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The MDOT Study:
Prevalence of Menstrual Disorder of Teenagers;
exploring typical menstruation, menstrual pain
(dysmenorrhoea), symptoms, PMS and endometriosis

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Abstract

There are few data available about the menstrual patterns of Australian teenagers and the prevalence of menstrual disorder in this age group.

Aims

- To establish the typical experience of menstruation in a sample of 16-18 year old women attending ACT Secondary Colleges of Education.
- To determine the number of teenagers experiencing menstrual disorder that could require further investigation and management.

Method

The MDOT questionnaire was used to survey participants about their usual pattern of menstruation, signs and symptoms experienced with menses and how menstruation affected various aspects of their lives including school attendance, completion of school work, relationships, social, sexual and physical activity. Data analysis included exploration of aggregated data, as well as individual scrutiny of each questionnaire to determine menstrual disturbance requiring follow up. Those participants whose questionnaire indicated a requirement for further investigation, and who consented to being contacted, were followed up through an MDOT Clinic.

Results

One thousand and fifty one (1,051) completed questionnaires - 98% response rate.

The typical experience of menstruation in the MDOT sample includes: bleeding patterns within normal parameters for this age group; menstrual pain, 94%; cramping pain, 71%; symptoms associated with menstruation, 98.4%; PMS symptoms, 96%; mood disturbance before or during periods, 73%; school absence related to menstruation, 26%; high menstrual interference on one or more life activity, 55.8%; asymptomatic menstruation, 1%; True response to ‘My periods seem pretty normal’ 71.4%.

Statistically significant associations were found between each and all of: menstrual pain, symptoms, interference on life activities and school absence. The prevalence of significant menstrual disturbance in the sample is approximately 25% where: 21% experienced severe pain; 26% reported school absence; 33% had seen a GP about periods; 26.9% think there is something wrong with periods; 23.5% require follow up based on individual scrutiny of each questionnaire; 10- 14% require further
investigation to rule out endometriosis. Referral and investigation of menstrual pain, symptoms, and diagnosis of menstrual pathology in the sample was low.

**Conclusion**

The MDOT questionnaire has helped to establish a clearer picture of typical menstruation in the population sample. Where 1% of girls reported having asymptomatic menstruation, the majority of teenagers in the study reported menstrual pain and symptoms that could be experienced as part of the dysmenorrhoeic syndrome of symptoms, PMS, or underlying pathology such as endometriosis. Due to the overlap in symptoms and a propensity to be dismissive of menstrual pain and symptoms, many girls are suffering menstrual morbidities that could be well managed with NSAIDs and the oral contraceptive pill (OCP) if non-pathological, or investigated further if a menstrual pathology is suspected.

Considering these results the reported school absence rate of 26% is not surprising. Whilst this study does not cost the true impact of menstrual disturbance on schooling, the results of the MDOT questionnaire reflect significant physical and emotional impact on a considerable number of teenager’s lives which could also have repercussions on education, schooling performance and other areas of their lives.

Future research is planned to determine the MDOT questionnaire’s validity for identifying pathological menstrual disorder so it can act as a screening tool to facilitate earlier detection. Replication of the MDOT study should be done in younger teenagers (from menarche) to determine menstrual disturbance in the younger age group.

Key words: menstrual pain, dysmenorrhoea, PMS, menstrual disorder, endometriosis, adolescence, teenagers, prevalence, screening tool.
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- My family, for understanding my passion and supporting me with their love, patience and belief in the importance of this research

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Dedication

This thesis is dedicated to all the teenagers and women around the world, diagnosed and undiagnosed, who suffer the pain and sequelae of menstrual disorder, in particular, endometriosis.
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## Abbreviations and Acronyms

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<th>Description</th>
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<tr>
<td>ACOG</td>
<td>American College of Obstetricians and Gynecologists</td>
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<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
</tr>
<tr>
<td>AUB</td>
<td>Abnormal uterine bleeding</td>
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<td>CPP</td>
<td>Chronic pelvic pain</td>
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<tr>
<td>DOB</td>
<td>Date of birth</td>
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<tr>
<td>GP</td>
<td>General practitioner</td>
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<tr>
<td>HRQL</td>
<td>Health related quality of life</td>
</tr>
<tr>
<td>IMP</td>
<td>Individual menstrual picture</td>
</tr>
<tr>
<td>MDOT</td>
<td>Menstrual disturbance of teenagers</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>OCP</td>
<td>Oral contraceptive pill</td>
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<tr>
<td>PCOS</td>
<td>Polycystic ovarian syndrome</td>
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<tr>
<td>PID</td>
<td>Pelvic inflammatory disease</td>
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<tr>
<td>PMS</td>
<td>Premenstrual syndrome</td>
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<tr>
<td>PMT</td>
<td>Premenstrual tension</td>
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<tr>
<td>SES</td>
<td>Socio-economic status</td>
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Chapter 1: Introduction

Human Development

Each human has enormous potential, most of which is probably only ever partially realized. The capacity to use all one’s faculties depends on many things including having one’s basic physical needs met, but also feeling loved and valued, and having the opportunity to express oneself in many different ways. (Herbert L. Friedman, 1999, p.1)

What is the question?

The teenage years are a physical and emotional roller coaster ride for many. During this time an adolescent girl will usually begin to menstruate. Whilst this is an exciting and significant landmark in the transition from girl to woman, the pathway can be bewildering due to the variation in symptoms associated with menstruation ranging from the physical - heavy bleeding and painful cramping, to the emotional - feeling teary, irritable or ‘down’. The experience of menstruation is not like any other previous event in a young woman’s life and there is no reference point or baseline from which to gauge the experience.

What is ‘normal’ menstruation for a teenager? What are the parameters for typical menstrual symptoms? Are the breadth and depth of symptoms experienced by teenage women the same as those experienced by adult menstruating women? On the flipside, what are the indicators of menstrual disorder in teenagers? How does a teenager know when her periods aren’t ‘normal’?

This research thesis examines the data collected through a self-reporting questionnaire from 16-18 year old teenagers attending four government secondary colleges of education (equivalent of senior high schools) in the Australian Capital Territory, to determine the typical experience of menstruation for the sample, as well as disordered menses in this age group.
**Why this research?**

A considerable amount of literature has consistently reported that the experience of pain with menstruation is common for 70-91% of teenagers (Andersch & Milsom, 1982; Hillen, Grbavac, Johnston, Stratton & Keogh, 1999; Johnson, 1988; Klein & Litt, 1981; Wilson & Keye, 1989). Also, there are a number of physical, psychological and emotional symptoms which occur premenstrually (PMS) and during menstruation which are reported by 96% of teenagers (Fisher, Trieller & Napolitano, 1989; Pennington, 1957; Wilson & Keye, 1989). Menstrual pain and symptoms cause school absence in 14-51% of teenagers (Andersch & Milsom, 1982; Johnson, 1988; Klein & Litt, 1981; Tepari & Rimpela, 1989; Widholm, 1979; Wilson & Keye, 1989) and interference in life activities for 15-59% (Andersch & Milsom, 1982; Hillen et al., 1999; Johnson, 1988; Wilson & Keye, 1989).

A large number of teenage girls, 38-71%, have reported taking medications for pain and symptoms experienced before and during menstruation (Andersch & Milsom, 1982; Fisher et al., 1989; Hillen et al; Johnson, 1988; Wilson & Keye, 1989), however, their lack of knowledge about appropriate and effective use of medications has been highlighted (Hillen et al; O'Connell, Davis & Westhoff, 2006).

Public perception of menstrual pain as a normal part of menstruation seems to persist with only 16-22% of girls consulting doctors about their period pain (Andersch & Milsom, 1982; Hillen et al; Johnson, 1988; Klein & Litt, 1981). O'Connell et al., (2006) found medical consultation to be low in a sample of teenage girls with moderate to severe menstrual pain (N=76), where only 37% had seen a doctor and 22% had seen a nurse.

Currently, non-steroidal anti-inflammatory drugs (NSAIDs) are considered the analgesia of choice for period pain (Zhang & Li, 1998), yet only 30% of girls who had consulted a doctor or nurse regarding menstrual pain had been advised to use a NSAID (Hillen et al.). While clinicians have been criticized in the past for being dismissive of period pain (Gardner, 1983), Hillen et al., suggest that the medical profession has advanced in its understanding and treatment of menstrual pain. While this may be true for some clinicians, continuing problems lie in the confusion caused by varying terminology surrounding menstrual pain. Terms include: primary and
secondary dysmenorrhoea, spasmodic (cramping) dysmenorrhoea, 'dysmenorrhoeic symptoms' and dysmenorrhoea syndrome which includes other symptoms associated with painful menstruation. The lack of a universal definition of menstrual pain creates confusion about what type, amount or frequency of menstrual pain is considered to be normal and when further investigation or referral is required (Hillen et al.).

Of great concern is that in a number of girls experiencing menstrual pain and symptoms, there is underlying pathological menstrual disorder which presents similarly to non-pathological menstrual pain and symptoms. Emerging from the literature on menstrual pain is consistent research which says that approximately 50-70% of adolescents with severe menstrual or pelvic pain, or pain and symptoms that are not responsive to NSAIDs or OCPs (oral contraceptive pill), are found to have endometriosis (Bullock, Massey & Gambrell, 1974; Goldstein, Cholnoky & Emans, 1980; Laufer, Goitein, Bush, Cramer & Emans, 1997; Missmer & Cramer, 2003; Reese, Reddy & Rock, 1996).

The combination of questionable aetiology, difficulties in diagnosis and treatment, and the absence of a cure, make endometriosis one of the most challenging diseases of our time. Failure to diagnose symptomatic progressive endometriosis early has serious implications for a girl's well being and quality of life during the teenage years as well as her potential to bear children should she wish to (American College of Obstetricians and Gynecologists {ACOG}, 2005; Ballwegg, 2003; Cramer & Missmer, 2002; Goldstein et al., 1980; Laufer, Sanfilippo, & Rose, 2003).

The global diagnostic delay for endometriosis of 6-11 years has been well researched (Arruda, Petta, Abrao & Benetti-Pinto, 2003; Dmowski, Lesniewicz, Rana, Pepping, & Noursalehi, 1997; Hadfield, Mardon, Barlow & Kennedy, 1996; Husby, Haugen & Moen, 2003;). The medical profession continues to see the impact of delayed diagnosis where some teenagers and women experience extensive disease progression that can lead to infertility, bowel or ureteric obstruction, pneumothorax, and severe debilitation to all areas of a woman’s life (ACOG, 2005; Reese et al., 1996; Stavroulis, Saridogan, Creighton, Cutner, 2006). Two-thirds of women with
endometriosis report commencement of symptoms prior to the age of 20 years (Ballwegg, 2003).

There is a paucity of Australian data that explores those teenagers with significant dysmenorrhea and symptomatology that warrants further investigation to confirm the presence, or absence of endometriosis. Concern about the high morbidity associated with teenage menstruation as well as the need for earlier screening and detection of endometriosis in teenagers is the reason why the MDOT study was conducted.

**Impact of menstrual disorder on schooling and life activities**

While there is sufficient data to confirm the negative affect that menstrual pain, symptoms and disorder have on school attendance and life activities, there is little data about the effect that menstrual disorder and school absence have on a student’s self-esteem and self-opinion of academic ability and the consequential effect these may have on academic grades.

As part of lifespan development, each adolescent faces what Hewitt and Brown (2004, p. 2) term “a unique set of temporary stressors (e.g. school grades, social pressures, awakening sexuality)” which require coping skills and mastery from an internal locus of control. According to psychosocial theory (the interaction between psychological needs and societal expectations), the number one developmental task in early adolescence (12-18 years) is ‘physical maturation’ (Newman & Newman, 1987:p33). Functional accomplishment of developmental tasks from one stage, play a major role in accomplishing the tasks of the next stage (Newman & Newman, 1987). The potential psycho-emotional impact of a complication in physical development during the teenage years, such as menstrual disorder, and the subsequent repercussions on schooling performance should not be underestimated.
Aims of the MDOT study

There has been little research into teenage menstruation and menstrual disorder in Australia. Where Hillen et al. focused their study on primary dysmenorrhoea (period pain without underlying pathology) the MDOT study has sought to establish the prevalence of all menstrual pain and symptoms, and their resultant effect on school absence and interference on life activities. Using both aggregated data and data from individual scrutiny of each questionnaire, the MDOT study has also sought to determine the number of girls experiencing significant menstrual disturbance requiring further investigation to rule out pathological menstrual disorder. Teenage attitudes towards menstruation have also been explored. In summary, the aims of this study were to:

- Establish the typical experience of menstruation in a sample of 16-18 year old women attending ACT Secondary Colleges of education.
  Determine the number of teenagers experiencing menstrual disorder that could require further investigation and management.
Chapter 2: Literature Review

Introduction

This literature review will examine the current research surrounding teenage menstrual patterns, the reported prevalence of menstrual pain and symptoms, as well as school absence and interference in life activities caused by menstruation. Menstrual disorder, in particular endometriosis, will be explored in terms of prevalence and key issues surrounding teenagers and endometriosis, the long term prognosis and impact of endometriosis on teenagers. Finally, the nurse or midwife’s role in teenage menstrual health will be examined, as well as the importance of the MDOT research and how it contributes to the existing body of knowledge surrounding menstrual patterns and menstrual disorder in adolescence.

Literature searches were conducted at the beginning of the research project, then, before and during thesis writing. Searches were done on Medline, Pubmed, Cinahl, Cochrane and independent sites such as Science Direct, Blackwell Synergy, Ebsco and Proquest. Recent issues of journals such as the Journal of Adolescent Health, Journal of Adolescent Health Care, Journal of Pediatric Adolescent Gynecology, Fertility and Sterility, and Human Reproduction were also searched. The main search terms used were: teenage, adolescen*, mentrua*, menstrual patterns, menstrual pain, dysmenorrhoea, menstrual disorder, endometriosis, screening tool, premenstrual syndrome and chronic pelvic pain. Cultural language variations in terms and spelling, and combinations of terms were explored.

Menstruation

Menarche

Menarche is the term given to the onset of menstruation during puberty, occurring when the reproductive organs become functional (Concise Medical Dictionary, Oxford Reference Online, 2002). The onset of menstruation is governed by a girl’s general health condition, genetic, socio-economic and nutritional factors, and is coordinated by the actions of the hypothalamic-pituitary-ovarian axis (Hickey & Balen, 2003).
Coleman and Coleman (2002) compared data from eleven UK and US studies which measured menarcheal age in each decade from the 1940's through to the 1990's, and found the lowest reported menarche to be 12.5 and the highest 13.47 years for white women. Data collected in black women in 1997 and 2000 showed a lower mean age at menarche of 12.16 and 12.2 respectively, and has been found in other research (Herman-Giddens, 2006). Current literature consensus is that the average age of menarche overall, has remained constant over the past 50 years (Coleman & Coleman, 2002; Whincup, Gilg, Odoki, Taylor & Cook, 2001), with studies consistently finding 12-13 years as the norm for menarche (Adams Hillard, 2002).

However, at a micro level, Herman-Giddens (2006) points to a decrease in average menarcheal age of three months (in whites) and five months (in blacks) in two large studies that compare data over 21-25 year spans. Whincup et al., (2001) found only a slight decrease in menarcheal age of less than six months when they compared 1166 contemporary British teenagers with data from teenagers born between 1950 and 1965.

In 1986, the World Health Organisation (WHO) task force on adolescent health published a two stage Multicenter Study on Menstrual and Ovulatory Patterns in Adolescent Girls (11-15 years) and found a similar median age of menarche across the different countries included in the study which ranged from 12 years, 9 months in the Hong Kong group (n=564), to 13 years, 9 months in the Nigerian group (n=378). Interestingly, there was a discrepancy between girls in urban Columbo in Sri Lanka where the median age of menarche was 13 years, 6 months (n=803), compared to girls in Peradeniya, a rural community in Sri Lanka where the median for menarche was 14 years and 5 months (n=912).

In the study by Whincup et al., of 1166 girls aged 12-16 years, almost one girl in eight (11.8%) reported having had their first period before leaving primary school. This has implications for the provision of sanitary hygiene facilities in primary schools and the initiation of menstrual health education in primary schools, and also by health professionals who have contact with this age group. Statistical data relating to menarche in Australian teenagers was not located.
Normal patterns of menstruation

Menstruation is the term given to the shedding of the endometrium, the internal lining of the uterus, during the menstrual cycle. Menstrual effluvium is composed of blood and tissue fragments. Across the menstrual lifespan of a woman, the menstrual pattern can vary in adulthood from what it was during adolescence, and may change after a woman has given birth. Menstrual bleeding patterns vary greatly amongst women, which results in broad parameters for ‘normal’ menstruation.

Menstrual bleeding patterns are characterised (Adams Hillard, 2002) by:

- Cycle length and regularity of occurrence – number of days from the first day of bleeding from one menstruation to the first day of bleeding at the next menstruation;
- Duration of bleeding – the number of days that menstrual bleeding occurs;
- Heaviness of bleeding – usually varies between light-moderate-heavy during each day of menstruation.

Current data on menstrual bleeding patterns of teenagers are reasonably consistent. Slap (2003) suggests that while approximately 80% of cycles are irregular in the first gynaecological year, there is a predictable range of 21-45 days between menses; bleeding will usually last 2-7 days; and teenagers will average three to six pads or tampons daily. Concordantly, Adams Hillard (2002) suggests that menstruation is often irregular for the first two to three years after menarche, cycles usually range from 21-45 days, and it takes two years to establish a regular ovulation cycle after menarche. Judgments about heaviness of bleeding are more difficult to measure quantitatively and individual reports of heaviness are highly subjective (Adams Hillard, 2002).

Most teenagers will establish an individual menstrual pattern by the sixth gynaecological year, or by the age of around 19-20 years (Adams Hillard, 2002; Slap, 2003), and the cycle length by adulthood is more likely to range between 21-35 days (Adams Hillard, 2002; Greydanus & McAnarney, 1982). When menstrual bleeding patterns become altered from the usual pattern for the individual, or from the teenage parameters for ‘normal’ bleeding patterns, then investigation is required.
Menstrual pain – normal or pathological?

Defining menstrual pain

The medical term given to painful menstruation is not menstrualgia or menorrhagia as one might expect, but instead, ‘dysmenorrhoea’. ‘Dys’ meaning: abnormal; difficult; impaired, and ‘menorrhoea’ meaning: normal menstrual flow (Medlineplus Medical Dictionary, Merriam-Webster, 2005). Technically, this is not an accurate term to describe painful menstruation as menstrual flow is not necessarily abnormal, difficult or impaired when teenagers or women experience menstrual pain.

Dysmenorrhoea is further distinguished as being either, primary, secondary or spasmodic. Primary dysmenorrhoea refers to menstrual pain in the absence of an underlying pathology and is related to the fluctuation of hormones and prostaglandins experienced during menstruation (Merck Manual Online, 2006). In order to control bleeding as the endometrium comes away during menstruation, prostaglandins (produced by the endometrium) enhance vasoconstriction and myometrial contraction leading to ischaemia of the endometrial lining (Song & Advincula, 2005; Slap, 2003). The excess of prostaglandins in some women causes uterine cramping and varies from mild to severe cramping pain, this is more specifically referred to as ‘spasmodic dysmenorrhoea’.

The lack of a universal definition of menstrual pain creates confusion about what type, amount or frequency of menstrual pain can be considered ‘normal’, as opposed to that which requires further investigation or referral (Hillen et al.; Golub, Lang & Menduke, 1958).

Primary dysmenorrhoea is distinguished by Song and Advincula (2005) as pain that is associated with menstrual flow and therefore not usually present before menses begins. The term secondary dysmenorrhoea is used to describe significant period pain that is caused by an underlying pathology or disease (Schroeder & Sanfilippo, 1999). Hickey and Balen (2003) question the existence of sufficient objective evidence to distinguish primary and secondary dysmenorrhoea as distinct conditions with differing pathologies, and that there is the inherent danger of too easily misdiagnosing...
teenagers with menstrual disorder, such as endometriosis, as having ‘spasmodic’
dysmenorrhoea.

Dysmenorrhoea, as a general term, has been described by Song and Advincula (2005, p. 372) as a syndrome of symptoms associated with menstruation: “Severe, cramping pain in the lower abdomen that occurs during and/or prior to menses. Pain may occur in the lower back and upper thighs and may be associated with nausea, vomiting and headache”. The description of dysmenorrhoea as a group of associated pain and symptoms is not new as almost twenty years ago Johnson (1988) used the term ‘dymenorrhoeic symptoms’ to describe a group of symptoms that occur with menstrual pain. A number of other studies have also highlighted the occurrence of various menstrual symptoms in conjunction with menstrual pain (Andersch & Milsom, 1982; Hillen et al.; O’Connell et al.; Pennington, 1957; Wilson & Keye, 1989). Common symptoms cited with menstrual pain are nausea, vomiting, diarrhoea, stomach cramps, altered appetite, backache, fatigue, headache, dizziness and syncope.

Confusion also comes about through the crossover between these ‘dysmenorrhoeic symptoms’ included as part of the dysmenorrhoea syndrome, and those described as being part of the premenstrual syndrome (PMS). While precise delineation between the dysmenorrhoea and PMS syndromes is difficult, PMS symptoms usually start 7-10 days before menstruation and continue into the first few days of menstruation (Steiner, 2000), and most research has found that in PMS, physical symptoms are accompanied by symptoms of mood lability (Bloch, Schmidt & Rubinow, 1997; Fisher et al.; Steiner, 2000).

The Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) in the United States of America, has recognized that there is a woman’s health problem that encompasses all three concepts of dysmenorrhoea, premenstrual syndrome (PMS) and premenstrual dysphoric disorder (PMDD) which they have termed ‘Cyclic perimenstrual pain and discomfort’ (CPPD) (Sharp, Taylor, Thomas, Killeen & Dawood, 2002). However, the focus of CPPD is on non-pathological menstrual pain and symptoms, and does not attempt to identify, or address menstrual disorders. CPPD is discussed further under ‘Nursing Perspective’ in this chapter.
Another term which may be used in relation to menstrual and pelvic pain is chronic pelvic pain (CPP). It is defined in the literature as pelvic pain, continual or intermittent, lasting longer than three months and may include pelvic pain that occurs independently of menstruation or is not related to the menstrual cycle (Holland-Hall & Brown, 2004). Once again there is an overlap of symptoms where teenagers with CPP may present with dysmenorrhoea; abnormal uterine bleeding with concurrent cramping; gastrointestinal symptoms including nausea, abdominal pain, diarrhoea, constipation; and bladder symptoms (Song & Advincula, 2005).

The prevalence of CPP in teenagers is unknown (Holland-Hall & Brown, 2004). Endometriosis has been reported to occur in 25-38.3% of women with CPP (Kontoravdis, Hassan, Hassiakos, Botsis, Kontoravdis, & Creatsas, 1999; Vercellini, Fedele, Arcaini, Bianchi, Rognoni, & Candiani, 1989).

The range in terminology surrounding menstrual pain and symptomatology, as well as similar symptoms being described as part of dysmenorrhoea, PMS, CPP and endometriosis, creates confusion for health professionals who have difficulty finding the line between normal menstrual pain and symptomatology, and underlying pathological disorder, thereby risking misdiagnosis in either direction.

**Prevalence of menstrual pain in teenagers**


A study by Klein & Litt (1981) examined dysmenorrhoea in data from the National Health Examination Survey cycle III which had been collected between 1966 and 1970 in 12-17 year old American adolescents. Despite the age of the data, the large sample of 2,699 teenagers gives a picture of dysmenorrhoea and school absence at that time and the research is still cited frequently. Klein & Litt (1981) found that 59.7% (n=1611) of girls reported discomfort or pain with menstruation, and of those
who reported pain, 49% rated their pain as mild, 37% as moderate, and 14% as severe. More specifically, Klein & Litt, (1981) found that menstrual pain was reported to occur in 39% of 12 year olds increasing up to 78% in 17 year olds.

Andersch and Milsom (1982) studied a random sample of 596 urban Swedish 19 year old women and found similar reports of menstrual pain in the older aged teenagers. The prevalence of dysmenorrhoea in their sample was 72.4% and they found a high rate of reported school absence of 50.9%. Severity of dysmenorrhoea was measured in two ways, firstly using a ‘linear analogue scale’ (0= ‘no pain at all’, 10= ‘unbearable pain’), and secondly using a ‘verbal multidirectional scoring system’ which consisted of four grades ranging from ‘Grade 0: Menstruation is not painful and daily activity is unaffected’ to ‘Grade 3: activity clearly inhibited. Poor effect of analgesics. Vegetative symptoms (eg. headache, tiredness, nausea, vomiting, and diarrhea). Severe pain.’ When divided into mild, moderate and severe, Andersch and Milsom (1982) reported 34.3% (n=201) with Grade 1/mild dysmenorrhoea, 22.7% (n=133) with Grade 2/moderate dysmenorrhoea, and 15.4% (n=90) with Grade 3/severe dysmenorrhoea.

The Western Australian study by Hillen et al. explored the prevalence of primary dysmenorrhoea in 388, 15 to 17 year old teenagers, including prevalence, impact on schooling and life activities, and knowledge and use of effective medications for the treatment of primary dysmenorrhoea. The study found that 80% (n=309) of their sample reported dysmenorrhoea and 42% (n=162) reported restrictions of their activities in general due to dysmenorrhoea.

Andersch and Milsom (1982), Klein and Litt (1981) and Hillen et al. are consistent in their findings of 72.4%, 78% and 80% (respectively) for older teenage respondents reporting dysmenorrhoea. The number of girls who rated their pain as severe in the three studies was also similar with 14% reported in Klein and Litt (1981), and 15.4% reported by Andersch and Milsom (1982). While Hillen et al. did not report a distinction in pain severity, they did measure the effect of menstrual pain on life activities and found that 18% of girls reported restrictions longer than 48 hours on their daily activities.
The following studies measuring menstrual pain in teenagers were located in the literature. Some of the studies also reported associated menstrual symptoms, PMS, related school absence and interference, as well use of medications.

### Table 1. Studies on menstrual pain and symptoms in teenagers

<table>
<thead>
<tr>
<th>Author/s</th>
<th>Sample size/age</th>
<th>Menstrual pain</th>
<th>Menstrual symptoms</th>
<th>School absence</th>
<th>Medication use</th>
<th>Interference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pennington (1957)</td>
<td>1000 H.S/C</td>
<td>62%</td>
<td>95%</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Golub, Lang &amp; Menduke (1958)</td>
<td>16,183</td>
<td>67.6%</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Widholm (1979)</td>
<td>331 13-20y.o</td>
<td>56% 17-20y</td>
<td>46.7% 12.5%</td>
<td>23.4% overall</td>
<td>20.6%</td>
<td>NR</td>
</tr>
<tr>
<td>Klein &amp; Litt (1981)</td>
<td>2699 12-17y.o</td>
<td>59.7% 72% (17y)</td>
<td>NR</td>
<td>14% 50% s.p</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Andersch &amp; Milsom (1982)</td>
<td>596 19y.o</td>
<td>72.4%</td>
<td>NR</td>
<td>50.9%</td>
<td>38.2%</td>
<td>15.4%</td>
</tr>
<tr>
<td>Johnson (1988)</td>
<td>182 14-18y.o</td>
<td>72.7%</td>
<td>50%</td>
<td>45.6%</td>
<td>71.3%</td>
<td>58.9%</td>
</tr>
<tr>
<td>Wilson &amp; Keye (1989)</td>
<td>88 14-18y.o</td>
<td>91%</td>
<td>86% PMS</td>
<td>26%</td>
<td>49%</td>
<td>55%</td>
</tr>
<tr>
<td>Teperi &amp; Rimpela (1989)</td>
<td>400 12-18y.o</td>
<td>79% 77% 50%12y</td>
<td>NR</td>
<td>54% s.p</td>
<td>69% s.p</td>
<td>NR</td>
</tr>
<tr>
<td>Hillen et al. (1999)</td>
<td>388 15-17y.o</td>
<td>80%</td>
<td>61%</td>
<td>45% *</td>
<td>58%</td>
<td>48%</td>
</tr>
<tr>
<td>O’Connell, et al., (2006)</td>
<td>76 ** ≤19yrs</td>
<td>100%**</td>
<td>55%</td>
<td>39%</td>
<td>93%</td>
<td>NR</td>
</tr>
</tbody>
</table>

#NR = Not Reported

H.S/C = High School & College aged women

y.o = year old

s.p. = severe pain

m.p. = mild pain

*school activity limited

**sample = girls with moderate to severe primary dysmenorrhoea

While ‘primary dysmenorrhoea’ may be considered an unfortunate symptom of normal menstruation for many girls, the impact on school attendance, schooling performance and interference with the life activities of teenagers should not be underestimated. Despite the high number of teenagers consistently reported in the literature to be affected by dysmenorrhoea (Table 1), the literature suggests that health
professionals (particularly doctors and school nurses) in contact with teenagers do not adequately discuss menstrual pain and the use of pharmacological and non-pharmacological treatment methods to help teenagers manage the impact of ‘normal’ menstrual pain on their lives (Adams Hillard, 2002; Hickey & Balen, 2003; Hillen et al.).

Medication is commonly used by teenagers for their menstrual pain. From Hillen at al.’s reported medication use by 58% of girls with period pain, to 93% (n=71) in O’Connell et al.’s sample of teenage girls with moderate to severe dysmenorrhoea (N=76). The availability of over the counter NSAIDs and the wider use and acceptance of the OCP for primary menstrual pain has provided relief for many women and teenagers. However, Hillen et al.’s Australian research highlighted the lack of adolescent knowledge and experience with effective treatment of primary dysmenorrhoea. The recent study by O’Connell et al. also highlighted the poor use of analgesics in terms of type and quantity.

In summary, the literature consistently reports that dysmenorrhoea is common in teenagers. This may cause a propensity for health professionals to classify pain as a ‘normal’ part of menstruation, thereby being dismissive of menstrual pain, with the view that teenagers will just ‘grow out of it’. Primary health care providers should take menstrual pain seriously in order to help teenagers manage menstrual pain to minimize disruption to their lives, as well as to determine when menstrual pain requires further investigation to rule out pathology.

Indicators for pathological menstrual pain are:

- significant cyclical and acyclical pain (usually associated with other symptomatology) that is not managed with NSAIDs and OCPs;
- pain that causes significant disturbance to a teenager’s daily functioning or participation in life activities.
PMS - Premenstrual Syndrome – normal or pathological?

In 1979, Katharina Dalton M.D. published a book titled: ‘Once a Month’. On the 2nd Edition front cover (1983), there is a quote:

“At last, it has a name: PREMENSTRUAL SYNDROME For years doctors have suggested that monthly symptoms are psychosomatic. Now, finally research has proved that millions of women actually suffer from a real and treatable hormonal disorder” – Family Circle magazine.

Dalton (1983) claims the first published medical paper (in conjunction with Greene, 1953) in the British medical literature about the premenstrual syndrome. Across the North Atlantic Ocean, Frank (1931) in the USA, had long before published an article entitled ‘The hormonal causes of premenstrual tension’ (p.1053) where he stated that it was well known for ‘normal’ women to suffer minor disturbances before the onset of menses which included increased fatigability, irritability, lack of concentration and attacks of pain.

