₀ | ☐ ₁ |
| b. pelvic pain <u>during or in the 24 hours after sexual intercourse</u>
(If you have not had intercourse in the last 12 months please answer this question by ticking 'no') | ☐ ₀ | ☐ ₁ |
| c. pelvic pain <u>NOT with periods or intercourse</u> , either on and off or constantly? | ☐ ₀ | ☐ ₁ |

If you answered 'No' to ALL three questions:

→ GO TO QUESTION 62
(start last blue section)

Otherwise:

→ CONTINUE WITH
QUESTION 22



Questions 22 to 26 are about **painful periods** (i.e. **pelvic pain** with your periods).

22. In the last 12 months, how often have you had painful periods?

Never ☐₀ → GO TO QUESTION 27

Occasionally (with less than a quarter of my periods) ☐₁

Often (with a quarter to half of my periods) ☐₂

Usually (with more than half of my periods) ☐₃

Always (with every period) ☐₄

→ CONTINUE WITH
QUESTION 23

23. How old were you when you **first** had painful periods? years old

24. When did you **last** have a painful period?

In the last month ☐₀

Between 1 and 3 months ago ☐₁

More than 3 months ago ☐₂

25. Typically, how bad is your period pain? (please tick✓ **one box**)

none ☐₀

mild ☐₁

moderate ☐₂

severe ☐₃

26. The following line is meant to show how bad pain can be, going from 'least possible pain' to 'worst possible pain'. Typically, how bad is your period pain? (please put a mark on the line)

LEAST
possible
pain



WORST
possible
pain

Questions 27 to 36 are about **sexual intercourse** and **pelvic pain**. We would like to remind you that ALL the answers you give in this questionnaire will remain **ENTIRELY CONFIDENTIAL**.

If you have objections to completing this section, please tick this box → ☐₁, and continue with question 37

27. In the last 12 months, have you had sexual intercourse ? (by sexual intercourse we mean vaginal penetration)

No ☐₀ → If No: was **pelvic pain** the reason you did not have not have intercourse in the last 12 months?

No ☐₀ } → GO TO
Yes ☐₁ } QUESTION 37

Yes ☐₁ → GO TO QUESTION 28



28. In the last 12 months, how often have you had pelvic pain with sexual intercourse? (we mean pain during or in the 24 hours following intercourse).

Never ☐₀ → GO TO QUESTION 37

Occasionally (less than a quarter of the times) ☐₁

Often (a quarter to half of the times) ☐₂

Usually (more than half of the times) ☐₃

Always ☐₄

→ CONTINUE WITH
QUESTION 29

29. At the times you had pelvic pain with sexual intercourse in the last 12 months, when have you felt the pain?

During intercourse ☐₀

In the 24 hours after intercourse ☐₁

Both during and after intercourse ☐₂

30. How old were you when you first had pelvic pain with sexual intercourse? years old

31. When did you last have pelvic pain with sexual intercourse?

In the last month ☐₀

Between 1 month and 3 months ago ☐₁

More than 3 months ago ☐₂

32. In the last 12 months, have you had sexual intercourse less often than you wished because of pelvic pain?

No ☐₀

Yes ☐₁

33. At the times you had the pain in the last 12 months, where have you felt the pain?

At the entrance to the vagina ☐₀

Deep inside ☐₁

Both at the entrance to the vagina and deep ☐₂

34. Typically, how bad is your pelvic pain during intercourse? (Please tick ✓ one box) none ☐₀

mild ☐₁

moderate ☐₂

severe ☐₃

35. Typically, how bad is your pelvic pain after intercourse? (Please tick ✓ one box) none ☐₀

mild ☐₁

moderate ☐₂

severe ☐₃



36. The following lines are meant to show how bad pain can be, going from 'least possible pain' to 'worst possible pain'.

a. Typically, how bad is your pelvic pain **during** intercourse? (please put a mark on the line)

