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University of Southampton

Faculty of Environmental and Life Sciences

Psychology

Dysmenorrhea and its Impact on the Health-Related Quality of Life of Adolescent Girls.

by

Polly Louise Hardy-Johnson

Thesis for the degree of Doctor of Philosophy

July, 2020

University of Southampton

Abstract

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Thesis Abstract

Dysmenorrhea, more commonly known as period-related pelvic pain, is a highly prevalent complaint among adolescent girls. Previous research has shown that up to 92% of adolescent girls (<18 years) report some form of menstrual pain, which is often poorly managed. Although evidence suggests that dysmenorrhea can have a profound negative impact on many aspects of adolescents' lives, research on this topic is still in its infancy. This work summarises the findings from one systematic review, two empirical qualitative studies conducted with adolescents and mothers, and one quantitative questionnaire study developed to address the gap in the current literature. In-depth, individual interviews were conducted with 20 adolescents (aged 12-18 years) experiencing dysmenorrhea, and 20 mothers of daughters with dysmenorrhea. This explorative research demonstrated that dysmenorrhea can have a profound negative impact on all aspects of the adolescents' health-related quality of life (HRQoL). The adolescents interviewed reported that dysmenorrhea had a negative impact on their psychological, social, physical and school functioning, and well-being. Mothers also reported that dysmenorrhea had a negative impact on many aspects of family functioning, including increased tensions within households and financial implications (e.g., mothers taking time off of work to care for their daughters). Exploratory qualitative methods allowed the adolescents and their mothers to provide detailed accounts of their experiences in their own voices. As a result, several novel findings came from these studies including that, for some adolescents, there was a perceived positive impact of dysmenorrhea. In addition, both sets of interviews showed that there were a variety of misconceptions about the causes and treatments of dysmenorrhea. The findings from the review of the existing literature and two qualitative studies informed the development of a working model whereby psychosocial factors influenced quality of life (QoL) outcomes among adolescent girls experiencing dysmenorrhea. The final, quantitative study of 333 adolescent girls aged 13-18 years showed that perception of other bodily symptoms (β=-.314, p=.000), levels of anxiety (β= -.194, p=.004) and depression (β= -.165, p=.005), usual severity of menstrual pain (β= -.152, p=.013), and pain coping (β= -.103, p=.035) significantly predicted QoL outcomes among adolescents experiencing dysmenorrhea. Family functioning and pain severity of the most recent menstruation did not significantly predict QoL outcomes. As predicted, psychological factors predicted QoL outcomes over and above the severity of pain. These findings can be used to inform the development of psychological interventions to improve QoL outcomes among adolescent girls experiencing dysmenorrhea. The final chapter of this thesis explores the implications of these findings for adolescent girls, their families, health care professionals, and future research.

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Research Thesis: Declaration of Authorship

Print name: Polly Louise Hardy-Johnson

Title of thesis: Dysmenorrhea and its Impact on the Health-Related Quality of Life of Adolescent Girls.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Date: 16.07.2020

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Definitions and Abbreviations

Abbreviation	**Definition**
QoL	Quality of Life
HRQoL	Health Related Quality of Life
ADL	Activities of Daily Living
PMS	Premenstrual Syndrome
HCPs	Health Care Professionals
IV	Independent Variable
DV	Dependent Variable
*M*age	Mean age
SD	Standard Deviation

Thesis Outline

Chapter One

An Introduction to Adolescent Dysmenorrhea

The first chapter of this thesis introduces the biological processes involved in menarche and dysmenorrhea. The aetiology and management (treatment and self-care strategies) of adolescent dysmenorrhea are also discussed. The introductory chapter leads into chapter Two, which introduces biopsychosocial models of paediatric chronic pain to formulate the theoretical basis for the thesis.

Chapter Two

Theoretical Approaches to Understanding the Development, Maintenance and Experience of Paediatric Chronic Pain

This chapter introduces theory from the paediatric chronic pain literature to formulate the theoretical basis for my research. The chapter begins with an introduction followed by a summary of the biopsychosocial approach to how chronic pain is developed and maintained. This is followed by a review of key biopsychosocial models that are used to facilitate understanding of the biological, psychological and social factors associated with paediatric chronic pain. These models are discussed in three sections: (1) Adolescence as a unique point in the lifecourse, (2) family-based theories (including operant-behavioural theory, family systems theories, an integrated model of parent and family factors, and a multifactorial model of parent factors), and (3) psychological functioning and chronic pain (the paediatric fear-avoidance model, the goal pursuit model, the ecological risk-resilience model, and self-determination theory).

Chapter Three

The Impact of Dysmenorrhea on Adolescent Girls' HRQoL: A Systematic Review

Chapter 3 presents a systematic review of empirical research investigating the impact of dysmenorrhea on the health-related quality of life (HRQoL) of young girls (aged <18 years). Conclusions from the review include that the existing research investigating adolescent dysmenorrhea is limited. Despite its high prevalence, unpleasant accompanying symptoms and reports of poor management, no studies have investigated the impact of adolescent dysmenorrhea on the young women experiencing it in England. The findings from the systematic review highlighted the need for further, methodologically rigorous research investigating the impact of dysmenorrhea on the lives of young girls and their families.

Chapter Four

The Methodological Approaches to Investigating Adolescent Dysmenorrhea and Health-Related Quality of Life

This chapter introduces the methodological approaches adopted in this thesis, and justifies the subsequent methods used to investigate adolescent dysmenorrhea and health-related quality of life. This chapter begins with a discussion of the major philosophies and paradigms of scientific research, and offers a rationale for the broad critical realist stance that guided this research. The respective strengths and weaknesses of quantitative and qualitative research are presented, followed by a rationale for taking a mixed-methods approach to the thesis. Finally, this chapter ends with an introduction and rationale for using the specific quantitative and qualitative methods selected and used in the following empirical studies.

Chapter Five

Exploring the Impact of Dysmenorrhea on the Lives of Adolescent Girls

To-date, no studies have investigated adolescent dysmenorrhea in England. Therefore, explorative, data-driven qualitative methodologies were adopted for the first two empirical studies of this thesis. The first used semi-structured interviews to explore the experiences of 20 adolescent girls with dysmenorrhea and its impact on all aspects of their lives. Adolescents reported that dysmenorrhea had a negative impact on all domains of HRQoL including physical, social, psychological and school functioning, and well-being. Adolescents reported that dysmenorrhea had a negative impact on all aspects of their lives. Four themes were identified from the data including: 1) Managing period pain, 2) Period pain is restrictive, 3) Negative emotions associated with dysmenorrhea and accompanying symptoms, and 4) The complexities of managing relationships while experiencing period pain. The girls' help-seeking behaviours were heavily influenced by gender as many were only willing to discuss it with, or seek help from, women. They relied heavily on their mothers while experiencing menstrual pain. The girls reported a negative impact on their physical functioning (e.g., walking, eating, sleeping) and ability to engage in their usual activities. The impact that dysmenorrhea had on their schooling was important to them. Negative emotions were experienced by all. There was a profound sense of anxiety and helplessness surrounding menstruation. Some described catastropising thoughts such as concerns that their pain was not 'normal' and actually a result of some sinister undiagnosed pathology. Finally, the difficulties in navigating relationships with family, peers and school staff due to dysmenorrhea and accompanying symptoms were emphasised by all of the girls.

Chapter Six

Maternal Perceptions of Adolescent Dysmenorrhea and its Impact on Family Functioning

The second qualitative study expanded on the first by exploring maternal perceptions of adolescent dysmenorrhea and its impact on the lives of family members and overall family functioning, from the perspectives of 20 mothers. Three themes were identified from a thematic analysis of the transcribed interviews including: 1) Differences in maternal responses to adolescent dysmenorrhea, 2) The importance of family functioning, and 3) The primary caregiver for issues related to menstruation. Mothers were aware of the negative impact of dysmenorrhea on their daughters' lives all reported a desire to support their daughters to cope effectively. However, there were clear differences in the way in which mothers responded to ther daughters' pain. These responses often fell into two categories: 1) mothers who encouraged their daughters to 'get on with it' and continue with their daily activities despite pain and 2) mothers who were sympathetic and protective in their responses and would often permit avoidance of activities. The importance of family communication was clear in the mothers' reports although gender did have an influence on how members of the family communicated about dysmenorrhea. Adolescent dysmenorrhea had a profound impact on daughters' mood and, in turn, on family functioning. Girls were described as 'unsociable' and 'moody' while menstruating which caused tensions and conflict among family members. Generally, mothers were heavily relied upon to support their daughters through the pain, sometimes sacrificing their sleep and taking absence from work to care for their daughters. This seemed to be a heavy burden on mothers, resulting in a profound negative emotional impact.