Frank (1931) also described two groups of women. In the first group, he had recognized the relationship between premenstrual pain and symptoms that were severe enough to require bed rest for one or two days, whereby pain was seen to play the predominant role. In the second group of women he described ‘grave systemic disorders’ that manifested during the premenstrual period and included epilepsy, severe asthma and suicidal tendencies. When sterilizing doses of roentgen ray was applied to the ovaries of these women, subsequent remission of the epilepsy, asthma and suicidal symptoms occurred whilst they continued to be amenorrhoeic. Amazingly, Frank (1931, p.1054) reported in a case study that blood taken at the height of ‘tension’ from the woman who was suicidal, contained ‘twice the amount of female sex hormone than normally found premenstrually’.

Compared to Frank’s premenstrual tension (PMT), the premenstrual syndrome (PMS) described by Dalton (1983) included many more symptoms experienced before and during menstruation. Although, essentially, Frank and Dalton were expressing the
same belief that PMS/PMT was an hormonal disease and should be diagnosed and treated to improve the lives of affected women. The term PMS is more commonly used in the literature, possibly because it provides a more comprehensive description of the symptoms experienced. PMS is reported to affect 75-87% of women but the more severe form – premenstrual dysphoric disorder PMDD is reported to affect 3-8% of women (Johnson, McChesney & Bean, 1988; Steiner, 2000). Diagnostic criteria for PMDD have been published in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R and DSM IV) (Steiner, 2000).

There has been a long relationship between menstrual pain and PMS in the literature, with researchers trying to delineate or establish the connection between the two. In 1963, Coppen and Kessel published a report in the British Journal of Psychiatry, that their research on ‘Menstruation and Personality’ in 500 British women had found that although dysmenorrhoea was significantly correlated with PMS “This survey provides no evidence to justify dysmenorrhoea being regarded as a psychosomatic condition or one that calls for psychological treatment” (p. 720). Historically, it took until the 1970’s for evidence to emerge that supported a physiological cause for menstrual cramping pain (Wilson & Keye, 1989).

PMS is known as a syndrome as it includes a number of both physical and psychological symptoms which occur during the luteal phase of the menstrual cycle, usually 7-10 days before menstruation and during the first few days of menstruation (Steiner, 2000) (Dalton, 1983). PMS symptoms include: fatigue, headache, backache, bloating, changes in appetite, breast tenderness, irritability, anxiety, mood lability, feeling overwhelmed and depression (Bloch et al., 1997). Dalton (1983) includes other lesser associated symptoms such as: red eye/conjunctivitis, styes, hay fever, asthma, epilepsy, hoarse throat, painful joints, swollen ankles and acne. While there may be other reasons for experiencing any of the above symptoms, in PMS, the symptoms are absent following menstruation (Dalton, 1983).

In her book, Dalton (1983, p28) describes premenstrual tiredness as being responsible ‘for the drop in mental ability before menstruation’ and may account for a 10% drop in grades during the premenstrual week compared with a rise of 20% in the week
immediately after menstruation. This is refuted by Richardson’s (1991) review of the literature on menstrual cycle and learning and his conclusion that female students have not been found to be at any considerable disadvantage when undergoing examinations during the paramenstrual period. However, Richardson (1991) does acknowledge that female students (and their families and friends) suffer considerable concern and possible distress from menstrual symptomatology.

Fisher, et al. found that premenstrual symptoms were common in their study of 207 teenagers with 96% of respondents experiencing one or more PMS symptoms. They also found that the number of PMS symptoms increased with reported severity of dysmenorrhoea and in those girls who were not taking an oral contraceptive pill (OCP). They concluded that the prevalence and severity of PMS symptoms did not differ significantly from a sample of adult women who used the same questionnaire and were from a similar socioeconomic background.

In summary, PMS is reported in the literature as occurring commonly in teenagers. PMS is experienced as part of the normal fluctuation of hormones in association with the menstrual cycle and can be treated to minimize the effect of PMS symptoms on teenager’s lives. Decisions surrounding treatment of PMS are governed by the number and severity of symptoms, and the disruption that PMS causes to life activities. Primary health care providers should also be vigilant for the small percentage of women who experience PMDD to ensure these women, including teenagers, receive appropriate treatment.

**Menstrual disorder**

**Defining menstrual disorder**

The definition of ‘disorder’ as a transitive verb means “to disturb the regular or normal functions of”, as a noun it means an “abnormal physical or mental condition” (MedlinePlus Medical Dictionary, Merriam-Webster, 2005). The question of whether menstrual pain/dysmenorrhoea is considered to be a menstrual disorder is probably governed by its severity, requirements for medication and interference on life activities. The word ‘dysmenorrhoea’ seems to imply more than just ‘menstrual pain’.
Indeed, it was proposed in older literature that use of the term ‘dysmenorrhoea’ is ‘justified’ when a woman self-medicates or consults medical personnel (Teperi & Rimpelä, 1989; Yliklorkala & Dawood, 1978). It seems that in the literature, dysmenorrhoea is commonly listed as a ‘menstrual disorder’ (Greydanus & McAnarney, 1982; McEvoy, Chang & Coupey, 2004; Walraven, Ekpo, Coleman, Scherf, Morison & Harlow, 2002).

Other menstrual disorders found in teenagers include: amenorrhoea – which usually occurs as a result of an underlying congenital anomaly or various endocrine dysfunctions; oligomenorrhoea – cycles occurring outside the usual 21-45 day cycle; Mullerian anomalies – congenital malformation of the female reproductive tract; Polycystic Ovarian Syndrome (PCOS); Pelvic Inflammatory Disease (PID); genital tract cancers; abnormal uterine bleeding (AUB) and endometriosis. (With the exception of endometriosis, definition and information on these disorders is located in Appendix 11).

Endometriosis

Historically thought of as a disease that affects adult women, endometriosis increasingly is being diagnosed in the adolescent population. This disorder, which was originally described more than a century ago, still presents a vague and perplexing entity that frequently results in chronic pelvic pain, adhesive disease, and infertility. Early diagnosis and treatment during adolescence may decrease disease progression and prevent subsequent infertility. (ACOG Committee on Adolescent Health Care, April 2005, p. 921).

What is endometriosis?

Endometriosis is a common pathology which may cause (secondary) dysmenorrhoea in adult women and teenagers (Merck Manual, 2006), and is defined as a disease where endometrial glands or stroma that usually line the uterine cavity, are found outside the uterus and on any of the organs or structures within the pelvic cavity (Whiteside & Falcone, 2003).
Active endometriosis is characterized by ectopic endometrial cells which are stimulated to bleed by the hormones of the menstrual cycle causing the formation of typical and atypical lesions, endometriomas (blood filled cysts), and adhesions. Adhesions from endometriosis and the inflammatory reaction it creates, can lead to pain, infertility and bowel obstruction (Corwin, 1997).

Paradoxically, regardless of the progression and extent of the disease, some women remain asymptomatic and do not exhibit pain symptoms. Asymptomatic women may present with infertility. The estimated prevalence of endometriosis in adult women is 10-15% (Corwin, 1997; EAPPG, 2004).

**Menstrual and symptom patterns in endometriosis.**

Women with endometriosis do not necessarily suffer from a higher prevalence of menstrual dysfunction in relation to bleeding patterns (Attaran, Falcone & Goldberg, 2002). Laufer et al. (1997) found that teenagers with endometriosis were more likely to have regular menstrual bleeding than teenagers without endometriosis. Laufer et al. (1997) propose that if retrograde menstruation contributes to the development of endometriosis then regular menses may lead to an earlier presentation of symptoms in those girls predisposed to endometriosis. Darrow, Vena, Batt, Zielezny, Michalek & Selman (1993) also found an elevated risk of endometriosis in those women under 30 years of age experiencing severe cramps whereby it was postulated that stronger uterine contractions cause retrograde flow of menstrual blood into the peritoneum which could precede the disease.

There are two menstrual risk factors for endometriosis that have been found consistently in epidemiological studies, these are early menarche deemed to be ≤ 11 years of age, and a shorter cycle length defined as ≤ 27days (Cramer & Missmer, 2002). The evidence surrounding duration of bleeding and heaviness of menstrual flow as risk factors is less consistent (Cramer & Missmer, 2002).

In early stages of symptomatic endometriosis in adults, symptom patterns are cyclical, peaking just before and at the beginning of menstruation. In progressive and severe
symptomatic disease in adult women, pain and symptoms are often present throughout
the menstrual cycle (acyclical). An interesting finding by Laufer et al. (1997) was that
90.6% of adolescents with endometriosis (N=46) experienced acyclic pain, 28.1%
(n=9) had acyclic pain only and 62.5% (n=20) had both cyclic and acyclic pain, with
only 9.4% (n=3) having cyclic pain. This finding is important because primary health
providers might only associate endometriosis with cyclic pain and therefore overlook
endometriosis as a diagnosis in those girls who experience acyclic pain (Laufer et al.,
1997).

Davis, Thillet, & Lindemann (1993), reported that all girls in their sample of
teenagers with severe dysmenorrhoea and endometriosis (N=46) stated that their
symptom complex (severe cramping and uterine pain, abdominal pain and other
associated symptoms such as gastrointestinal symptoms) was worse just before and
during menstruation.

From a registry of 4,000 women diagnosed with endometriosis from the American
Association of Endometriosis (Ballwegg, 2003) the most commonly reported
symptoms were: pain at menstruation (95%), fatigue/exhaustion (87%),
diarrhoea/painful bowel movement or other intestinal upset at time of period (85%),
abdominal bloating (84%), heavy or irregular bleeding (65%), pain with or after sex
(64%), nausea/stomach upset at time of period (64%), dizziness/headaches at times of
period (63%). When a similar survey was conducted on 3,000 women 10 years
previously, comparison of results between the two groups revealed that in the first
study only 15% of women reported their first symptoms before the age of 15,
compared to 38% in the second survey. Sixty-six percent of women in the latter
survey reported pelvic symptoms before the age of 20. The survey also revealed a
trend whereby the severity of symptoms experienced by women was associated with a
younger age at onset of symptoms (Ballwegg, 2003). There is a clear message here for
adequate investigation of menstrual and pelvic pain in teenagers.

There are genetic factors surrounding increased predisposition to endometriosis. The
risk of endometriosis recurring in first-degree relatives is 5-7% with the rate being a
little higher in mothers than for sisters, but of greater concern is that endometriosis in
women who have an affected mother or sister is more likely to be severe than mild or moderate (Simpson et al., 2003).

Relationships between immune disorders, allergies and endometriosis have also been suggested in self reported data from 4,000 women with endometriosis (from the American Endometriosis Association) where more frequent experiences of allergies to pollen (41% versus 13%), asthma (14% versus 6%) and eczema (17% versus 6%) were reported in comparison to the general population, using data from the American Academy of Allergy and Immunology (Ballwegg, 2003).

**Research surrounding teenagers and endometriosis**

In 1974, Bullock et al. published an article entitled: *Symptomatic Endometriosis in Teen-agers, A Reappraisal* which stated that medical teaching and literature proposed that endometriosis was quite rare in women younger than 20 years of age even though there were cases of endometriosis in teenagers reported in the literature as far back as 1946. The article reported on their finding of endometriosis in nine teenagers (out of 18) who had not responded to symptomatic management of menstrual pain with analgesia and OCPs.

Five years later, Birnbaum (1978) wrote a letter to the American Journal of Obstetrics and Gynecology in response to an article in a previous issue which had suggested that the failure of girls to respond to OCP for their dysmenorrhoea might indicate “an unusually large psychogenic component contributing to the pain”. He commented that in his practice, over the previous three years, four out of seven girls who had severe dysmenorrhoea had been found to have endometriosis. His view was that “endometriosis in young women is a common disease...(and that) far too many patients have been labelled as having a psychosomatic disorder when indeed they have organic disease” (Birnbaum, 1978 p.228). This view was evident in a study reported by Goldstein et al, where they found endometriosis in 66 out 140 teenagers who underwent laparoscopy for chronic pelvic pain, of which ten had been referred for psychiatric evaluation.
Goldstein et al. (1980, p. 37) also challenged the thinking surrounding the ‘typical’ patient with endometriosis who had been described as “underweight, overanxious, intelligent, well-to-do, egocentric and perfectionistic”.

Throughout the 1980’s and 1990’s a number of studies on dysmenorrhoea reported its affect on a large number of teenagers (59.7-91%), that dysmenorrhoea interfered with teenagers lives and school attendance (Klein & Litt, 1981), (Andersch & Milsom, 1982), (Johnson, 1988), (Wilson & Keye, 1989), and that a high proportion of girls, 47-73%, with severe menstrual pain or pain that didn’t respond to NSAIDS or the OCP were found to have endometriosis (Bullock et al.; Davis et al., 1993; Goldstein et al; Laufer, et al. 1997; Reese et al.). This latter finding was startling because it was much greater than the reported prevalence of endometriosis in adult women with pelvic pain which had ranged in a number of studies from 5% to 21% (Cramer & Missmer, 2002).

Australian research conducted in 1996 among Victorian GP’s (N=266) found that 35.3% thought that endometriosis was rare in teenagers, a further 9% said it did not exist in teenagers and was very rare in women aged in their 20s (Montegue & Wood, 1997). This means that close to half of the sample (44.3%) were not looking for, or thinking about endometriosis as a possible cause of dysmenorrhoea in their teenage clients.

In the new Millenium, primary and secondary dysmenorrhoea are established in the literature as causing significant health disturbance to teenage women, but there is concern over the lack of treatment knowledge (Hillen et al.) and evaluation and screening techniques to diagnose menstrual disorders in teenagers, including endometriosis (Slap, 2003), (Hickey & Balen, 2003), (Song & Advincula, 2005), (Laufer, Sanfilippo & Rose, 2003) (Attaran et al., 2002).

**Laparoscopic diagnosis and treatment of endometriosis**

Medical intervention is deemed appropriate if teenagers are experiencing interference in their usual life activities and missing school due to pain (Laufer et al, 2003). When Reese et al. conducted a retrospective review of 67 client records for 11-19 year old
teenagers who underwent laparoscopy for non-responsiveness to analgesia and OCP treatment of pelvic pain, they noted that endometriosis was found in 73% (n=49) of the sample. They also found that three quarters of the girls had not had any previous surgical procedures to investigate their pain which suggested “a lack of diagnostic aggressiveness to investigate their complaints” (p. 128).

In symptomatic endometriosis, a high index of suspicion can be established through the combination of a comprehensive history taken from the patient, charting of symptoms over time, and clinical examination that may elicit pain or reveal palpable nodes or adnexal mass/es. Endometriosis is definitively diagnosed through laparoscopy where lesions are visualized by a gynaecological surgeon, or more accurately, excised during surgery and confirmed histologically.

Endometriosis can occur anywhere in the abdominal and pelvic cavities between the diaphragm and the Pouch of Douglas. The well known, typical appearance of endometriosis is considered to be brown-black, black or puckered black, yet, it is estimated that one third of women diagnosed with endometriosis have only the atypical lesions, which may account for significant under-diagnosis (Howard, 2003). The atypical lesions are colourless, white, red, brown, yellow or angioma looking, whereby, the frequency of laparoscopically diagnosed endometriosis increases from 42-72% when the surgeon has a raised awareness of atypical lesions and liberally uses biopsy for histological confirmation (Howard, 2003). Many gynaecological surgeons are not trained to excise endometriosis and therefore do not remove atypical or suspect lesions and do not send them for histological confirmation. Over time, the process of gaining histological confirmation will assist surgeons to become more familiar with the various appearances of endometriosis.

Unfortunately, excisional surgery is often difficult and dangerous because endometriosis grows on peritoneum, pelvic and abdominal organs. Due to endometriosis and adhesions the location of nerves and blood vessels becomes altered and their appearance is often unrecognizable. Batt and Mitwally (2003), and Laufer et al., (2003), advocate the referral of teenagers to a gynaecologist who is familiar with
the appearance of endometriosis in teenagers, and comfortable with the appropriate treatment options for this age group.

Laparoscopic studies in adolescents with endometriosis have shown that endometritic lesions are more likely to be atypical with red (Davis et al.) or “clear papules, red, flame-like lesions, white lesions and glandular lesions” (Attaran & Gidwani, 2003, p 382), rather than the black lesions that are seen more commonly in older women. The chemicals active in red endometritic lesions are thought to cause greater pain and might account for the increased pelvic pain felt by adolescents (Attaran & Gidwani, 2003). Davis et al. also reported a predominance of red endometritic lesions in teenagers with the severe dysmenorrhoea symptom complex when compared to adult women, and that the red lesions were present in a high percentage of the teenagers reporting gastrointestinal symptoms.

Laparoscopies done on teenagers with endometriosis consistently reveal early stage endometriosis as classified by the American Fertility Society classification system of endometriosis, although, there are reported cases in the literature of severe endometriosis in teenagers (Laufer et al., 2003). Stavroulis et al. (2006) reported severe endometriosis in six adolescents aged between 18-20 years whereby laparoscopic resection of bowel and/or ureter was required, as well as excision of endometriosis from the rectovaginal (between the rectum and vagina) and uterovesical (between the uterus and the bladder) spaces. All of these teenagers had dysmenorrhoea and it is interesting to note that they are older teenagers.

Endometriosis is thought to be a progressive disease (Reese et al; Laufer et al., 1997) which begs the question: Would diagnosis and appropriate treatment of endometriosis at 14 years of age have prevented the need for bowel or ureteric resection at 18 or 20 years of age? There is good reason to diagnose early if it can stop progression of the disease and avoid long-term effects such as pain, adhesions, endometriomas, infiltrating nodes and masses, and infertility (Laufer et al., 2003).
Diagnostic delay

Diagnostic delay is defined as the time that elapses between onset of symptoms and the definitive diagnosis of disease. Studies from around the world consistently identify a diagnostic delay, in years, for endometriosis. An Australian study found that the diagnostic delay for endometriosis was 6.1 years (Wood, 1992, cited in Montegue & Wood, 1997). Husby, Haugen & Moen, (2003) reported a diagnostic delay of five years in Norway. Dmowski et al. (1997) reported 6.4 years in America. A study by Hadfield et al., (1996) conducted in the USA and UK reported 11.7 and 8 years respectively.

There are multiple reasons for this delay. The main ones being, the persistent misconception that endometriosis does not occur in teenagers and young women and is therefore not considered or investigated as a possibility (Laufer et al., 2003), poor awareness by health professionals of the signs and symptoms of symptomatic endometriosis (Dmowski et al.), whether pain or infertility is the presenting symptom (Arruda et al., 2003; Dmowski et al.), the delay by some women to see a health professional (Montegue & Wood, 1997), misdiagnosis, and a reluctance to laparoscope teenagers and young women (Brosens, Puttemans, Campo, Gordts, & Brosens, 2003).

Aruda, Petta Abrao & Benetti-Pinto (2003) interviewed a group of Brazilian women (N=200) with surgically confirmed endometriosis and found the median time from onset of symptoms to diagnosis of endometriosis to be seven years, with a range of 3.5-12.1 years. This study also reported a longer delay in diagnosis for younger women, with a median of 12.1 years for women ≤ 19 years and 3.3 years for women aged ≥ 30 years. This is possibly related to the traditional thinking by doctors that endometriosis occurs in women aged over 30 years (Ballweg, 2003), particularly for those ‘career women’ who had delayed childbearing. This myth was challenged by Darrow et al. (1993) when they studied characteristics of menstruation and the risk of endometriosis: “Results overall, do not support simplistic assumptions that characterize endometriosis patients as career women who voluntarily delay pregnancy.”
More alarming is the finding by Arruda et al. that there was also a difference in diagnostic delay related to the woman’s main complaint. If a woman presented with infertility, the median time period for diagnosis was shorter (4 years) than if she presented with pelvic pain (7.4 years) as her chief complaint. This study suggests that women in pain suffer almost twice as many years before they obtain a diagnosis. Dmowski et al. had a similar finding where the mean diagnostic delay for their pain group (n=357) was 6.4 years versus 3.1 years for the infertile group (n=336). The irony of this may be that if women with pelvic pain from endometriosis were diagnosed sooner, their outcomes for fertility might be improved.

Diagnostic delay of endometriosis is sometimes caused by misdiagnosis as symptomatic endometriosis includes symptoms found in areas of the body other than the reproductive organs. Endometriosis on the bowel may cause symptoms similar to irritable bowel syndrome (IBS), while endometrioma (blood filled cyst) on the ovary may be misdiagnosed as ovarian cyst (Cox, Henderson, Wood & Cagliarini, 2003). Indeed, Davis et al. (1993), report on 17 patients experiencing bowel complaints including nausea, constipation and diarrhoea that were evaluated by a gastroenterologist who did not find any organic bowel disease, yet, seven of these women had palpable rectovaginal nodes that were not visible at sigmoidoscopy. All women had been treated for IBS, although not surprisingly, none of them had shown improvement.

Lack of knowledge about the symptoms of endometriosis means that women’s symptoms will often be investigated, for example, a cystoscopy may be done for bladder symptoms, but when nothing is found because endometriosis is not usually visible from inside the bladder, the woman will be told that nothing was found and a subsequent assumption made that there is ‘nothing wrong’. The Western approach to medicine has doctors divided into specialties where there is a propensity to compartmentalize symptoms and make a diagnosis without doing an holistic assessment of the patient. Therefore women with thoracic or shoulder tip pain from symptomatic endometriosis on the diaphragm will be difficult to diagnose as a chest physician will be unlikely to ask questions about the woman’s menstrual health, and
will be unlikely to make the connection unless they are knowledgeable about endometriosis and think to look for it.

Of concern is that Ballwegg (2003) reports that with a younger onset of symptoms, there is a greater number of doctors required to be seen to obtain a diagnosis of endometriosis. Teenagers whose symptoms commenced before the age of 15 saw an average of 4.2 doctors, those aged between 15-19 years saw an average of 3.85 doctors, and women aged 30-34 years of age saw 2.64 doctors before they were diagnosed with endometriosis. Overall, 47% of women saw a doctor five times or more before being diagnosed or referred to a specialist.

Australian GP’s (N=266) were found, on the whole, to have a poor in-depth knowledge of common endometriosis symptoms (Montegue & Wood, 1997). The GP’s reported two key issues which impeded the diagnosis of endometriosis. These were the lack of a simple diagnostic clinical test (cited by 47.7% as a diagnostic barrier), and an overall lack of understanding surrounding the nature and pattern of the disease (38.0%). The fact that there was no clear and consistent symptomatology created a barrier for 41% of GP’s, and 21.8% reported difficulty with deciding when to refer.

Delayed diagnosis of endometriosis can have significant and often irreversible repercussions for teenage women, which is discussed under ‘Impact of menstrual pain, PMS and endometriosis on teenagers’.

**Impact of menstrual pain, PMS and endometriosis on teenagers**

**Impact of menstrual pain on school attendance**

While a number of studies (Andersch & Milsom, 1982; Hillen et al., 1999; Houston et al., 2006; Johnson, 1988; Wilson & Keye, 1989) have reported that dysmenorrhoea causes interference on teenagers lives in terms of participation in life activities and school attendance, little research has been done to measure the effect of dysmenorrhoea on school grades and the quality of school work presented by these
teenagers. In a study by Wilson and Keye (1989) (N=88), 55% of the girls reported that cramps affected their academic work with 26% missing classes. The literature indicates that 14-51% of teenagers take time off school related to their periods (Andersch & Milsom, 1982; Johnson, 1988; Klein & Litt, 1981; Teperi & Rimpelä, 1989; Widholm, 1979; Wilson & Keye, 1989). Smaller numbers were found by Andersch & Milsom (1982) to take time off school every period - 7.9%, and O’Connell (2006) reported 14% (of girls with moderate to severe dysmenorrhea) missing two or more days.

School absence related to menstrual pain and symptoms is a significant problem that has been inadequately addressed by families, health professionals and the education system, and accordingly, Johnson (1988) has identified it as a ‘public health problem for this age group’ (adolescents).

Of considerable concern is that the rate of school absence rises in those girls reporting severe dysmenorrhoea, where Klein & Litt (1981) reported 50%, and Teperi & Rimpelä (1989) reported 54%. Severe dysmenorrhoea has been reported to occur in teenagers at varying rates of 14-15% (Andersch & Milsom, 1982; Klein & Litt, 1981), and more recently, 23% (Fisher et al., 1989; Teperi & Rimpelä, 1989; Wilson & Keye, 1989).

**Social impact of menstrual pain**

Research suggests that while menstrual pain and symptoms cause school absence for teenagers, they also interfere with life activities. Hillen et al., found that 53% of girls with dysmenorrhoea reported interference and/or limitation of activities, 48% on sporting activities, 46% social activities, 45% said their school activities were limited and 18% reported interference longer than 48 hours. Johnson (1988) reported 58.9% of girls who said that menstrual cramps caused a decrease in their activities such as participation in sports and going out with friends. There are implications here for social and physical development in teenage girls which can affect the formation of relationships, self esteem and self-view in relation to peers, confidence in sporting activities, overall physical fitness, well-being and body weight management.
Overall impact of menstrual pain

The overall and long term impact of menstrual pain on teenagers is perhaps best summarized by Wilson and Keye (1989) who express a substantial price paid for needless suffering where some girls may develop a fear of menstruation and the thinking that they are 'sick' or less capable during menses especially if they are bedridden with pain and unable to perform at their full potential. However, the impact is not only on the teenager, Wilson & Keye (1989, p. 320) highlight the other people and roles that are affected: “Thus, all suffer – the student and her education, the athlete and her individual and team performance, the employee and her career, the mother/wife and her family, society as a whole”.

Hillen et al., (1999, p.45) also bemoan the needless impact that menstrual pain has on teenagers: “Given that simple and effective treatment is readily available, it is disturbing that dysmenorrhoea should continue to have such a negative impact on the lives of young women”.

The greatest impact of not treating menstrual pain is the risk of leaving underlying diseases (such as endometriosis, uterine anomaly, PID) undiagnosed and untreated. For the teenage girl, this creates a situation of continual menstrual distress with lack of validation of severity and impact of symptoms, possible infertility and eventual risk of surgical removal of advanced disease along with pelvic and reproductive organs (Wilson & Keye, 1989). It must not be overlooked that teenagers are a unique population of patients who are in their ‘formative years’, which has implications for functional lifespan development (Song & Advincula, 2005).

Seventy to ninety percent of teenagers report menstrual pain. Menstrual-related morbidity such as school absenteeism should be a trigger for further investigation. Primary dysmenorrhoea can usually be managed with NSAIDs and the OCP and menstrual pain that cannot be managed is usually an indication of possible disorder and should be investigated accordingly.
**Premenstrual syndrome (PMS)**

The impact of PMS on schooling and life activities of teenagers should not be underestimated. PMS symptoms can be too readily dismissed by health professionals as hormonal fluctuations and consequently ignored and not dealt with (Wilson & Keye, 1989). There has been little measurement of the impact of PMS on teenagers. From a small sample of teenagers (N=88), Wilson & Keye (1989) found that 17% (n=15) missed classes because of PMS symptoms and that 44% (n=39) reported that PMS affected their ability to concentrate, study, or take tests.

Certainly there is a sense that untreated PMS has a long term ‘flow on’ effect. Years of premenstrual depression, anxiety, irritability and fatigue erodes self-esteem, assertiveness and self-confidence which then have considerable impact on completing education, employment and career opportunities, and relationships with others (Wilson & Keye, 1989).

**Endometriosis**

The American College of Obstetricians and Gynecologists recognizes the impact of endometriosis on teenagers and has developed the following consensus statement:

> In young women, pelvic pain associated with endometriosis often interferes with school attendance as well as physical and social activities. Prompt diagnosis and adequate therapy, therefore, may return normal psychosocial development and self-esteem, improve scholastic performance, and lead to a return to normal daily activities. (ACOG Committee on Adolescent Health Care, 2005, p 922).

While there is a growing body of data on the prevalence of endometriosis in teenagers with severe dysmenorrhoea and chronic pelvic pain, little has been done to measure the impact of endometriosis on teenagers. A recent literature review on the health related quality of life (HRQL) burden for women and teenagers with endometriosis found that endometriosis was associated with significant pain and disturbance to psychological and social functioning (Gao, Yeh, Outley, Botteman, & Spalding, 2006). The review also found that appropriate and effective pharmacological and surgical treatment of endometriosis was able to improve women’s pain levels,
physical and psychological functioning, vitality and general health. However, the review also acknowledged that while disease specific instruments appeared to be more responsive to measurements of quality of life changes (Outley, Gao, Simon, Spalding & Botteman, 2006), few studies used disease specific instruments to examine the health related quality of life burden of endometriosis (Gao et al., 2006).

Overall, there was minimal literature examining the HRQL impact of endometriosis in the teenage population, there was no HRQL instrument for teenagers with endometriosis located, and the appropriateness of using the existing HRQL instruments in adolescents had not been evaluated (Gao et al.). Yet, Gao et al. (2006, p.1796) surmise that because teenagers will have prolonged duration of endometriosis, they are also more likely to have the most 'profound adverse impact' on their HRQL. How much of this impact is preventable or reversible if teenagers are diagnosed quickly and then given best practice treatment and support?

**Benefits of early diagnosis and long term prognosis for teenagers with endometriosis**

There is no cure for endometriosis. Teenagers diagnosed with symptomatic endometriosis have a long path ahead of them as data suggests that teenagers who develop symptoms at the youngest ages are found to have the most number of symptoms, and the most severe symptoms over the long-term course of the disease (Ballwegg, 2004). The goal is comprehensive management of the disease in order to minimalise its impact on the life of the teenager and to preserve fertility.

To achieve these goals, good support systems are necessary for the teenager. Parental support and a working relationship with a multidisciplinary team of health professionals is required to deal with disease progression and symptomatic relief, as well as the psychological and emotional impact of endometriosis (ACOG, 2005). It is important that the teenager maintain a sense of control of the disease which comes about through planned management interventions.

Currently, there is a paucity of data on the long term benefits of early diagnosis of endometriosis in teenagers in terms of disease progression, HRQL and future fertility.
However, prompt evaluation and serious consideration of the adverse effects of endometriosis is recognized as being essential in this age group (ACOG, 2005).

Nursing Perspective

**Educating girls about puberty and menstruation**

Global studies reflect poor education and preparation of girls for menstruation well ahead of menarche (Abioye-Kuteyi, 2000; Kissling, 1996b; Walraven et al., 2002). The studies suggest that, in general, teenagers are ill-prepared for menstruation in terms of timing, type and amount of information given (or in some cases complete lack of information). Studies have shown that in the past 40 years mothers have been the primary and most relied upon source of information regarding menstruation (Ackard & Neumark-Sztainer, 2001; Larsen, 1961) which, of course, is widely influenced by the mother’s own attitudes towards menstruation.

In a report on Menstrual Disorders of School-Girls in 1913, (cited in Journal MSMA, 2002, p. 256) E.F. Howard (MD) wrote:

> The first point that strikes us in considering these cases is the dense ignorance of most girls on the subject of their menstrual functions. They have had no training, no advice, no education in such matters. The average girl doesn’t know when she began mensturating, unless the date is a very recent one, whether she has been regular or irregular, and is as ignorant as an unborn babe of what constitutes a normal period.