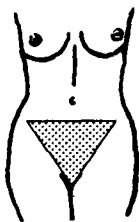
LEAST possible pain |-----| WORST possible pain

b. Typically, how bad is your pelvic pain **after** intercourse? (please put a mark on the line)

LEAST possible pain |-----| WORST possible pain

Questions 37 to 47 are about pelvic pain NOT with your periods or sexual intercourse

37. In the last 12 months, have you had pelvic pain NOT with your periods or sexual intercourse?



Just to remind you:
we mean pain in the
shaded area of the
picture

No ☐₀ → GO TO QUESTION 49

Yes, 'on and off' ☐₁ → CONTINUE WITH QUESTION 38

Yes, (almost) constantly ☐₂ → GO TO QUESTION 41

38. In the last 12 months, have you had this pain always at about the same time in your cycle?

No ☐₀

Yes ☐₁ → If yes: **When** in your cycle?

Shortly before a period ☐₀

Don't know ☐₂

Shortly after a period ☐₁

At mid-cycle ☐₂

39. In the last 12 months, how long did a typical episode of pelvic pain last?

One hour or less ☐₀

6-10 days ☐₃

A few hours to 1 day ☐₁

More than 10 days ☐₄ → if so, about how many days? days

2 to 5 days ☐₂

40. In the last 12 months, how many of these pelvic pain episodes have you had approximately?

1-2 ☐₀

3-5 ☐₁

6-10 ☐₂

More than 10 ☐₃ → if so, about how many episodes? episodes

41. How long ago did you have this pelvic pain for the first time?

Less than 3 months ago ☐₀ → GO TO QUESTION 49

3-5 months ago ☐₁

6-12 months ago ☐₂

More than 1 year ago ☐₃

_____ → GO TO

_____ → if so: how many years ago? years

QUESTION 42



42. When did you last have this pelvic pain? In the last month ☐_0
Between 1 month and 3 months ago ☐_1
More than 3 months ago ☐_2

43. Typically, how bad is your pelvic pain (not with periods or intercourse)? (Please tick ✓ **one** box)
- none ☐_0
mild ☐_1
moderate ☐_2
severe ☐_3

44. The following line is meant to show how bad pain can be, going from 'least possible pain' to 'worst possible pain'. Typically, how bad is your pelvic pain (not with periods or intercourse)?
(please put a mark on the line)



45. The following list shows some words that can be used to describe how pain feels and how severe it is. Please show how your typical pelvic pain (NOT with periods or intercourse) feels. (If you feel a word does not apply: tick 'none'. If you feel a word does apply: tick if it is 'mild', 'moderate', or 'severe').

(Please tick ✓ **one** box on each line)

	None	Mild	Moderate	Severe
Throbbing	☐ _0	☐ _1	☐ _2	☐ _3
Shooting	☐ _0	☐ _1	☐ _2	☐ _3
Stabbing	☐ _0	☐ _1	☐ _2	☐ _3
Sharp	☐ _0	☐ _1	☐ _2	☐ _3
Cramping	☐ _0	☐ _1	☐ _2	☐ _3
Gnawing	☐ _0	☐ _1	☐ _2	☐ _3
Hot-burning	☐ _0	☐ _1	☐ _2	☐ _3
Aching	☐ _0	☐ _1	☐ _2	☐ _3
Heavy	☐ _0	☐ _1	☐ _2	☐ _3
Tender	☐ _0	☐ _1	☐ _2	☐ _3
Splitting	☐ _0	☐ _1	☐ _2	☐ _3
Tiring-exhausting	☐ _0	☐ _1	☐ _2	☐ _3
Sickening	☐ _0	☐ _1	☐ _2	☐ _3
Fearful	☐ _0	☐ _1	☐ _2	☐ _3
Punishing-cruel	☐ _0	☐ _1	☐ _2	☐ _3