Chapter Seven

Psychosocial Predictors of Quality of Life Outcomes among Adolescents Experiencing Dysmenorrhea

The systematic review and two qualitative studies corroborated the findings from the wider chronic pain literature. The findings indicated that dysmenorrhea had a negative impact on all aspects of adolescent HRQoL. Based on these findings and wider reading of the literature, a cross-sectional survey study was conducted to identify a model of psychological determinants of QoL outcomes among adolescents experiencing dysmenorrhea. Data from 333 adolescent girls (13-18 years) experiencing dysmenorrhea were collected on somatisation, coping strategies (e.g., pain catastrophising), pain severity (most recent and usual), family functioning, levels of anxiety and depression, and overall HRQoL. A working model of psychological predictors of QoL outcomes among adolescents experiencing dysmenorrhea has been developed based on these findings whereby levels of depression and anxiety, somatisation, pain catastrophizing, and usual pain severity predict HRQoL outcomes among adolescents experiencing dysmenorrhea.

Chapter Eight

General Discussion

Finally, a general discussion is presented in chapter eight; this began with an overview of the thesis aims, followed by the main findings. A discussion around what the findings add to the existing literature is then presented. This is followed by a discussion of the main findings in relation to some of the biopsychosocial theories presented in Chapter 2. The order of this is as follows: Dysmenorrhea and HRQoL, Dysmenorrhea and emotion, Dysmenorrhea and pain-catastrophising, Dysmenorrhea and somatisation, and Dysmenorrhea and family functioning. Finally, the key strengths and limitations of the research, along with ideas for future research and interventions is discussed.

Chapter 1 An Introduction to Adolescent Dysmenorrhea

1.1 Dysmenorrhea

Dysmenorrhea is the most common gynaecological complaint of adolescent girls (Iacovides, Avidon, & Baker, 2015; Klein & Litt, 1981). It is a condition characterised primarily by recurrent, crampy, lower abdominal pain during menstruation (Sager & Laufer, 2013). Other unpleasant symptoms associated with dysmenorrhea include nausea, vomiting, loss of appetite, headaches, backache, diarrhoea, flushing, sleeplessness, and weakness (Harel, 2006). Dysmenorrhea can be categorised as primary or secondary, with primary dysmenorrhea being the most common type found in adolescents (Klein & Litt, 1981).

Individuals are diagnosed with primary dysmenorrhea when they experience symptoms without any pelvic abnormalities and have a normal ovulatory cycle (Lefebvre et al., 2005). The causes of primary dysmenorrhea are not fully understood, although mechanisms such as myometrial hypercontractility (MH) (intense contractions of the uterus) and arterioral vasoconstriction (AV) (constriction of the arteries) are thought to contribute to menstrual pain (Akerlund, 1994). Factors associated with MH and AV include an excessive secretion of prostaglandins (Tzafettas, 2006) and vasopressin (Akerlund, 1994; Alvin & Litt, 1982; Tzafettas, 2006) which are muscle contractants initiated in the uterus during menstruation. Other possible contributors to menstrual pain include oxytocin, via oxytocin receptor immunoreactivity, which may promote the production of prostaglandins (Nie, Liu, & Guo, 2010), and increases in innervation of the endometrial and myometrial layers of the uterus (Aguilar & Mitchell, 2010). Although these factors are associated with dysmenorrhea, more research on uterine contractility is needed (Aguilar & Mitchell, 2010) to fully understand the mechanisms behind menstrual pain. In contrast to primary dysmenorrhea, secondary dysmenorrhea, seen in approximately 10% of adolescents and young adults with painful menstruation, is associated with pelvic abnormalities including reproductive tract abnormalities, abscesses, pelvic inflammatory disease, and endometriosis (the presence and growth of endometrial glands and stroma outside of the uterine cavity) (Harel, 2006).

When girls first present dysmenorrheic symptoms to their health care professional, the initial treatment approach for both primary and secondary dysmenorrhea is often the same. In terms of pharmacological treatment, non-steroidal anti-inflammatory drugs (NSAIDs) are the most common initial treatment for both types of dysmenorrhea (Harel, 2006). In cases where symptoms persist following treatment with NSAIDs, different treatment approaches for girls with primary and secondary dysmenorrhea are required (Harel, 2006). Other pharmacological treatments for primary dysmenorrhea include long-acting progestin-only hormonal contraceptives, whereas treatment for secondary dysmenorrhea often involves invasive surgical procedures (Harel, 2006). For example, laparoscopy is the most common procedure used to diagnose and treat endometriosis whereby visible implants of endometriosis can be removed by laser vaporization (Propst & Laufer, 1999).

Dysmenorrhea is primarily a cyclic pain; however, recurrent nociceptive inputting as a result of painful menstruation is associated with central changes that persist beyond the duration of a period (Vincent et al., 2011). Similarities between women with dysmenorrhea and those with other chronic pain conditions, including suppression of the hypothalamic-pituitary-adrenal axis and increased responses to noxious stimuli, have been reported. For example, lower cortisol responses were found in those who experienced regular menstrual pain, compared to those who did not. These changes were still present in the other phases of the menstrual cycle (without background pain) and occurred in response to stimuli located at different areas of the body than the dysmenorrheic pain suggesting that recurrent painful menstruation could predispose women to develop acyclic chronic pain (Harel, 2006). This notion is supported by (Iacovides et al., 2015) who argue that, as women become more sensitized to painful stimuli as a result of recurrent menstrual pain (Arendt-Nielsen, Madsen, Jarrell, Gregersen, & Drewes, 2014), therefore, primary dysmenorrhea should be re-classified as a central-sensitisation syndrome (Lacovides et al., 2015).

To determine the prevalence and possible correlates of menstrual pain, Klein and Litt (1981) conducted one of the largest adolescent dysmenorrhea surveys, recruiting 7000 noninstitutionalised American adolescents (12-17 years). Of that sample, 2699 were menarcheal girls who reported a high prevalence (59.7%) of discomfort or pain associated with menstruation. Of those 59.7% who reported pain, 14% described the pain as severe, 37% as moderate, and 49% as mild. The prevalence of dysmenorrhea increased with age (39% of 12 year olds and 72% in 17 year olds) and sexual maturity (38% in adolescents at tanner stage three and 66% at tanner stage five). More recent studies have reported similarly high prevalence rates of dysmenorrhea (55-85%) among adolescent girls (Banikarim, Chacko, & Kelder, 2000; Strinić et al., 2003). However, in the Klein and Litt study only 29% of those reporting severe pain and 14.5% of the entire sample had sought medical help (Klein & Litt, 1981). It appears that although dysmenorrhea prevalence rates are high, many young girls do not present their symptoms to medical professionals. This may be due to the fact that, unlike other recurrent or chronic pain conditions, pain during menstruation is often seen as a normal occurrence (Wong, 2011b).

As girls do not report their pain to HCPs, dysmenorrhea often goes undiagnosed and therefore not treated sufficiently (Proctor & Farquhar, 2006). In addition to not presenting to medical professionals, many young girls with dysmenorrhea are using often ineffective, nonpharmacological methods to relieve their symptoms (Campbell & McGrath, 1999). In a study of 289 school girls (Campbell & McGrath, 1999), nearly all the sample (98%) used only nonpharmacological methods such as heat, rest or distraction to treat dysmenorrhea despite many girls perceiving the efficacy of these methods as low (40%). The combination of under-reporting and reliance on, these ineffective, non-pharmacological methods suggests that dysmenorrhea is poorly managed in the adolescent population and it is therefore unsurprising that numerous studies investigating the impact of adolescent dysmenorrhea on health-related quality of life (HRQoL) found it to have a profound negative impact on various aspects of life (Banikarim et al., 2000; Chaudhuri & Singh, 2012; Gagua, Tkeshelashvili, Gagua, & McHedlishvili, 2013; Klein & Litt, 1981; Nur Azurah, Sanci, Moore, & Grover, 2013).

1.2 Dysmenorrhea and HRQoL

There are a variety of adolescent stereotypes, in particular the media portray adolescents as an egocentric, lazy, promiscuous cohort who engage in risk taking and aggressive behaviours (Bremner, 2017). In addition to this, adolescence is an important time of life, characterised by developmental and cognitive changes (Bremner, 2017). Cognitive functioning including information processing, memory, intelligence, and reasoning, and selective attention develops during the adolescent period. As children transition into adolescence, they are more able to be selective to the types of stimuli (e.g., painful stimuli) that they pay attention to (Bremner, 2017). In addition, social and personality development during adolescence is complex with a dynamic interaction between psychosocial factors. For example, adolescents begin experiencing new emotions and developing a wider social circle. Specifically, adolescence is a time whereby autonomy and self-identity are developing, and individuals form close relationships with their peers (Bremner, 2017).