While it is assumed that teenagers are generally more informed today than they were 100 years ago, literature from some countries, particularly those that are ‘developing’, indicate that there are still many hygiene issues, cultural views and taboos that surround menstruation and that these also affect how young teenagers and their families view menstruation (Abioye-Kuteyi, 2000).

Kissling (1996a) conducted extended interviews with eleven 12-16 year old North American teenagers and their mothers about menstruation and found that there exists a powerful taboo against talking about menstruation socially, which creates discomfort and embarrassment surrounding the topic. Kissling (1996a) found that to
counteract this, teenagers, who still felt a strong need to share information about menstruation with their peers, had developed creative communication strategies, such as slang terms and euphemisms, to decrease the embarrassment and maintain the menstrual concealment, yet still allowed them to talk about it.

Kissling (1996b) also found that the teenagers reported two distinct types of menstrual knowledge: scientific knowledge about the physiological and anatomical aspects of menstruation; and what the teenagers called the more ‘realistic’ side of menstruation that included practical information about managing the experience of menstruation. This has implications for identifying and structuring the education needs of teenage women about menstruation. The teenagers in Kissling’s (1996b) study described the menstrual education from school as ‘medical’ and ‘scientific’ compared to information from their mother that was more ‘realistic’ and talked about practicalities such as types of feminine hygiene products.

At least two studies have explored negative attitudes by teenagers towards menstruation, which have been found to persist once established (Koff & Rierdan, 1996), and may be expressed (in African-American teenagers) as school absenteeism and missed activities (Houston, Abraham, Huang & D’Angelo, 2006). This supports the case for adequate and appropriate education of teenagers about menstruation to minimize impact and disruption to life activities.

Adams Hillard (2002) suggests that parents may be uncertain about how to help their daughters cope with menstruation, particularly those who display early maturation. Also, parents may be unsure about what constitutes normal development. Hillen et al. identifies clinicians as well placed to help young girls and their families prepare for menarche and understand current norms surrounding menstruation as well as address issues of self-confidence, body image and sexuality which are so important to human development.

Furthermore, the health professionals who have contact with teenagers should enquire about menstrual health in order to identify menstrual pain and discuss effective medication for managing primary dysmenorrhoea to avoid school absence and
lifestyle interference (Hillen et al.; Holland-Hall & Brown, 2004). Nurses and midwives are well-placed to undertake health education with teenage girls.

**Educating girls about puberty and menstruation - role of the nurse & midwife**

While menstrual problems and endometriosis are predominantly dealt with by general practitioners (GP's) and gynaecologists, nurses and midwives have contact with teenagers through their work in outpatient gynaecology clinics, surgical gynaecology wards, day surgery units, youth health centres, family planning clinics, GP's surgeries, schools, colleges and universities. Contact with prepubescent and pubescent girls provides the opportunity for health surveillance and education with the best access to young people being through the education system.

While school nurses have existed in Australia since the early 1900's (Perry, 2003), “There seems to be a clear move away from mass screening of children in schools, both interstate and internationally, and a move towards targeting of services according to local priorities.” (Perry, 2003, p. 4). In Victoria, comprehensive school nurse programs including both primary and secondary schools, place nurses directly in contact with young people and their families where they play an instrumental part in providing individual health counseling, health promotion and planning, school community development activities (including positive parenting), group work, school health policy development, early identification of health problems, and as a resource and referral service. Their model for secondary school nurses is as follows:

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Source: Office for Children, Victorian State Government, Department of Human Services, Australia
There is a role for nurses and midwives to provide menstrual health education and surveillance to teenagers so they are prepared for menarche and menstruation, have a healthy view of their bodies and menstruation, and can experience a healthy transition into adulthood that will optimize their wellbeing and fertility. Nurses and midwives can also provide assistance and guidance for girls who suffer menstrual pain and symptomatology that interferes with schooling and other areas of their lives, ensuring that problematic menstruation is investigated by the appropriate health professionals, and menstrual disorder diagnosed and treated according to current ‘best practice’. Nurses can support teenagers and their families through this process with the outcome being the maintenance of the teenager’s healthy functioning in schooling and life activities, and a positive view of themselves and their bodies.

In terms of screening for endometriosis through the school system, New Zealand leads the way. The ‘Me’ (Menstrual Health and Endometriosis) Programme has been operating in New Zealand schools for over nine years and has as it’s aims: to raise awareness of endometriosis; to reduce the chronic emotional and physical effects caused by the symptoms of endometriosis; to avoid infertility; to reduce diagnostic delay; and to ensure young women receive ‘best practice’ treatment (Bush, 2006). The programme has seen a 300% increase in the number of women under 19 years of age presenting with symptoms of endometriosis, 90% of the young women who have proceeded to laparoscopy, have been diagnosed with endometriosis (Bush, 2006). The New Zealand Endometriosis Foundation (NZEF) engaged a teacher to design a curriculum and resources suitable for senior school aged teenagers which the students have found to be ‘fun, informative and highly interactive’ (Bush, 2006). NZEF runs the programmes in the schools with funding from various organizations and sponsors.

The New Zealand Endometriosis Foundation directors have welcomed the MDOT study’s data and focus on typical menstruation, menstrual disturbance and endometriosis in teenagers, as it supports and validates the work that they are doing through the ‘Me’ programme.
The nursing perspective on menstrual pain and PMS

Rather than compartmentalize menstrual pain and PMS, the (North American) Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) conducted a research project to “describe a woman’s health problem that encompasses more than the individual concepts of dysmenorrhea, PMS, and premenstrual dysphoric disorder” (Collins Sharp, Taylor, Thomas, Killeen & Dawood, 2002, p. 637). The project aimed to “advance the translation of research into nursing practice, thereby improving patient health-related outcomes and daily nursing practice” (Collins Sharp et al., 2002, p. 637). After their review of the literature, the project team developed a name to describe the cyclic pelvic pain and cluster of physical and emotive symptoms associated with menstruation which they termed: Cyclic Perimenstrual Pain and Discomfort (CPPD). A review of the literature had indicated to the AWHONN research team that the combination of menstrual pain and associated menstrual symptoms caused significant impact on a woman’s functional status and quality of life as well as self-care, lost time at school and work, visits to health professionals and use of over-the-counter treatments.

CPPD is made up of symptom clusters of related discomforts that women commonly experience in association with the menstrual cycle. The three clusters include cyclic pelvic pain, perimenstrual discomfort symptoms (physical symptoms such as fatigue and headaches) and psycho-emotional symptoms such as, depression, anxiety, mood swings, and decreased libido. This formalised recognition of CPPD has governed the development of a research-based clinical guideline that incorporates screening (using four questions), assessment and diagnosis, intervention and management.

There are two particularly positive aspects to this guideline. Firstly, the understanding that the woman’s experience of CPPD is an interaction between her experience of symptoms and her perception and evaluation of symptoms. This first aspect recognises CPPD as a highly individual experience, and that concordantly, symptom management should be tailored for each woman. Secondly the guideline provides a list of available interventions and management strategies which have been presented in the light of current literature, evidence and science. The list includes complementary therapy strategies and highlights areas where further research can be targeted to support and validate the use of some complementary therapies.
The project team concluded that CPPD was a common and important women’s health problem for which nurses could explore the evidence base and further develop the research on various nursing interventions, such as NSAIDS, TENS, heat therapy, vitamins, exercise and relaxation, in order to provide evidence based management and comfort nursing of the woman with CPPD. As this program is tailored to the individual woman, it could be tailored and applied to teenage women as well.

In the presentation of the concept of CPPD there was no acknowledgement of the possibility of underlying menstrual disorder which can display the same symptoms as those included in CPPD. There is also no discussion of the responsibility of the nurse or midwife to be vigilant and knowledgeable about possible menstrual disorders, such as endometriosis, in order to facilitate early investigation and diagnosis of menstrual disorder.

**Summary**

In this chapter I have examined the current literature pertaining to adolescent menstrual patterns, as well as the prevalence of dysmenorrhoea, PMS, CPP and endometriosis in adolescents. There is consistent data showing that dysmenorrhoea and PMS are common in teenagers and cause considerable impact in terms of school absence and interference with life activities. Research evidence suggests that there is poor preparation of teenagers for menstruation as well as a lack of information about pain and symptom relief. There is effective pain relief available for primary dysmenorrhoea yet studies show that teenagers are still unsure about which types and quantities of pain relief are most effective, which could be contributing to menstrual morbidity.

There is consistent data showing the significant relationship between severe menstrual pain that doesn’t respond to NSAIDs and OCPs and endometriosis. There is an overlap in the symptoms of dysmenorrhoea, PMS and endometriosis that can cause diagnostic confusion, making it difficult for health care providers to diagnose endometriosis. This has not been helped by the persistent belief that endometriosis is rare in teenagers.
Significant diagnostic delay of endometriosis has been established globally, but of concern is the finding that women presenting with infertility are diagnosed in half the time than women presenting with pain – which would encompass the teenage population. More worrying for teenagers, is the finding that the earlier the onset of symptoms the longer the diagnostic delay. There is also data suggesting an increase in the number of women with endometriosis who experienced their first symptoms before the age of 15 years and that there is increased severity of the disease the earlier the onset of symptoms. There is a paucity of data on the impact of endometriosis on teenagers and no HRQL questionnaires have been located for this purpose.

Inadequate diagnosis and treatment of menstrual disturbance in a teenager’s developmental and ‘formative years’, has the potential to negatively affect human development, quality of life and future fertility. Research into teenage women’s experiences and perceptions of menstrual pain, symptomatology and the signs and symptoms of menstrual disturbance can establish the current depth of problematic menstruation in this unique and important population. New data about problematic menstruation and endometriosis in teenagers can contribute to: the raised awareness of inherent issues; diagnostic guidelines; formation of policy; the education needs of teenagers, parents, health professionals and the school system; as well as identify areas requiring further research.

Purpose of the MDOT Study
The purpose of the MDOT study was to survey 16-18 year old teenagers about their perceptions and attitudes towards menstruation, as well as collect data about their menstrual bleeding patterns, pain, symptoms, school absence, and interference on life activities, in order to:

- Establish a picture of the typical experience of menstruation in 16-18 year old women
- Determine the prevalence of menstrual disorder.
Chapter 3: Method

Introduction
In this chapter I will describe the method used to conduct the MDOT study. Firstly, the research components of the study will be addressed including the design, sampling, and population. Secondly, I will describe how the study was conducted, including recruitment and participation of the secondary colleges, promotion of the project within the secondary colleges, information sessions conducted for participants and teachers, the collection of data, the questionnaire and its development, confidentiality and anonymity, analysis of the data, following up the respondents and ethics.

Research method and components

Design
An exploratory, descriptive survey design (Beanland, Schneider, LoBiondo-Wood & Haber, 1999) was chosen as the most suitable method of data collection to suit the purpose of the MDOT study. The benefits of using a questionnaire to collect data are that it can reach more participants and requires fewer researchers compared with methods such as interviewing or focus groups (LoBiondo-Wood & Haber, 1994). A large sample was needed for the MDOT study in order to collect sufficient data to create a reasonably representative collective menstrual picture of the population being studied, in this case 16-18 year old teenagers (LoBiondo-Wood & Haber, 1994).

One risk of using questionnaires is the inability to predict the response rate. Neuman (1994) suggests that a response rate lower than 50% is considered poor and above 90 percent considered excellent. The problem with a response rate lower than 50 percent is that the representativeness of the sample becomes jeopardized (Burns & Grove, 1997). More difficult still are mailed questionnaires which commonly attract small response rates of 25-30%, and struggle to form a representative sample (Burns & Grove, 1997). For this reason it was decided that the MDOT questionnaire would be completed on the spot and collected directly.
The study design also included the offer of follow-up to each participant if they wished to be contacted should their questionnaire show the need for information (by post), or further consultation and investigation. To meet this purpose, a clinic (called the MDOT clinic) for teenagers with problematic menstruation was set up at The Canberra Hospital and run by Dr Anne Sneddon (Staff specialist in Obstetrics and Gynaecology) and myself. The MDOT clinic would also investigate teenagers who were suspected of having endometriosis, using as a guideline, the protocol which has been established over the past ten years, ‘Protocol for evaluation and treatment of adolescent pelvic pain and endometriosis’, (ACOG, 2005, p.923), (see Appendix 10). While the process of scrutinizing questionnaires and identifying those participants requiring follow-up was included in the MDOT project, the actual follow-up of participants is not reported in this thesis.

**Study population, sample size and participant recruitment**

The study population was made up of 16-18 year old females attending ACT Government senior high schools, called ‘secondary colleges’, or just ‘colleges’. The target sample size was 1,000. This number was chosen because the representativeness of the population being studied increases with the size of the sample (Lo Biondo, Wood & Haber, 1994). The secondary college population represents 87% of 16-18 year old women in the ACT (actual school retention rates from Year 10 - 11, and from Year 11 - 12, February 2005 census, ACT Department of Education and Training).

Access to the secondary colleges was required in order to recruit a large sample that would be reasonably representative of this age group. In this case recruitment was through non-randomised single-stage cluster sampling. Cluster sampling involves random sampling of staged clusters beginning with a large cluster, for example, all schools statewide, to progressively smaller clusters in cities then districts (Lo Biondo, Wood & Haber, 1994). It is possible to sample one cluster only which is termed single stage cluster sampling. In this case, the cluster was comprised of all ACT government secondary colleges spread across the nine school districts of the ACT (n=8). The colleges were not randomly chosen because it was more economical in terms of time.
and logistics, to use less colleges by selecting those with larger enrolments. In this way, it was estimated that four of the eight colleges would be required to reach the target sample size. Each college was located in a different school district, and the four colleges were spread in a North, South, East, West distribution across the ACT.

**School recruitment and participation**

Prior to school recruitment, permission was sought from the ACT Department of Education and Training through a formal application process. In order to secure approval, the questionnaire was modified to exclude some questions about sexual activity that were not crucial to the aims of the study. Four colleges were approached and approval was given by all four school principals. The method of data collection and degree of participation varied across the colleges. Two colleges facilitated data collection *en masse* during year meetings. One college facilitated data collection through English classes as there were too many students to gather all together at one time. One college facilitated data collection via selected classes and time spent in the student cafeteria.

In appreciation of the colleges’ full participation, Dr Sneddon and I agreed to run one or two on-site clinics for girls who might want to see us about their menstrual concerns.

**Promoting the project**

In the weeks leading up to the planned data collection day, a promotional table was set up in the corridors or cafeterias (during lunch hours) at least once or twice in each college, to raise awareness about the research and discuss the benefits of the research to the potential participants. Offering participant follow-up and on-site clinics at the colleges created a *quid pro quo* situation between us and the participants and colleges.

**Information sessions prior to data collection**

**Students**

One to two weeks prior to Questionnaire Day (Q Day), the three colleges that were providing access to all female students provided us with an opportunity to speak *en masse* to the students. Using a humorous, light-hearted approach, the research team highlighted the common problems associated with menstruation in teenagers and
emphasized the importance of the research, as well as how, where and when the questionnaires would be administered.

During this session comprehensive Participant and Parent Information Sheets (see Appendices 4 & 5) were given out. The information sheets were very similar in content, but the language was directed towards either the participants or the parents. As the information sheets were similar in appearance they were printed on different coloured paper. Also, the Parent Information Sheet included a section that could be signed and returned if they did not want their daughter to participate. Contact phone numbers for the principal researcher, project supervisors and ethics committees were included on the information sheets should participants or parents require further information. Ethics approval was given by the ACT Health and Human Research Ethics Committee, the University of Canberra Committee for Ethics in Human Research and the ACT Department of Education and Training. Following ethics approval, permission was required from each of the secondary college principals.

**Teachers**

Dr Sneddon and I attended staff meetings at the three full-participation colleges and spoke about the importance of the project, the full support of the principal and what was required of the teachers. All of the school principals endorsed the project at the staff meetings. With the exception of the college that was collecting questionnaires in their English classes, teacher involvement was actually very little. Some teachers were required at the mass gatherings and some of them acted as witnesses on the consent forms during these sessions. Written information about the project was also distributed to teachers at the staff meetings (included in Appendix 6).

**Q Day (Questionnaire Day/data collection)**

The success of data collection relied heavily upon the school’s cooperation in terms of making a time available for the research team to access the female population. In the first college all the year 11 and 12 girls were brought together in the school auditorium and the questionnaires were given to the girls as they walked in. They filled in the consent forms which were then collected by the research team while the girls filled in the questionnaire. It was important for the girls to see that the questionnaires were de-identified and collected separately from the consent forms.
When the questionnaires were completed, they handed them in and left the auditorium.

In the second college, data collection was done similarly, but over two weeks where Year 11 girls filled out the questionnaire one week and year 12 filled it out the following week.

Data was collected at the third secondary college through English classes where girls were provided with 20 minutes at the end of the lesson to complete the questionnaire. Although more time and labour intensive, and reliant on teacher cooperation, it proved to be highly effective (n=398).

At the fourth secondary college I was required to phone the teachers individually to set up times for collecting data from various classes. This approach was more time consuming as sometimes a trip was made to the college to collect data from one class. Whilst at the college, I also maximized opportunity by setting up a table in the cafeteria in the lunch hour and inviting girls who met the age criteria to complete a questionnaire if they wished. This was reasonably successful with the girls being quite willing to participate once the purpose for the research was explained. Data collection continued at this college until I exceeded the nominated target (1,000).

Overall, data collection from four secondary colleges took approximately one month to conduct. 1072 questionnaires were given out, and 1051 were returned completed. Included in the results section are the participation rates for each college as school absence for various reasons would be expected on any given school day. The questionnaires were numbered which meant we could calculate how many were given out at each session. The participation rate was calculated by subtracting the number of participants who presented at the data collection sessions from the number of females enrolled at each college. The response rate was calculated by subtracting the total number of completed questionnaires from the total number of questionnaires given out at the data collection sessions.
The Questionnaire

Designing and creating the tool

Based on the literature review and the clinical expertise of the research team, a questionnaire was designed specifically to gather data for our research. The questionnaire collected data about the characteristics of a 'usual' period in terms of regularity, duration, and heaviness; school absence due to menstruation; pain experienced with menstruation, use and effectiveness of medication; physical and emotional symptoms experienced during the menstrual cycle; interference of menstruation on various activities in the daily life of a teenager; and true/false statements regarding various aspects and perceptions surrounding menstruation.

The questionnaire was structured with repetitions in themes and questions to measure the consistency of responses and was designed to be completed within 20 minutes. A mixture of question types were used, including single and multiple response, rating scales, true/false and an open question at the end. The purpose of multiple measures in a questionnaire is to gain a more complete picture of respondent views than if only one type of measure was used (Beanland, Schneider, LoBiondo-Wood & Haber, 1999).

The following figure presents a detailed break down and description of the questions in the questionnaire. A copy of the questionnaire is included in Appendix 1.
Table 2. Questionnaire content

<table>
<thead>
<tr>
<th>Section</th>
<th>Questions Qty</th>
<th>Type</th>
<th>Topic of questions in that section</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5</td>
<td>Closed numeric</td>
<td>DOB, weight, height, age at menarche</td>
</tr>
<tr>
<td>2</td>
<td>15</td>
<td>Multiple response</td>
<td>Characteristics of a ‘usual’ period: eg. length, heaviness of flow, pain, clots, spotting, school absence, use and effectiveness of pain medication</td>
</tr>
<tr>
<td>3</td>
<td>25</td>
<td>Multiple response</td>
<td>Symptoms experienced with the menstrual cycle such as specific types of pain and locations, nausea, indigestion, bowel and bladder symptoms, headaches, depression, dizziness, etc</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
<td>Rating scale from 0-10</td>
<td>Interference of menstruation on lifestyle: eg. school attendance and performance, casual work, social activities, relationships and exercise. Menstrual symptoms that are most interfering</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Multiple response</td>
<td>Frequency of interference</td>
</tr>
<tr>
<td>5</td>
<td>42</td>
<td>True/False</td>
<td>Questions about use of OCP, tampons, pads, perceived ‘normality’ or problems with periods, people they talk to about their periods, emotions experienced surrounding their periods</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>Open-ended</td>
<td>Allergies to medications, foods or ‘other’</td>
</tr>
<tr>
<td>7</td>
<td>8</td>
<td>Yes/No</td>
<td>Diseases respondents had heard of Diseases experienced by mother or sister</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Open-ended</td>
<td>Anything else participants wanted to tell us.</td>
</tr>
<tr>
<td>Total</td>
<td>116</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The questionnaire was submitted to various persons and groups to evaluate the content and structure (face validity) (LoBiondo-Wood & Haber, 1994) of the instrument in terms of the concept we were measuring – the experience and patterns of menstruation in older teenagers. These included The Canberra Hospital Survey Resource Group, the Director from the Canberra Hospital Centre for Advances in Epidemiology and IT, the President of the Management Committee for the Endometriosis Association of Victoria, colleagues from the Research Centre for Nursing and Midwifery Practice, and two teenagers of a similar age to the proposed participants to check for ease of understanding.

The first pilot test was done through ‘The Junction’, a youth health centre for 12-25 years olds. Over two visits to the centre eight questionnaires were completed. The pilot revealed a serious flaw in the structure of one of the questions which also
affected the way the following question was answered. It was also apparent that a
glossary was needed to explain some of the terms (despite our efforts to make them as
teenage-friendly as possible).

After making these changes, the questionnaire was piloted a second time, this time in
a class of twenty teenagers from the fourth secondary college with partial
involvement. The second pilot indicated that there was still a problem with the format
of one of the sections which was then changed. Although this reformatting required
the addition of another page, it improved the clarity of the section, the flow of the
questionnaire and allowed room for an open-ended question and the glossary.

**Confidentiality and anonymity**

All questionnaires and consent forms were numbered and given out together.
Participants were asked on their consent form if they wanted to be contacted should
their questionnaire indicate a need for further investigation. If their answer was ‘Yes’,
then additional contact details were required on the consent form. After the consent
forms were completed they were collected separately from the questionnaires,
subsequently making the questionnaires de-identified. The questionnaires and consent
forms were only matched up during individual scrutiny of the questionnaires if the
participant needed to be contacted and had consented to this.

**Analysis of data**

Data was entered into an SPSS (Statistical Package for Social Sciences) database by a
local data management company. An audit of data entry was done by myself, whereby
every 50th questionnaire (starting at questionnaire No.1) was scrutinized for
transcription errors. There were data entry errors in three of the twenty questionnaires.
Two of the three errors had occurred when the entries became ‘out of sync’ which
meant that there were subsequent errors that arose out of the one mistake. To correct
‘out of sync’ errors the data entry personnel are required to enter each new page
number in order to interrupt continuous entry so that any ‘out of sync’ errors are not
continued throughout data entry of the questionnaire.

An executive from the data management company and myself spent three sessions of
approximately one hour looking through print outs of frequency analyses of all the
responses to deal with invalid responses and clean up the data. The data set was also visually examined by myself for errors and inconsistent or missing data.

The data was then analysed using SPSS (Versions 12 and 14) where initially, frequencies and descriptive statistics were performed. Some of the data was recoded to facilitate correlational, parametric and non-parametric testing. Assistance with data analysis was given by the statistical consultant from the University of Canberra.

**Creating the Individual Menstrual Picture (IMP)**

The second part of data analysis consisted of scrutinizing each questionnaire to develop an individual menstrual picture (IMP) for each respondent. The purpose of creating an IMP was to identify those participants who required further consultation and investigation to rule out menstrual disorder. Those respondents who had consented to follow up would be offered consultation by Dr Sneddon through the MDOT clinic at The Canberra Hospital.

Each questionnaire (N=1051) was scrutinized and entered into an excel database. The database fields were based on respondents reports of school absence, pain and medication use; number of symptoms experienced, interference with life activities, OCP (oral contraceptive pill) usage and a score of the number of positive responses for statements indicating problematic menstruation from the true/false section of the questionnaire.

The pain scores (which had been recorded by respondents on a scale of 0-10) were further divided into mild (scoring 1-3), moderate (4-7) and severe (8-10) categories. A separate field was made for cramping/aching type pain symptoms. Templates were devised and used to separate PMS (premenstrual syndrome) symptoms from the symptom list, and then PMS symptoms were further divided into two categories - physical and psycho-emotional. Scores were also recorded for the interference section by counting the number of activity categories that the respondent had scored five and above. A field was included in the database to record those girls who had given a ‘true’ answer to the statement: ‘I am sure there is something ‘wrong’ with my periods’.
After considering the scores in each section (school absence, pain, symptoms and interference) and the overall menstrual picture of the respondent, the questionnaire was sorted into one of the following categories:

- no action required
- send information about dysmenorrhoea, PMS or both
- consult by phone (to determine if a clinic visit is necessary)
- invite to the MDOT clinic for consultation and investigation (if warranted)

When a category for the questionnaire had been chosen, the questionnaire was matched to the consent form and a record was made on the database if consent for contact had been given. Those respondents who did not need to be contacted or had not consented to being contacted were de-identified (questionnaires were separated from the consent forms). Finally, those who required contact and had consented to being contacted, were sorted into groups according to the type of contact that needed to be made.

**Method for contacting respondents who consented to follow up**

Information was sent to the girls whose IMP indicated considerable dysmenorrhoea or PMS symptoms. Initially, some girls were invited to attend the clinic by letter but none of them contacted us. Dr Sneddon's secretaries also contacted some of the girls to see if they wanted to book in to the clinic but this method was also unsuccessful. The best approach was for me to phone them and discuss their questionnaire, in particular those aspects that were troubling them. In this way, it could be explained how the clinic might be able to help and the girls could decide whether they needed to attend or not. In some instances, just discussing the troublesome aspects was enough to clarify issues or provide reassurance so that the girls did not need to attend the clinic.

When phoned, some girls said that after doing the questionnaire they realized that there were problems with their periods and had been motivated to visit their general practitioner and had sorted out the problem (and therefore did not need to attend the clinic).
To determine the order of contact, I prioritized those questionnaires from both Year 11 and Year 12 girls that indicated the most menstrual disturbance, but I attempted to contact the Year 12 girls first as it was anticipated that some of them would leave Canberra at the end of Year 12.

Attendance at the MDOT clinic includes a semi-structured interview to illicit further information about the teenager’s menstrual history and symptoms, discussion about the need for further investigation or treatment, discussion about options for investigation and treatment, as well as provide information and address any questions or issues the teenagers may have.

It seems that once a girl has attended our clinic, if she needs to return for further follow up, the attendance rate is considerably higher than those booked for a first visit. This willingness to return to the clinic indicates that the teenagers are gaining a benefit in some way.

It is not the intention of this thesis to present results on the follow-up stage of this project. However, one of the teenagers who was followed up through the MDOT clinic has written her story, which is included in Appendix 12, under ‘Sally’.

**Ethics**

Ethics approval was given by the ACT Health and Human Research Ethics Committee, the University of Canberra Committee for Ethics in Human Research and the ACT Department of Education and Training (Appendices 7, 8, & 9). Following ethics approval, permission was required from each of the secondary college principals.

**The ethical nature of consent in young people.**

According to the National Statement on Ethical Conduct in Research Involving Humans issued by the National Health and Medical Research Council (NHMRC) in accordance with the *NHMRC Act, 1992* (Cth), the ethical and legal requirements of consent (for the purpose of research) includes the provision of (appropriate) information and the capacity to make voluntary choice. Teenagers fall in to the
classification of ‘young people’ who are defined in the following way: “Subject to the law in the relevant jurisdiction, a minor who may have the maturity to make a decision whether or not to participate in research.” (NHMRC, 1999, Appendix 3, p. 66). In the ACT the Age of Majority is 18 years (Age of Majority Act, 1974, p. 2) which means that the 16-17 year olds participating in the research would be legally viewed as minors. The consent of ‘young people’ to participate in research must be obtained from the young person and a parent or guardian (National Statement on Ethical Conduct in Research Involving Humans, 1999).

One to two weeks before conducting the MDOT questionnaire, separate Information Sheets for participants and the parents were given out. A consent slip was included on the Parent Information Sheet that parents could send back if they did not want their daughter to participate.

It took some planning to devise questionnaires that would be de-identifiable, consent forms that also obtained consent to contact participants including their contact details, and that ultimately, would satisfy all three ethics committees.

**Data storage requirements**

The storage and security of personal information must be kept in accordance with the principles set out in Appendix 2 of the *National Statement on Ethical Conduct in Research Involving Humans* issued by the NHMRC (1999). The Canberra Hospital and University of Canberra Research Centre for Nursing and Midwifery Practice (located at The Canberra Hospital) has provision for securing questionnaires and identifiable data using secure passwords on computer and lockable rooms. The MDOT questionnaires are stored in the Research Centre for Nursing and Midwifery Practice at The Canberra Hospital in a double locked room that is situated in a locked office that is only accessed by Research Centre staff.
Summary
This chapter has outlined the purpose and research components of the MDOT study, including the study design, sampling, population, recruitment, data analysis and ethical considerations for the population studied. An exploratory, descriptive survey design was used to collect data about menstrual patterns of teenagers. The MDOT questionnaire was developed specifically for this purpose and piloted in the population before data collection. One thousand and fifty one completed questionnaires were collected and the data was analysed and results aggregated for a collective picture of menstruation in the sample, as well as individual scrutiny of each questionnaire for an IMP. The next chapter will outline the results of the collective menstrual picture and the individual menstrual picture of more than one thousand 16-18 year old women.
Chapter 5: Results

Introduction
The previous chapter described the methods used in the MDOT study including recruitment of schools and participants, questionnaire development, data collection and analysis. This chapter will present the results of data analysis including descriptive statistics, measures of association and tests of significance. Results will include participation and response rates, bleeding patterns, school absence, pain and pain medications, symptom patterns, interference with life activities, and a series of true/false statements that explored a range of themes. Associations between pain, symptoms, interference, school absence and other variables have also been explored.

Participation and response rates

Participation rate
Table 3 shows the participation rates for questionnaire completion across the colleges. The participation rate for the colleges that involved all girls varied between 62%-80%. The college that only involved select classes had a participation rate of 17%.

<table>
<thead>
<tr>
<th>Recruitment target</th>
<th>College 1</th>
<th>College 2</th>
<th>College 3</th>
<th>Sub-total</th>
<th>College 4</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female enrolments*</td>
<td>415</td>
<td>471</td>
<td>496</td>
<td>1382</td>
<td>421</td>
<td>1803</td>
</tr>
<tr>
<td>Participants</td>
<td>291</td>
<td>294</td>
<td>398</td>
<td>983</td>
<td>71</td>
<td>1055</td>
</tr>
<tr>
<td>Participation rate</td>
<td>70%</td>
<td>62%</td>
<td>80%</td>
<td>71%</td>
<td>17%</td>
<td>58.5%</td>
</tr>
</tbody>
</table>

* February census 2005

Non-participation response from parents
The parent’s information sheet contained a section on the back that could be signed if parents did not want their daughter to participate. We received four signed forms from one college and one other form from another college. Only five forms in total were returned to the research team.
Response rate

1,071 questionnaires were given out. 1,055 questionnaires were returned. Three were incomplete. One was blank. 1051 were completed. This gave a response rate of 98%.

![Response Rate Diagram]

Figure 1. Response Rate

Representativeness of sample in the ACT

Table 4. Female enrolments in government and non-government ACT secondary colleges/senior high schools.