46. When you had this pelvic pain (not with periods or intercourse) in the last 12 months, how often:

	Never	Occasionally (Less than a a quarter of the times)	Often (A quarter to half of the times)	Usually (More than half of the times)	Always
a. did you pass urine <u>more frequently</u> <u>than usual</u> ?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4
b. did you feel ' <u>stinging</u> ' on passing urine?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4
c. was the <u>urge</u> to pass urine greater than usual?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4

47. When you had this pelvic pain (not with periods or intercourse) in the last 12 months, how often:

	Never	Occasionally (Less than a a quarter of the times)	Often (A quarter to half of the times)	Usually (More than half of the times)	Always
a. was this pain <u>relieved</u> by bowel movements?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4
b. did you have to open your bowels <u>more frequently than usual</u> ?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4
c. did you have to open your bowels <u>less frequently than usual</u> ?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4
d. did you have <u>looser</u> bowel movements?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4
e. did you have <u>harder</u> bowel movements?	☐ _0	☐ _1	☐ _2	☐ _3	☐ _4



Question 48 is about your bowel habits in general

48. In the last 12 months, how often:

	Never	Occasionally (Less than a a quarter of the times)	Often (A quarter to half of the times)	Usually (More than half of the times)	Always
a. have you had to open your bowels <u>more than 3 times a day</u> ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
b. have you had to open your bowels <u>less than 3 times a week</u> ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
c. have you had <u>loose/watery</u> bowel movements?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
d. have you had <u>hard/pellety</u> bowel movements?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
e. have you had to <u>strain</u> (make a strenuous effort) to open your bowels or to finish?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
f. have you had <u>urgency</u> (having to rush to the toilet)?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
g. have you left the toilet feeling that you had <u>not emptied your bowels</u> <u>completely</u> ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
h. have you seen <u>mucus</u> (slime) on the surface of the stool or on the toilet paper?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄
i. has your belly felt <u>bloated/distended</u> ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄



Questions 49 to 56 are about visits to doctors that you may have made and medication you may have used for **ANY TYPE OF PELVIC PAIN** (with periods, intercourse or not with either of these) in the last 12 months

49. In the last 12 months, have you seen a GP for: (Please tick ✓ **No** or **Yes** to each question)

	No	Yes	
a. pelvic pain with your <u>periods</u> ? (including irregular bleeding or bleeding while on the Pill or Hormone Replacement Therapy)	☐ ₀	☐ ₁	If you answered 'No' to ALL three questions: → GO TO QUESTION 51 Otherwise: → CONTINUE WITH QUESTION 50
b. pelvic pain <u>during or in the 24 hours after sexual intercourse</u> (If you have not had intercourse in the last 12 months please answer this question by ticking 'no')	☐ ₀	☐ ₁	
c. pelvic pain <u>NOT with periods or intercourse</u> , either on and off or constantly?	☐ ₀	☐ ₁	

50. In the last 12 months, how many times (in total) have you seen a GP for any type of pelvic pain?

- Once or twice ☐₀
3 to 5 times ☐₁
6 to 10 times ☐₂
More than 10 times ☐₃

51. In the last 12 months, have you seen a hospital doctor for:

(Please tick ✓ **No** or **Yes** to each question)

	No	Yes	
a. pelvic pain with your <u>periods</u> ? (including irregular bleeding or bleeding while on the Pill or Hormone Replacement Therapy)	☐ ₀	☐ ₁	If you answered 'No' to ALL three questions: → GO TO QUESTION 54 Otherwise: → CONTINUE WITH QUESTION 52
b. pelvic pain <u>during or in the 24 hours after sexual intercourse</u> (If you have not had intercourse in the last 12 months please answer this question by ticking 'no')	☐ ₀	☐ ₁	
c. pelvic pain <u>NOT with periods or intercourse</u> , either on and off or constantly?	☐ ₀	☐ ₁	

52. In the last 12 months, how many times (in total) have you seen a hospital doctor for any pelvic pain?

- Once or twice ☐₀
3 to 5 times ☐₁
6 to 10 times ☐₂
More than 10 times ☐₃



53. In the last 12 months, have you been given medication (drugs) for any pelvic pain by a hospital doctor?

No ☐_0

Yes ☐_1 → What medication were you given? *(please give names of products)*

.....
.....
.....