HRQoL is a multidimensional construct defined as how well an individual functions in daily life and their perceived well-being, encompassing physical, social, and psychological functioning, and well-being (Colwell, Mathias, Pasta, Henning, & Steege, 1998; Hays, Anderson, & Revicki, 1993). HRQoL is measured with generic or disease specific instruments which include measures of physical, social and psychological functioning, and many measures require patients to both report their current functioning within those domains and also report how they value their current functioning (Levine, 1987), or their satisfaction with that, compared to how participants would ideally like to be functioning (Levine, 1987). Based on this multidimensional definition of HRQoL, studies investigating the impact of adolescent dysmenorrhea on HRQoL have found limitations in all domains of functioning. Chronic and recurrent pain in childhood and adolescence is associated with difficulties in academic achievement, psychological well-being, and peer and family functioning (Hunfeld et al., 2002; Palermo, 2000). Klein and Litt (1981) found that 14% of adolescents frequently missed school because of dysmenorrhea. Chaudhuri and Singh (2012) reported high rates of sickness absenteeism (25.8%) among school girls due to menstrual cramps, as well as difficulty concentrating and poor school performance. Recent studies have found adolescents with dysmenorrhea to have lower physical functioning compared to adolescent girls with other menstrual problems (Nur Azurah et al., 2013), and significantly higher levels of depression and anxiety compared to healthy controls (Gagua et al., 2013). Beal et al. (2014) carried out a three year longitudinal study to examine the relationship between menstrual symptom reporting and depressive symptoms among adolescent girls. Girls who reported higher levels of depression and somatization were significantly more likely to report menstrual pain and other symptoms across adolescence. Therefore, it appears that dysmenorrhea, with its high prevalence and under-reported, poorly managed symptoms, negatively impacts on every aspect of life among adolescent girls who experience it.

These associations between dysmenorrhea and physical, social and emotional functioning can be explained using a biopsychosocial approach to chronic pain conditions. From this perspective, pain is viewed as a complex and dynamic interaction between biological, social and psychological factors, an approach which has been widely accepted as the most holistic in understanding chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). This approach distinguishes between nociception, nerve stimulation resulting in information about tissue damage being sent to the brain, and pain, a subjective perception resulting from the transduction, transmission, and modulation of sensory information (Gatchel et al., 2007). Many factors can influence nociceptive processing including peripheral and central processing, genetics, cognitions (e.g., expectations, appraisal, attention), conditioning, psychological functioning, emotions, and sociocultural influences (e.g., environmental stressors, cultural factors, social expectations, interpersonal relations, activities of daily living) (Gatchel et al., 2007; Tracey & Mantyh, 2007). Chronic pain can develop when pain-related cognitions, such as catastrophizing, attach to the emotional experience of pain, triggering additional affective reactions. This can amplify the perception of pain and result in a perpetuated cycle of nociception, pain, distress and disability (Gatchel et al., 2007). Therefore, a developmentally appropriate, biopsychosocial approach, which takes into account all factors that might be associated with menstrual pain, should be accounted for when in investigating the experience of adolescent dysmenorrhea.

As with adult pain, paediatric chronic pain is a biopsychosocial construct, experienced uniquely through the dynamic interaction of the factors previously discussed (Gatchel et al., 2007; Rajapakse, Liossi, & Howard, 2014). Studies investigating both adult women and premenstrual girls have found that menstrual attitudes and beliefs are culturally and socially constructed (Anson, 1999; Marván, Vacio, & Espinosa-Hernández, 2003), and that adult women of varying cultures and ethnicities differ in menstrual symptom reports (Anson, 1999; McMaster, Cormie, & Pitts, 1997; Van Den Akker, Eves, Service, & Lennon, 1995). For example, a study of adult women found that menstrual attitudes and premenstrual experiences were influenced by premenstrual symptoms in women family members and messages received about menstruation during adolescence (Anson, 1999). Specifically, women who had a more traditional upbringing were more likely to perceive menstruation as a debilitating event and, as a result, reported more severe menstrual and premenstrual experiences. Finally, studies of adolescent dysmenorrhea have found that ethnicity influences both the prevalence of dysmenorrhea and its impact on school absenteeism (Banikarim et al., 2000; Klein & Litt, 1981). This suggests that culture may influence the meaning of menstrual pain and the way in which menstrual symptoms are treated (Banikarim et al., 2000). Therefore, as opposed to a biomedical approach, a more holistic, biopsychosocial model should be adopted to fully understand what causes adolescent dysmenorrhea, how it is maintained, and what impact it has on the lives of young girls.

Dysmenorrhea is a highly prevalent, recurrent experience, characterised by pain, associated with unpleasant accompanying symptoms, poorly diagnosed and managed, with an association to increased sensitivity to painful stimuli. A scoping search of the literature has indicated that the impact of adolescent dysmenorrhea in the UK is under researched, having been largely neglected (more detail on this is provided in chapter two); although, evidence from the wider chronic and recurrent pain literature show that pain in childhood and adolescence is associated with difficulties in school functioning, academic achievement, psychological well-being, and peer and family functioning (Hunfeld et al., 2002; Palermo, 2000). Therefore this thesis aims to explore the impact of dysmenorrhea on all aspects of the lives of adolescents living in England, UK. To address this question, the first study of this four study thesis aimed to identify and review the existing literature investigating the impact of adolescent dysmenorrhea on HRQoL, and provide a rational for the further three studies of this thesis.

1.3 The Overarching Aims of this Thesis

1. To identify and review the existing literature investigating adolescent dysmenorrhea and health-related quality of life; to identify gaps in the existing literature and make recommendations for research (chapter three).

2. To use qualitative methods to explore adolescent dysmenorrhea and its impact on all aspects of life, from the perspectives of adolescents themselves (chapter five).
3. To explore maternal perceptions of adolescent dysmenorrhea, its impact on their daughters' lives, and its impact on family functioning (chapter six).
4. To develop a working model of the psychosocial predictors of health-related quality of life among adolescents experiencing dysmenorrhea (chapter seven)

To consider the implications of the working model developed in chapter seven for future work and interventions (chapter eight).

Chapter 2 Theoretical approaches to understanding the development, maintenance and experience of paediatric chronic pain.

2.1 Introduction

Dysmenorrhea, characterised by recurrent abdominal pain during menstruation (Sager & Laufer, 2013), shares many similarities with chronic pain disorders (Berkley, 2013). The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”, with chronic pain lasting for three months or more (Kumar & Elavarasi, 2016; Merskey, 1994). Although dysmenorrhea is normally a cyclic pain, recurrent painful menstruation could predispose women to develop acyclic chronic pain (Harel, 2006). As there are no existing theoretical models currently aimed at facilitating understanding of adolescent dysmenorrhea, this chapter considers the theoretical underpinnings of this research from the paediatric chronic pain literature to inform this thesis. This chapter begins with an introduction to the overarching biopsychosocial model of adolescent chronic pain. This is followed by a review of key models which are used to facilitate understanding of the biopsychosocial factors associated with paediatric chronic pain. This theory is discussed in three sections of the chapter: 1) adolescence as a unique point in the lifecourse, 2) family-based theories (including operant-behavioural theory, family systems theories, an integrated model of parent and family factors, and a multifactorial model of parent factors) and 3) psychological functioning and chronic pain (the paediatric fear-avoidance model, the goal pursuit model, the ecological risk-resilience model, and self-determination theory).

2.2 An introduction to the biopsychosocial model of chronic pain

Historically, research has taken a dualistic approach to chronic pain, favouring a biomedical approach to understanding its development and maintenance (Melzack & Wall, 1965). Pain was seen to be a result of tissue damage, until it became clear that the severity and duration of pain is rarely directly proportional to the extent of injury (Gatchel et al., 2007). This began to change in 1965 when the first biopsychosocial model, gate control theory, represented the interrelation of both biological and psychological factors in the experience of chronic pain (Gatchel et al., 2007; Pillai Riddell, Racine, Craig, & Campbell, 2013). The gate control theory was first model which aimed to explain: a) the variability in the relationship between an injury and the severity and duration of pain experienced; b) how non-noxious stimuli can result in pain; c) differences between the location of pain and tissue damage; d) pain remaining after injured tissue has healed; e) the nature and location of pain can change; f) pain is multidimensional; and g) limited effective pain treatments. The gate-control theory proposes that the experience of pain is a result of multiple factors including sensory, cognitive and motivational features. This model posits that a neurological mechanism acts as a 'gate' that either inhibits or facilitates transmission of pain from nociceptive input to the brain. Psychological variables such as anticipation of pain and attention are thought to contribute to the 'opening or closing' of this gate, therefore having an influence on pain experience (Melzack, 1996). Since the publication of the gate control theory, models have been developed which include a variety of psychological and social factors (Pillai Riddell et al., 2013). These models aim to improve understanding about how paediatric chronic pain develops, what influences its maintenance, and how children and adolescents experience it (Pillai Riddell et al., 2013). Recent research aims to view chronic pain from a biopsychosocial perspective, considering the interrelation between biology, psychology and the social environment in the development, management and maintenance of chronic pain (Liossi & Howard, 2016).