<table>
<thead>
<tr>
<th></th>
<th>Government Year 11 &amp; Year 12 enrolments in 2005</th>
<th>Non-government Year 11 &amp; Year 12 enrolments in 2005</th>
<th>Total ACT Year 11 &amp; 12 enrolments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>2,964</td>
<td>1,766</td>
<td>4,730</td>
</tr>
<tr>
<td>No. of females surveyed</td>
<td>1,051 (35.5%)</td>
<td>Not surveyed</td>
<td>1,051 (22%)</td>
</tr>
</tbody>
</table>

The large sample size (N=1051) included just over one third of all government secondary college female students in the ACT, and one fifth of all female secondary college students in the ACT i.e. both government and non-government female students (Table 4).

The school cluster accounts for the majority of 16-18 year old females in the ACT as the ACT retention rate of students from Year 10 to year 11 and from year 11 to year 12 is 87 % (ACT Department of Education and Training, February 2005 census)
figures). There are government secondary colleges in six of the nine school districts. The colleges that participated in the study were in a North, South, East, West spread across the territory with each college located in a different school district.

Survey results

Demographics

A small number of demographic questions collected information about date of birth, weight, height and age at menarche. In the locations where data was collected there was no provision for girls to measure their height and weight so these are self-reported estimates. The height/weight information contributed to the individual menstrual picture (IMP) of each questionnaire. The average age of respondents in the sample was 16 years 10 months (16.83 years), the youngest age in the sample was 14 years 9 months (14.75 years) and the oldest was 19 years 3 months (19.25 years).

Menarchical age

The earliest menarchical age reported was 8 years and the oldest was 19 years (Table 5). The most frequently reported age for menarche (mode) was 13 years (n=319, 32.6%), followed closely by 12 years (n=276, 28.2%) and the average age of menarche for the sample was 12.74 years (12 years, 9 months).

Table 5. Self-reported age at menarche

<table>
<thead>
<tr>
<th>Menarcheal age in years</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>1</td>
<td>4</td>
<td>24</td>
<td>123</td>
<td>276</td>
<td>319</td>
<td>146</td>
<td>50</td>
<td>23</td>
<td>10</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>%</td>
<td>0.1</td>
<td>0.4</td>
<td>2.4</td>
<td>12.6</td>
<td>28.2</td>
<td>32.6</td>
<td>14.9</td>
<td>5.1</td>
<td>2.3</td>
<td>1.0</td>
<td>0.0</td>
<td>0.1</td>
</tr>
</tbody>
</table>

Menstrual bleeding patterns

Amenorrhoea

Respondents were asked: ‘Do you have periods?’ Ninety-nine percent (n=1039) answered ‘yes’ with only one percent (n=12) of respondents indicating that they don’t have a period. Of the twelve respondents not menstruating, seven reported taking an OCP for singular or combined reasons: to prevent pregnancy (n=5), to regulate
periods (n=4), and to help period pain (n=2). Five respondents from the total sample (N=1051) reported amenorrhoea and were not taking an OCP.

**Regularity of periods**

Regular menstrual periods were reported by 61.9% (n=644) of respondents, 30.5% (n=317) reported irregular menstrual periods, and 7.6% (n=79) answered ‘don’t know’.

**Menstrual cycle**

The respondents were asked ‘What is the usual number of days from the first day of bleeding at one period to the first day of bleeding at your next period? (cycle length)’

One thousand and thirty-three (n=1033) girls answered this question. Almost one fifth (17.3%, n=179) of respondents circled ‘don’t know’, 16.1% (n=166) circled ‘periods irregular’, and 19.8% (n=204) answered the question incorrectly, instead, recording the number of bleeding days for a period. Cycle lengths ranging from 18-44 days were recorded by 46.9% (n=484) of girls. Of these, 25.8% (n=125) of girls reported a cycle length of 18-27 days, 71.9% (n=348) reported a cycle length of 28-37 days and 2.3% (n=11) 40-44 days.

**Length and heaviness of menstrual bleeding**

A high percentage of respondents reported menstrual bleeding lasting one to five days (range 87.0-98.0%), with 31.8% (n=334) still reporting bleeding on day seven, and approximately 5.0% of respondents reporting bleeding on days nine and ten (Table 6). A small number of girls (1.0%, n=11) reported bleeding lasting longer than ten days. Excluding the girls whose menstrual bleeding lasted longer than 10 days, the average length of menstrual bleeding was 5.93 days.

**Table 6. Frequency of respondent menstrual bleeding for each day of menses**

<table>
<thead>
<tr>
<th>Menses Day</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>1027</td>
<td>1027</td>
<td>1027</td>
<td>1008</td>
<td>914</td>
<td>593</td>
<td>334</td>
<td>104</td>
<td>56</td>
<td>47</td>
</tr>
<tr>
<td>%</td>
<td>97.7</td>
<td>97.7</td>
<td>97.7</td>
<td>95.9</td>
<td>87.0</td>
<td>56.4</td>
<td>31.8</td>
<td>9.9</td>
<td>5.3</td>
<td>4.5</td>
</tr>
</tbody>
</table>
Figure 2 demonstrates patterns of menstrual bleeding for the sample across one menstrual period in terms of the heaviness and length of bleeding. The bleeding pattern for the MDOT sample shows that the majority of girls experience heavier bleeding at the beginning of a period and lighter bleeding towards the end.

**Blood clots with menstrual bleeding**

Fifty-eight percent (n=589) of girls reported clots in their menstrual blood, of these girls, 76.5% (n=457) reported clots ‘sometimes’, 18.6% (n=111) reported ‘most of the time’, while 4.7% (n=28) reported clots ‘all the time’ (43.5%, 10.6%, 2.7% of total sample N=1051 respectively).

**Premenstrual spotting**

Premenstrual spotting ‘just before a period’ was reported by 34% (n=340) of respondents and 5.4% (n=54) reported spotting ‘in between periods’.
School absence due to menstruation

Twenty four percent (24%, n=240) of girls reported missing school with some periods, 2.2% (n=22) reported missing school with every period. Of the girls who miss school, the majority (60%, n=183) stay home for 1 day, 20% for 1-2 days, 9% for 2 days with only 8 girls missing 3-4 days. Seventy-four percent (74.2%, n=757) of girls responded ‘no’ to missing school because of periods. To facilitate data analysis the two ‘yes’ categories were combined so that there were only ‘yes’ (26.2%, n=262) and ‘no’ categories for school absence.

The girls who reported missing school (n=262) were also asked what symptoms caused them to miss school, although 305 girls answered this question. There were five multiple response answers and respondents could circle more than one response. The most popular reason circled was ‘too painful’ (94%, n=286), followed by ‘nausea’ (37%, n=113), ‘blood flow too heavy’ (24.6%, n=75), and ‘vomiting’ (13.8%, n=42). The fifth response category was ‘other’. The most commonly listed symptoms under ‘other’ were cramps/period/stomach pain (1.5%, n=15), headache (1%, n=10), tiredness/fatigue (0.9%, n=9) followed equally by back pain and dizziness (0.6%, n=6).

Symptoms worsening

Twenty three percent (n=235) of girls reported their period symptoms worsening over the 12 months prior to completing the questionnaire.

Pain and pain medication

Reports of pain

Respondents were asked to rate their pain on a scale of 0-10 which was later grouped into no/mild pain (0-3), moderate pain (4-7) and severe pain (8-10). Thirty-one percent (n=317) reported no or mild pain, 48.6% (n=505) reported moderate pain, and 20.9% (n=217) reported severe pain.

Use of pain medication

Sixty six percent (66% n=646) of respondents said that they take medication for period pain. NSAIDs (n=501) were the more popular choice of analgesia over
paracetamol (n=378) and other analgesics. The types of medication taken are shown in Table 7.

**Table 7. Analgesic treatments used by respondents**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>No of girls reporting use of analgesic treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSAID</td>
<td>501</td>
</tr>
<tr>
<td>Paracetamol</td>
<td>378</td>
</tr>
<tr>
<td>Aspirin</td>
<td>30</td>
</tr>
<tr>
<td>Mersyndol</td>
<td>4</td>
</tr>
<tr>
<td>Prescription (panadeine forte, buscopan,</td>
<td>8</td>
</tr>
<tr>
<td>digesic)</td>
<td></td>
</tr>
<tr>
<td>Herbal</td>
<td>8</td>
</tr>
<tr>
<td>OCP</td>
<td>8</td>
</tr>
</tbody>
</table>

**Reported effectiveness of pain medication**

Those respondents who took medication for period pain were asked how effective the medication was in relieving their pain. They rated the effectiveness on a scale of 0-10 (0=not effective, 10=highly effective) which was later grouped into no/mild effect (0-3) moderately effective (4-7) and highly effective (8-10). The results for these groupings were 14.6% (n=96), 44.3% (n=291), and 41.1% (n=270) respectively.

**Reported frequency of menstrual symptoms**

Section 3 of the MDOT questionnaire included a table of 25 symptoms. Respondents were asked: ‘Over the past 12 months, have you experienced any of the following symptoms in relation to your monthly period cycle? (Tick as many as applicable)’. Response categories included: ‘Doesn’t apply to me’, ‘No or Never’, ‘Just before a period’, ‘At the time of period’, ‘Anytime of month’, ‘All the time’, ‘Sometimes’. From the list of 25 symptoms, the five most frequently reported symptoms were: ‘feeling really tired’ 77.6% (n=791), ‘pelvic pain-cramping’ 71.1% (n=701), ‘feeling ‘down’ or depressed’ 64.7% (n=654), ‘headaches’ 63.8% (n=641), and ‘bloating’ 61.6% (n=618).

The following table (Table 8) lists the 25 symptoms from most frequent, to least frequently reported. Because girls could tick more than one response option for each symptom, additional columns have been included in Table 8 to indicate how many times a symptom was ticked.
Forty-seven (47) respondents reported an 'other' symptom of which twenty-nine (n=29, 8.3%) were psycho-emotional (examples included moody, angry, bitchy, and grumpy) and eighteen (n=18, 5.2%) were physical (examples included sore breasts, feverish, leg cramps and pimples).

Table 8. List of menstrual symptoms ranked in order of frequency (percentage-wise).

<table>
<thead>
<tr>
<th>Rank by %</th>
<th>Symptom</th>
<th>Total no of respondents</th>
<th>Yes 1 response n=</th>
<th>%</th>
<th>Total no of responses n=</th>
<th>Yes &gt;1 response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Feeling really tired</td>
<td>1019</td>
<td>791</td>
<td>77.6</td>
<td>1101</td>
<td>870 79.0</td>
</tr>
<tr>
<td>2</td>
<td>Pelvic pain - cramping</td>
<td>986</td>
<td>701</td>
<td>71.1</td>
<td>1084</td>
<td>796 73.4</td>
</tr>
<tr>
<td>3</td>
<td>Feeling down or depressed</td>
<td>1011</td>
<td>654</td>
<td>64.7</td>
<td>1089</td>
<td>727 66.8</td>
</tr>
<tr>
<td>4</td>
<td>Headaches</td>
<td>1004</td>
<td>641</td>
<td>63.8</td>
<td>1050</td>
<td>682 65.0</td>
</tr>
<tr>
<td>5</td>
<td>Bloating</td>
<td>1003</td>
<td>618</td>
<td>61.6</td>
<td>1112</td>
<td>711 63.9</td>
</tr>
<tr>
<td>6</td>
<td>Pelvic pain - aching</td>
<td>976</td>
<td>604</td>
<td>61.9</td>
<td>1073</td>
<td>666 62.1</td>
</tr>
<tr>
<td>7</td>
<td>Changes in appetite</td>
<td>1005</td>
<td>607</td>
<td>60.4</td>
<td>1088</td>
<td>680 62.5</td>
</tr>
<tr>
<td>8</td>
<td>Lower back pain</td>
<td>1002</td>
<td>580</td>
<td>57.9</td>
<td>1093</td>
<td>660 60.4</td>
</tr>
<tr>
<td>9</td>
<td>Pelvic pain - stabbing</td>
<td>917</td>
<td>370</td>
<td>40.4</td>
<td>969</td>
<td>416 42.9</td>
</tr>
<tr>
<td>10</td>
<td>Nausea</td>
<td>1002</td>
<td>372</td>
<td>37.1</td>
<td>1047</td>
<td>403 38.5</td>
</tr>
<tr>
<td>11</td>
<td>Dizziness/fainting/pass out</td>
<td>1005</td>
<td>345</td>
<td>34.3</td>
<td>1039</td>
<td>370 35.6</td>
</tr>
<tr>
<td>12</td>
<td>Need to pass urine often</td>
<td>1007</td>
<td>308</td>
<td>30.6</td>
<td>1025</td>
<td>315 30.7</td>
</tr>
<tr>
<td>13</td>
<td>Aching down the legs</td>
<td>993</td>
<td>285</td>
<td>28.7</td>
<td>1039</td>
<td>315 30.3</td>
</tr>
<tr>
<td>14</td>
<td>Aching outside vagina</td>
<td>995</td>
<td>261</td>
<td>26.2</td>
<td>1035</td>
<td>284 27.4</td>
</tr>
<tr>
<td>15</td>
<td>Diarrhoea/constipation</td>
<td>995</td>
<td>249</td>
<td>25.0</td>
<td>1036</td>
<td>270 26.1</td>
</tr>
<tr>
<td>16</td>
<td>Indigestion, reflux, heartburn</td>
<td>990</td>
<td>182</td>
<td>18.4</td>
<td>1019</td>
<td>191 18.7</td>
</tr>
<tr>
<td>17</td>
<td>Urgent need to empty bowels</td>
<td>998</td>
<td>174</td>
<td>17.4</td>
<td>1021</td>
<td>183 17.9</td>
</tr>
<tr>
<td>18</td>
<td>Thrush</td>
<td>996</td>
<td>187</td>
<td>18.8</td>
<td>1012</td>
<td>193 19.1</td>
</tr>
<tr>
<td>19</td>
<td>Pain during or after sexual intercourse</td>
<td>1007</td>
<td>133</td>
<td>13.2</td>
<td>1021</td>
<td>137 13.4</td>
</tr>
<tr>
<td>20</td>
<td>Vomiting</td>
<td>988</td>
<td>120</td>
<td>12.2</td>
<td>1036</td>
<td>133 12.8</td>
</tr>
<tr>
<td>21</td>
<td>Pain when emptying bowels</td>
<td>996</td>
<td>116</td>
<td>11.7</td>
<td>1019</td>
<td>124 12.2</td>
</tr>
<tr>
<td>22</td>
<td>Pain during or after passing urine</td>
<td>993</td>
<td>95</td>
<td>9.6</td>
<td>1012</td>
<td>97 9.6</td>
</tr>
<tr>
<td>23</td>
<td>Pain with full bladder</td>
<td>992</td>
<td>190</td>
<td>9.5</td>
<td>1016</td>
<td>196 19.3</td>
</tr>
<tr>
<td>24</td>
<td>Pain before or when passing wind</td>
<td>999</td>
<td>93</td>
<td>9.3</td>
<td>1025</td>
<td>102 10.0</td>
</tr>
<tr>
<td>25</td>
<td>Bleeding from anus</td>
<td>998</td>
<td>45</td>
<td>4.5</td>
<td>1017</td>
<td>45 4.4</td>
</tr>
<tr>
<td>'Other' symptoms</td>
<td>349</td>
<td>42</td>
<td>12.0</td>
<td>363</td>
<td>53 14.6</td>
<td></td>
</tr>
</tbody>
</table>
All symptoms
To facilitate data analysis the 25 listed menstrual symptoms were also aggregated to produce frequencies for symptom reporting. Symptoms could be ticked more than once to account for symptoms experienced at different times of the menstrual cycle. When all symptoms were aggregated, the possible range for frequency of reported symptoms was 0-40. All the aggregated scores for each respondent fell between 0-31, except for one respondent who scored 40.

Pelvic pain symptoms
There were three types of pelvic pain listed in the symptoms – cramping, aching and stabbing. All three were in the top ten most commonly reported symptoms 71.1% (n=701), 61.9% (n=604), and 40.4% (n=370) respectively. There was a fourth pelvic pain category which was: ‘pelvic pain other (please state)’ whereby two girls reported ‘throbbing’.

PMS Symptoms
Ninety-six percent (n=990) of girls reported experiencing one or more PMS symptoms with their menstrual period. Sixty-eight percent (68.5%) of respondents reported 5 or more PMS symptoms. The maximum number of PMS symptoms that could be reported was eleven (Table 9).

Table 9. Frequency of reported PMS symptoms

<table>
<thead>
<tr>
<th>No of PMS symptoms reported</th>
<th>No of respondents n=1032</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>42</td>
<td>4.1</td>
</tr>
<tr>
<td>1</td>
<td>55</td>
<td>5.3</td>
</tr>
<tr>
<td>2</td>
<td>66</td>
<td>6.4</td>
</tr>
<tr>
<td>3</td>
<td>71</td>
<td>6.9</td>
</tr>
<tr>
<td>4</td>
<td>91</td>
<td>8.8</td>
</tr>
<tr>
<td>5</td>
<td>27</td>
<td>12.3</td>
</tr>
<tr>
<td>6</td>
<td>130</td>
<td>12.6</td>
</tr>
<tr>
<td>7</td>
<td>128</td>
<td>12.4</td>
</tr>
<tr>
<td>8</td>
<td>141</td>
<td>13.7</td>
</tr>
<tr>
<td>9</td>
<td>88</td>
<td>8.5</td>
</tr>
<tr>
<td>10</td>
<td>58</td>
<td>5.6</td>
</tr>
<tr>
<td>11</td>
<td>35</td>
<td>3.4</td>
</tr>
<tr>
<td>Total no of respondents reporting PMS symptom/s</td>
<td>990 (95.9%)</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Physical and psycho-emotional (mood) symptoms were fairly evenly represented in their reporting with the percentages being 90.6% (n=945) and 86.8% (n=902) respectively.

Tables 10 and 11 indicate the frequency of PMS symptoms, divided between the physical and psycho-emotional clusters used during analysis. When questionnaires were scrutinised to gather an Individual Menstrual Picture for each respondent, purpose specific templates were used to isolate PMS symptoms (For more explanation of questionnaire scrutiny and the IMP, see the ‘Methods’ chapter).

The physical PMS symptoms were listed in the symptom list on the questionnaire, but the psycho-emotional symptoms (with the exception of ‘feeling down or depressed’) were included in the true/false section of the questionnaire.

**Table 10. Frequency of physical PMS Symptoms**

<table>
<thead>
<tr>
<th>Symptoms*</th>
<th>PMS Symptoms (physical)</th>
<th>Yes (n=)</th>
<th>Yes %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Feeling really tired</td>
<td>791</td>
<td>77.6</td>
</tr>
<tr>
<td>2</td>
<td>Headaches</td>
<td>641</td>
<td>63.8</td>
</tr>
<tr>
<td>3</td>
<td>Bloating</td>
<td>618</td>
<td>61.6</td>
</tr>
<tr>
<td>4</td>
<td>Changes in appetite</td>
<td>607</td>
<td>60.4</td>
</tr>
<tr>
<td>5</td>
<td>Lower back pain</td>
<td>580</td>
<td>57.9</td>
</tr>
<tr>
<td>6</td>
<td>Diarrhoea/constipation</td>
<td>249</td>
<td>25.1</td>
</tr>
</tbody>
</table>

*ranked by frequency

**Table 11. Frequency of psycho-emotional PMS Symptoms**

<table>
<thead>
<tr>
<th>Symptoms*</th>
<th>PMS Symptoms psycho-emotional</th>
<th>Yes (n=)</th>
<th>Yes %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Grumpy</td>
<td>757</td>
<td>73.1</td>
</tr>
<tr>
<td>2</td>
<td>Feeling down or depressed</td>
<td>654</td>
<td>65.1</td>
</tr>
<tr>
<td>3</td>
<td>Teary</td>
<td>536</td>
<td>51.6</td>
</tr>
<tr>
<td>4</td>
<td>Overwhelmed, can't cope</td>
<td>325</td>
<td>31.5</td>
</tr>
<tr>
<td>5</td>
<td>Want to withdraw and hide</td>
<td>263</td>
<td>25.4</td>
</tr>
</tbody>
</table>

*ranked by frequency

**Menstrual Interference on life activities**

Section 4 of the questionnaire collected data about how menstrual periods affect the life activities of a teenager. Respondents were asked to rate nine individual activities...
(listed in Table 12), using a rating scale from 0-10, where 0=no interference and 10=major interference. Three out of the nine activities were potentially not applicable to some respondents, these were, 'Casual paid work', 'Relationship with partner' and 'Sexual activity'. This is evident in Table 12 where the 'not applicable' scores for these activities were considerably higher.

The 0-10 rating scales measuring interference of menstruation on daily activities were recoded into low interference (a rating of 0-4), and high interference (a rating of 5-10) categories. The activities that were reported to be most interfered with by menstruation were sexual activity (n=255/662, 38.5%) and sport and exercise (n=336/993, 33.8%).

Table 12. Life activities listed in order (percentage-wise) from highest reported interference to lowest reported interference.

<table>
<thead>
<tr>
<th>Activity</th>
<th>No. of respondents</th>
<th>N/A</th>
<th><strong>High Interference</strong></th>
<th><strong>Low Interference</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual activity</td>
<td>1020</td>
<td>358</td>
<td>255 (38.5)</td>
<td>407 (61.5)</td>
</tr>
<tr>
<td>Sport and exercise</td>
<td>1030</td>
<td>37</td>
<td>336 (33.8)</td>
<td>657 (66.2)</td>
</tr>
<tr>
<td>Social activities</td>
<td>1027</td>
<td>23</td>
<td>262 (26.1)</td>
<td>742 (73.9)</td>
</tr>
<tr>
<td>Relationship with family</td>
<td>1031</td>
<td>31</td>
<td>237 (23.7)</td>
<td>763 (76.3)</td>
</tr>
<tr>
<td>Relationship with partner</td>
<td>1020</td>
<td>153</td>
<td>151 (19.7)</td>
<td>616 (80.3)</td>
</tr>
<tr>
<td>Completing school work</td>
<td>1031</td>
<td>32</td>
<td>158 (15.8)</td>
<td>841 (84.2)</td>
</tr>
<tr>
<td>Relationship with friends</td>
<td>1032</td>
<td>32</td>
<td>153 (15.3)</td>
<td>847 (84.7)</td>
</tr>
<tr>
<td>Casual paid work</td>
<td>1025</td>
<td>167</td>
<td>117 (13.6)</td>
<td>741 (86.4)</td>
</tr>
<tr>
<td>Attending school</td>
<td>1035</td>
<td>27</td>
<td>120 (11.9)</td>
<td>888 (88.1)</td>
</tr>
</tbody>
</table>

*high interference = 5-10 (on 0-10 rating scale)
**low interference = 0-4 (on 0-10 rating scale)
( ) percentages are included in parentheses

**Aspects of menstruation that cause interference with life activities**

After recording menstrual interference on life activities, respondents were asked 'What is it about your period that interferes with your life?' which was also measured on a 0-10 rating scale where 0 = least interfering, 10 = most interfering. Answer options included: pain, heavy blood flow, tiredness/fatigue, moods, generally feeling unwell, as well as an 'other' option. As shown in Figure 3, the respondents rated
moods above pain as the most interfering, followed equally by tiredness/fatigue, heavy blood flow and generally feeling unwell.

Figure 3. Aspects of menstruation that cause interference with life activities

Responses to themed statements
Participants were asked a series of statements for which they could respond ‘true’, ‘false’, ‘don’t know’, or ‘not applicable’. The statements reflected the following themes: perception of normal menstruation, perception of problematic menstruation, use of OCPs, feminine hygiene products, people girls talk to about periods, emotions surrounding menstruation. When the statements are grouped into themes the responses are reasonably consistent. Some of the statements appear in more than one theme category. In the following results tables, statements have been grouped into the themes identified above.
**Teenage perceptions of menstruation**

### Table 13. Perceptions of normality regarding menstrual periods

<table>
<thead>
<tr>
<th>Statements of normal menstruation</th>
<th>True</th>
<th>True %</th>
<th>False</th>
<th>Don't know</th>
<th>N/A</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I usually have period every month</td>
<td>870</td>
<td>83.9</td>
<td>134</td>
<td>27</td>
<td>6</td>
<td>1037</td>
</tr>
<tr>
<td>My periods seem pretty normal</td>
<td>740</td>
<td>71.4</td>
<td>169</td>
<td>125</td>
<td>3</td>
<td>1037</td>
</tr>
<tr>
<td>I think my periods are 'normal' most of the time</td>
<td>816</td>
<td>78.4</td>
<td>131</td>
<td>92</td>
<td>2</td>
<td>1041</td>
</tr>
<tr>
<td>Periods don’t worry me too much</td>
<td>688</td>
<td>66.9</td>
<td>253</td>
<td>84</td>
<td>3</td>
<td>1028</td>
</tr>
<tr>
<td>I have never missed a period</td>
<td>412</td>
<td>39.7</td>
<td>522</td>
<td>97</td>
<td>7</td>
<td>1038</td>
</tr>
</tbody>
</table>

### Table 14. Problematic menstruation: reported perceptions, consultation and investigation

<table>
<thead>
<tr>
<th>Statements of problematic menstruation</th>
<th>True</th>
<th>True %</th>
<th>False</th>
<th>Don't know</th>
<th>N/A</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have had problems with my periods</td>
<td>360</td>
<td>34.8</td>
<td>510</td>
<td>137</td>
<td>28</td>
<td>1035</td>
</tr>
<tr>
<td>I have talked to my GP about my periods</td>
<td>341</td>
<td>33</td>
<td>660</td>
<td>7</td>
<td>26</td>
<td>1034</td>
</tr>
<tr>
<td>I sometimes think there is something ‘wrong’ with my periods</td>
<td>279</td>
<td>26.9</td>
<td>683</td>
<td>60</td>
<td>17</td>
<td>1039</td>
</tr>
<tr>
<td>I am sure there is something is wrong with my period</td>
<td>101</td>
<td>9.7</td>
<td>824</td>
<td>86</td>
<td>28</td>
<td>1039</td>
</tr>
<tr>
<td>Periods worry me a lot</td>
<td>165</td>
<td>16.1</td>
<td>759</td>
<td>73</td>
<td>28</td>
<td>1025</td>
</tr>
<tr>
<td>I have had tests because things weren’t right with my period</td>
<td>110</td>
<td>10.6</td>
<td>818</td>
<td>21</td>
<td>87</td>
<td>1036</td>
</tr>
<tr>
<td>I’ve had a blood test for my period pain</td>
<td>40</td>
<td>3.9</td>
<td>941</td>
<td>14</td>
<td>42</td>
<td>1037</td>
</tr>
<tr>
<td>I’ve had an ultrasound to look for causes of my pain</td>
<td>56</td>
<td>5.4</td>
<td>918</td>
<td>8</td>
<td>52</td>
<td>1034</td>
</tr>
<tr>
<td>I’ve talked to a specialist doctor about my periods</td>
<td>89</td>
<td>8.6</td>
<td>914</td>
<td>2</td>
<td>29</td>
<td>1034</td>
</tr>
<tr>
<td>I’ve had an operation to look for causes of my pain</td>
<td>9</td>
<td>0.9</td>
<td>970</td>
<td>8</td>
<td>51</td>
<td>1038</td>
</tr>
<tr>
<td>I have a period problem that has a name</td>
<td>25</td>
<td>2.7</td>
<td>601</td>
<td>73</td>
<td>238</td>
<td>937</td>
</tr>
</tbody>
</table>

**Oral Contraceptive Pill (OCP)**

Twenty two percent (n=225) of respondents reported taking the oral contraceptive pill (OCP). Out of the total sample, 15% (n=156) reported taking the OCP to regulate periods, 13.5% (n=138) to reduce period pain, 16.7% (n=172) to prevent pregnancy, while 62.2% (n=638) said they had never taken the pill.
### Menstrual hygiene products used by teenagers

**Table 15. Menstrual hygiene products used by teenagers**

<table>
<thead>
<tr>
<th>Statements of pad and tampon use during menstruation</th>
<th>True</th>
<th>True %</th>
<th>False</th>
<th>Don't know</th>
<th>N/A</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I only use tampons</td>
<td>163</td>
<td>15.8</td>
<td>824</td>
<td>5</td>
<td>42</td>
<td>1034</td>
</tr>
<tr>
<td>I only use pads (sanitary napkins)</td>
<td>383</td>
<td>37</td>
<td>641</td>
<td>4</td>
<td>7</td>
<td>1035</td>
</tr>
<tr>
<td>I use pads and tampons</td>
<td>565</td>
<td>55.2</td>
<td>419</td>
<td>5</td>
<td>34</td>
<td>1023</td>
</tr>
<tr>
<td>I am not interested in using a tampon</td>
<td>236</td>
<td>22.7</td>
<td>749</td>
<td>37</td>
<td>17</td>
<td>1039</td>
</tr>
<tr>
<td>I have tried to use a tampon but can’t get it in</td>
<td>93</td>
<td>9.0</td>
<td>886</td>
<td>8</td>
<td>50</td>
<td>1037</td>
</tr>
<tr>
<td>I can insert a tampon but it is too uncomfortable</td>
<td>100</td>
<td>9.7</td>
<td>810</td>
<td>26</td>
<td>97</td>
<td>1033</td>
</tr>
<tr>
<td>I have never used a tampon</td>
<td>310</td>
<td>29.8</td>
<td>719</td>
<td>2</td>
<td>9</td>
<td>1040</td>
</tr>
</tbody>
</table>

### People teenagers talk to about menstruation

**Table 16. People teenagers talk to about menstruation**

<table>
<thead>
<tr>
<th>Statements of people teenagers talk to about menstruation</th>
<th>True</th>
<th>True %</th>
<th>False</th>
<th>Don’t know</th>
<th>N/A</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I talk to someone in my family about my periods</td>
<td>659</td>
<td>63.5</td>
<td>352</td>
<td>13</td>
<td>14</td>
<td>1038</td>
</tr>
<tr>
<td>I talk to my friends about my periods</td>
<td>707</td>
<td>68.2</td>
<td>289</td>
<td>25</td>
<td>15</td>
<td>1036</td>
</tr>
<tr>
<td>I’ve talked to my teacher/school counselor about my periods</td>
<td>21</td>
<td>2</td>
<td>987</td>
<td>3</td>
<td>25</td>
<td>1036</td>
</tr>
<tr>
<td>I’ve talked to my GP about my periods</td>
<td>341</td>
<td>33</td>
<td>660</td>
<td>7</td>
<td>26</td>
<td>1034</td>
</tr>
<tr>
<td>I’ve talked to a specialist doctor about my periods</td>
<td>89</td>
<td>8.6</td>
<td>914</td>
<td>2</td>
<td>29</td>
<td>1034</td>
</tr>
<tr>
<td>I’ve talked to a naturopath/herbalist/acupuncturist about my periods</td>
<td>59</td>
<td>5.8</td>
<td>931</td>
<td>4</td>
<td>28</td>
<td>1022</td>
</tr>
</tbody>
</table>

### Teenage reports of moods experienced with menstruation

**Table 17. Teenage reports of moods experienced with menstruation**

<table>
<thead>
<tr>
<th>Statements of moods experienced With menstruation</th>
<th>True</th>
<th>True %</th>
<th>False</th>
<th>Don’t know</th>
<th>N/A</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am grumpy before or during my periods</td>
<td>757</td>
<td>73.1</td>
<td>217</td>
<td>54</td>
<td>8</td>
<td>1036</td>
</tr>
<tr>
<td>I am grumpy all the time</td>
<td>100</td>
<td>9.7</td>
<td>866</td>
<td>53</td>
<td>15</td>
<td>1034</td>
</tr>
<tr>
<td>I get teary before or during a period</td>
<td>536</td>
<td>51.6</td>
<td>441</td>
<td>48</td>
<td>13</td>
<td>1038</td>
</tr>
<tr>
<td>Feel overwhelmed and not able to cope before or during periods</td>
<td>325</td>
<td>31.5</td>
<td>629</td>
<td>55</td>
<td>24</td>
<td>1033</td>
</tr>
<tr>
<td>Often want to withdraw or hide when I have my period</td>
<td>263</td>
<td>25.4</td>
<td>700</td>
<td>49</td>
<td>24</td>
<td>1036</td>
</tr>
<tr>
<td>Periods don’t affect my moods</td>
<td>200</td>
<td>19.3</td>
<td>752</td>
<td>69</td>
<td>14</td>
<td>1035</td>
</tr>
</tbody>
</table>
Respondent reporting of menstrual problems in family.