54. In the last 12 months, have you seen any other therapist for pelvic pain?

No ☐_0

Yes ☐_1 → please tick ✓ which therapists you have seen:

	No	Yes
a. Homeopath	☐ _0	☐ _1
b. Acupuncturist	☐ _0	☐ _1
c. Osteopath	☐ _0	☐ _1
d. Herbalist	☐ _0	☐ _1
e. Other:		

(please describe)

55. In the last 12 months, have you taken any pain-killers that you can buy without a prescription (e.g. aspirin, paracetamol, Nurofen etc.) to relieve your pelvic pain?

No ☐_0

Yes ☐_1 → At the times you had pelvic pain, **how often** have you taken such pain-killers?

Occasionally (less than a quarter of the times) ☐_0
Often (a quarter to half of the times) ☐_1
Usually (more than half of the times) ☐_2
Always ☐_3

56. In the last 12 months, have you used any other treatments to relieve your pelvic pain?

No ☐_0

Yes ☐_1 → please describe:.....
.....
.....
.....
.....



Questions 57 and 58 are about reasons you may have been given and tests you may have had for any type of pelvic pain (with periods, intercourse, or not with either of these) **AT ANY TIME IN THE PAST**

57. Have you ever been given a reason for your pelvic pain by a GP or a hospital doctor?

No ☐₀ → CONTINUE WITH QUESTION 58

Yes ☐₁ → Which of the following reasons were you given:

(you can tick ✓ any number)

Endometriosis ☐₀

Pelvic infection ☐₁

Adhesions ☐₂

Uterine fibroids ☐₃

Ovarian cyst(s) ☐₄

Uterine/vaginal prolapse ☐₅

Pelvic congestion ☐₆

Cystitis ☐₇

Stress ☐₈

Appendicitis ☐₉

Constipation ☐₁₀

Irritable bowel syndrome ☐₁₁

Back pain/problems ☐₁₂

Inflammatory bowel disease
(e.g. Crohn's/ulcerative colitis/diverticulitis) ☐₁₃

Can't remember ☐₁₄

Other reason(s):
.....
.....
.....
.....



58. Have you ever had any tests for your pelvic pain?

No ☐_0 → GO TO QUESTION 59

Yes ☐_1 → Have you ever had any of the following tests for your pelvic pain?
If so, please indicate if you have had one in the last 12 months, and how many of these tests for pelvic pain you have had in total (ever since you first had the pain)

	No	Yes, in the last 12 months	Yes, but not in the last 12 months	How many have you had for pelvic pain in total? ↓
a. An ultrasound scan	☐ _0	☐ _1	☐ _2	
b. An x-ray	☐ _0	☐ _1	☐ _2	
c. Surgery in which a tube was inserted into your belly (laparoscopy)	☐ _0	☐ _1	☐ _2	
d. Insertion of a tube to look inside your back- passage (sigmoidoscopy/colonoscopy)	☐ _0	☐ _1	☐ _2	
e. Other :1.....	☐ _0	☐ _1	☐ _2	
2.....	☐ _0	☐ _1	☐ _2	
(please describe)				

Questions 59 to 61 are about how you experience your pelvic pain (with periods, intercourse, or not with either of these)

59. Does your pelvic pain affect what you can or cannot do? If so, please describe.

.....

.....

.....

.....

.....

.....

.....

.....

.....

60. What troubles you most about the pelvic pain?

.....

.....

.....

.....

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.....

.....



61. If you have **any extra comments** to make about your **pelvic pain**, or if you feel you have not been able to explain your situation completely in the questions above, please give more details:

.....