Paediatric chronic pain is a complex phenomenon. The importance of various environmental, cultural, familial and individual factors have led to the development of many conceptual models that aim to explain the biopsychosocial factors associated paediatric chronic pain (Pillai Riddell et al., 2013). Many of the more recent models that will be reviewed in this chapter have developed from the operant model of pain and social learning theory. The operant model of pain has been used in previous research to explain the influence of the environment on a child's response to pain and development of chronic pain (Turk, Flor, & Rudy, 1987). Research into the operant model of pain introduced the notion that environmental responses (e.g., parental responses) to a child's pain can either negatively or positively reinforce increased pain behaviours (e.g., crying) (Turk et al., 1987). For example, parental reinforcement such as attending to their child's pain behaviours with increased affection, attention or enabling school-absenteeism has been associated with increased pain behaviours in children (Walker & Zeman, 1992). There are gaps, however, in what an operant model approach to pain can explain (Pillai Riddell et al., 2013). For example, unlike social learning theory, the operant model does not consider other forms of learning associated with chronic pain. Social learning theory provides a perspective of the wider influences on children's learned response to pain by proposing that children learn by observing and then modelling what they have observed from their social context (Bandura & Walters, 1977). From this perspective, children can learn certain pain behaviours by observing and modelling others in their social environment. Previous research supports this model by showing that children often model the pain behaviours of their parents (Chambers, Craig, & Bennett, 2002). The operant model of pain and social learning theory were the basis of many of the biopsychosocial models of paediatric chronic pain which is considered the most heuristic approach to chronic pain (Gatchel et al., 2007).

2.3 Biological, psychological and social factors associated with paediatric chronic pain

Models of paediatric chronic pain need to include all of the possible biopsychosocial determinants (Hadjistavropoulos et al., 2011). Viewing chronic pain through a biopsychosocial lens can help us to understand the multiple factors associated with pain, while integrating them and considering the relationships between them (Gatchel et al., 2007). A good example of an inclusive biopsychosocial model is one developed by Palermo (2012) which extended an earlier family-bassed model (Palermo & Chambers, 2005) (see section 2.4) to develop an overarching conceptual framework of paediatric chronic pain and disability which includes biological, psychological and social factors in the context of development and family influences. This comprehensive model considers the biological processes involved in chronic pain including a child's physiological development, genetic factors, central nervous system functioning, sex and pubertal status. The psychological factors include individual beliefs, coping, mood, anxiety and fear. Finally, the social factors in this model include socioeconomic status, school environment and the healthcare environment. The model also acknowledges the role of health habits in paediatric pain and disability. This model proposes interrelations between the biological processes, psychological and social factors nested within the psychological context of the child which are nested within social contexts (Palermo, 2012; Pillai Riddell et al., 2013).

Integrative models of paediatric cchronic pain are not as well formed as those for acute pain. Therefore, to better understand the interplay of biological, psychological and social processes involved in paediatric chronic pain it is important to review additional theories and models to generate more specific research questions and hypotheses. The most significant limitation of the existing biopsychosocial models is how little is known about the developmental changes that occur through childhood and adolescence in relation to chronic pain (Pillai Riddell et al., 2013). All existing models acknowledge the importance of development; however, research exploring how biopsychosocial factors associated with chronic pain change/ interact differently throughout childhood and adolescence is sparse (Pillai Riddell et al., 2013). Therefore, a developmental perspective is considered in the following section, highlighting adolescence as an important and unique time in the life course.

2.4 Adolescence as a unique point in the lifecourse

Chronic pain and pain-related disability has been found to be more prevalent in adolescents than other age groups (Roth-Isigkeit et al., 2005). This may be a result of key developmental changes that occur during adolescence including pubertal development (e.g., reaching menarche). A critical gap that has been identified in biopsychosocial models of paediatric chronic pain is the lack of specific attention to developmental factors in biological, behavioural, and social functioning (Pillai Riddell et al., 2013). Biopsychosocial factors are important in understanding development; however, the salience of those biological, psychological and social factors change throughout the life course (Sameroff, 2010). For example, the significance of social-cultural contexts and familial relationships change as children and adolescents enter different new spheres of influence such as secondary school, college and university (Sameroff, 2010). Adolescence, specifically, is a unique time, unlike any other in the life course. From a historical point of view, adolescence starts with the commencement of puberty, and ends with transitions into marriage and parenthood (Feldman & Elliott, 1990; Patton et al., 2016). However, more recently the definition of when adolescence begins and ends is less consistent, with varying definitions. Adolescence is now commonly defined based on the adoption of responsibilities and stereotypically ‘adult’ behaviours. This includes becoming employed and financially independent, in addition to forming serious personal relationships. To add more complexity, these typically ‘adult’ behaviours differ significantly depending on context and culture (Patton et al., 2016). In this thesis, the World Health Organization’s (WHO) definition of adolescence as between the ages of 10 and 19 years was adopted. The age range (12-18 years) for recruitment of adolescent participants in this study was based on both the average age of adolescents having reached menarche and on the fact that adolescents were recruited through secondary schools.

Adolescence is a time of considerable behavioural, cognitive, and physiological development (Blakemore, 2019; Blakemore & Choudhury, 2006). This transition from childhood to adulthood is characterised by dramatic changes in identity, self-consciousness, and cognitive flexibility (Rutter & Rutter, 1993). This increased neuroplasticity makes adolescence an important time for learning health-related behaviours (Blakemore & Choudhury, 2006), including pain responses or coping strategies. However, ‘adaptive’ behaviours that are conducive to health improvement are not always easily learnt during this time. In adolescence, specific neurological and brain matter changes occur which map onto certain behaviours commonly associated with the adolescent period (Blakemore & Choudhury, 2006). Puberty represents a time of synaptic reorganisation and as a result, the brain may be more sensitive to experiential input at this period of time in the realm of executive function (the ability to control and coordinate our thoughts and behaviours) and social cognition (Blakemore & Choudhury, 2006). This may provide some explanation for why adolescence is a period of peak risk taking behaviours (including sensation seeking and impulsive action). Specifically, adolescence is associated with increased incidence of unintentional injuries, violence, substance abuse, unintended pregnancy, and sexually transmitted diseases (Casey, Getz, & Galvan, 2008). Thus, as adolescence is a time when new behaviours can be easily learned alongside a tendency to engage in risk-taking and unhealthy behaviours, it is important to understand how to engage adolescents in appropriate pain-coping strategies and other health behaviours.

Increased autonomy and/or emotional separatedness from parents is achieved during adolescence (Palermo, Valrie, & Karlson, 2014). In addition, peer influence becomes increasingly important during adolescence. Adolescents display a far greater sensitivity to the presence of their peers, viewing the impact of their behaviours to their social reputation as highly important (Patton et al., 2016; Somerville, 2013). Adolescence is the time in which an individual establishes the social, cultural, emotional, educational, and economic resources to maintain their health and wellbeing throughout their lives (Engström, 2008). Research has shown that adolescents value their relationships and time with their peers over and above that of their family (Patton et al., 2016). For adolescents, peer influences on health and wellbeing are greater than at any other time in the life course (Resnick, Catalano, Sawyer, Viner, & Patton, 2012; Steinberg & Monahan, 2007). This sensitivity to peers in decision making is often targeted by teen-oriented entertainment and marketing. In this way the media, particularly social media, shapes attitudes, values, and behaviours in this age group more than any other (Brown, Halpern, & L'Engle, 2005). This highlights the salience of an adolescents' social world in relation to health and illness. Previous research has shown that chronic pain has a profound impact on an adolescent's social world, and that peers can have a significant influence on pain management behaviours. Finally, these are foundational years whereby much of an individuals' future relationships, health behaviours, employment and future parenthood are decided (Lloyd, 2007; Patton et al., 2016). Due to the high prevalence and poor management of dysmenorrhea outlined in Chapter 1, it is important to understand the ways in which developmental factors, including family factors are related to the experience of adolescent dysmenorrhea.

2.5 Family-based theories

Family-based models of paediatric chronic pain

Despite growing autonomy during adolescence, families (particularly parents) play a critical role in the development, maintenance and experience of chronic pain. Although peers are highly valued during adolescence, families provide the primary structure within which children are born, grow, and develop (Elzakkers, Danner, Hoek, Schmidt, & van Elburg, 2014; Patton et al., 2016). Families are an important context for understanding, assessing, and managing paediatric chronic pain (Chambers et al., 2002). The association between the family and paediatric chronic pain is complex and bidirectional in nature. Previous research has shown that paediatric chronic pain can have a profound impact on family life, including parental burden, stress, and emotional impact (Hunfeld et al., 2001). In addition, parental characteristics are associated with the experience of paediatric chronic pain. These parental factors include parenting style and pain responses (Connelly, Bromberg, Anthony, Gil, & Schanberg, 2017), psychological functioning (Campo et al., 2007) and parental chronic pain (Campo et al., 2007). There are both complex interactional processes and individual factors that predict children's and parent's emotional, cognitive, and behavioural responses to pain which influences the child's overall functioning (Palermo & Chambers, 2005; Palermo et al., 2014). In exploring the familial factors associated with paediatric chronic pain, operant behavioural and family systems frameworks have been used to explore social learning factors and family functioning related to children's pain-related behaviours (Palermo & Chambers, 2005), both of which are discussed in this section. An integrated model combining both operant and family systems theories is then presented, followed by a recently proposed multifactorial model of parent factors in paediatric chronic pain.