Table 18. Respondent reports of mother/sister with period problems

<table>
<thead>
<tr>
<th>Does your mother or sister have any of the following?</th>
<th>Yes</th>
<th>%</th>
<th>No</th>
<th>%</th>
<th>Don’t know</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe period pain</td>
<td>281</td>
<td>27.2</td>
<td>494</td>
<td>47.9</td>
<td>247</td>
<td>23.9</td>
</tr>
<tr>
<td>Period problems</td>
<td>229</td>
<td>22.2</td>
<td>541</td>
<td>52.4</td>
<td>251</td>
<td>24.3</td>
</tr>
<tr>
<td>Endometriosis</td>
<td>14</td>
<td>1.4</td>
<td>692</td>
<td>67.4</td>
<td>307</td>
<td>29.9</td>
</tr>
<tr>
<td>PCOS*</td>
<td>20</td>
<td>1.9</td>
<td>694</td>
<td>67.5</td>
<td>300</td>
<td>29.2</td>
</tr>
<tr>
<td>PID**</td>
<td>5</td>
<td>0.5</td>
<td>716</td>
<td>69.5</td>
<td>295</td>
<td>28.6</td>
</tr>
</tbody>
</table>

*PCOS = polycystic ovarian syndrome
**PID = pelvic inflammatory disease

Respondents were also asked if they had heard of polycystic ovarian syndrome (PCOS), endometriosis or pelvic inflammatory disease (PID). Responses in the positive were 19.2% (n=192), 23.6% (n=244) and 28.7% (n=296) respectively.

Associations between menstrual bleeding patterns, pain, symptoms, interference, and school absence

An alpha level of .01 was used for all statistical tests.

Menstrual cycle length and pain.

No statistically significant associations were found when short cycle length (18-27 days) was crosstabulated against menarcheal age, the three pain categories, school absence and the number of bleeding days in a menstrual period. However, the girls who indicated a short menstrual cycle ≤ 27 days (n=125) had a higher percentage-wise representation in the severe pain group (24.0% vs 19.9%) and lower representation in the mild pain group (24.0% vs 30.3%) in comparison to those girls whose menstrual cycle was 28-47 days. The spread of girls with a short menstrual cycle (≤ 27 days) (n=125) across the categories of mild, moderate or severe pain was 52% (n=65) of girls reported moderate pain, while 24% (n=30) reported mild pain and 24% (n=30) reported severe pain.
Menstrual pain and school absence due to menstruation

There is a statistically significant association, ($\chi^2 = 104.5, 2 \, df, p=0.000$) between the three pain categories, (no/mild, moderate, severe) and the variable relating to school absence due to menstrual periods.

As seen in Table 19, 89.7% (n=278) of girls in the no/mild pain category did not miss school while 10.3% (n=32) reported missing school. In the severe pain group, more girls reported missing school 50.0% (n=106) but it was equal to the number of girls who did not miss school 50.0% (n=106).

Table 19. Crosstabulation of levels of menstrual pain with school absence due to menstruation

<table>
<thead>
<tr>
<th>Reported menstrual pain</th>
<th>School absence due to menstruation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>No/mild pain</td>
<td></td>
<td>278</td>
</tr>
<tr>
<td>%</td>
<td>89.7</td>
<td>10.3</td>
</tr>
<tr>
<td>Moderate pain</td>
<td></td>
<td>372</td>
</tr>
<tr>
<td>%</td>
<td>75.3</td>
<td>24.7</td>
</tr>
<tr>
<td>Severe pain</td>
<td></td>
<td>106</td>
</tr>
<tr>
<td>%</td>
<td>50.0</td>
<td>50.0</td>
</tr>
<tr>
<td>Total</td>
<td>n= 756</td>
<td>260</td>
</tr>
<tr>
<td>%</td>
<td>74.4</td>
<td>25.6</td>
</tr>
</tbody>
</table>

Menstrual pain and menstrual interference on life activities

Figure 4 uses a boxplot to show the relationship between the three categories of pain and the mean interference of menstruation on the respondents' lifestyles. The Kruskal Wallis Test demonstrated a statistically significant association ($\chi^2 = 91.1, 2 \, df, p=0.000$) between levels of pain and the mean interference of menstruation on life activities. There are a number of outliers in the no/mild pain group who have indicated a high mean for menstrual interference on daily activities.
Non-parametric tests were also performed on each daily activity for the three pain categories, as shown in Table 20.

Table 20. Association between menstrual pain and menstrual interference on life activities

<table>
<thead>
<tr>
<th>Life Activity</th>
<th>Median 3 pain categories</th>
<th>$\chi^2 (1)$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
</tr>
<tr>
<td>Attending school</td>
<td>0.00</td>
<td>1.00</td>
<td>3.00</td>
</tr>
<tr>
<td>Completing school work</td>
<td>0.00</td>
<td>1.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Casual paid work</td>
<td>0.00</td>
<td>0.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Social activities</td>
<td>1.00</td>
<td>3.00</td>
<td>4.00</td>
</tr>
<tr>
<td>Relationship with family</td>
<td>0.00</td>
<td>2.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Relationship with friends</td>
<td>0.00</td>
<td>1.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Relationship with partner</td>
<td>0.00</td>
<td>0.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Sexual activity</td>
<td>0.00</td>
<td>2.00</td>
<td>5.00</td>
</tr>
<tr>
<td>Sport and exercise</td>
<td>1.00</td>
<td>3.00</td>
<td>5.00</td>
</tr>
</tbody>
</table>
Frequency of menstrual symptoms and school absence due to menstruation

The following boxplot (Figure 5) measures the frequency of symptoms reported against school absence due to menstruation. The median for frequency of symptoms in the group who do not miss school due to menstruation was seven (7) versus twelve (12) for those who reported missing school (the means were 8.2 and 12.7 respectively). There is a statistically significant association ($\chi^2 = 120.4$, 1 df, $p=0.000$) between the frequency of reported symptoms and school absence. There were some outliers in the ‘do not miss school’ group who reported a high frequency of symptoms.

Figure 5. Association between mean number of menstrual symptoms reported and school absence due to menstruation
Frequency of menstrual symptoms and menstrual interference on life activities

Non-parametric testing using Spearman’s rho showed a highly significant correlation ($r (1030) = 0.468, p=0.000$) between frequency of menstrual symptoms experienced and reported interference in life activities by the teenagers.

Most common symptoms crosstabulated against school absence and pain categories

When the most frequently reported menstrual symptoms were crosstabulated against reported school absence, it was observed that ‘feeling really tired’, ‘headaches’, and ‘feeling down or depressed’ in the girls who also said yes to missing school, were spread more across the menstrual cycle with reported rates ‘at the time of period’ of 34.6% (n=89), 25.2% (n=64), 23.4% (n=59), respectively. In comparison, bloating, back pain and pelvic cramping pain were more concentrated ‘At the time of period’ and responses were, 43.1% (n=107), 43.7% (n=108), 62% (n=155) respectively. When the same symptoms were crosstabulated against the three pain categories (no/mild, moderate and severe) there was also a similar finding where bloating, back pain and pelvic cramping pain were more concentrated ‘at the time of period’ for those girls with severe pain, 42.9% (n=90), 47.6% (n=98), and 68.4% (n=141) respectively, when compared with ‘feeling really tired’ 33.2% (n=71), ‘headache’ 19.4% (n=40), and ‘feeling down or depressed’ 21.3% (n=45).

Menstrual interference on life activities and school absence due to menstruation

A relationship was evident between menstrual interference on life activities and school absence due to menstruation. In Figure 6 the boxplot demonstrates that the girls who are missing school are also those indicating a higher mean for interference of menstruation on their life activities. The median for menstrual interference and not missing school was 0.111, whereas the median in the group who reported missing school was higher at 0.310. A Kruskal Wallis Test demonstrated a statistically significant association ($\chi^2 = 80.33, 1 \text{ df}, p=0.000$) between menstrual interference on life activities and school absence due to menstruation. Once again there were outliers
who indicated a high interference of menstruation on their life activities but did not take time off school.

Figure 6. Association between menstrual interference on life activities and school absence due to menstruation

**Exploration of associations between short cycle length, menarcheal age and pain severity, school absence**

**Short cycle length**

Twelve percent (12%, n=125) of the MDOT sample indicated menstrual cycles of 18-27 days. No statistically significant associations were found when these respondents were crosstabulated against menarcheal age, the three pain categories, school absence, or the number of bleeding days in a menstrual period. However, the girls who indicated a short menstrual cycle ≤ 27 days had a higher percentage-wise representation in the severe pain group (24.0% vs 19.9%) and lower representation in the mild pain group (24.0% vs 30.3%) when compared with those girls whose menstrual cycle was 28-47 days.
Menarche
Menarche for the sample was divided into three age groups, 8-11, 12-14 and 15-19 years. When these three age categories were cross tabulated against school absence and the three pain categories, there was a statistically significant reduction in reports of pain and school absence \((p=0.006)\) and \((p=0.003)\) respectively, in those girls who were \(\geq 15\) years at menarche.

Typical menstruation in MDOT sample
One hundred and sixteen questions collected considerable information surrounding menses in 16-18 year old teenagers. The collective menstrual picture from aggregated data gives the following picture of menstruation in the population sample:

- Menstrual pain is common – 94% report pain with menstruation, 70% report moderate to severe pain with menstruation, and 71% specifically report pelvic cramping type pain. (Pelvic cramping, aching, and stabbing pain all featured in the top 10 symptoms).
- PMS symptoms are common – 96% report one or more PMS symptom, 68% report 5 or more PMS symptoms (out of a total of 11 symptoms).
- Mood disturbance is common – 73% report feeling grumpy, 65% feel down or depressed.
- A quarter of the sample (26%), miss school because of their menstrual periods.
- 55.8% report high interference on one or more life activities
- Moods, followed by pain were the most frequently reported aspects of menstruation that interfere with life activities.

There were statistically significant associations between each and all of the following: pain, menstrual symptomatology, school absence and interference in life activities.

- 71-79% of the teenagers considered their periods to be ‘pretty normal’/‘most of the time’
- Only 1% of MDOT teenagers had asymptomatic menstruation.

Overall, menstruation causes considerable pain, symptoms and disturbance to many 16-18 year old girls.
Individual menstrual picture (IMP) results

Each questionnaire was scrutinized to form an IMP for each respondent (explained in the method chapter). IMP results suggested that 60% of the entire sample (N=1051) required either postal, telephone or clinic follow up. Thirty-seven percent of girls (n=386) required follow up information about primary dysmenorrhoea and PMS symptoms, 18% (n=186) required follow-up through our MDOT clinic to investigate menstrual problems/disturbance, and 5% (n=57) required follow up by phone to determine if a clinic visit was needed.

There were 11 girls (1%) out of the total study population (N=1051) who reported menstruation that was asymptomatic. That is, no pain or PMS symptoms. At the other end of the spectrum, there were 187 (18%) who were identified for follow-up in the MDOT clinic, of which 142 (14%) have symptoms that warrant the exclusion of endometriosis, however, not all of these respondents gave consent to be followed up.

Respondent consent to be contacted

Thirty-nine percent (n=404) of girls answered ‘Yes’ to the question: ‘Do you wish to be contacted if the research team would like to discuss your questionnaire findings with you?’ Forty-nine percent (n=508) answered ‘No’, and 13% (n=136) left the question blank.

Table 21. Respondent follow up matched to respondent consent.

<table>
<thead>
<tr>
<th>Follow-up categories</th>
<th>Consent for contact</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Send info</td>
<td>Yes 121</td>
<td>386</td>
</tr>
<tr>
<td></td>
<td>No 209</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blank 56</td>
<td></td>
</tr>
<tr>
<td>Clinic follow up</td>
<td>Yes 118</td>
<td>186</td>
</tr>
<tr>
<td></td>
<td>No 46</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blank 22</td>
<td></td>
</tr>
<tr>
<td>Phone</td>
<td>Yes 43</td>
<td>57</td>
</tr>
<tr>
<td></td>
<td>No 11</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blank 3</td>
<td></td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td>Yes 284</td>
<td>629</td>
</tr>
<tr>
<td></td>
<td>No 266</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blank 81</td>
<td></td>
</tr>
<tr>
<td>Nil action required</td>
<td>Yes 122</td>
<td>419</td>
</tr>
<tr>
<td></td>
<td>No 242</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blank 55</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>Yes 404</td>
<td>1048*</td>
</tr>
<tr>
<td></td>
<td>No 508</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blank 136</td>
<td></td>
</tr>
</tbody>
</table>

* Three consent forms were missing.
Problematic menstruation

The collective picture of MDOT results is a consistent figure of approximately 25% of girls indicating considerable menstrual disturbance:

- 21% reported severe pain
- 26% take time off school
- >24% reported high interference on 4 (out of 9) life activities
- 23.5% of IMPs required phone or clinic follow up.
- 26.5% think there is something wrong with their periods
- 27.2% report mother or sister with severe period pain
- 22.2% report mother or sister with period problems

More than one third of all respondents (35%, n=360) reported ‘problems with their periods’ and one third reported talking to a GP about their periods (33%, n=341). Approximately 10% are ‘sure there is something wrong’ (9.7%) with their periods and ‘have talked to a specialist’ (8.6%) about their period.

Forty (n=40) girls gave a written response for ‘I have a period problem that has a name’, however, only ten listed a clinical diagnosis such as PCOS (n=8) or endometriosis (n=2) (another two respondents said they were being investigated for endometriosis).

Summary

The MDOT study has collected a diverse range of data about menstruation in ACT teenagers. A collective picture of typical menstruation for the sample is obtainable from the data. The data also shows a high reporting by respondents of menstrual pain, symptoms and interference. Statistical associations between pain, symptoms, interference and school absence suggest that a quarter of the MDOT sample have significant menstrual disturbance, with 10-14% requiring investigation to rule out menstrual disorder.

The discussion chapter will examine the important findings from the MDOT data in regard to the aims of the study and the issues highlighted in the literature review.
Chapter 6: Discussion

The problem
While menstruation is a normal, healthy part of adolescence, the literature suggests that a significant number of teenagers suffer menstrual pain and symptoms that keep them home from school and interfere with their life activities. The literature also suggests that 50-70% of teenagers with menstrual and pelvic pain that does not respond to OCPs and NSAIDs are found to have endometriosis. This thesis has sought to determine typical menstrual patterns for older ACT teenagers and the prevalence of menstrual disturbance in the sample by viewing the data collectively, as well as examining each questionnaire individually (Individual Menstrual Picture).

Introduction
The first part of the Discussion chapter will discuss the results of the research components of the MDOT study including: participation rates of the secondary colleges, response rate, sample representativeness of the population being studied, and generalisability to ACT private school girls and those 16-18 year old girls located outside the ACT. In terms of survey research the consistency of the questionnaire will also be discussed.

The second half of the chapter will discuss the main MDOT survey findings with a focus on MDOT data pertinent to the issues highlighted in the literature review. These include menstrual bleeding patterns, typical picture of menstrual pain and symptoms for the MDOT sample, impact of menstruation on respondents, prevalence of menstrual disturbance and severe menstrual pain and endometriosis. Limitations of the study and whether the method satisfied the purpose of the MDOT study will also be discussed.
The Survey

Participation rate of colleges

Three of the four secondary colleges made time available for all enrolled girls to participate in data collection. Factors affecting participation on the day would have included non-volition, parental non-consent, absence from school (due to illness, appointments, excursions, truancy, etc), and those girls who were 15 years of age and did not meet the age criteria of 16-18 years for the study. For the three colleges who had full participation in the MDOT study, the participation rate on the days of data collection varied between 62-80%, with the average across the three colleges being 71%. The fourth college with only partial participation had a participation rate of 17%. The lower participation rate demonstrates the advantage of having the full support of the college principals to involve all the girls. Fortunately, full participation by the fourth college was not required to achieve our target sample size of 1,000.

Response to questionnaire

One thousand and seventy one questionnaires were given out and 1051 completed questionnaires were returned. A response rate of 98% is exceptionally high and a rarity in survey research. There were two factors that contributed to the high rate. The first one was the preparation done in the schools before data collection which included the promotional tables and information sessions. The second and more influential reason for the high response rate was the involvement of the colleges and their facilitation of data collection. The combination of the full support of the college principals and key teaching staff to encourage all girls to participate, as well as the provision of time for completion of the questionnaire on the spot so that it could be collected immediately after completion, contributed to the high response rate.

Population representativeness of the sample

The ACT provides researchers with a unique opportunity to study various populations that are ‘encapsulated’ within the territory. The MDOT sample of 1051 girls represents one third of all female government secondary college students and one fifth of all female secondary college/senior high school students in the ACT (i.e.
government and non-government). In the ACT, the secondary college/senior high school population accounts for 87% of all 16-18 year old teenagers (Year 10-11 and Year 11-12 retention rate, 2005 February census, ACT Government Secondary Colleges).

The generalisability of a sample to the population requires that the sample be representative of the population being studied and large enough for the results to accurately represent the population (Scriven, 1976; Lo Biondo, Wood & Haber, 1990). Due to the large sample size and even spread across the ACT, the MDOT results are reasonably representative of 16-18 year old females attending government secondary colleges in the ACT. Also, the geographical and socio-economic layout of the ACT makes any major shift in the results from other government colleges unlikely. However, this was not tested and the generalisability of the MDOT results to all 16-18 year old girls in the ACT and other locations around Australia can only be speculated upon.

There are factors surrounding economic status that could possibly influence teenage menstrual health. For example, the affordability of seeking health professional advice sooner rather than later may determine how soon a female of young age with menstrual disorder is diagnosed and treated. Also, poor diet and/or emotional upset from living in a high stress home environment (e.g. one with financial and relationship difficulties) could affect menstrual bleeding patterns and cause amenorrhoea (Adams Hillard, 2006).

The average weekly equivalised gross household income in the ACT is 29% higher than the Australian average, with NSW the next highest at 6% above the national average (Source: ABS 2001 Census of Population and Housing). The proportion of people in the lowest income households was lowest in the ACT at 11%, with the other states and territories ranging between 18-27% (Source: ABS 2001 Census of Population and Housing). This may mean there is less variation between government and non-government senior high school students in the ACT, and that ACT government senior high schools (secondary colleges) may not be comparable with
other government senior high schools in other locations around Australia (particularly lower socioeconomic areas).

In the Western Australian study of primary dysmenorrhoea in 388, 15-17 year old schoolgirls, Hillen et al. found a significant difference ($\chi^2 = 7.5, df = 2, p < .05$) [sic] in the prevalence of self-reported dysmenorrhoea between a private single-sex school, and two co-educational state high schools - one with a higher socio-economic status (SES) and one with a lower SES, with figures of 74%, 84%, and 87% respectively. Hillen et al. does not postulate on possible causes for the differences in the prevalence of dysmenorrhoea across the schools, but suggests that there may be some selection bias in their sample towards higher SES as only 18% of respondents were from the low SES school, which means their results may underestimate the prevalence of dysmenorrhoea in their target population (15-17 year old schoolgirls).

Rapkin, Tsao, Turk, Anderson & Zeltzer (2006) also suggest that social class can influence adolescent physical development as children of higher SES groups usually grow taller and heavier and experience earlier maturation. However, they also state that “the effect of social class is due to a complicated interaction between genetic and environmental factors, and at a certain level of economic prosperity, developmental differences between rich and poor may no longer be significant” (Rapkin et al. 2006, p. 186). This may be applicable to the ACT given the higher than average household incomes and the lower proportion of ACT households being amongst lowest household incomes compared to other states.

The Questionnaire
The questionnaire was structured with repetitions in themes and questions to assess the consistency of responses. Pain and moods were themes that were consistently reported as being experienced with menstruation by the majority (approximately three quarters) of the study sample, and also reported as the symptoms that interfered with life the most. Answers were also consistent in the true/false statements as evidenced in themed tables in the results section. For example, in the three statements regarding
the perception that menstrual periods were for the most part, ‘normal’, responses were consistent where they ranged between 67-78% of respondents.

After using the questionnaire, there were only a few minor changes that would be made if the tool were to be used again. For example, ‘breast tenderness’ and ‘irritability’ would be added to the symptom list and the wording of one of the true/false statements which was ‘I usually have a period every month’ would be changed. Some girls might ‘usually have a period’ but it may not be ‘every month’. Survey items must only ask one question (LoBiondo-Wood & Haber, 1994).

**Survey results**

**Menstrual bleeding patterns of the MDOT sample**

**Menarche**

Current literature suggests that the average age of menarche is currently between 12 - 13 years of age (Adams Hillard, 2002). The average age of menarche for the MDOT sample fell within this range at 12 years, 9 months (12.74 years). Sixty-one percent of the MDOT sample reported menarche at the age of 12 or 13 years. The MDOT sample also demonstrated a wide range in menarchical age from the youngest reported at 8 years to the oldest at 19 years. Onset of menstruation in Whincup et al.’s study of 1166 British girls was found to be 0.8, 3.6, and 21.7 percent at 10, 11 and 12 years respectively. In comparison, the MDOT results were higher at 2.4, 12.6, and 28.2 percent for the same ages respectively.

**Regularity**

Amenorrhoea was surprisingly low in the sample with 99% of MDOT respondents reporting that they were menstruating, 62% reporting regular menstruation and 30.5% reporting irregular menstruation. Comparative data for the same age group was lacking, but, in a younger teenage sample, similar menstrual regularity was reported in the WHO study (1986) of 548, 11-15 year olds as 67.7% where a regular cycle pattern occurred within a range of ten days, with cycles lasting between 20-40 days.
Cycle
The majority of the MDOT sample who answered this question had a cycle length that fell within the reported usual cycle length for teenagers of 21-45 days (Adams Hillard, 2002). From the total sample, 46.9% (n=484) of girls recorded cycle lengths ranging from 18-44 days. Of these, 25.8% (n=125) of girls reported a cycle length ranging from 18-27 days, 71.9% (n=348) reported a cycle length between 28-37 days and 2.3% (n=11) 40-44 days.

Length
Length of menstrual bleeding for 87% of the MDOT sample was 1-5 days, with 90.1% completing bleeding by day eight. This is consistent with current literature which suggests that 80-90% of teenagers bleed menstrually for 2-7 days (Adams Hillard, 2003; Slap, 2003).

Summary of typical menstrual patterns for MDOT sample
According to MDOT data, typical menstruation for ACT teenagers is menarche at age 12 or 13 (60.8%) (88.3% between 11-14 years), regular cycles ranging from 21-35 days for 94% (n=455) of girls who reported a cycle length (n=484), and menstrual bleeding lasting on average 5.93 days. The MDOT sample did not exhibit any atypical trends from current literature in regard to menstrual patterns.

Menstrual pain and symptoms in the MDOT sample
The MDOT findings for menstrual pain are consistent with the teenage reports of menstrual pain/dysmenorrhea reported in other studies (Andersch & Milsom, 1982; Hillen et al.; Johnson, 1988; Klein & Litt, 1981; Teperi & Rimpalä, 1989). The total number of girls who reported pain with menstruation in the MDOT sample was 94%, of whom 69.5% reported moderate to severe pain, and 71% reported cramping pain. Similarly, a high proportion of MDOT girls (98.4%) reported one or more symptoms occurring in relation to menstruation. The literature has recognized that there are a number of symptoms that occur in conjunction with dysmenorrhea creating a type of syndrome (Andersch & Milsom, 1982; Hillen et al.; Johnson, 1988; O’Connell et al.; Pennington, 1957; Song & Advincula, 2005; Wilson & Keye, 1989). However, there
is also an overlap between these symptoms, those of PMS and pathological menstruation including endometriosis, making it difficult to distinguish the symptoms and consequently the causes. When the PMS symptoms were separated, they were still found to affect 96% of the MDOT sample who reported one or more symptoms associated with their periods.

**Mood disturbance surrounding menstruation**

In the literature, mood symptoms related to menstruation are commonly reported with, or as PMS symptoms, which tends to dilute their impact. When examined separately from physical symptoms there is evidence of significant disturbance to a high number of respondents where 72% of girls in the MDOT sample reported feeling grumpy, 64.7% felt depressed, 51.6% were teary, 31.5% were overwhelmed and unable to cope, and 25% wanting to withdraw or hide during their period. Although 19.3% reported that periods did not affect their moods, only 13% of girls did not report a mood symptom. Our study finding that mood rated higher than pain as the most interfering aspect of menstruation, as reported by MDOT respondents, has not previously been reported. However, other studies also confirm the impact of menstrual mood disturbance on teenagers’ lives (Fisher et al.; Wilson & Keye, 1989). Fisher et al. found that 50% of teenagers had impaired social functioning (e.g. quarrelling, want to be alone), 66% with depressive changes and 33% with impulsive behaviour (e.g. temper outbursts). The depressive changes are almost the same as the 64.7% found in the MDOT sample.

**Impact of menstruation**

**School absence due to menstruation**

The findings from the MDOT study regarding menstruation and school absence rates of 26% is consistent with the 14-51% reported in the literature (Andersch & Milsom, 1982; Johnson, 1988; Klein & Litt, 1981; Teperi & Rimpelä, 1989; Widholm, 1979; Wilson & Keye, 1989). MDOT findings for school absence in teenagers experiencing severe pain (50%) is also consistent with the reported 50% and 54% found by Klein and Litt (1981) and Teperi and Rimpelä (1989) respectively.


**Menstrual interference with life activities**

A considerable number of MDOT participants reported interference by menstruation on life activities. There were 55.8% respondents who gave one or more of the nine activities a score of five or higher, on a scale of 0-10 (where 0=no interference and 10=major interference). Twenty-eight percent (28.4%) gave three or more activities a score of five or higher. These results were comparable with reports of menstrual interference from other studies, ranging from 15.4%-58.9% (Andersch & Milsom, 1982; Hillen et al.; Johnson, 1988; Wilson & Keye, 1989).

**Use of pain medication for the sample**

Two thirds of the MDOT sample reported using pain medication for period pain. Hillen et al.’s research seven years ago showed that more girls used simple analgesics (53%) than NSAIDs (42%). However, the MDOT results suggest that more girls are now using NSAIDs instead of simple analgesics. Of the girls who reported taking medication, 78% (n=501) circled or listed a NSAID, and 64% circled or listed a simple analgesic such as paracetamol n=378, aspirin n=30, or Mersyndol n=4. It also appears that some girls take more than one type of analgesic.

O’Connell et al.’s more recent research also found that more teenagers were taking NSAIDS for period pain, however, they suggested that medication dosing used by teenagers is sub-therapeutic. Of those girls in the MDOT sample who rated the effectiveness of their medication use, 44.3% said it was moderately effective and 41.1% highly effective. In the ‘no/mildly effective’ (14.6%) and ‘moderately effective’ pain relief groups, proper dosing might help sort out those girls who are not using medications effectively from those with underlying menstrual disorder.

**Overall picture of typical menstruation for the MDOT sample**

From the MDOT data, it was surprising that only 11 girls (1%) reported asymptomatic menstruation - that is, no pain and no symptoms associated with menstruation. It seems that typical menstruation for the 16-18 year old women in the MDOT sample includes considerable pain, physical and mood symptoms, and interference with life.
activities. The collective menstrual picture from aggregated data gives the following picture of menstruation in the population sample:

- Menstrual pain is common - 72% report moderate to severe pain with menstruation, and 71% specifically report pelvic cramping type pain. (Pelvic cramping, aching, and stabbing pain all featured in the top 10 symptoms).
- PMS symptoms are common – 96% report one or more PMS symptoms, 68% report 5 or more PMS symptoms (out of a total of 11 symptoms).
- Mood disturbance is common – 73% report feeling grumpy, 65% feel down or depressed.
- A quarter of the sample (26%), miss school because of their menstrual periods.
- 55.8% report high interference on one or more life activity
- Moods and pain are the most frequently reported aspects of menstruation that interfere with life activities.
- There are statistically significant associations between each and all of the following: pain, symptomatology, school absence and interference in life activities.
- 71-79% of the teenagers consider their periods to be ‘pretty normal’/‘most of the time’
- 60% have sufficient symptoms or disturbance to require information by post or follow up through the MDOT clinic
- Only 1% of MDOT teenagers have asymptomatic menstruation.

Interestingly, despite the high rates of menstrual pain (94%) and PMS symptoms (96%) reported in this study, 71-79% of the teenagers still considered their periods to be ‘pretty normal’/‘normal most of the time’. When menstrual pain is narrowed to those reporting moderate to severe (71.6%) and PMS symptoms to those teenagers reporting five or more symptoms (68%), this is still many more than the 10% who were sure that there was something wrong with their periods, or the 25% who thought there might be something wrong with their periods. It appears that teenagers in this sample consider significant pain and symptoms to be a normal part of menstruation.
Associations between pain, symptoms, school absence, and interference

Important findings to come out of the MDOT study are the statistical associations between menstrual pain severity, number of menstrual symptoms reported, school absence and interference on life activities. Whilst there is much data in the literature measuring dysmenorrhoea, PMS and menstrual interference in teenagers, there is a paucity of data that explores the associations between these. MDOT data found a highly significant association between pain severity and the mean number of symptoms reported ($\chi^2 = 215.36, 2 \text{ df, } p<0.001$). Menstrual pain and symptoms were both associated with interference on life activities and school absence. This relationship was identified anecdotally, 75 years ago by Frank (1931) in women with menstrual pain and symptoms who needed one or two days bed rest. More recently, Fisher et al. (1989) identified a statistical association between premenstrual physical changes and dysmenorrhoea, as well as mood and behaviour changes with increasing frequency and severity of menstrual cramps (in the absence of oral contraceptives). Klein and Litt (1981) also reported an association between menstrual cramps and school absence. MDOT results showed that the interference of menstruation on sexual activity (38.5%) and sport and exercise (33.8%) was higher, in comparison to completing school work (15.8%) and attending school (11.9%). However, when menstrual interference was crosstabulated against pain severity there were highly statistically significant associations with all life activities, the highest being school absence ($\chi^2 = 116.21, 2 \text{ df, } p<0.001$), followed by completing school work ($\chi^2 = 100.81, 2 \text{ df, } p<0.001$), social activities ($\chi^2 = 88.0, 2 \text{ df, } p<0.001$) and sport and exercise ($\chi^2 = 55.44, 2 \text{ df, } p<0.001$). Also, 50% of girls with severe pain reported missing school. MDOT data has demonstrated that increasing severity in menstrual pain causes greater interference and impact on teenage girls’ lives.