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PAST MEDICAL HISTORY

62. Have you ever had any of the following operations/procedures?
If so, did you have it in the last 12 months?

	No	Yes, in the last 12 months	Yes, but not in the last 12 months
a. Surgery in which your womb was removed (hysterectomy)	☐ _0	☐ _1	☐ _2
b. Surgery in which one or both ovaries were removed	☐ _0	☐ _1	☐ _2
			If yes: Have you still got one ovary left? No Yes Don't know ☐_0 ☐_1 ☐_2
c. Surgery in which one or both tubes were removed	☐ _0	☐ _1	☐ _2
			If yes: Have you still got one tube left? No Yes Don't know ☐_0 ☐_1 ☐_2
d. Radiotherapy in the area of your belly	☐ _0	☐ _1	☐ _2
e. Other operation/procedure(s) in your belly (the area below your navel):			
1.....	☐ _0	☐ _1	☐ _2
2.....	☐ _0	☐ _1	☐ _2
(please describe)			

63. In the last 12 months, have you suffered from any serious or long-standing illnesses or disabilities?
(either physical or psychological, e.g. diabetes, cancer, heart disease, depression)

No ☐_0 → GO TO QUESTION 64

Yes ☐_1 → If so, please describe:.....

.....

.....



EMPLOYMENT AND HEALTH

64. In the last 12 months, have you been employed?

No ☐₀ → GO TO QUESTION 65

Yes ☐₁ → Please answer questions a to c:

a. In the last 12 months, how many hours a week have you gone to work on average?

..... hours a week

b. In the last 12 months, how much time have you taken off work because you did not feel well?

(Please tick ✓ one box)

No time/less than 1 day ☐₀

1-2 days ☐₁

3-5 days ☐₂

6-10 days ☐₃

More than 10 days ☐₄ → if so, about how many days? days

c. In the last 12 months, how much time have you taken off work because you had any type of pelvic pain?

(Please tick ✓ one box)

No time/less than 1 day ☐₀

1-2 days ☐₁

3-5 days ☐₂

6-10 days ☐₃

More than 10 days ☐₄ → if so, about how many days? days

HISTORY OF CONTRACEPTION

65. Have you ever been sterilised ('had your tubes tied')?

No ☐₀ → GO TO QUESTION 66

Yes ☐₁ → Please give the month and year you had the sterilisation:

...../19....
(month/year)



66. Please indicate for each of the following methods of contraception if you have **ever** used it, and if so, whether you have used it in the **last 12 months**.

(Please tick ✓ **one** box on each line)

Have you ever used:	No	Yes, in the last 12 months	Yes, but not in the last 12 months
a. The Pill?	☐ ₀	☐ ₁	☐ ₂
b. Hormonal injections (e.g. Depo-provera)?	☐ ₀	☐ ₁	☐ ₂
c. A condom?	☐ ₀	☐ ₁	☐ ₂
d. A diaphragm ('cap')?	☐ ₀	☐ ₁	☐ ₂
e. An intra-uterine device (=IUD/'coil')?	☐ ₀	☐ ₁	☐ ₂
f. Other method(s)?	☐ ₀	☐ ₁	☐ ₂
1..... →		☐ ₁	☐ ₂
2..... →		☐ ₁	☐ ₂

(if so, please describe)

HORMONE REPLACEMENT THERAPY (HRT)

67. Have you **ever** been on Hormone Replacement Therapy (HRT)?

No ☐₀ → GO TO QUESTION 68

Yes ☐₁ → Please answer questions a to d:

a. How old were you when you **first started** using HRT? years old

b. When did you **last** use HRT?

In the last 3 months ☐₀

Between 3 months and 1 year ago ☐₁

More than 1 year ago ☐₂ → If so, how many years ago? years

c. How long have you used HRT for in **total**? (If you used HRT on and off please add up all the time-periods you have used HRT for)

Less than 3 months ☐₀

3 months to 1 year ☐₁

2 to 5 years ☐₂

More than 5 years ☐₃

d. What type of HRT have you used **most recently**?