Operant-behavioural theories

Operant-behavioural theories are centred on the role of social reinforcement in maintaining maladaptive pain behaviours (Fordyce, Shelton, & Dundore, 1982). Operant models were first used to explain and treat adult chronic pain (Fordyce, 1976) but have since been used to treat paediatric pain by reinforcing adaptive pain behaviours (Sanders, Shepherd, Cleghorn, & Woolford, 1994). Research on operant models of paediatric pain have shown that families play a major role in positively and negatively reinforcing pain behaviours, which are key to understanding how pain responses develop and are maintained (Turk et al., 1987). For example, parents who respond to their children's pain by allowing them to avoid certain activities are reinforcing pain behaviours. This is associated with lower pain-related functioning (Walker & Zeman, 1992).

Parental catastrophizing may lead to parental reinforcement of a child's maladaptive pain behaviours. Pain catastrophizing is a cognitive process categorised by rumination, magnification, and helplessness (Sullivan, Bishop, & Pivik, 1995). Previous research has shown that high levels of parental anxiety and catastrophising about chronic pain are associated with more protective responses to their child's pain (Logan, Simons, & Carpino, 2012; Stone, Bruehl, Smith, Garber, & Walker, 2018). Moreover, protective responses are associated with increased paediatric pain, functional disability and children's depressive symptoms (Claar, Guite, Kaczynski, & Logan, 2010). Often, high levels of catastrophic thinking around pain is associated with emotional distress which predicts protective responses in families experiencing paediatric pain. Protective responses may be characterised as restricting their child's engagement with activities that they think will worsen the pain (Caes, Vervoort, Eccleston, Vandenhende, & Goubert, 2011).

Through observation and modelling, children often learn to catastrophise about pain from their parents. Paediatric pain catastrophising is also related to maladaptive coping strategies, including avoidance (Simons, Sieberg, Carpino, Logan, & Berde, 2011). They may adopt these pain-related catastrophic thoughts and the subsequent 'escape behaviours' as their own. Research has also suggested that both positive (provision of emotional support) and negative (punishing) parental responses (Vervoort, Eccleston, Goubert, Buysse, & Crombez, 2010) to their children's pain has been associated with children pain catastrophizing themselves. Children who catastrophise about their pain tend to focus on negative information about their pain experience and functioning (Sullivan et al., 1995). From this perspective, exploring the role of pain catastrophising among both parents and children may provide insight into concomitants of parental overprotectiveness and reinforcement of maladaptive pain behaviours in (Caruso, Grolnick, Rabner, & Lebel, 2019).

Family systems theories

In contrast, family systems theories such as the McMaster model of family functioning (Epstein, Bishop, & Levin, 1978), emphasize an individuals' behaviour within the context of their family situations. For example, these models might investigate the child's response to pain within the context of the overall family environment and functioning. Family systems theories describe families as a *'fully interactive collection of subsystems, where changes in one system influence changes in all others'* (Guite, Russell, Homan, Tepe, & Williams, 2018). For example, a child's chronic pain condition may negatively influence a parent's mental health which in turn may influence parent-child communication and the child's overall chronic pain outcomes. Family functioning is usually assessed in five areas: family organisation, cohesion, communication, affective environment, and problem solving (Liossi & Howard, 2016). Families that are considered to be functioning poorly are therefore disorganised, lack cohesion, find it difficult to communicate clearly, and express conflict in response to a stressor (Liossi & Howard, 2016). Family systems theories have been used to inform paediatric chronic pain interventions by targeting dysfunctional patterns and communicating within families (Palermo, Valrie, & Karlson, 2014). Many adolescents and children experiencing chronic pain report disturbances in family functioning, which is also associated with worse physical and psychological functioning. Previous research has found significant differences in family functioning between families with children/adolescents with and without chronic pain. Specifically, poorer family functioning was associated with increased disability and increased likelihood that chronic pain would continue throughout childhood and adolescence, and into adulthood (Wickrama, Conger, Wallace, & Elder Jr, 2003). Overall, families of children with chronic pain generally report poorer family functioning than healthy populations. Family functioning is thought to negatively influence paediatric chronic pain outcomes, over and above pain intensity (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010).

Integrative model of parent and family factors in paediatric chronic pain and associated disability.

This integrated model conceptualising family factors in paediatric chronic pain developed by Palermo and Chambers (2005) is the predecessor to the guiding conceptual model for understanding paediatric chronic pain and disability (Palermo, 2012). Palermo and Chambers (2005) combined the operant and family systems theories into an integrative framework for research on the role of parent and family factors in children's pain. This model aims to improve understanding of the influence of both parent and family factors in paediatric chronic pain through investigating how factors at three different levels, individual parenting level (parenting style, reinforcement), dyadic (quality of parent-child interactions), and family level (global family environment and family functioning), can influence children's pain and disability. This model presents the various levels at which the familial factors can be assessed.

This model demonstrates the complex nature of the relationship between the family and paediatric pain. The model highlights the reciprocal influence of the pain itself and its accompanying levels of disability, as well as child and/or parental factors (e.g. child age, gender, parental pain history), in interacting with the family at all three levels: individual, dyadic and family. Importantly, these relationships are situated in a developmental context. It is proposed that different family variables are important to consider in correspondence with the age and developmental status of the child, therefore addressing the gap presented by previous biopsychosocial models which overlooked development.

A unified model of parental factors

Finally, a recent publication has presented a newly developed, unified model of parental factors which are usually investigated separately (Cordts, Stone, Beveridge, Wilson, & Noel, 2019). This model assesses the interrelation between parental factors, paediatric pain and psychological functioning (Cordts et al., 2019). Interestingly, and in contrast to previous work (Vowles, Cohen, McCracken, & Eccleston, 2010), parental responses were not found to be associated with paediatric pain (Cordts et al., 2019). Parental factors that were investigated included chronic pain (pain frequency, location of pain, pain intensity and chronic pain status), physical function (pain interference and physical function) and psychological factors (catastrophising, anxiety and levels of depression) (Cordts et al., 2019). Based on previous operant and integrated models of paediatric chronic pain, family-based interventions have focussed on addressing parental responses to their child's pain. However, this model suggests that parental responses may not be a key influence on children's chronic pain, functioning, or psychological well-being (Cordts et al., 2019). Instead, interventions should target parental chronic pain outcomes and physical and psychological functioning. However, more research with different populations is needed to test this model further.

2.6 Psychological Functioning and Chronic Pain

It is well established that mental health conditions and chronic pain often coincide (Gatchel, 2004). From a biopsychosocial perspective, poor psychological functioning can be both a contributor to paediatric pain and disability, and occur as a result of persistent pain (Liossi & Howard, 2016). Moreover, bidirectional relationships have been found between children's cognitions (e.g., their beliefs about chronic pain) and levels of pain and disability. A commonly cited example of this is the bidirectional relationship between pain catastrophizing, pain and disability, and health-related quality of life outcomes (Tran et al., 2015). Although psychological factors are known to be important in the development, maintenance and experience of paediatric chronic pain, few models focus on understanding the role of psychological factors. In this final section of the chapter, key psychological models of paediatric chronic pain are reviewed, beginning with the well-established paediatric fear-avoidance model of chronic pain (Asmundson, Noel, Petter, & Parkerson, 2012). Following this, the goal pursuit model of chronic pain and the ecological risk-resilience model of paediatric chronic pain are described. Finally, self-determination theory is presented as a way of building on these models, while including a developmental perspective in psychological models of paediatric chronic pain.

The paediatric fear-avoidance model of chronic pain

As a key guiding framework for research in chronic pain, the fear-avoidance model (FAM) of chronic musculoskeletal pain explains why and how people who experience a painful injury might develop a chronic pain syndrome (Vlaeyen & Linton, 2012). It should be noted that fear of pain and pain-related anxiety are two distinct constructs. Fear of pain is conceptualised as a response to an immediate pain-related threat (e.g., initiating a painful activity), and pain-related anxiety is a response that occurs in anticipation of pain-related threat (e.g., expecting an activity to be painful) (Asmundson et al., 2012). FAM posits that both pain related fear and anxiety influence the development and maintenance of disabling musculoskeletal chronic pain (Asmundson et al., 2012; Leeuw et al., 2007; Vlaeyen & Linton, 2012). Appraisal of a painful experience (such as an injury) is thought to play a role in the development of chronic pain. Pain catastrophising in response to a painful injury often leads an individual to experience both fear of pain and pain-related anxiety (Leeuw et al., 2007). This anxiety has the potential to spiral into a self-perpetuating cycle that results in avoidance, functional disability, depression and additional pain and catastrophizing (Asmundson et al., 2012). FAM has developed since its inception, with three adaptations taking place. One adaptation, named the interpersonal fear avoidance model of pain (IFAM), saw the inclusion of interpersonal (e.g., including relationships between family members) and contextual variables (e.g., school-related variables) (Goubert & Simons, 2013).