The establishment of these associations is important because it suggests that the girls who are experiencing moderate to severe menstrual pain are also experiencing more menstrual symptoms, and they are also the girls who are reporting school absence and interference in their life activities. Based on this knowledge, if we took seriously girls’ complaints of moderate to severe menstrual pain and symptomatology, applying appropriate investigation, treatment and management, menstrual morbidities that are
not pathologically related could be reduced considerably. At the same time, investigation would facilitate early diagnosis of those girls who have a menstrual disorder, which could also be treated and managed with the aim of reducing menstrual morbidities and disruption to teenager’s lives.

**Menstrual disturbance requiring investigation**

The statistically significant associations between menstrual pain, symptoms, interference and school absence, suggest that it is possibly the same MDOT respondents (which appears to be approximately 25% of the sample) who are consistently reporting considerable menstrual disturbance:

- severe pain - 21%
- take time off school - 26%
- high menstrual interference on social activities – 26.1%
- high number (8-11) of PMS symptoms – 31.2%
- require follow up according to their IMP - 23.5%.
- think there is something wrong with their periods - 26.9%
- symptoms worsening over the past 12 months - 23.1%
- analgesia for menstrual pain ineffective – 14.6%
- take the pill to regulate periods and help period pain – 28.5%
- feel overwhelmed and unable to cope with their periods – 31.5%
- often want to withdraw and hide with their period – 25.4%
- mother or sister with severe period pain – 27.2%
- mother or sister with period problems – 22.2%

These results suggest that approximately 25% of girls from the MDOT sample experience menstrual disturbance that possibly will require further investigation and/or management.
Teenage perceptions of problematic menstruation

The MDOT study collected data about teenage girls’ perceptions of their menstruation. Thirty-five percent (35%) reported ‘having problems with their periods’ while a similar number (33%) reported ‘talking to a GP’ about their periods. The MDOT findings suggest that approximately 25% of the sample require investigation of menstrual disturbance which is consistent with the 26.9% who ‘think’ there is something wrong with their periods and the 9.7% who were ‘sure’ that there is something wrong with their periods. Reported diagnosis of menstrual disorder in the MDOT sample is low as only 1% were able to list a clinical diagnosis for menstrual disorder (such as PCOS, endometriosis, amenorrhoea) under ‘I have a period problem that has a name (please state)’.

Lack of support for girls with menstrual problems in the ACT school system

While teenagers talk to friends, family and the GP about their periods, it is evident that school counsellors or teachers are not people they would commonly talk to about menstruation (n=21, 2%). This also demonstrates that the school system in the ACT does not provide a source person for girls to talk to about health issues such as menstruation, whether they have general questions or are particularly concerned. Hillen et al. reported that 40% of their sample had spoken to the school nurse about menstruation while a much smaller number had seen a doctor (18%). The school nurse may be a popular choice of person to talk to about menstrual problems as they are independent from family and friends, easily accessible and there is no financial cost to see them. At an onsite clinic conducted (by the MDOT team) at one of the ACT secondary colleges, there was a popular response from the girls. Many girls were lined up and down the corridor and there was not enough time to see them in the short space of a lunch hour.

However, school nurses must be well educated about managing menstrual pain and symptoms and knowing when to refer girls for investigation of menstrual disorder as Hillen et al.’s study showed that only a quarter of the girls who saw the school nurse for period pain were advised to use a NSAID. The Endometriosis Association
(Victoria) has recognised this need and has conducted information sessions for Victorian school nurses about menstrual pain and symptoms of endometriosis. Considering the Victorian school nurse model presented in the literature review, school nurses are well placed to provide health promotion, counselling, information, referral and education programs to student’s and their families through the school community. They also have the potential to be integral to the school’s health policy development.

**MDOT teenagers are talking but who’s listening?**
The MDOT results suggest that this sample of teenagers are talking about their menstrual periods to family (63.5%) almost as much as they are talking to their friends (68%), while a third have taken the next step and seen a GP (33%), and almost 6% having spoken to a naturopath, herbalist or acupuncturist. Other studies have shown wide variation in the people teenage girls see or talk to about menstruation. Visits to doctors range from 14-37% (Andersch & Milsom, 1982; Hillen et al.; Johnson, 1988; O’Connell et al.), visits to nurses 16-40% (Hillen et al.; Johnson, 1988; O’Connell et al.), talking to mothers 84-85% (Houston et al., 2006; O’Connell et al.) and talking to friends 67% (O’Connell et al.).

**Low rate of investigation**
The rate of investigation for the MDOT sample seems low considering the 35% who said they had had problems with their periods, the estimated 25% reporting significant menstrual disturbance, and the 33% that have seen a GP about their menstruation. Almost 50% of the girls who reported having problems with their periods had talked to a GP. It appears that approximately half the girls who have seen a GP have been put on an OCP. This includes the 16.7% of respondents who reported taking the pill to prevent pregnancy, 15% who were put on the pill to regulate their periods and 13.5% who were put on the pill to help period pain. It is interesting that MDOT girls are more likely to be prescribed or take an OCP for pregnancy prevention and menstrual irregularity than for period pain. As discussed in the literature review, doctors are more likely to take action sooner if women present with symptoms such as infertility rather than pelvic pain (Arruda et al.; Dmowski et al.).
Only 10.6% of girls said that they had had tests ‘because things weren’t right with my period’. Only 5.4% reported having an ultrasound scan, and 3.9% reported having blood tests. Despite the estimated 25% of girls with significant menstrual disturbance, it appears that only 8.6% of the MDOT sample have been referred to a specialist doctor (not necessarily a gynaecologist), with only a very small number, 0.9%, reporting an operation ‘to look for causes of my pain’.

The low rate of referral and investigation may imply that menstrual disturbance is not taken seriously enough by doctors and consequently, there is a lack of diagnostic aggressiveness which may be related to the age of the sample and the persistent belief by doctors that there is unlikely to be serious underlying pathology or menstrual disorder such as endometriosis.

While the tests available for investigating menstrual disturbance have been used little in the MDOT study, there are problems with the use of ultrasound scans and blood tests which may be useful to rule out PCOS, but not other serious pathology. Endometriosis is not detectable through blood tests, and does not show up on ultrasound scanning, however an endometrioma (endometriosis cyst filled with old blood) may be visible on ultrasound as a fluid filled sack, but can be confused with other ovarian cysts. These tests may be helpful for investigating some menstrual disorders, but can be falsely reassuring for others, such as endometriosis.

**Lack of ‘diagnostic aggressiveness’ in MDOT sample**

For the number of girls with menstrual problems who reported seeking medical help (33%), very few (1%) have a diagnosis. In a sample of 1051 teenage girls, it might reasonably be expected that more than ten girls (1%) in the whole sample would be afflicted by a menstrual disorder such as endometriosis, or polycystic ovarian syndrome (PCOS) which singularly, is estimated to occur in 5-10% of pre-menopausal women (Gordon, 1999).

While the girls report talking to parents (63.5%) and doctors (33%) about their periods, it seems that those who do have a significant problem (which the MDOT results estimate to be approx 25% of the sample) are not receiving adequate
investigation, diagnosis and management according to current best practice, despite the existence of guidelines such as the ‘Protocol for evaluation and treatment of adolescent pelvic pain and endometriosis’ devised by Laufer et al. (2003) and modified by Laufer, Sanfilippo and Solnik (2005). While the girls are talking, it seems that health professionals, and perhaps parents, are not listening and not taking their concerns seriously enough to investigate adequately or appropriately.

In summary, 35% of teenagers reported period problems, while 33% reported seeking medical help. Of the whole MDOT sample, only 10% of teenagers have been referred to, or investigated by, a medical specialist, with only 10 girls (≤1%) able to report a clinical diagnosis.

As discussed in the literature review, there exists a diagnostic delay of 6-11 years for symptomatic endometriosis with common reasons including delayed presentation by women to health professionals, poor awareness by health professionals of the signs and symptoms of symptomatic endometriosis, age of the woman at presentation, whether women present with pain or infertility, misdiagnosis, a reluctance to laparoscope teenagers and young women, and the persistent misconception that teenagers and young women do not, or rarely, have endometriosis. The common factor in all of these is education. The education of teenagers, parents, GP’s, nurses, gynaecologists and other health professionals about typical menstruation in teenagers, treatment of menstrual symptoms that cause morbidities and appropriate investigation of girls who do not respond to first line treatment, could improve the lack of diagnostic aggressiveness and the confusion caused by the overlap of pathological and non-pathological symptoms.

**Menstrual disturbance and endometriosis**

Almost a quarter of the MDOT sample (23.6%) reported that they had heard of endometriosis and 1.4% reported that their mother or sister had endometriosis. It appears that two girls out of the entire sample have been diagnosed with endometriosis where they listed endometriosis under “I have a period problem that has a name”. There were another two girls who listed endometriosis as a ‘maybe’.
Severe menstrual pain and endometriosis

Twenty one percent (20.9%) of adolescents in the MDOT study reported severe period pain (n=217). The literature suggests that 47-73% of girls with severe menstrual pain or pain that doesn’t respond to NSAIDS or the OCP are found to have endometriosis (Bullock et al.; Davis et al.; Goldstein et al; Laufer et al., 1997; Reese et al.). If applied to our study this would equate to approximately 10-14% of the study sample (approximately 100-140 respondents). Similarly, questionnaire scrutiny identified 142 (13.5%) girls that warrant further investigation to exclude a diagnosis of endometriosis.

In the list of menstrual symptoms included in the MDOT questionnaire, there were four symptoms which are not part of the dysmenorrhea syndrome or recognized as PMS symptoms, but more exclusively experienced by teenagers and women with endometriosis. They included pain with emptying bowels, wind pain, pain during or after passing urine and dyspareunia (pain during or after sex). The four symptoms were reported by approximately 9.3-13.2% of the study sample which is similar to the proportion of girls with severe pain in the sample who, based on suggestions in the literature, may have endometriosis (50-70%). However, not all women with endometriosis experience these symptoms. Almost a third of the 4000 women surveyed through the Endometriosis Association reported bladder pain (Ballwegg, 2003), yet two studies conducted in teenagers with endometriosis have reported bladder symptoms to occur in only 5-13% of girls (Goldstein et al.; Laufer et al., 1997), although, these were small sample sizes of N=114 and N=46 respectively. Dyspareunia has been reported to occur in 25% of teenagers with endometriosis (Goldstein et al.) and 64% of all women with endometriosis (Ballwegg, 2003). It is likely that not all teenagers with endometriosis are also sexually active. The high reporting of these four symptoms is perplexing because it infers that these symptoms are common in the girls in the sample who possibly have endometriosis, there may be more girls in the sample with endometriosis than the estimated 10-14%, or there is a cause for these symptoms other than endometriosis.
Of great concern in the MDOT findings is the poor rate of referral in the severe pain group where almost 50% of girls had spoken to a GP but only 10% had spoken to a specialist. This suggests that GP’s are not referring girls with severe pain to a specialist. The data also suggest an overall lack of diagnostic aggressiveness by GP’s and gynaecologists as investigation in the girls with severe pain was low with only 10% having had an ultrasound, 8% blood tests and only one girl in the severe pain group had had an operation to look for causes of menstrual pain.

When compared to the entire MDOT sample, girls in the severe pain group were more likely to talk to family and friends (75%, equally) about their periods versus 63.5% (family) and 68.2% (friends) in the total sample.

There is also a large impact for the girls who indicated severe pain, as 50% also reported missing school, which is consistent with reported rates of 50% by Klein & Litt (1981), and 54% by Teperi & Rimpelä (1989). Effectiveness of analgesia in the severe pain group was lower where only 33.3% reported it to be highly effective, compared to 46.9% of girls in the no/mild pain group. There were 15.4% in the severe pain group who reported that analgesia had no/mild effectiveness. Allowing for those girls who are not taking the medication effectively, there is still a group of girls with severe pain, who are not responding to analgesia.

**Menstrual risk factors related to endometriosis**

There are two menstrual risk factors for endometriosis that have been found consistently in epidemiological studies, these are early menarche, deemed to be ≤ 11 years of age, and a shorter cycle length defined as ≤ 27 days (Cramer & Missmer, 2002).

**Short cycle length**

While 12% (n=125) of the MDOT sample indicated menstrual cycles of 18-27 days, no statistically significant associations were found when these respondents were crosstabulated against menarcheal age, the three pain categories, school absence, or the number of bleeding days in a menstrual period. However, the girls who indicated a short menstrual cycle ≤ 27 days had a higher percentage-wise representation in the
severe pain group (24.0% vs 19.9%) and lower representation in the mild pain group (24.0% vs 30.3%) when compared with those girls whose menstrual cycle was 28-47 days.

**Early menarche**

The MDOT data did show that when menarchical age categories (8-11, 12-14 and 15-19 years) were crosstabulated against school absence and the three pain categories, statistically significant reductions in reports of pain and school absence, \((p=0.006)\) and \((p=0.003)\) respectively, were found in those girls who were \(\geq 15\) years at menarche \((n=84, 8.5\%)\).

**Limitations of the MDOT study**

**Consent to contact respondents**

One limitation of the MDOT study was that respondent follow up was voluntary. The response to whether the participants consented to being contacted for follow up was ‘No’ = 48%, ‘Yes’ = 39%, Blank = 13%. The completion of questionnaires *en masse* may have influenced whether girls circled ‘Yes’ or ‘No’. The high ‘No’ response could just as easily have been related to the desire of participants to remain anonymous. They may have been worried about making themselves contactable as it has an element of vulnerability and unknown commitment. The uncertainty may have led them to circle ‘no’ to being contacted. The fact that almost half of the sample did not want to be contacted meant that there were fewer girls to follow up through the clinic, providing a reduced cohort available for future longitudinal research.

The consent for contact question was situated on the back of the consent form. It is possible that a majority of the 13% of respondents who left this blank did not realize that there was more to complete on the back of the consent form. If the study were to be repeated, the consent to contact question should be relocated on the consent form.

**Survey research/limitations of a questionnaire**

Data collected on a questionnaire is self-reported and relies on the respondent’s recall. Even though the girls were asked to report on a ‘usual period’ or over the past 12 months it may be human nature to report the most recent menstrual period as it would
be easier to remember, or to recall the most memorable menstrual period which may have been very painful. The questionnaire collected a subjective snapshot of menstrual life for each respondent and a collective snapshot for ACT teenage girls.

**Validation of questionnaire and determining prevalence of menstrual disorder**

Ideally, part of the MDOT study would include measuring the questionnaire’s ability to predict menstrual disorder following respondent identification through the IMP. For scientific rigour it would be advantageous to laparoscope all the participants in the study to determine the presence or absence of menstrual disorder. This would also reveal those girls with menstrual disorder who were not identified through their IMP. Laparoscopy (preferably with histological confirmation) is considered the definitive method for obtaining a diagnosis of endometriosis. In teenagers, best practice for the investigation of menstrual and pelvic pain is to try managing the symptoms with OCPs and NSAIDs prior to using invasive surgery. Ethically, it is not feasible, nor best practice, to laparoscope all the participants for the purpose of research. The greatest limitation to this study is that because it is not ethical to perform laparoscopy on all the teenage participants we are not able to determine the prevalence of definitively diagnosed endometriosis in our sample. At best, we can make an estimate based on available data and findings in current literature.

**Generalisability**

Data collected from over 1,000 teenagers in the ACT has provided a collective picture of typical menstruation in the 16-18 year age group. A limitation of this study is that the picture given by ACT teenagers may be a 'best case scenario' due to the ACT being an encapsulated population with the highest gross household income that is 29% higher than the Australian average. If socioeconomic status affects menstrual pain, which was suggested by Hillen et al., then the MDOT results may be amplified in other teenage populations with lower SES in Australia. This study has not collected data about socioeconomic status, ethnic or indigenous populations.

In summary, the main limitations are:

- Data was not collected from younger teenagers aged from 12-15 years
That further testing and validation is required of the MDOT questionnaire before it can be used as a screening tool for menstrual disorder

Participants identified through their IMP as requiring first line treatment and or investigation of menstrual disturbance are not being longitudinally studied as part of this study to determine their diagnosis

Data was not collected about current menstrual health education programs used in ACT high schools and colleges

Data was not collected about the current knowledge and clinical practice of GP’s regarding menstrual morbidity in teenagers

Therefore future research should include:

- Collection of data from 12-15 years old to determine the typical menstrual picture for this age group
- Streamlining and further testing of the MDOT questionnaire as a screening tool for detecting menstrual disorder in teenagers
- Longitudinal follow up of MDOT participants through the MDOT clinic to determine their ultimate diagnosis
- Determination of the current menstrual health education programs used in ACT high schools and colleges
- Collection of data about the current knowledge and clinical practice of GP’s in the ACT regarding menstrual morbidity in teenagers

**Did the method satisfy the purpose?**

The first purpose of the MDOT study was to establish the typical menstrual experience of older teenage girls. The MDOT sample (N=1051) was able to provide an aggregate of approximately 1,000 responses for most questions. The responses of one thousand 16-18 year old women, has provided the largest, most comprehensive (and only the second known) Australian collective menstrual picture of this age group. The combined methods for promoting, informing, recruiting and collecting data for the MDOT study proved to be highly effective as the target sample was achieved.
The second purpose of the MDOT study was to determine the prevalence of menstrual disturbance in the sample. From the MDOT data it was possible to determine that menstrual disturbance and morbidity was high as measured by the severity of menstrual pain, the number of menstrual symptoms experienced as well as school absence and interference on life activities. Through aggregated data and individual scrutiny of the questionnaires it was also possible to determine that approximately 25% of the sample had significant disturbance that could require further investigation. The method for conducting the MDOT study was appropriate and effective for satisfying the purpose of the study.

Summary
The MDOT questionnaire has proved to be suitable for data collection from women in the 16-18 year age group which was evidenced by the high response rate (98%). Allowing for the limitations of a self-reporting questionnaire, we cannot ignore the high proportion of girls who reported moderate to severe pain with menstruation (70%), and those who reported mood disturbance associated with menstruation (73%). The themes of pain and mood disturbance were consistent throughout the questionnaire with a high number of respondents also reporting pelvic cramping pain (71%) and ‘feeling down or depressed’ (65%).

Considering these results, the reported school absence rate of 26% is not surprising. Even though there are a substantial number of girls who do not miss school in relation to their menstruation (74%), there may well be some degree of underperformance resulting from pain and symptoms which has not been explored in this study. The MDOT study did not determine the characteristics of those respondents that did not take time off compared to those that did, and there may well be a number of confounding influences as to why young women do or do not take time off schooling. Whilst it is not possible from this study to cost the true impact of menstrual disturbance on schooling, the results of the MDOT questionnaire reflect a significant physical and emotional impact on the teenagers’ lives which could also have implications for education and schooling performance.
The MDOT questionnaire has helped to establish a clearer picture of menstrual patterns of 16-18 year old teenagers in the ACT. Where only 11 girls reported having asymptomatic menstruation, the majority of teenagers in the study experienced the cyclical hormonal effects of menstruation that manifest as menstrual pain and symptoms and PMS.

Of particular concern are the 25% of respondents who consistently reported significant menstrual disturbance requiring further investigation to rule out the possibility of a menstrual disorder, or those who expressed sufficient concern and perceived disturbance to require follow-up.

Further value of the MDOT study is the action taken on data findings which provides direct care (using best practice guidelines) to those girls with menstrual disturbance, who consented to being contacted.

Further research to determine the questionnaire’s validity for identifying pathological menstrual disorders is planned for the future. It is hoped that a questionnaire/screening tool will facilitate earlier detection of menstrual disorders and would be readily available and user friendly for teenagers, women and primary health care providers.
Chapter 7: Conclusion

Menstruation is a normal, natural process for teenagers and women of child-bearing age. It should be discussed and viewed as such for the development of healthy attitudes towards menstruation by teenagers. The aims of the MDOT study were to establish the typical experience of menstruation for a large sample of 16-18 year old teenagers in the ACT and to determine the number of teenagers in the sample who were suffering from menstrual disturbance that warranted further investigation and management.

The MDOT study was able to establish a collective picture of typical menstruation in 16-18 year old girls which has shown a high prevalence of menstrual pain, physical and psycho-emotional symptoms and interference in life activities for approximately 70% of the sample. The MDOT findings are consistent with other evidence in the literature that menstrual pain and symptomatology are commonly experienced by teenagers before or during menstruation, along with interference on life activities that for some teenagers, includes absence from school.

The high prevalence of menstrual disturbance highlights the extensive need for information and education about the use of pharmacological and non-pharmacological methods of treating menstrual pain and symptoms. Menstrual pain and symptoms that do not have a pathological origin should be manageable with first line treatment including the effective use of NSAIDs, the OCP, and maintenance of good health practices such as adequate sleep, balanced diet and regular exercise.

Findings from the MDOT study have identified a consistent 25% of girls who experience significant menstrual morbidity, with highly significant associations found between all combinations of pain, symptoms, life interference and school absence. Menstrual pain and symptomatology that does not respond promptly to first line treatment, and causes significant interference to life activities, including school attendance, should be investigated by a gynaecological specialist knowledgeable in CPP and endometriosis. This specialist should be comfortable working with the
teenage population and have the appropriate expertise to identify, excise and confirm the presence or absence of endometriosis (Batt & Mitwally, 2003; Laufer et al., 2003).

The literature review highlighted the issues surrounding teenage menstrual pain and symptoms, including the confusion caused by the term ‘dysmenorrhoea’ and the overlap in symptoms experienced with menstrual pain/dysmenorrhoea, PMS and endometriosis. The difficulty in distinguishing primary menstrual pain from secondary menstrual pain is a contributor to the diagnostic delay of endometriosis in teenagers. Low rates of investigation and referral, particularly in girls with severe pain, were evident in the MDOT data.

Although there is a paucity of data on the impact of significant menstrual disturbance and endometriosis on the lives of teenagers, teenage onset of symptomatic endometriosis prolongs the lifespan of the disease, and suffering, and is therefore more likely to have a profound adverse impact on physical, psychological and emotional health related quality of life; with resultant disruption to education and subsequent work life; and the possibility of infertility.

When consulting teenagers about their menstruation, the presence of dyspareunia; GI symptoms, bowel or bladder symptoms; excessive ovulation pain, fatigue, abdominal bloating, dizziness and headaches should also alert the primary health provider to a high index of suspicion for endometriosis, leading to referral and prompt investigation by an appropriate gynaecological specialist. Based on findings in the current literature regarding the incidence of endometriosis in girls with dysmenorrhoea and severe pelvic pain, as well as findings in the MDOT study from individual scrutiny of each questionnaire and the number of girls with severe pain and menstrual morbidities, it is possible that 10-14% of the MDOT sample would require further investigation to rule out a diagnosis of endometriosis.

The MDOT study has highlighted gaps in education, clinical practice and research modalities. Implications for each modality will be presented with the overall aim of addressing the menstrual health of teenage girls, including the diagnosis and treatment of menstrual disturbance and disorders to improve long term health outcomes.
Implications for education

Education of teenage girls

Studies have shown that there are shortfalls in teenager’s knowledge of effective treatment for menstrual pain and symptoms (Johnson, 1988; Hillen et al.). Individual scrutiny of the MDOT questionnaires identified almost 40% of girls from the sample whose menstrual pain and symptoms warranted information about these, as well as suggested treatments. A further 25% of respondents required contact and follow up because of the severity and impact of their menstrual pain and symptoms. This is a total of approximately 65% who require in the least, information about menstruation. In this way, the MDOT study justifies the need for a comprehensive education approach for all teenage girls about menstruation as so many are affected by pain and symptoms.

The collective picture of typical menstruation created by the MDOT study can be used to inform and educate older teenagers about ‘normal’ parameters of menstruation as well as the signs of problematic menstruation and how to determine when help should be sought. Education of teenagers about menstruation should address pharmacological and non-pharmacological strategies and available treatments for pain and symptoms, including the most effective types of analgesia and how they can be taken. Teenage girls also need to know how and where they can find medical advice and support for menstruation.

The ‘Me’ program that is used in New Zealand is an example of the type of program that can be run through schools to educate teenage girls about menstruation as well as signs of menstrual disturbance requiring investigation.

Weekend workshops for mothers and daughters covering many aspects of menstruation have been run by nurses and education staff from the ACT Women’s Centre for Health Matters in the past. This is a positive program for mothers and daughters where both receive information about menstruation and celebrate the uniqueness of women. The MDOT findings emphasise the need for this type of
education for ACT teenagers and is a great way to educate mothers and female guardians as well.

**Educating parents**

The literature suggests that mothers are a major source of information regarding menstruation (Hollander, 2002; Kissling, 1996b; Larsen, 1961). It is important that mothers are reflecting positive attitudes towards menstruation as well as appropriate and helpful information and advice. Nurses working within the education system and school community are well placed to access parents, run information seminars within the school community and provide useful information about menstruation.

**Educating health professionals**

The education of health professionals involves increasing knowledge and awareness, dispelling myths and negative attitudes and developing guidelines and strategies for sound clinical practice which is discussed in ‘Implications for clinical practice’.

**Implications for clinical practice**

**Teach health professionals about managing primary menstrual pain and symptomatology**

Menstrual pain, PMS symptoms and mood disturbance are common features of teenage menstruation as evidenced by findings from the MDOT study and current literature. It is important that nurses, doctors and allied health professionals are aware of best practice pathways for managing menstrual pain and symptoms. Health professionals should also be able to teach teenagers how to manage primary menstrual pain and PMS symptoms to prevent disruption to schooling and interference on teenagers’ lives. There are a number of strategies that health professionals can teach and discuss with teenagers including: the appropriate use of analgesia; lifestyle factors such as diet, sleep and exercise; charting of symptoms; complementary therapies such as relaxation, massage, acupuncture, vitamin and mineral supplementation; and oral contraceptives can also be trialled.
Increasing health professional’s awareness of menstrual disorder and endometriosis

The MDOT study found that while girls were talking to their families and doctors about menstruation, little investigation and diagnosis had been done, suggesting a tendency for primary health care professionals to be dismissive of teenager’s reports of menstrual pain. This is possibly due to established beliefs surrounding menstruation, as well as gaps in the knowledge of health professionals. The gaps in the knowledge of health professionals include:

- Distinguishing primary menstrual pain and symptomatology from significant pain and menstrual disturbance.
- Screening teenagers with problematic menstruation and commencing investigation for underlying disorder and referral to appropriate specialists.
- Best practice pathways available for investigating pelvic pain in teenagers, including when to refer to appropriate specialists trained to investigate laparoscopically and excise endometriosis found in teenagers.

Awareness that endometriosis occurs in teenagers, including the symptoms and disturbance that should alert doctors and nurses to suspect and investigate this disease.

Screening of all girls experiencing moderate to severe menstrual pain.

There is consistent literature suggesting that 50-70% of girls who report severe pelvic pain and who don’t respond to NSAIDs or OCPs will be found to have endometriosis at laparoscopy (Bullock et al.; Davis et al.; Goldstein et al.; Laufer et al., 1997; Reese et al.). Indeed, it would be prudent to screen all girls with moderate to severe menstrual pain to detect the girls with underlying menstrual disorder, while providing information and education to the girls without underlying pathology, but still needing strategies for managing menstrual pain and symptoms.

Development of the MDOT Clinic

To this point the MDOT Clinic has served to provide information and options for investigation and treatment to teenagers with problematic menstruation. Further development of the clinic would include multidisciplinary health professionals for
ongoing management of the pain and symptoms of endometriosis, including holistic life management for living with a chronic disease.

In the future the MDOT clinic would also provide the opportunity to train undergraduate medical students, student nurses and midwives, and students from other health disciplines about menstrual health and menstrual disorders such as endometriosis, in teenagers.

It is expected that the MDOT clinic will also act as a centre where research can be initiated and conducted by multidisciplinary staff, students and the teenagers/women affected by problematic menstruation or menstrual disorder.

Implications for further research

Research problematic periods (repeat MDOT) in a younger population

The MDOT study has successfully collected data about menstruation in 16-18 year old teenage girls. It would be beneficial to survey younger teenagers to determine the prevalence of problematic menstruation in the younger age group (from menarche onwards). With the knowledge already gained from the MDOT findings, surveying the younger population could be coupled with screening and education.

Endometriosis screening tool

MDOT findings and data can be utilized for the development of a menstrual disorder and endometriosis screening tool for teenagers. At the 9th World Congress on Endometriosis (September, 2005), there was a pre-conference discussion with consensus that there is a dire need for an endometriosis screening tool which could improve the diagnostic delay in teenagers and women with endometriosis. The MDOT study was deemed to be one of the closest steps towards development of a screening tool for teenagers, and conference participants from other countries expressed great interest in trialling a tool after initial development.
Tool for measuring impact of endometriosis on teenagers and HRQL

The literature revealed the absence of a tool for measuring the impact of endometriosis on health related quality of life in teenagers (Gao et al.). Future research through the MDOT Clinic could include the development and/or testing of a HRQL tool for measuring the impact of endometriosis on those teenagers who are diagnosed with the disease. It would be useful to measure the impact of endometriosis on teenagers where there is early diagnosis, best practice treatment and adequate support to manage and cope with the disease long term, in comparison to those teenagers with delayed diagnosis and poor management of the disease.

Impact of endometriosis on teenage women

There was also little data found in the literature that had attempted to measure the impact of endometriosis on teenagers (Gao et al.). The collection of impact data through the MDOT clinic would assist in identifying and meeting the needs of teenagers and their families who are trying to cope and live with endometriosis. Families need to know how they can support their teenage daughter (sister and granddaughter) who is diagnosed with endometriosis.

Assessment of the current education programs regarding menstrual health used in ACT schools and colleges

The MDOT findings have highlighted the need for adequate education of the 70% of teenagers who suffer moderate to severe pain, other physical symptoms and mood disturbance during menstruation. Further research is required to determine the current status of menstrual education occurring in ACT primary and secondary schools and secondary colleges.

Further research or auditing could be done to determine:

- What education is currently provided about menstrual health in ACT schools and colleges?
- Is the education program uniform across schools and colleges?
- Does the education program provide ‘practical’ as well as scientific information for girls?
• Are girls alerted to signs of menstrual disturbance that require further consultation and investigation?
• Is information provided regarding places where girls can seek further help regarding their menstrual health?
• Is information provided for parents as well as teenagers?
• How do educational needs differ across the various teen age groups?
• How can the education program be improved to meet the needs of teenagers?

It appears that currently, there is little or no menstrual education provided in primary schools. Literature suggests that almost one in eight girls commence menstruation before they leave primary school (Whincup et al.). It would seem that menstrual education should begin in primary school to incorporate those girls who mature early, as well as prepare in advance the pre-menarchical girls.