(please give product name)



LIFE STYLE

68. Do you smoke or have you ever smoked cigarettes?

No ☐₀ → GO TO QUESTION 69

Yes ☐₁ → Please answer questions a to c:

a. How old were you when you first smoked cigarettes regularly (at least once a day)?

..... years old

b. Do you currently smoke at least one cigarette a day?

Yes ☐₀ → GO TO QUESTION c

No, I smoke less than one cigarette a day ☐₁ → GO TO QUESTION 69

No, I stopped smoking ☐₂ → If so, how long ago did you stop?

In the last 3 months ☐₀

Between 3 months and 1 year ago ☐₁

More than 1 year ago ☐₂

} → GO TO
QUESTION 69

c. In the last 12 months, how many cigarettes have you smoked a day on average?

..... cigarettes/day

69. During an average week, how much do you drink of each of the following:

(Please tick ✓ one box on each line)

	None	1-3	4-6	7-10	11-15	16-20	21+
a. Beer/lager/cider (<u>half pints</u>)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
b. Sherry/vermouth/port (<u>glasses</u>)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
c. Wine (<u>glasses</u>)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆
d. Spirits/liqueurs (<u>single measures</u>)	☐ ₀	☐ ₁	☐ ₂	☐ ₃	☐ ₄	☐ ₅	☐ ₆

HISTORY OF CONTRACEPTION

70. Please state your:

a. Date of birth:/...../.....
day month year

b. Height ft inches If you prefer, you can give your height in cm: cm

c. Weight stone pounds If you prefer, you can give your weight in kg: kg



d. Present marital status: (Please tick✓ one box)

Single and living with a partner ☐_0

Married ☐_1

Single and not living with a partner ☐_2

Divorced/separated ☐_3

Widowed ☐_4



→ If one of these: do you have a partner at present?

No ☐_0

Yes ☐_1

71. What is your current employment status?

Working full-time (30 hours or more per week) ☐_0

Working part-time (less than 30 hours per week) ☐_1

Caring for home or family (not seeking paid work) ☐_2

Unemployed and looking for work ☐_3

Unable to look for work due to illness or disability ☐_4

Student ☐_5

Other:
(please describe)

72. a. What is your present or most recent occupation?.....

.....
(please write name of job and describe in a few words what this work involves)

b. In this job, are/were you: An employer ☐_0

Self-employed (without employees) ☐_1

An employee ☐_2 → if so, please tick if you were:

A supervisor ☐_0

A manager ☐_1

Neither of these ☐_2

73. a. What is your partner's present or most recent occupation? (if you do not have a partner, please continue with question 74)

.....
(please write name of job and describe in a few words what this work involves)

b. In this job, is/was your partner: An employer ☐_0

Self-employed (without employees) ☐_1

An employee ☐_2 → if so, please tick if your partner is/was:

A supervisor ☐_0

A manager ☐_1

Neither of these ☐_2



74. How would you describe your ethnic origin?

(Please tick ✓ **one** box)

Bangladeshi	☐	0	Indian	☐	5
Black African	☐	1	Pakistani	☐	6
Black Caribbean	☐	2	Other Asian	☐	7
Black Other	☐	3	White	☐	8
Chinese	☐	4	Mixed race	☐	9
Other	☐	10	→ (please describe)		

75. Please state today's date (i.e. the date on which you completed this questionnaire):

...../...../.....
day month year

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE

**If you wish, please feel free to tell us your opinion of this questionnaire and of the
Oxfordshire Women's Health Study in general:**

.....

.....

.....

.....

.....

.....

.....

**Please return this questionnaire to us in the envelope provided
No stamp is needed**





The Oxfordshire Women's Health Study

The University of Oxford

Division of Public Health and Primary Health Care &
Nuffield Department of Obstetrics and Gynaecology

Dear Ms,

We are asking for your help with a survey about the health of women in Oxfordshire and surrounding area, and would like you to complete the enclosed questionnaire. The aim of the survey is to obtain information which will improve the understanding of some pain problems experienced specifically by women, and which will enable better services to be provided for women in the long-term.