The adult FAM of chronic pain (Asmundson et al., 2012; Leeuw et al., 2007; Vlaeyen & Linton, 2012) has been adapted to account for the unique aspects of paediatric chronic pain (Asmundson et al., 2012). The Paediatric FAM of chronic pain represents both child and adolescent, as well as parental, factors and potential effects of interactions between these groups (Asmundson et al., 2012). Adaptations of the original model include the recognition of distinct fear/escape and anxiety/avoidance pathways, and the expansion of possible influences of psychological factors. In addition, the adapted model recognises the bidirectional association between child and parental factors. Specifically, parental factors including management behaviours (e.g., protectiveness) and psychological responses (e.g., pain catastrophising) are considered to influence child pain responses. FAM suggests that one way to escape the 'spiral' of fear and avoidance is to engage in important personal goals which can lead to recovery (Riggenbach, Goubert, Van Petegem, & Amouroux, 2019). This has led to the development of the next model to be described in this section.

The goal pursuit model of paediatric chronic pain

Although the FAM has guided paediatric pain research and clinical practice, this model emphasises maladaptive behaviours and activity avoidance in paediatric chronic pain, without exploring the reasons why some children appear resilient and actively pursue goals despite experiencing pain. The goal pursuit model of paediatric chronic pain (Fisher, Keogh, & Eccleston, 2016; Fisher & Palermo, 2016) provides a new framework for understanding the difference between children who continue to engage in activity versus those who avoid activity when experiencing pain. This model proposes that children's experience of pain is modified by child factors such as the perceived importance of the goal to the child, motivation and energy to pursue the goal, pain-related anxiety/fear, and self-efficacy. The model also posits that parent factors influence pain experience. These parental factors include parental expectations for pain, protectiveness behaviours, and parent anxiety. Both child and parental factors then lead to specific goal pursuit behaviours for example, whether children engage with or avoid pursuit of their valued goals. Goal pursuit in paediatric pain is associated with improved pain and disability outcomes as it is thought to interfere with the downward spiral proposed by the paediatric FAM (Fisher & Palermo, 2016; Riggenbach et al., 2019). However, as this is a new model of paediatric chronic pain, there is limited research to assess its validity and so further evidence is needed to test it further (Fisher & Palermo, 2016).

The ecological risk-resilience model of paediatric chronic pain

It is important to identify the underlying psychological mechanisms associated with resilience (e.g., goal pursuit) in paediatric chronic pain (Riggenbach et al., 2019). If understood, there is the possibility of targeting these mechanisms in future interventions to support the wider paediatric pain population. The ecological risk-resilience model of paediatric chronic pain was recently developed to deepen understanding of resilience (Cousins, Kalapurakkel, Cohen, & Simons, 2015). This model aims to explain the resources and mechanisms that are involved in recovery from disability in paediatric chronic pain (Riggenbach et al., 2019). Within this model, resilience is defined as a person's ability to respond effectively to adversity. Resilience resources are influenced by a myriad of factors, including developmental, social, cultural and environmental factors (Masten, 2001). Individual resilience resources include both practices such as mindfulness and personality characteristics such as optimism (Pielech, 2017). Interpersonal resilience resources are those that are associated with another person and include positive peer relationships and social support from wider family members. Parental resilience mechanisms that might be associated with paediatric chronic pain include parental psychological flexibility such as pain acceptance. In contrast, fears and pain catastrophising (including parental fear and pain catastrophising) are considered as individual risk mechanisms.

Overall, FAM has been a major framework for guiding pain research and management in children and adolescents (Simons & Kaczynski, 2012; Vlaeyen & Linton, 2012). Although FAM, IFAM, goal pursuit model, and the ecological risk-resilience model of paediatric chronic pain explain many of the dynamics involved in the development and maintenance of paediatric chronic pain and disability, as well as factors that might be associated with reduced disability, these models do not include a developmental perspective (Pillai Riddell et al., 2013; Riggenbach et al., 2019). To address this gap, the self-determination theory (SDT) may provide further insight into factors that facilitate goal pursuit across childhood and adolescence (Riggenbach et al., 2019).

Self-determination theory

Finally, a self-determination theory (SDT) perspective of paediatric chronic pain is presented as a way of understanding the psychological processes involved in the development, maintenance and self-management of pain, while including a developmental perspective. SDT (Deci & Ryan, 2008) is a framework for understanding the choices people make without external influence and interference. This framework, similarly to the perspective of positive psychology, presents ways in which individuals' can achieve personal growth and flourishing (Deci & Vansteenkiste, 2004). Specifically, SDT (Deci & Ryan, 2008) is a theory of human emotion that concerns an individual's innate psychological needs which include competence, autonomy, and psychological relatedness. This theory posits that individuals seek to become skilled at particular things (competence). When individuals feel that they have the skills needed to succeed, they are more likely to take actions that will help them to achieve their goals. Individuals also generally have the need to feel related to others (relatedness). This is the desire to want to interact, be connected to, and experience caring for others. Finally, individuals need to feel in control of their own destiny (autonomy), to be causal agents of one's own life. Deci and Ryan (2008) posited that if these universal needs are met, individuals will function and grow optimally. To actualise potential, an individual's social environment needs to nurture these needs. Within this theory, motivation is categorised as extrinsic and intrinsic. People are able to become intrinsically determined when their needs for competence, connection and autonomy are fulfilled. Paediatric chronic pain challenges an individuals' basic psychological needs by impacting competence (e.g., to perform activities of daily living), autonomy (e.g., by needing assistance to perform otherwise individual tasks) and relatedness (by having an impact on peer and familial relationships). This model posits that satisfaction of these key psychological needs are resilience factors that can reduce disability associated with paediatric chronic pain (Riggenbach et al., 2019).

SDT may also provide a perspective that facilitates understanding of paediatric pain self-management as it provides a motivational perspective. This is crucial to exploring the processes underlying children's engagement in health behaviours and the familial environment that might support these behaviours that are important for long-term health. Deci and Ryan (2008) discussed different types of regulation (motivation) for engaging in behaviours. These are: 1) external regulation whereby children might adhere to treatment regimen to avoid disappointing parents, 2) introjected regulation where a child might enact a behaviour to avoid punishment, 3) introjected regulation where a child might adhere to treatment to gain approval or avoid guilt and, 4) identified regulation (the most autonomous form of regulation) whereby individuals engage in behaviour out of personal value or perceived importance. A child demonstrating autonomous regulation chooses to engage in behaviours to fulfil their goals (Caruso et al., 2019). SDT (Deci & Ryan, 2008) can provide a framework for understanding how children and adolescents regulate treatment behaviours to manage pain. SDT posits that individuals' behaviours become increasingly self-regulated through the process of internalisation, during which individuals move from regulating their behaviour due to external factors to more autonomous regulation. Environmental factors influence this internalisation process. SDT can help to explain differences in treatment adherence in chronic pain management (Caruso et al., 2019). In Caruso's study, higher levels of maternal autonomy support were significantly related to children's higher treatment adherence. The authors suggested that parenting techniques could therefore improve children's response to pain management, including the introduction of their children in treatment-related problem solving and decision making (Caruso et al., 2019). Parental autonomy support is associated with increased self-determination and likelihood for engaging in health behaviours (Grolnick & Ryan, 1989). This involves parents taking children's perspectives into account, allowing choice and input into decision making and solving problems jointly (Grolnick & Ryan, 1989). In contrast, research has linked parental protectiveness to psychological reactance (rebellious/defensive behaviours) in adolescent community and clinical samples. Therefore, it is important for children experiencing chronic pain to take an active role in managing their health. Early management and engagement with treatment and health behaviours (such as medication adherence, good nutrition, and exercise) sets the stage for good pain management into adulthood (Antonaci et al., 2014).