Impact of menstrual pain and symptoms on school work and life activities

The literature review reported a lack of data about the degree of impact that menstrual pain and symptoms have on teenage girls. Research that measures aspects such as completion of school work, quality of school work, academic grades and perhaps long term work and study outcomes in girls with menstrual disturbance might give an indication of the depth of interference that unmanaged menstrual pain and symptoms have on these girls. Also, the degree of impact on other life activities including social, sport and exercise, relationships, sexual intercourse and employment might help to illuminate the depth of interference from problematic menstruation.

Implications for policy

This research has highlighted that problematic menstruation, due to menstrual pain, symptoms and PMS, affects a considerable number of teenagers. Also, that 25% of girls have significant menstrual disturbance resulting in menstrual morbidities such as school absence, difficulty completing school work and interference on other life activities. Underperformance at school due to menstruation was not measured in this study, but the possibility cannot be ignored considering the number of girls
experiencing menstrual morbidities. This underscores the dire need for public health policy, ideally through the school system, that addresses menstrual education and screening of teenage girls.

Role of the nurse in education, clinical practice and research

The MDOT Clinic

The MDOT Clinic has arisen out of the MDOT study in order to provide follow up for those girls needing further investigation of their pain and symptoms. There is an important nursing role as co-ordinator of the MDOT clinic which currently includes contacting teenagers to discuss their questionnaires and organize appointments if necessary; counselling girls who visit the clinic about treatment options; answering questions and providing information; and putting together useful information packages for teenagers. This nursing role has also provided pre and post-operative counselling to those teenagers requiring surgery, as well as anaesthetic nursing during the surgery. To date, this has been a successful model of continuity of care for teenage clients requiring surgical investigation. The symbiotic relationship created between Dr Sneddon and myself enhances and maximizes what we have been able to achieve through the MDOT research, as well as the level of care and support we can provide to teenage women (see Sally’s story in Appendix 12).

This team approach has been extended to an endometriosis clinic for adult women still in early development (see Jacqui’s story in Appendix 12). Due to the long term nature of endometriosis, teenagers who are diagnosed with endometriosis through the MDOT clinic will need ongoing care, support and chronic disease management skills that can be provided in the future through the adult women’s clinic.

Long term plans for both clinics involve a multidisciplinary team addressing pain management, pain and chronic illness psychology and counselling, nutrition and movement therapy, of which the nurse would be viewed as coordinator. The clinic coordinator would also need to liaise with community groups, GP’s, specialists and other health care professionals.
**Nurse Practitioner**

In the future there could be a possible role for a nurse practitioner who can prescribe the oral contraceptive pill as a first line treatment for girls with problematic menstrual pain and symptoms. A nurse practitioner could run clinics in high schools and colleges to screen girls with menstrual disturbance and refer the girls needing further investigation to the MDOT clinic, in particular those who haven’t responded to OCPs or NSAIDs.

**Nurses role within the ACT education system**

In the ACT education system, nurses provide immunizations and health screening for school children but are not based or assigned to individual schools. However, most ACT government schools have a school counsellor who is a trained psychologist. Only 2% of MDOT respondents spoke to a teacher or school counsellor about their periods. It seems that there is room here to provide increased health support for teenage girls within the ACT school system. The employment of nurses in the ACT school system under a similar model to that currently in use in Victoria, could be a first step in addressing menstrual disturbance in school age girls.

The ‘Me’ program from New Zealand is a school program that is already established and has proven to be successful and well received by teenagers, and could be adopted and run within the ACT education system. It is a program that nurses, as public health educators, could conduct.

**Summary**

The high response rate to the MDOT study (98%) provided sufficient, quality data to fulfil the two main aims of the study. These included: the establishment of a collective picture of typical menstruation in 16-18 year old teenagers attending ACT government colleges (senior high school); and determination of the prevalence of menstrual disturbance in the sample.
Typical menstruation for the sample consisted of: menstrual bleeding patterns that were within expected parameters of current literature for teenage menstruation; 1% of girls with asymptomatic menstruation (no pain or symptoms); 29% with mild pain and symptoms that were not problematic; and 70% with problematic menstruation due to pain, moods and a variety of physical symptoms. The prevalence of significant menstrual disturbance was determined to be an approximate 25% of the sample, with 10-14% of these girls showing signs and symptoms requiring further investigation for possible endometriosis.

The MDOT study is unique as no other studies were located in the literature that have explored menstrual disturbance and the possibility of endometriosis through individual scrutiny of each questionnaire and the provision of follow up to participants if warranted. The prevalence of symptomatic endometriosis in the teenage population is largely unknown, but the MDOT findings suggest that it may be similar to the estimated prevalence of 10-15% (Corwin, 1997; EAPPG, 2004) in adult women.

MDOT findings for menstrual pain, symptoms and PMS were consistent with similar studies in the literature. The large sample size of 1,051 respondents enhances the generalisability of MDOT findings to the population being studied.

The MDOT findings have highlighted the need for comprehensive education of teenagers, their families and health professionals about menstrual pain and symptoms in order to minimize the negative impact of menstruation on the schooling and life activities of teenage women, as well as facilitate the diagnosis of menstrual disorder if present.

Further research is required in regard to: the menstrual education programs currently provided in the ACT education system; typical menstruation and the prevalence of menstrual disturbance in younger teenagers (from menarche); development of a screening tool for endometriosis in teenagers; development of a tool to measure HRQL in teenagers with endometriosis; and longitudinal study of the impact of endometriosis on teenagers.
Menstrual pain and symptoms in teenagers should not be ignored. Treatment is available to manage the pain and symptoms of menstruation, while ensuring normal daily functioning and minimal interruption to teenage girls’ lives. Menstrual disorder, such as endometriosis, should be suspected and investigated where menstrual pain and symptoms are persistent, non-manageable and interfering in the normal healthy development and functioning to which every teenage girl is entitled.
It was at adolescence, then, in their transition to a healthy womanhood, that girls were seen by (G. Stanley) Hall to be in the direst need of educational support and regimen from society. “To understand a woman’s body and soul”, he remarked, “is a larger problem than to understand a man’s, because reproduction plays a larger role in her life... The quality of motherhood has nowhere a more critical test that in meeting the needs of this epoch.” At no time, therefore, was the correct maintenance of the relation of female body to mind, of reproduction to production, feelings to intellect, intuition to reason, evolution to devolution and nature to civilization more critical. (Vertinsky, 1994, p.182-183) from *The Eternally Wounded Woman*
References


Ballweg, M.L. (2004). Impact of endometriosis on women's health: Comparative historical data show that the earlier the onset, the more severe the disease. Best Practice & Research Clinical Obstetrics & Gynaecology, 18, 201-218.


Presentations and Awards for the MDOT study

May 2006

*Poster presentation:* MDOT Study: Menstrual Disorders of Teenagers. University of Canberra Research Student Poster Competition 2006

*Award:* The Pro-Vice Chancellor's Research and Information Management Prize for Research Student Poster Competition 2006.

September 2005


*Award:* First prize winner for 'Best Poster'.

August 2005

*Oral presentation:* at the 11th Annual National Health Outcomes Conference held in Canberra.

July 2005

*Oral presentation:* at the Health and Medical Research in the Canberra Region 11th Annual Conference held at The Canberra Hospital.

June 2005

*Oral presentation:* at the University of Canberra Research Corroboree

May 2005

*Oral presentation:* at The Canberra Hospital Auditorium for the Nursing and Midwifery Grand Rounds.

Media coverage of the MDOT Study:

November 4th, 2005

Reports of the MDOT Study were featured on ABC Radio news bulletin, on air interview with Alex Sloane ABC morning radio, ABC TV 7.00pm news bulletin, 6.00pm WIN TV news bulletin, ABC JJJ Radio news bulletin and article in The Canberra Times 5th November 2005.
Appendices
Appendix 1 – Questionnaire
The prevalence of menstrual disorders of teenage women: Questionnaire

Please note that this questionnaire is 6 pages long, and has a glossary of unfamiliar words and terms at the end to help you.

Section 1. General information

<table>
<thead>
<tr>
<th>Today’s date:</th>
<th><em><strong><strong>/</strong></strong></em>/_____ (dd/mm/yy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight:</td>
<td>_____kgs (approx)</td>
</tr>
<tr>
<td>Your DOB:</td>
<td><em><strong><strong>/</strong></strong></em>/_____ (dd/mm/yy)</td>
</tr>
<tr>
<td>Height:</td>
<td>_____cms (approx)</td>
</tr>
<tr>
<td>How old were you when you got your first period?</td>
<td>_____yrs (approx)</td>
</tr>
</tbody>
</table>

Section 2. About your usual periods (*Please circle the appropriate response*)

1. Do you have periods?  **Yes**  **No**  (If no, go to Section 5)

2. Over the past 12 months have your periods been:
   - regular
   - irregular
   - don’t know
   (regular = the time between periods is usually about the same length, irregular = if the length of time between periods often changes)

3. What is the *usual* number of days from the first day of bleeding at one period to the first day of bleeding at your next period? (Cycle length)
   - _____ days
   - periods irregular
   - don’t know

4. Please tick the column that indicates the heaviness of your bleeding for each day of your period (how it usually is):

<table>
<thead>
<tr>
<th>Day</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Light</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
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<td></td>
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<tr>
<td>Medium</td>
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<tr>
<td>Heavy</td>
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<td></td>
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</tr>
</tbody>
</table>

If longer, please specify how many more days: ______________________

5. Does your bleeding contain clots?  **Yes**  **No**  (If no, go to question 7)

6. If ‘yes’, how often does it contain clots?
   - Sometimes
   - Most of the time
   - All the time

7. Do you ever notice spots of blood on your underpants?
   - Just before a period
   - In between periods
   - Never

8. Do you miss school because of your periods?
   - No……(please go to question 11)
   - Yes – Every period
   - Yes – Just with some periods

9. If yes, how many days of your period do you usually stay home for? _________

10. What is it about your period that causes you to miss school? (You can circle more than one)
    - Too painful
    - Blood flow too heavy
    - Nausea
    - Vomiting
    - Other, _________

11. Have your period symptoms (such as the ones in question 10) worsened over the past 12 months?
    - **Yes**  **No**  **Not Applicable**
The prevalence of menstrual disorders of teenage women: Questionnaire

12. Please rate any period pain you have had over the past 6 months?
   No pain 0 1 2 3 4 5 6 7 8 9 10 Worst pain
   (If 'no pain', please go to Section 3)

13. If you have period pain do you take medication?
   Yes No (If no, please go to Section 3)

14. If yes, which medication/s do you usually take? (You can circle more than one)
   Panadol Aspirin/Aspro Ponstan Naprosyn Nurofen
   Other/s ____________________________

14. How effective is the medication in relieving your pain?
   Not effective 0 1 2 3 4 5 6 7 8 9 10 Highly effective

Section 3. Over the past 12 months, have you experienced any of the following symptoms in relation to your monthly period cycle? (Tick as many as applicable)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Doesn't apply to me</th>
<th>No or Never</th>
<th>Just before a period</th>
<th>At the time of period</th>
<th>Any time of the month</th>
<th>All the time</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea (feel like vomiting)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Bloating (swollen tummy)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhoea/constipation or both</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indigestion, reflux, heartburn</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aching outside your vagina</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Aching down the legs</td>
<td></td>
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</tr>
<tr>
<td>Pelvic pain</td>
<td>aching</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>cramping</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>stabbing</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Other (please state):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower back pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain during or after passing urine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain when your bladder is full</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain before or when passing wind</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain when emptying your bowels</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling an urgent need to empty your bowels</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bleeding from your bottom (anus)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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The prevalence of menstrual disorders of teenage women: Questionnaire

Section 4.
Do your periods affect your lifestyle?
Please circle a number between 0 and 10 to show us how much your periods over the past 12 months have interfered with the following:
0 = no interference, 10 = major interference, N/A = Not Applicable (to me)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Scale of 0 to 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending school</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Completing school work</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Casual paid work</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Social activities</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Relationship with family</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Relationship with friends</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Relationship with partner</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Sexual activity</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Sport and exercise</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
</tbody>
</table>

Does the above interference with lifestyle occur with:
Some periods       Most periods       All periods       Not applicable to me

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What is it about your period that interferes with your life?
Please circle a number between 0 and 10 to show us how much the following symptoms interfere with your life.
0 = no interference, 10 = major interference, N/A = Not Applicable (to me)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Scale of 0 to 10</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Heavy blood flow</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Tiredness/fatigue</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Moods</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Generally feeling unwell</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

(Please name symptom)

Does the above interference occur with:
Some periods  Most periods  All periods  Not applicable to me

Section 5. The following is a list of statements related to periods. Please place a tick in the column that best represents your own experience for each statement.
N/A = Not Applicable (to me)

<table>
<thead>
<tr>
<th>Statement</th>
<th>True</th>
<th>False</th>
<th>Don't know</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>I usually have a period every month</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have never missed a period</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have had problems with my periods</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My periods seem pretty normal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have had tests because things weren't right with my period</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a period problem that has a name: (Please state)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am on the pill</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take the pill to regulate my periods</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take the pill to prevent pregnancy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take the pill to help period pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have never taken the pill</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Periods don't worry me too much</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Periods worry me a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section 6. Questions on Menstrual Disorders

#### Medication/s:

#### Foods:

#### Other (eg. bee stings):

---

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Section 7.

Have you ever heard of any of the following?  

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polycystic ovarian syndrome/polycystic ovaries (PCOS)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometriosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pelvic inflammatory disease (PID)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Does your mother or sister have any of the following?  

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe period pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pelvic inflammatory disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polycystic ovarian syndrome/polycystic ovaries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometriosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is there anything else that you would like to tell us about your periods or something that has changed your periods? (Any extra information is helpful for the researchers)

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

You have finished! Thank you for completing this questionnaire.

Glossary

<table>
<thead>
<tr>
<th>Word/terms</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>emptying bowels</td>
<td>doing a poo</td>
</tr>
<tr>
<td>indigestion</td>
<td>heartburn, stomach pain after eating, reflux, acid pain in the stomach</td>
</tr>
<tr>
<td>pelvic pain</td>
<td>pain in lower tummy, below belly button</td>
</tr>
<tr>
<td>passing wind</td>
<td>farting</td>
</tr>
<tr>
<td>Not Applicable or N/A</td>
<td>this doesn’t apply to me</td>
</tr>
</tbody>
</table>

If there are other words in the questionnaire that you do not understand please raise your hand and someone will help you.

© Melissa Parker 2004
Appendix 2 – Questionnaire Cover Letter
Welcome to our study!

We really appreciate your time in filling out this questionnaire.

- The information we collect will help us learn more about what is a ‘normal’ period for a teenager and help us pick up the signs of periods that need further investigation. Early detection can prevent long-term problems such as pain and infertility (unable to fall pregnant).
- Please answer the questions for yourself only - whatever the usual experience is for you.
- Filling out this questionnaire is voluntary. You can change your mind and withdraw from the study before, during or after completing your questionnaire if you wish.
- If there is a word or question that you are not sure about, please put up your hand and one of us will help you out.
- The information collected in this questionnaire will be kept confidential (it’s the law) and will be kept in locked storage in the Research Centre for Nursing Practice at The Canberra Hospital.
- If you provide your contact details on your consent form, they will only be used if you need to be contacted based on the findings from your questionnaire.
- You will only be notified if we think there may be a problem.
- If something is worrying you, you don’t have to wait for us to contact you, you can seek help from your GP or other health professional at any time.

Thanks again,

Melissa Parker
ACTHMRC Research Fellow
Master of Nursing Research Student UC
Appendix 3 – Consent Form
Consent Form to Participate in a Research Project

I, ____________________________________________
(name of participant)

of ____________________________________________
(street)

__________________________________________
(suburb/town)  (state & postcode)

have been asked to consent to participate in a research project entitled:

**Prevalence of menstrual disorders in teenage women**

In relation to this project I have read the Participant Information Sheet and have been informed of the following points:

1. Approval for the project has been given by the ACT Department of Health Human Research Ethics Committee, The University of Canberra Committee for Ethics in Human Research and the ACT Department of Education.

2. I know that by providing my identification and contact details I am consenting to be followed up if necessary.

3. Participation in the study will involve completing a questionnaire, which asks questions about my period and other health and lifestyle information.

4. If I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact the ACT Department of Health Human Research Ethics Committee Secretary on Second Floor, North Building, London Circuit, Canberra City, ACT 2601 or on phone number 02 6205 0846, or, the Secretary of the University Research Committee, telephone (02) 6201 2466, University of Canberra, ACT 2601.

5. I can refuse to take part in this project or withdraw from it at any time.

6. I understand that the results of the research will be made accessible and that my involvement and my identity will not be revealed.

After considering all these points, I accept the invitation to participate in this project.

Signature: ___________________________  Date: ___/___/_____
(of participant)

Witness: ___________________________  (Please print name)
Do you wish to be contacted if the project team would like to discuss your questionnaire findings with you?
(Please circle your response)

YES  NO

If yes, please provide these additional details:

Name  

College  Year:

Date of birth ___/___/_____

Postal address (if different from residential address above)


Phone number/s  Home  Mobile
Appendix 4 – Student Information Sheet
Dear Participant
We will be attending your college to conduct a written questionnaire amongst 16-18 year old women about their menstrual periods.

**Why are we doing this study?**
Firstly, we wish to find out how many 16-18 year old women from ACT colleges have problems with their periods. Secondly, the information we collect will assist in the design of a screening tool that will help teenagers and women with period problems get diagnosed more quickly. We want to shorten the time taken for diagnosis because we know that early detection can prevent long-term problems such as pain and infertility (the inability to fall pregnant).

**Who is conducting the study?**
Melissa Parker - Registered Nurse/Midwife/Research Fellow working at The Canberra Hospital and University of Canberra Research Centre for Nursing Practice - received a Research Fellowship grant from the ACT Health, Health and Medical Research Council to conduct this project. Melissa has been actively involved in women’s health issues through her work at The Canberra Hospital and within the Canberra community (particularly in relation to endometriosis) over the past 14 years. Melissa is also a Master of Nursing Research student at the University of Canberra. 

The project is supervised by Dr Anne Sneddon, Staff Specialist in Obstetrics and Gynaecology at The Canberra Hospital and ANU Medical School, and Dr Paul Arbon, Professor of Acute Care Nursing and Director of the Research Centre for Nursing Practice at The Canberra Hospital and University of Canberra.

**Does the project have the proper approvals?**
Yes, it is approved by the ACT Department of Education, your College Principal and two ethics committees: The ACT Health Human Research Ethics Committee (ACTHREC) and the University of Canberra Committee for Ethics in Human Research.
**Is the study voluntary?**
Yes, 16-18 year old females who wish to participate will need to read the Participant Information Sheet and sign the Consent Form before completing the questionnaire.

**Is the study anonymous?**
It is anonymous in that the information collected during the project will be reported in a way that does not identify any individual participants. The questionnaires do not contain any identifying information. The questionnaires are coded so that we can find your details if we need to contact you. The questionnaires and the contact details are stored separately. We can only contact you if you have agreed to this on the Consent Form. Ethics guidelines set out by the National Health and Medical Research Council require that all questionnaires and personal information be kept in locked storage in the Research Centre and any electronic information be protected with passwords.

**If participants do not want to be contacted about their questionnaire findings, we respect this decision and will still appreciate the information provided through completing the questionnaire.**

**What are the questions about?**
Questions are about the qualities of your 'usual periods', signs and symptoms experienced by teenagers during the menstrual cycle, whether periods affect your lifestyle and any allergies and intolerances the participant may have. There are two questions that refer to pain related to sexual activity, and participants can choose not to answer these if they wish. There are no questions about alcohol and drug consumption or sexual abuse. It is anticipated that the questionnaire will take about 15-20 mins to complete.

**Can participants take the questionnaire home?**
No. Questionnaires that are given or posted out have a notoriously low rate of return. The college is providing time for the questionnaires to be completed and they will be collected immediately afterwards. The success of this study is highly dependent on collecting information from a large number of teenage women (our target is 1000).

**How will a menstrual problem be detected?**
The information we collect will help us learn more about what is a ‘normal’ period for a teenager and what the signs are for periods that need further investigation, as well as the number of teenagers who have problems with their period. After data collection all questionnaires will be analysed by Melissa Parker and Dr Anne Sneddon using set criteria. Participants identified as having a possible menstrual disorder will be contacted (if they have consented to this) and
provided with information, counselling if necessary, and a recommendation to seek further investigation through their GP or other health professional/s.

**How will participants be notified?**
Those participants who require further investigation will be contacted either by phone or mail (depending on the contact details given to us) and every effort will be made to discuss their individual findings, including their options for further investigation. We will recommend that participants have a parent or significant other person present at this discussion.

**Participants please note**
Researchers must comply with the privacy and confidentiality guidelines set down by the National Health and Medical Research Council, which prevent us from giving information about you to your parents unless we have your express permission. We therefore recommend that you maintain open communication with your parents about your participation in the study, including their involvement and support should you need it.

Any participant who is concerned about their menstrual periods does not need to wait to be contacted, they can contact their GP or other health professional at any time.
Participants whose periods are considered to be within the ‘normal’ range for a 16-18 year old woman will not be contacted.

**How will the results of the project be reported?**
To ensure privacy and confidentiality, results are reported in an aggregated form (ie. all together) and do not identify any individual participants. At the completion of the project a full report will be submitted to the funding body, the ACT Health, Health and Medical Research Council, and also to the ACT Department of Education. A condensed report will be given to the participating colleges and interested persons. A Masters thesis will also be written about the project, articles may be published in related medical and nursing journals as well as oral or poster presentations at relevant conferences.

**Further questions?**
Please feel free to direct any further questions you may have to the Project Team:

Melissa Parker
ACTHMRC Research Fellow
Master of Nursing Research student UC
The Canberra Hospital and University of Canberra
Research Centre for Nursing Practice
Telephone: 6244 2396
Email: melissa.parker@act.gov.au

Dr Anne Sneddon
Project Supervisor
Staff Specialist in Obstetrics and Gynaecology
The Canberra Hospital & ANU Medical School
Telephone: 6244 3677
Email: anne.sneddon@act.gov.au

Dr Paul Arbon
Project Supervisor
Professor of Acute Care Nursing
Research Centre for Nursing Practice
The Canberra Hospital and University of Canberra
Telephone: 6244 2396
Email: paul.arbon@act.gov.au

Contacts regarding ethics:

ACT Department of Health Human Research Ethics Committee Secretary
Second Floor, North Building
London Circuit
Canberra City ACT 2601
Telephone (02) 6205 0846

Secretary of the University Research Committee
University of Canberra, ACT 2601
Telephone (02) 6201 2466,
Appendix 5 – Parent Information Sheet
Parent

Information Sheet

Prevalence of Menstrual Disorders in Teenagers - MDOT Study

Dear Parent/Guardian
In the next few weeks we will be attending your child’s college to conduct a questionnaire amongst 16-18 year old women about their menstrual periods.

Why are we doing this study?
Firstly, we wish to find out how many 16-18 year old women from ACT colleges have problems with their periods. Secondly, the information we collect will assist in the design of a screening tool that will help teenagers and women with period problems get diagnosed more quickly. We want to shorten the time taken for diagnosis because we know that early detection can prevent long-term problems such as pain and infertility (inability to fall pregnant).

Who is conducting the study?
Melissa Parker - Registered Nurse/Midwife/Research Fellow working at The Canberra Hospital and University of Canberra Research Centre for Nursing Practice - received a Research Fellowship grant from the ACT Health, Health and Medical Research Council to conduct this project. Melissa has been actively involved in women’s health issues through her work at The Canberra Hospital and within the Canberra community (particularly in relation to endometriosis) over the past 14 years. Melissa is also a Master of Nursing Research student at the University of Canberra.
The project is supervised by Dr Anne Sneddon, Staff Specialist in Obstetrics and Gynaecology at The Canberra Hospital and ANU Medical School, and Dr Paul Arbon, Professor of Acute Care Nursing and Director of the Research Centre for Nursing Practice at The Canberra Hospital and University of Canberra.

Does the project have the proper approvals?
Yes, it is approved by the ACT Department of Education, the College Principal and two ethics committees: The ACT Health Human Research Ethics Committee (ACTHREC) and the University of Canberra Committee for Ethics in Human Research.
**Is the study voluntary?**
Yes, 16-18 year old females who wish to participate will need to read the Participant Information Sheet and sign the Consent Form before completing the questionnaire.

**Is the study anonymous?**
It is anonymous in that the information collected during the project will be reported in a way that does not identify any individual participants. The questionnaires do not contain any identifying information. The questionnaires are coded so that we can find your child’s details if we need to contact them. The questionnaires and the contact details are stored separately. We can only contact your child if they have agreed to this on the Consent Form. Ethics guidelines set out by the National Health and Medical Research Council require that all questionnaires and personal information be kept in locked storage in the Research Centre and any electronic information be protected with passwords.

**If participants do not want to be contacted about their questionnaire findings, we respect this decision and will still appreciate the information provided through completing the questionnaire.**

**What are the questions about?**
Questions are about the qualities of their ‘usual periods’, signs and symptoms experienced by teenagers during the menstrual cycle, whether periods affect their lifestyle and any allergies and intolerances. There are two questions that refer to pain related to sexual activity, and participants can choose not to answer these if they wish. There are no questions about alcohol and drug consumption or sexual abuse. It is anticipated that the questionnaire will take about 15-20 mins to complete.

**Can participants take the questionnaire home?**
No. The college is providing time for the questionnaires to be completed and they will be collected straight after. The reason for this is to increase our rate of returned questionnaires. Questionnaires that are given or posted out have a notoriously low rate of return. The success of this study is highly dependent on collecting information from a large number of teenage women (our target is 1000).

**How will a menstrual problem be detected?**
The information we collect will help us learn more about what is a ‘normal’ period for a teenager, what are the signs of periods that need further investigation, as well as the number of teenagers who have problems with their period. After data collection all questionnaires will be analysed by Melissa Parker and Dr Anne Sneddon using set criteria. Participants identified as having a possible menstrual disorder will be contacted and provided with information,
counselling if necessary, and a recommendation to seek further investigation through their GP or other health professional/s.

**How will participants be notified?**
Those participants who require further investigation will be contacted either by phone or mail (depending on the contact details given to us). Every effort will be made to discuss individual findings with these participants including their options for further investigation. We will recommend that participants have a parent or significant other person present at this discussion.

---

**Parents please note**

Researchers must comply with the privacy and confidentiality guidelines set down by the National Health and Medical Research Council which prevent us from giving information to you about your child unless we have the express permission of your child. We therefore recommend that you maintain open communication with your child about their participation in the study and let them know that you are genuinely interested in their health and well-being and the level of support you are prepared to provide should they need it.

Any participant who is concerned about their menstrual periods does not need to wait to be contacted, they can contact their GP or other health professional at any time. **Participants whose periods are considered to be within the ‘normal’ range for a 16-18 year old woman will not be contacted.**

**How will the results of the project be reported?**
To ensure privacy and confidentiality, results are reported in an aggregated form (ie. all together so no individual can be identified). At the completion of the project a full report will be submitted to the funding body, the ACT Health, Health and Medical Research Council. A full report will also be submitted to the ACT Department of Education. A condensed report will be given to the participating colleges and interested persons. A Masters thesis will also be written about the project, articles may be published in related medical and nursing journals as well as oral or poster presentations at relevant conferences.

**Further questions?**
Please feel free to direct any further questions you may have to the Project Team:

Melissa Parker
ACTHMRC Research Fellow
Master of Nursing Research student UC
The Canberra Hospital and University of Canberra
Research Centre for Nursing Practice
Telephone: 6244 2396
Email: melissa.parker@act.gov.au

Dr Anne Sneddon
Project Supervisor
Staff Specialist in Obstetrics and Gynaecology
The Canberra Hospital and ANU Medical School
Telephone: 6244 3677
Email: anne.sneddon@act.gov.au

Dr Paul Arbon
Project Supervisor
Professor of Acute Care Nursing
Research Centre for Nursing Practice
The Canberra Hospital and University of Canberra
Telephone: 6244 2396
Email: paul.arbon@act.gov.au

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London Circuit
Canberra City ACT 2601
Telephone: (02) 6205 0846

Secretary of the University Research Committee
University of Canberra, ACT 2601
Telephone: (02) 6201 2466

MDOT Study – Parent Form for Non-Participation in Questionnaire.

Only return this section to the college if you do not want your daughter to participate in this study.

I do not wish my daughter to participate in this study and ask that she does not complete a questionnaire.

Daughter’s name

Class

College

________________________________________________________________________

_________________________________________ Date ___________

Signed Parent/Guardian
Appendix 6 – Teacher Information Sheet
The Canberra Hospital and University of Canberra Research Centre for Nursing Practice is conducting a study on the menstrual patterns of women aged between 16 and 18 in the ACT. To do this we have chosen ACT Secondary Colleges and aim to get 1000 questionnaires answered. The aim of this study is to collect data on the range of menstrual patterns in this age group. The data will be used to create a screening tool that can be used by a wide range of people that may be in the position of caring for young women with menstrual disorders. These would include GP’s, health workers, teachers and ancillary staff dealing with young women.

There is no similar data available in Australia. There are smaller studies from the USA and the UK whereby period and pelvic pain is reported to occur in 40–80% of adolescents with associated school absence rates of 14–23%. Approximately 50% of adolescents with severe pelvic pain are found to have endometriosis. Endometriosis is a condition which affects 10% of all adult menstruating women. It is a major reason for significant morbidity, absenteeism, underachievement and loss of fertility. At present the average time from onset of symptoms to diagnosis is 6–9 years. Future research based on this study will aim to minimise the lengthy time to diagnosis, and therefore aim to reduce the impact of these menstrual disorders on young women.

The current study involves completing a questionnaire which will take about 20 minutes. Information Sheets for participants and parents will be sent home prior to Questionnaire Day, and any parents who do not want their daughter to participate can sign the ‘non-participation’ section included on the Parent Information Sheet. The young women who choose to participate will be asked to sign a consent form just prior to commencing the questionnaire. Participants will be given contact details to gather further information should the questionnaire reveal any concerns. However, each questionnaire that reveals a concern to the researchers will be individually followed up.
The role of teachers may include handing out the information sheets, collecting 'non-participation' forms that are returned by students, and witnessing the participant signatures on the consent forms on the day of the questionnaire. During the process of conducting this study, teachers may also find themselves in the position of being asked questions. Please feel free to refer parents, students, or any queries to the Project Team:

Melissa Parker  
ACTHMRC Research Fellow  
Master of Nursing Research student UC  
The Canberra Hospital and University of Canberra  
Research Centre for Nursing Practice  
Telephone: 6244 2396  
Email: melissa.parker@act.gov.au

Dr Anne Sneddon  
Project Supervisor  
Staff Specialist in Obstetrics and Gynaecology  
The Canberra Hospital & ANU Medical School  
Telephone: 6244 3677  
Email: anne.sneddon@act.gov.au

Dr Paul Arbon  
Project Supervisor  
Professor of Acute Care Nursing  
The Canberra Hospital and University of Canberra  
Research Centre for Nursing Practice  
The Canberra Hospital  
Telephone: 6244 2396  
Email: paul.arbon@act.gov.au

Other numbers which may be of use:
The Junction Youth Medical Centre  ph: 6247 5567  
The Women's Centre for Health Matters:  ph 6290 2166  
The Canberra Sexual Health Centre  (at The Canberra Hospital)  ph: 6244 2186  
Sexual Health and Family Planning  ph: 6247 3077  
General Practitioners

Dates to Remember (Narrabundah College):
8 March 2005  
Project will be introduced at special girls assembly. Information sheets will be given out to Year 11 & 12 girls aged 16-18 years.