You are one of 4,000 women (a cross-section of all women aged 18 to 50 living in the area covered by the Oxfordshire Health Authority) whom we are asking to take part in the survey. We are specifically asking **all women**, including those who consider themselves very healthy and have not had any pain, to take part. Completing the questionnaire would take you about 30-40 minutes, but would be quicker if you have not had any pain.

All the information you give in the questionnaire will remain **entirely confidential**. Your results will be anonymised and grouped together with results from other women taking part. The grouped results will be published in established medical journals and presented at scientific conferences so that they can be used for the promotion of women's health. Your GP has been given general information about the survey, but he/she does not know that you have been approached to participate, nor will he/she get to know the answers you give.

You are free to decide not to take part in the survey. This would not make any difference to your normal medical care. We would very much appreciate your participation, since the information we collect will be more reliable if a lot of the women return the questionnaire.

If you choose to take part, please complete the questionnaire and return it to us in the enclosed pre-paid envelope. Feel free to make extra comments if you like. If you have any questions or problems, please contact the study co-ordinator.

Yours sincerely,

Martin Vessey
Professor of Public Health

Stephen Kennedy
Consultant Gynaecologist

Krina Zondervan
Study Co-ordinator

Address for correspondence:

Division of Public Health and Primary Health Care, University of Oxford,
Gibson Building, Radcliffe Infirmary, Oxford OX2 6HE Tel: 01865-319112



The Oxfordshire Women's Health Study

The University of Oxford

Division of Public Health and Primary Health Care &
Nuffield Department of Obstetrics and Gynaecology

MEDIA RELEASE

Date: 29 September 1997

FIRST UK STUDY INTO THE OCCURRENCE OF CHRONIC PELVIC PAIN IN WOMEN

This week, *'The Oxfordshire Women's Health Study'* is being launched by medical researchers at Oxford University. The aim of the study is to determine how many women suffer from chronic pelvic pain (CPP). This condition, defined as constant or recurrent pain in the lower part of the abdomen, probably affects millions of women world-wide and causes considerable suffering. Unfortunately, the causes of CPP are poorly understood. This study aims to improve our understanding of CPP which will lead, in the future, to better treatment.

'Clinical experience indicates that CPP results in emotional distress, relationship problems, loss of work, and reduced quality of life', according to Professor Martin Vessey, head of the Division of Public Health & Primary Health Care, who is known internationally for his research into contraception. The study investigates for the first time how many women in the general population in the UK suffer from CPP and how it affects their lives. A similar study has been done once before, recently in the USA, showing that as many as 15% of 5,000 women aged 18-50 suffered from CPP.

For the UK study, which aims to be more detailed than the American study, 4,000 women aged 18-50 and living in the Oxfordshire Health Authority region will receive a postal questionnaire. The questionnaire collects information about general health, pregnancy and childbirth, periods, contraception, life-style, and pelvic pain. A pilot study of 200 women that was carried out in the last few months showed that it is a topic perceived to be important by women: 71% of women participated and women often gave additional comments such as 'finally someone takes notice' and 'this is an excellent idea, thank you for caring'. The results of the pilot study will be combined with those of the main study.

The study is a unique collaborative project between the Division of Public Health & Primary Health Care and the Nuffield Department of Obstetrics & Gynaecology. The first results, anonymised and grouped together, will be available early/mid 1998. The information given by individual women will remain entirely confidential. All 4,000 women who are approached are asked to participate, whether they have pelvic pain or not. Only this way can the study give an accurate figure of the percentage of women suffering from CPP.

For further information:

Krina Zondervan (Study Co-ordinator)
Division of Public Health & Primary Health Care
Tel: 01865-319112

or Stephen Kennedy (Collaborating Gynaecologist)
Nuffield Dept. of Obstetrics & Gynaecology
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