2.7 Conclusion

Overall, the models reviewed in this chapter highlight the importance of considering the biopsychosocial factors associated with paediatric chronic pain. The evidence strongly suggests that in order to advance our understanding of paediatric chronic pain, and therefore to assess and manage it appropriately, there is a need for comprehensive models that are inclusive of all determinants (Hadjistavropoulos et al., 2011). There are currently no biopsychosocial models of adolescent dysmenorrhea. Although adolescent dysmenorrhea shares many similarities with other paediatric chronic pain disorders there are factors that make dysmenorrhea unique. For example, dysmenorrhea is a regular, cyclic pain associated with menstruation which is often perceived as a ‘normal’ part of womanhood. This therefore suggests the need for an exploration of the biopsychosocial factors associated with adolescent dysmenorrhea. The development of a biopsychosocial working model of adolescent dysmenorrhea would be useful to help improve understanding of girls’s experiences. This review of biopsychosocial models of paediatric chronic pain suggest that future models of adolescent dysmenorrhea need to take into consideration the familial and psychological factors associated with dysmenorrhea. The importance of adolescence as a unique time point in the life course, characterised by transition and the development of autonomy has also been highlighted, along with the crucial role of the family in the paediatric chronic pain. Finally, a review of the FAM, goal pursuit and ecological risk-resilience models emphasised the need for a comprehensive model that considers individual and interpersonal factors associated with paediatric chronic pain. The SDT perspective provides an opportunity to consider the interplay of all of these factors, through a developmental lens. The overarching aim of this thesis was to explore the impact of dysmenorrhea on the lives of adolescent girls. An explorative approach to adolescent dysmenorrhea, using qualitative methods in the early stages, was taken to ensure that all of the possible biopsychosocial determinants were considered. Specifically, the developmental stage of participants and the role of the family were considered when interpreting the data. Both interpersonal and individual factors that emerge from the qualitative data were also considered.

Chapter 3 The Impact of Dysmenorrhea on Adolescent Girls' Health-Related Quality of Life: A Systematic Review

3.1 Introduction

This chapter presents a systematic review of the current empirical evidence investigating the impact of dysmenorrhea on health-related quality of life (HRQoL). This chapter begins with the rationale for conducting a systematic review of adolescent dysmenorrhea, followed by the review methodologies used, the narrative synthesis of 42 included studies investigating the impact of adolescent dysmenorrhea on HRQoL, and a discussion of the study outcomes and implications for future research.

Chronic and recurrent pain is a biopsychosocial construct. Despite evidence that interactions between biological, psychological and social factors are involved in the experience of menstrual pain, existing reviews have focussed on biomedical aspects of adolescent menstrual pain rather than how the experience of pain and other related symptoms impacts on the lives of adolescent girls. Some early reports have briefly commented on HRQoL for example, a very early review Ylikorkala and Dawood (1978) focussed on the aetiology of primary dysmenorrhea in adolescent and adult women. In addition, they produced a short summary of the impact of primary dysmenorrhea on school and work attendance, concluding that overall, post-menarcheal women lost approximately 140 million hours of school and work annually in America. Davis and Westhoff (2001) conducted a systematic review examining the prevalence, associated morbidity, and treatment of primary dysmenorrhea in adolescent girls. This review did briefly address the impact of primary dysmenorrhea based on school and activity participation although other HRQoL aspects were not reviewed. Recently, two review articles have aimed to provide a comprehensive overview of dysmenorrhea and endometriosis in young women (Gagua, Tkeshelashvili, & Gagua, 2012; Harada, 2013). However again, these focussed on biological aspects including aetiology, prevalence, symptoms and management of dysmenorrhea and endometriosis, neglecting the impact that the pain has on the adolescents themselves. Gao et al. (2006) conducted a systematic review investigating the burden of endometriosis, one of the primary causes of secondary dysmenorrhea, on the HRQoL of adults and adolescents. They found that endometriosis was associated with impaired HRQoL, including pain, psychological functioning and social functioning. In addition to the evidence summarised above, this review shows that gynaecological symptoms such as pain have a profound impact on the lives of adolescents.

Despite the evidence indicating that adolescent dysmenorrhea has a negative impact on many aspects of life for adolescents, there has not yet been a comprehensive and systematic review of the literature relating to dysmenorrhea (primary and secondary) and its impact on the HRQoL of young girls (<18 years old). The aim of this systematic review therefore was to investigate, using evidence from the existing literature, what impact primary and secondary dysmenorrhea has on the HRQoL of adolescents (<18 years old).

3.2 Methods

3.2.1 Systematic review protocol

A protocol for the systematic review was developed by the primary researcher following Akers’ (2009) guidelines from the University of York, CRD. The protocol was reviewed by two methodological experts, PhD academic psychologists, and two subject experts, paediatric gynaecologists with a special interest in adolescent dysmenorrhea. The following modifications were suggested and incorporated into the protocol: a) search strategy changes including i) the elimination of MESH headings to be replaced by specific keywords, ii) ordering the search terms consistently throughout and iii) the addition of search terms (i.e. ‘mood’ and ‘affect’), and b) improvements to specific medical terminology used.

The amended protocol was registered to PROSPERO (registration no: CRD42014009998), an international database of prospectively registered systematic reviews. After finalising and registering the protocol, the current review, following the PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009), was conducted.

3.2.2 Search strategy

The studies included in this review were identified through a three-stage search of CINAHL, MEDLINE, EMBASE and PsychINFO databases for articles available in English language between 1960 and 2014. Pre-determined search terms used in the first stage were generated following an initial scope of the literature relevant to adolescent dysmenorrhea and HRQoL.

The key words of articles obtained in the initial search were evaluated for inclusion in a secondary search of the same databases. The secondary search included the additional term "activities of daily living". The final database search of PsychINFO, CINAHL, EMBASE, and MEDLINE was conducted to identify any articles that had been added between June 2014 (when the original search was conducted) and May 25th 2015.

A wider search including a visual scanning of the reference lists from all obtained articles was then conducted. Also, citation searches of three key included studies (Banikarim et al., 2000; Klein & Litt, 1981; Wilson & Keye, 1989) identified in the earlier search stages using PsychINFO, CINAHL, and Google Scholar were conducted. Key papers were identified through discussion with academic supervisors. Citation searches were carried out for these key papers. A search for unpublished articles was not carried out due to resource and time limitations (one researcher was carrying out all searches within a limited time-frame).

Search terms included:

adolescen* OR child OR paediatric* OR pediatric* OR young females OR school girls AND Dysmenorrhea OR endometriosis OR menst* disorders OR pelvic pain OR chronic pelvic pain OR menstrual cycle OR period pain OR painful menstruation AND

quality of life OR health-related quality of life OR QoL OR HRQoL OR well-being OR family function* OR school function* OR school absen* OR school attendance OR academic performance OR social isolation OR social function* OR emotional function*OR physical function* OR psychological function* OR depress* OR anxiety OR affect OR mood OR disab* OR peer relationships

Note. see appendix A & B for full search strategy

3.2.3 Study selection

In order to be eligible for inclusion in the systematic review, each study was required to meet the following inclusion criteria:

1. Available in English Language between 01-01-1960 and 25-05-2015
2. Studies investigating the impact of dysmenorrhea on HRQoL, or its constituent parts.
3. Included a sample of post-menarcheal children or adolescent girls (<18 years old) experiencing primary or secondary dysmenorrhea of any severity.

The following types of study were excluded from this review: randomised control trials (RCTs), other intervention studies investigating dysmenorrhea treatments, studies investigating the impact of another menstrual problem such as premenstrual syndrome which may also include menstrual pain, studies that explored the impact of dysmenorrhea on the HRQoL of adolescents from another person's perspective (such as their parents), grey literature (including theses and conference abstracts), and studies that included both adult and adolescent data, except in cases where adolescent data (<18years) had been provided separately. Studies that either did not report participant's age range, or where the range exceeded 18 years, were included if they met the following criteria: participants must be a) <19.5 years old, b) with a mean and standard deviation (if available) <18 years, and c) recruited from secondary schools. Among samples with which these criteria were met, it can be assumed that very few participants were >18 years.

Before conducting the systematic review, the inclusion criteria were piloted by using them to decide whether a small selection of sample papers should be included in the review (Akers, 2009). This was conducted to ensure that possibly relevant studies were being reliably assessed and interpreted in terms of eligibility (Akers, 2009).

A broad definition of HRQoL which refers to how well individuals function in their daily life and their perceived well-being was adopted (Hays et al., 1993) which included the following domains: Physical, social, psychological, and school functioning and well-being. Reports of actual functioning compared to how participants would ideally like to function were reviewed as an indication of well-being (Ryan & Deci, 2001). Studies that measured any constituent aspects of HRQoL were included. An initial scoping of the literature informed which specific search terms were used to represent HRQoL (see appendix A). Studies that used a wide range of measures were accepted, including generic multidimensional and condition-specific HRQoL instruments.

In terms of measuring paediatric pain, there are three fundamental approaches which include self-report, observational or behavioural and physiological measures (Howard et al., 2008). Self-report is considered the 'gold-standard' measurement of pain however, it could also be useful for researchers to incorporate a composite measure including self-report and a behavioural (behavioural distress, or distress perceived by parent/ caregiver) or physiological measure (physiological arousal resulting from pain) of pain (Howard et al., 2008). However, this is not always practical or feasible and self-report is therefore the most common approach used to measure paediatric pain in research (Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006). Therefore, studies that used self-report, behavioural or physiological measures of menstrual pain were included in this review.