9 March 2005  
Project information desk will run from 1.15-2pm in B block foyer.

10-11 March 2005  
Participants will complete questionnaires in classes

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Appendix 7 – Ethics Approval Letter: ACT Health and Human Research Ethics Committee
Outcome of Consideration of Protocol

Submission No: ETH.9/04.467 Date of Approval: 30 November 2004

Project Title:
Prevalence of Menstrual Disorders in Teenage Women

Submitted by:
Ms Melissa Parker

Your project was considered by the ACT Health and Community Care Human Research Ethics Committee and approved the study for a period of one year.

Further Action required:

Review due: November 2005

The Ethics Committee require as part of the review process that:

- At regular periods, and not less frequently than annually, Principal Investigators are to provide reports on matters including:
  - security of records
  - compliance with approved consent procedures and documentation
  - compliance with other approved procedures.
  - as a condition of approval of the protocol, that Investigators report immediately:
    - adverse affects on subjects
    - proposed changes in the protocol
    - unforeseen events that might affect continued ethical acceptability of the project.

- All published reports to carry an acknowledgement stating:
  - approved on 30 November 2004 by the ACT Health and Community Care Human Research Ethics Committee.

MS ELIZABETH GRANT AM, CHAIR Date: 30 November 2004
Appendix 8 - Ethics Approval Letter: University of Canberra Committee for Ethics in Human Research
Document for people who are participants in a research project

CONTACTS FOR INFORMATION ON THE PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE

The following study has been reviewed and approved by the Committee for Ethics in Human Research:

Project title: ...Prevalence of menstrual disorders in teenage women

Project number: 04/81 Principal researcher: Mrs Melissa Parker

As a participant or potential participant in research, you will have received written information about the research project. If you have questions or problems which are not answered in the information you have been given, you should consult the researcher or (if the researcher is a student) the research supervisor. For this project, the appropriate person is

Name: Professor Paul Arbon
Contact details: School of Health Sciences, Division of Health, Design & Science, University of Canberra
Phone: 02) 6201 2396 Fax: 02) 6244 2375
E-mail: paul.arbon@canberra.edu.au

2. If you wish to discuss with an independent person a complaint relating to
   - conduct of the project, or
   - your rights as a participant, or
   - University policy on research involving human participants,
   you should contact the Secretary of the University Research Committee
   Telephone (02) 6201 2466 Room 1D85, Secretariat, University of Canberra, ACT 2601.

Providing research participants with this information is a requirement of the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans, which applies to all research with human participants conducted in Australia. Further information on University of Canberra research policy is available in University of Canberra Guidelines for Responsible Practice in Research and Dealing with Problems of Research Misconduct and the Committee for Ethics in Human Research Human Ethics Manual. These documents are available from the Research Office at the above address or on the University’s web site at http://wasp.canberra.edu.au:80/secretariat/respprac.html (Research Guidelines) http://www.canberra.edu.au/secretariat/ethics/human_ethics/ (Human Ethics Manual)
Appendix 9 – Ethics Approval Letter: ACT Department of Education and Training
Melissa Parker  
8 Gehrs Close  
NICHOLLS ACT 2913

Dear Melissa

Thank you for your request for the proposed research titled *Prevalence of menstrual disorders in teenagers*. I am pleased to inform you that the department has approved your research.

This approval is given on the understanding that consideration be given to addressing the inclusion of items relating to sexual activity is an optional attachment. Please contact Ms Marilyn Higgins, Health Promoting Schools Officer, 6205 7189 to assist with contacts and dissemination.

It is understood that the research will be completed within twelve months of the date of this letter. Any extension of this timeframe must be approved in writing.

You may now approach the principals of schools directly, with a copy of this approval letter, for permission to carry out your research. It will be at the discretion of the principal at each school as to whether your research can proceed.

This approval is subject to the condition that, upon completion, you forward a copy of your report to the Education Policy and Planning Section at the address below.

For further assistance please contact Joy Newton on (02) 62057582.

Best wishes with your research.

Yours sincerely

Joanne Howard  
Director  
Schools Central  
20 January 2005
Appendix 10 – Protocol for Evaluation and Treatment of Adolescent Pelvic Pain / Endometriosis
Fig. 1. Protocol for evaluation and treatment of adolescent pelvic pain and endometriosis. (Modified with permission from Bandera CA, Brown LR, Laufer MR. Adolescents and endometriosis. Clin Consult Obstet Gynecol 1995;7:206.)
Appendix 11 - Menstrual disorders found in teenagers

Menstrual disorders found in teenagers include: amenorrhoea – as a result of an underlying congenital anomalies or various endocrine dysfunctions; Mullerian anomalies – congenital malformation of the female reproductive tract which may only become apparent by amenorrhoea in adolescence; Polycystic ovarian syndrome (PCOS); Pelvic inflammatory disease (PID); genital tract cancers; abnormal uterine bleeding (AUB) and endometriosis.

Amenorrhoea

Amenorrhoea is the term given to the absence of menstrual periods. Primary amenorrhoea refers to menarche that has not occurred by 16 years of age. While this is a figure commonly touted by text books, it is interesting to note that in North America, the 95th percentile for menarche is now 14.5 years (Slap, 2003), (Merck Manual Online, 2006). If a girl ceases to menstruate for three or more consecutive menstrual periods after her first menstrual period (menarche), then this is termed secondary amenorrhoea (Slap, 2003). It is normal for women not to menstruate before puberty, during pregnancy and breastfeeding and after menopause (Merck Manual Online, 2006). Amenorrhoea should be investigated to rule out possible causes such as: congenital anomalies of the reproductive tract; endocrine dysfunction and disruption to the functioning of the hypothalamus, pituitary or thyroid glands; ovarian dysfunction; anorexia nervosa; low BMI (body mass index) and weight fluctuations; intense or strenuous exercise; psychological, emotional and physical stress (Merck Manual Online, 2006), (Miller & Keane, 1983).

The aim with amenorrhoea in teenagers is to determine the underlying cause so that treatment can be considered.

Müllerian anomalies

The müllerian ducts are a pair of embryonic ducts that develop in the female to become the reproductive organs (Miller and Keane, 1983). The upper 2 thirds of the vagina, the cervix, uterus and fallopian tubes derive from the müllerian ducts (Syed, Hussain & Weadock, 2002). According to US (United States) figures, it is thought that mullerian tract anomalies occur in approximately 0.1-0.5% of women, however,
this figure is likely to be conservative considering those women with mullerian anomalies who are never diagnosed because they are able to conceive and birth naturally, or those women who do not attempt to have children and therefore, do not encounter problems with fertility due to mullerian anomalies (Syed, Hussain & Weadock, 2002). In a large study of 679 women in Spain, the reported incidence of mullerian anomalies in the “normal fertile population” was 3.2% (22/679) (Simon, Martinez, Pardo, Tortajada & Pellicer, 1991).

A teenage woman with an obstructed mullerian system may present in adolescence because of primary amenorrhoea (Syed, Hussain & Weadock, 2002).

**Polycystic ovarian syndrome**

PCOS is a disease of unknown origin, presenting clinically with one or more of: hirsuitism, obesity, oligomenorrhoea, anovulation and infertility, but a criteria of ‘definite’ and ‘probable’ factors are used to obtain a diagnosis of this disease that occurs in 5% - 10% of menstruating women. (Gordon, 1999).

PCOS is termed as a syndrome because it encompasses a spectrum of disorders associated with excess androgen production from the ovaries, adrenal glands or both (Gordon, 1999). Signs of PCOS can usually be seen in adolescence and manifest from aberration of four physiological processes including: maturation of the pattern of LH secretion, increase in adrenal androgen production, increase in body mass and onset of an adult pattern of insulin resistance (Gordon, 1999). Treatment centres on correction of these four anomalies.

Implications for teenagers include long-term disease management, but particularly, management of weight gain, hirsuitism and acne to prevent the negative effects these may have on the self-esteem of the developing and vulnerable teenage woman (Gordon, 1999).

**Pelvic inflammatory disease (PID)**

Pelvic inflammatory disease is the term given to infection of the female genital tract (above the cervix) from a variety of organisms singularly or simultaneously, the main ones being Neisseria Gonorrhoeae and Chlamydia Trachomatis (Reyes & Abbuhl, 2006). The infection can cause inflammation of the uterine cavity, fallopian tubes, peritoneum, ovaries and occasionally a tubo-ovarian abscess (Reyes & Abbuhl, 2006) (Merck Manual Online, 2006).
PID can be asymptomatic in some women and therefore remains undiagnosed. The long term-sequelae of untreated PID include infertility, ectopic pregnancy and chronic pelvic pain (Merck Manual Online, 2006). Common presenting symptoms are fever, acute or chronic pelvic pain (abdominal pain with peritoneal involvement), irregular vaginal bleeding, vaginal discharge and lower back pain (Holland-Hall & Brown, 2004), (Merck Manual Online, 2006), (Reyes & Abbuhl, 2006).

PID is included amongst menstrual disorders as it can cause irregular uterine bleeding with symptoms occurring during or after menstruation (Merck Manual Online, 2006). PID should be considered in the adolescent population because it is more common in sexually active women under the age of 25-35 years (Merck Manual Online, 2006), (Reyes & Abbuhl, 2006).

**Cancers**

The ACT Health, Cancer in the ACT Report for 1996-2000 had no reported cases of genital tract cancers in the 15-19 year old age group. The previous report covering from 1983-1992 had 1 report of ‘cancer of the ovary and other uterine adnexa’ in the 15-19 year age group but no report of death in the same time period (Cancer in the ACT, 1983-1992, ACT Health).

According to the National Cancer Institute (2006) ovarian cancer and carcinoma of the vagina and cervix are categorized as ‘unusual cancers of childhood’. The most common presenting symptoms for young women with ovarian cancer are dysmenorrhoea and abdominal pain (National Cancer Institute, 2006). While individual types of ovarian cancers are discussed in the literature, overall incidence figures were not found.

McNall et al (2004) report a single case of adenocarcinoma of the cervix and vagina in a 13 year old girl, and also looked at 37 other reported cases of ovarian cancer in women aged 18 years and below. The predominant symptom in these 38 cases was vaginal bleeding, and 62% of the girls had been exposed to diethylstilbestrol in utero (McNall et al, 2004).

While vaginal tract cancers remain rare in the population studied in the MDOT study, it is prudent to not dismiss them altogether as the common presenting symptoms are common with those of other menstrual disorders.
**Abnormal uterine bleeding**

Slap (2003) defines uterine bleeding as ‘abnormal’ if it occurs more frequently than every 21 days, lasts longer than 7 days, and requires more than six pads or tampons per day. These teenagers should be investigated for dysfunctional uterine bleeding relating to anovulation; sexually transmitted infections if sexually active; and pregnancy related causes of bleeding such as ectopic pregnancy or threatened/spontaneous/incomplete abortion.

**References**


Cancer in the ACT, 1996-2000. Population Health Research Centre, ACT Health: Health Series No 34, ACT Government, Canberra ACT.


Appendix 12 – Stories from teenagers and one adult woman about their experiences of menstrual pain and pathway to diagnosis of endometriosis.

Kate (Age 15)

I had my first symptoms when I first got my period. I had really bad pains in my pelvis, but at the time I never realised it would be my period. It was a really dark brown colour for the first couple of hours. I must have had it for about 5 hours before I realised it was my period.

My symptoms have been:-
servere pain, sometimes I even got refured pain, it even occasionally made me feel sick. It stopped me doing everything, school, being with my friends and moving. I stayed in a ball shape on the couch. I missed out on pretty much a whole term of school. plus at least 6 weeks on and off for every time I got my period.

I had been to the doctor several times before the gynaecologist. My doctor put me on the pill. He tried me on I think it was 2 or 3 different pills before mum took me to go and see her gynaecologist. But the doctor did suggest endo once but he said it probably wont be it, but there was a possibility.

I had a few visits to the gynaecologist before I was scheduled for a laproscopy. When I was diagnosed with endo I was pretty emotional, especially when he said it was incurable and I was pretty much the youngest person he had seen with endo.

The melb. doctor seemed to be more propper and it felt like he explained things more thoroughly. They made me feel less stressed and like I had nothing to worry about.... I was sooo scared and I was worried there would be something really wrong with me because I was in so much pain. but the melb. doctor was really good about it and he delt with it every day. He was really suprised with the amount of endo he found. He had never seen that much in someone my age before.

Endo has been very life changing. I no im not the only one with it but
because i live in the country it seems like no one understands because there
is no one around that has experienced it. If there is they arnt my age. But
i have found a few of my friends to be really supportive. One of my friends
said i was wagging school which really hurt my feelings. i still cant forgive
her. but when things like this happen you really do find out who your real
friends are. So far the surgery has worked. but i still think its too early to tell.
Sally (Age 19)

I had my first period when I was ten. It wasn’t very pleasant as I was the first person to get my period out of everyone I knew, even my older friends. It was very irregular, coming once a fortnight to once a year. It started evening up when I was 16, but it was still coming once a fortnight to once every 2 months. What made it really horrible however wasn’t the irregularity but the pain that came with it. My first few years of menstruation were not too bad, but around the age of 16-17 I started getting exceptionally bad period pain. Period pain is horrible for most, but there isn’t a standard scale to say “your period pain is a lot worse than your friends period pain” because everyone is different. Mine was so bad that sometimes I had to curl up in the foetal position and just wait, and others I would just get a cramp which went away with neurophen.

When I was in my first sexual relationship at 17, the problems really started. I had been overseas resulting in Post Traumatic Stress disorder, I had developed a peptic ulcer and was very depressed. My relations with my partner worsened and as sex was quite painful it put more tension on the already frail relationship. I went to my GP a few times about this pain, but it was put down to my gastrointestinal problems and possible coeliac disease. My GP is a trained gynaecologist so I was never really referred to a specialist. I had regular STI screens and pap smears and even had an ultrasound for endometriosis (which came back negative) but after that I just forgot about it. By the time I was 18 I was very stressed at school, was having intense pains in my abdomen and had really bad gastritis and reflux. I went on to see a gastroenterologist who tested for Crohn’s and Coeliac Disease but after a scope and colonoscopy I was only diagnosed with a mild gluten sensitivity. The only problem was that I was still having intense concentrated pain around my bowel area and abdomen that left me quite breathless, lasting from 30 seconds to 5 minutes. This made it really hard to concentrate at work or school, and when I had my period it was much much worse. However, how was I supposed to know that this wasn’t normal?

One day at college all the boys were kicked out of our English class and all the girls were left to do a survey about period pain. I thought nothing more of it until I was called and given an opportunity to have a follow up chat with the nurse. I was a little dubious at first but went. I had a chat bout my period pains in general, answered some specific questions and the nurse spoke to me about endometriosis. I had heard of it once before and my GP had referred me for an
ultrasound but he said nothing about it after. My symptoms sounded a lot like the endometriosis symptoms, even down to the extreme concentrated pain at a certain point on my bowel. I agreed to fill in a pain chart and try taking neurophen a few days before my period and then booked in a follow up appointment with the doctor running the clinic. I had a few appointments with the doctor and an ultrasound at the gynaecology clinic and a decision was made for me to have a laparoscopy. I was a little scared at first because I had had investigative operations done for my gastritis and a reoccurring injury (after a car accident) with no conclusive results, which suggested to me that I was exaggerating the pain I was feeling. I was scared that I might have been making it all up in my head or was being a hypochondriac and was terrified that they would do the operation and there would be nothing there. I agreed in the end to put my mind at ease.

On the day of the operation I was really scared. I had had the procedure explained to me and it sounded so complicated. I was so nervous that the nurse had to hold my hand and comfort me. My biggest fear however was still that there would be nothing there and it would all be a waste of time.

When I woke up from the surgery it felt like I had been hit by a bus. I was a little shocked to see that I was lying in a little pool of blood and my abdomen was throbbing. I was even more shocked when I went to the toilet and there was a large amount of blood in the bowl.

The first thing I asked was whether they found anything and sighed a huge sigh of relief when I was told that I did have endometriosis and they had been able to cut it out. What was even more relieving was that an adhesion had been found on my bowel, where I had been getting the pain. I was so happy that all the pain I had been going through was not my imagination but endometriosis. I suddenly didn't feel like I was a bad person for wasting all these lovely people’s time. I was also happy that it had been caught so early as my mother’s friend had had investigative surgery and her entire abdomen was a web of endometriosis that had gone undiagnosed.

I was discharged and allowed to go home, but the shoulder tip pain was horrible and I had a huge tummy which looked like I was 3 months pregnant. I was surprised to see however that I had just 4 little neat incisions in a diamond shape
on my belly; one was in my belly button so you couldn’t even see it. The pain was worth it though as I had a diagnosis and it was real.

If I hadn’t been picked up on the study it would have been quite a while before my endometriosis was diagnosed, and I shudder to think what it would have been like then. Instead of having two little spots and a little adhesion it would have been much worse. The incisions healed up very nicely and I now have three little scars. In the follow up appointment with the doctor, she explained the findings of the laparoscopy and showed me photo’s of the endometriosis and adhesion from the operation which helped to understand what endometriosis was. It was hard to believe that those little red spots had been causing me so much pain!

The shoulder tip pain and abdominal pain lasted almost a week after the operation and every so often I get bad period pain but the occurrence and severity had dropped so much. I am also taking the mini-pill straight and only having one period every three months. My friend was having really bad period pain and from talking to her she went and saw a specialist and also had a laparoscopy and was also found to have endometriosis. It took her a long time to get the operation but she thinks it is well worth it too, especially for the peace of mind it gives.

I am so grateful for Melissa and Dr Sneddon for investigating my period pain when my GP/Gynaecologist dismissed it as “normal” period pain. I have my sanity back, and can get out and do things that I didn’t want to do when my pain was at its worst.
Jacqui (Age 37)

My story: pain and disdain

There are 2 main themes in the story of my struggle with severe endometriosis: pain (from the disease itself) and disdain (from the medical profession).

1 Pain

1.1 The long road to diagnosis

Welcome to womanhood

I first started menstruating when I was 11 (in 1980, when I was in 6th class). My first period was memorable: I suffered severe pain, bled very heavily for about 2 weeks (I had to wear adult nappies) and passed large blood clots (about the size of half your palm). Luckily the very heavy bleeding and clots stopped after the 1st period, but the pain didn’t. The pain was very severe, crampy pain. I would break into a sweat, shake and have to keep going to the toilet (someone later told me that the hormones that make the uterus contract also affect the bowel, which also starts to contract). I have never had a child, but from what I have heard what I experienced was like childbirth (though not as severe of course)! My periods were very irregular, so these symptoms would strike when my period decided to arrive.

My mother took me to a gynaecologist not long after I first started menstruating. He examined me anally, which I found extremely traumatic (especially when my mother told me before the appointment that he just wanted to talk to me). I think this is why I have a phobia as far as gynaecologists are concerned: for some people it is after having a traumatic experience at the dentist, for me it is gynaecologists!

High school blues

The severe pain and other symptoms continued until I was 14 (in 1983, when I was in year 9). The GP referred me to a gynaecologist (not the fellow I saw when I was 11, but I was still terrified!), who performed a laparoscopy. He reported no abnormalities, and recommended that I go on the pill. This helped to regulate my periods, and the pain was not as severe, but it certainly still interfered with my life. From 14 to 17 (I was 17 in June 1986, when I was in year 12), I remember having to take 1-2 days a month off school when I got my period, and relying on pain killers and my trusty hot water bottle to get me through those days. I remember feeling really tired too. I tried to take the pill (actually, stop
taking the pill!) each month so that my period would start on a weekend, but this was not always successful (the doctor didn’t tell me that I could take the pill continuously to avoid monthly periods—to be fair I’m not sure whether doctors were giving that advice way back in 1983—and it didn’t occur to me to do it). The pain had a detrimental effect on my education and social life, including having to constantly miss school and catch up on missed school work, and cancel social activities because I had my period. I also remember doing homework while I was sitting up in bed with a hot water bottle!

Looking back, I wonder whether the conclusions from the laparoscopy were correct. Did I have endometriosis then? If not, it certainly arrived soon after!

**No change when in the workforce**

I took a year off in 1987 (I turned 18 in June 1987) to work, before going to university. I still had the same problems: time off due to pain and other symptoms, having to take painkillers etc. This is the year that I started having sexual intercourse, and it was excruciatingly painful. The 1st few times I put down to inexperience, but it got to the stage that I was pleased when the relationship ended (I was moving interstate to go to university) so that I could avoid sex! This is obviously a major ‘effect on my teenage years’: the beginning of one’s sexual life should be an exciting and happy time, but mine was painful and traumatic. Of course I didn’t even contemplate seeing a gynaecologist. I think this symptom is 1 of the major indicators that I had endometriosis as a teenager. If I didn’t have it when I was 14, I think I certainly had it when I was 18. Another indicator is that the nature of the pain changed too: from crampy pain to a sharper pain.

**University ‘life’**

I was at university from 1988 to 1995. The symptoms surrounding my periods were getting worse: the pain was more severe and the fatigue was really debilitating. No improvement on the private life front, so I just stopped having relationships. What should have taken 5 years undergraduate and 1 year post-graduate took me 8 years. I was diagnosed with glandular fever in 1988, which also really affected my health for many years afterwards. I had to defer university half-way through 1991, and again half-way through 1993. I was diagnosed with chronic fatigue syndrome in mid-1993, but looking back I think it was endometriosis that was causing the symptoms I was experiencing.
Diagnosis
I was finally diagnosed with endometriosis in January 1994 (I was 24). I went to
the GP (during university holidays, but I was working) when my symptoms were
such that I couldn’t function at all: severe pain with periods (that’s not new!),
chronic bowel symptoms (alternating diarrhoea and constipation, passing blood),
and terrible fatigue. The GP referred me to a gastroenterologist (even though
now, looking back, I had all the classic symptoms of endometriosis). The
gastroenterologist performed 2 colonoscopies, and when that was all normal he
suggested I see a gynaecologist (gulp!! But I guess it shows how ill I was, and
how desperate I was that I summoned up the courage to go) The gynaecologist
(the same chap who’d done the laparoscopy in 1983) diagnosed extensive
endometriosis, and said “we should have done this (meaning the laparoscopy) a
long time ago”. He did not remove any of the endometriosis. When he saw me
after the laparoscopy he just told me I had endometriosis (I hadn’t even heard of
it!), and to make an appointment to see him. When I got home from the hospital
I rang the MBF Helpline (this was before the internet!), and they told me what it
was and sent brochures to me.

When I saw the gynaecologist he gave me some information about endometriosis.
I was just about to start my honours year at university and asked him if I should
defer. He said not to, that I’d “be right in a few weeks” (maybe I should ring
him and tell him that 12 years later I’m still not “right”??!!).

The long-term effects of delayed diagnosis
There are 4 major long-term effects. The first detrimental effect is on my career
prospects. I had to interrupt my studies due to ill-health, which in turn affected
my career prospects. Through sheer determination and hard work I achieved the
results at university that I set out to achieve (looking back I really don’t know
how I did it). However, the 2 deferrals were recorded on my academic record ‘as
withdrawal without failure’, and this was a blight on my academic record. Also, I
had to extend my formal education by 2 years because I deferred my studies.

The second is not having the social life at university that I could have had if I was
well, which in turn affected the social network that I had after university. My
social life was 1 of the first things to be sacrificed. I had a finite resource (ie time
when I felt well enough to do anything). I had to spend this time on my studies
and work commitments. Very little time was left for a social life. Also, I
constantly had to cancel activities because of ill-health, which tries the patience of even the best of friends.

The third is on my private life. Because of the pain I simply stopped having relationships.

The fourth is that I feel like I’ve been robbed of years of my life: all of the time lost because of ill-health, and the suffering that I could have avoided if I was diagnosed with endometriosis earlier. However, I am aware that an earlier diagnosis probably would not have made much difference in my case. An early diagnosis makes a difference only if it is followed by effective treatment, which unfortunately has not been my experience.

1.2 The long road to effective treatment

1994 and beyond

My first treatment for endometriosis was Danazol. I took it for 6 months, but it didn’t agree with me (I felt really off-colour, my voice deepened and I had some facial hair growth). I saw another gynaecologist (in Canberra) who prescribed Duphaston, which didn’t help the symptoms (it didn’t stop the bleeding, and I always suffered a great deal of pain with bleeding). She did a laparoscopy at the end of 1994, and said “you’ve got plenty of scar tissue but no ‘fresh’ endometriosis, what’s the matter with you?” Looking back (again) I think she just missed what was there.

I continued to suffer from pain, bowel problems etc. I had another laparoscopy in May 2002. The gynaecologist (another one!) lasered off 2 patches of endometriosis on my uterus and left ovary.

I had relief from symptoms for about 12 months after the May 2002 laparoscopy. My pain etc returned in June 2003. I first saw the wonderful Dr Anne Sneddon in 2004. I saw Anne again when she returned from maternity leave. She recommended surgery, but understood why I was reluctant to have surgery. She went through the pros and cons with me carefully. I was still hesitant, so she ordered an ultrasound. The ultrasound showed an endometrioma in the left ovary. I know that the drugs aren’t effective against an endometrioma, and that the presence of an endometrioma usually means there is endometriosis elsewhere, so if I wanted any relief from the symptoms, I had to have surgery.
I had a laparoscopy in October 2005. The operation lasted for 4.5 hours. Anne found extensive and invasive endometriosis, including on my bowel, bladder, pelvic wall and diaphragm, and an endometrioma in my left ovary. Anne removed all of the endometriosis except the endometriosis on my bowel and diaphragm. Though Anne (gently) suggested I would need more surgery if I wanted complete relief, we tried Zoladex, as I was hoping to avoid bowel surgery (I was frightened by the possibility of a colostomy). Unfortunately the Zoladex didn’t alleviate my symptoms, and the side-effects were awful: hot flushes, night sweats and severe dizziness. I had my most recent laparoscopy on 16 August 2006. 15 cm of bowel was removed.

I’m REALLY hoping that that is the last of the surgery, and now that FINALLY all the endometriosis is gone I will have NO SYMPTOMS!! I’ve had enough!!

2 Disdain
2.1 Many examples, unfortunately
I have found that one of the most difficult aspects of having a serious medical condition (especially when I hadn’t been diagnosed and was searching desperately for an answer) is dealing with the medical profession. I turned to these people for help, when I was suffering a great deal and was at my lowest ebb, and I was treated very badly. I was subjected to the whole spectrum of poor behaviour: indifference, rudeness, contempt and insults. The following are some examples of the way I have been treated.

With indifference
I felt that I was not being listened to by many doctors. I often felt that they didn’t take my description of my symptoms seriously (I was never actually told by a GP that I was exaggerating my symptoms or that I had a psychological problem, but that is the impression that some gave).

Very rudely
I had a pelvic ultrasound before diagnosis in 1994. I was in a great deal of pain (I had to drink about 3 litres of water before the ultrasound, and hold it). I told the person at the counter about my pain, as I felt that I couldn’t hold the liquid for much longer. When the person who took the ultrasound saw me she said (very nastily) ‘oh, the lady with the full bladder’. I explained that that wasn’t my problem, that in fact I was in a great deal of pain. She ignored my comment.
When she was taking the ultrasound I asked if she could see anything, and she was extremely rude and abrupt.

**With contempt**
The example that I mentioned above, of the specialist who performed the late 1994 laparoscopy ie “you've got plenty of scar tissue but no 'fresh' endometriosis, what's the matter with you?”

**Being insulted (while conscious)**
As recently as June 2005 I was told by a specialist at a specialty endometriosis clinic (I saw him because the wonderful Anne Sneddon was on maternity leave, and I was getting desperate) that “of course, it (my symptoms) could be psychological”. I was absolutely stunned by this comment. I had asked the doctor whether the symptoms I was experiencing could be due to something other than endometriosis, particularly given the change in the nature and severity of the bowel symptoms. He mentioned bowel disorders, then stated “and of course it could be psychological”. I was absolutely stunned by that comment, and said something like "I don't think so, doctor, the pain is worse with bleeding”.

His comment was extremely offensive. By making that statement, he was denying the reality of the symptoms I was experiencing. He was effectively saying that he didn’t believe me. I travelled interstate to see him after months of severe pain and other unpleasant symptoms. I would not have gone to the expense and trouble of travelling interstate if I was not desperate. And to then be told that my symptoms "could be psychological"! The verbal equivalent of a slap in the face. There is no way that a doctor-patient relationship could be established after that.

Not only was the doctor’s comment offensive, it was inappropriate. When I saw him I hadn’t read Dr Susan Evans’ excellent book, Endometriosis and other pelvic pain (Lothian Books 2005). She devotes a whole chapter to causes of pelvic pain other than endometriosis (not one of which is 'psychological'). Indeed, she states "I find that most women with endometriosis have more than one cause for their pain.” (at p 37). So to suggest a psychological cause before exploring other possible causes of pelvic pain is surely not good clinical practice. Any suggestion that a patient’s complaint is psychological should be made only after all physical causes have been excluded, not 10 minutes after first meeting the patient.
The doctor also used a hectoring tome throughout the consultation. I told him that I was reluctant to have more surgery, as I hadn’t reacted well to the anaesthetic after my last surgery. I asked him about the GnRH agonists. The specialist made it very clear that he would not prescribe them to me. I did not question his professional opinion. Of course I respected and valued his professional opinion: he is the specialist. However, I don’t know whether he realised how confronting his delivery of his opinion was. To use a legal analogy, I felt like I was a hostile witness under cross-examination. For example, the doctor mentioned that the GnRH agonists are expensive. He then stated that if I was prescribed Zoladex now, and needed to take it again in the future, “would you be prepared to pay for it?”.

At the end of the consultation the specialist said something about the Hippocratic oath, about doing no harm. The experience was quite upsetting for me, and the failure to establish a doctor-patient relationship delayed my treatment and prolonged my suffering.

He certainly harmed me.

**Being insulted (while unconscious)**

When Anne was operating on me she sought the advice of a surgeon about the endometriosis on my diaphragm. She later told me he said that if I was experiencing symptoms from the endometriosis there, that I had a problem here (he tapped his head), not there (pointing to my diaphragm). When Anne told me that I thought that the medical profession has sunk to a new low: they even insult you when you are unconscious!

**2.2 Finally, a positive experience**

I feel very fortunate to have finally found an extremely competent and very caring specialist, Dr Anne Sneddon. Anne is wonderful. She listens carefully, explains options and respects her patient’s decisions. She is the most committed and sympathetic doctor that I have ever met. The following is just 1 example of Anne’s dedication: after the major surgery that Anne performed in October 2005, she telephoned me at home every day (including weekends) for about 5 days after the surgery to see how I was. She is truly extraordinary.

Anne’s team at the Canberra Hospital is wonderful too. I was very nervous before the surgery, and I remember being reassured and comforted by a lovely
nurse called Melissa Parker. Melissa also looked after me during my surgery and even took the time to visit me in the ward after the surgery to see how I was feeling.

The care and concern shown by Anne and Melissa really made a difference.