Study selection (See Figure 1) was carried out in two stages (Akers, 2009). During the first stage, all abstracts and titles generated from the initial search were screened. Decisions regarding the inclusion/ exclusion of titles were systematically documented. In the second stage, the researcher screened the full papers identified as potentially relevant in the initial screening stage.

The researchers assessed full papers against the inclusion criteria to increase the reliability of the decision process. Lists of the included and excluded studies and any study eligibility concerns were discussed with the supervisory team.

3.2.4 Search results

The initial search of the electronic databases generated (n=1879) search results. Specifically, (n=199) from CINAHL, (n=911) from MEDLINE, (n=135) from PsychINFO, and (n=634) from EMBASE. A second search of the databases, using the additional search term “activities of daily living” identified a further 15 records. Citation searches identified 636 records. The final updated search to identify articles added to the databases from the initial search in June 2014 to May 2015 produced an additional 222 results (see PRISMA diagram for overall findings). Finally, a visual scanning of the references lists of included studies was conducted, producing 31 possibly relevant articles. After duplicates were removed using EndNote referencing software, 1915 studies remained. Following screening of titles, abstracts and full-text articles, overall 42 studies were deemed appropriate for inclusion (see Fig.1 for details).

3.2.5 Data extraction

Data extraction was carried out with the aim of being as reliable and un-biased as possible (Akers, 2009). A tabulated guide to the data extraction process was developed based on guidance in (Akers, 2009). For each included study, general study information, characteristics, participant demographics and medical characteristics, measures and statistical analysis used, and study outcome and results were tabulated. This format was chosen to ensure that all relevant information was captured and that included studies were assessed in a standardized way.

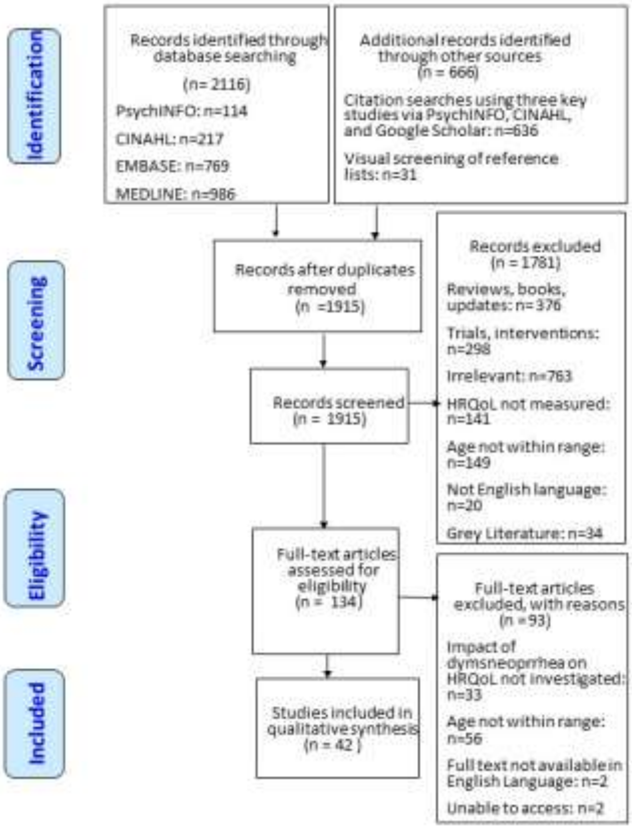


Figure 1 Search strategy flow chart (Moher et al., 2009)

3.2.6 Quality assessment

The methodological quality of the included studies was formally assessed using a 17-item modified version (appendix C) of the Downs and Black checklist for non-randomised studies (Downs & Black, 1998). During the development of the quality assessment tool, questions were modified based on Akers' (2009) guidelines regarding risk of bias in observational studies. Each of the checklist criteria was analysed and evaluated in terms of how well it would meet the requirements of the review in assessing the quality of observational studies reporting the impact of adolescent dysmenorrhea on HRQoL. Following this evaluation, inappropriate checklist criteria were deleted which usually occurred when items referred exclusively to studies investigating the efficacy of an intervention. For example, question 8 of the original checklist was deleted because it referred to any adverse effects that occurred as a result of the study intervention(s). In addition, several original questions were modified to relate specifically to dysmenorrhea and HRQoL. The quality assessment checklist was then piloted and the following modifications were made: a) for question 13, the option 'no data dredging' was included to provide an option for studies that did not use this technique, b) where appropriate, questions were modified to allow for studies that did not use a comparator or control group, c) question 12 was added to give case-control studies more weighting than descriptive studies, d) the option ‘not applicable’ was added to question 17 to give comparative studies more weighting than descriptive studies. All possible answers to each criteria included ‘yes’ and ‘no’. For 5 items there was also the possibility of answering ‘unable to determine’ (UTD). This response indicated that researchers were unable to determine the answer based on limited information provided in the report. One item included the response ‘no data dredging’ which indicated that no data dredging had taken place. Finally, one item included the response ‘not applicable’ which, if marked, indicated that the studies had not attempted to compare results between groups of participants. Each study received an overall quality assessment score and a score for quality in three areas: reporting (scores from questions 1-8), external validity bias (scores from questions 9-15), and selection bias and power (scores from questions 16-17). Higher scores indicate better quality.

Because some items included in the checklist required a degree of subjective judgement, the quality assessment was conducted by myself, the primary researcher (PL) and one supervisor (CL) independently. Any discrepancies in scoring were resolved through discussion. Quality assessment scores for each study were tabulated (appendix E).

3.2.7 Narrative synthesis

Due to the variation in the included studies regarding outcomes reported, measures used, and study type, a narrative synthesis was chosen to summarise the data. To begin with, the researcher read each of the included articles repeatedly until sufficiently familiarised with the content. A three stage version of Popay et al.’s (2006) framework for conducting a narrative synthesis was followed as the first stage of the original framework, ‘theory development’ referred specifically to intervention reviews. Theories of how and why dysmenorrhea impacts on HRQoL however, are discussed and referred to throughout the overall report. The main elements of this synthesis, which were not followed consecutively, included: a) preliminary synthesis, b) exploring relationships in the data and finally, and c) assessing robustness of the synthesis.

A) Preliminary synthesis

In the preliminary synthesis stage, the researcher synthesised the included studies to describe patterns across the studies in terms of direction and size of effects. This stage involved collating, organising, and describing all of the findings. The researcher (PL) produced a brief overview of each included study. This included descriptions of the direction and size of effect of dysmenorrhea on all reported aspects of HRQoL. Thirteen studies singularly investigated the impact of dysmenorrhea on school functioning and were therefore summarised together.

Descriptive information about each included study in terms of design, participants, measures, and HRQoL outcomes was also tabulated (appendix D). Main findings of all primary outcomes including: a) psychological functioning, b) activities of daily living, c) social relationships and activities, d) academic performance, and e) school absenteeism, were then summarised.

B) Exploring relationships in the data

In this stage, relationships within and between all of the studies were explored, patterns emerging from the data during the previous stage were identified, and critical analysis was used to identify factors that might explain any variations in study outcomes. Patterns and characteristics across included studies were described including: a) study design, b) cultural origins, c) recruitment procedures, d) sample age, e) menarchal age, f) accompanying symptoms, g) definitions of dysmenorrhea used, h) prevalence of dysmenorrhea, and i) pain intensity. In the discussion section, differences within these characteristics might help explain variations in HRQoL outcomes were explored.

C) Assessing robustness of the synthesis

In the final stage of synthesis, robustness, in terms of methodological quality and trustworthiness of the narrative synthesis was assessed. As patterns across the study results began to emerge from the previous stage, the researcher interpreted these results to identify factors that might explain differences in size and the direction of effect and to understand why dysmenorrhea might impact on adolescent girls HRQoL. The credibility of the synthesis will depend on both the quality and quantity of the evidence analysed and the method of synthesis and transparency of its description (Akers, 2009). Therefore, the methodological rigour of the included studies and the impact of this on the overall conclusions are discussed.

3.3 Results

This section will begin by describing similarities and differences across all of the included studies in terms of study design, cultural origins, recruitment procedures, participant ages, age of menarche, accompanying symptoms, definitions of dysmenorrhea used, prevalence of dysmenorrhea, and menstrual pain intensity reported. Relevant outcomes of each included study are then summarised followed by a synthesis of all main findings for each aspect of HRQoL affected by dysmenorrhea. Finally, an outline of the quality assessment of included studies is provided, and the relevance of the scores in terms of methodological rigour is briefly discussed.

3.3.1 Overview of the included studies

All of the included studies were cross-sectional and descriptive in nature. Of these, three studies had a case-control design (Alam, Hakimi, Deliana, & Lubis, 2011; Fontana & Rees, 1982; Rapkin, Tsao, Turk, Anderson, & Zeltzer, 2006). Over half of the included studies (n=26) were conducted in non-western cultures. Of those investigating dysmenorrhea in western cultures, studies were conducted in the USA (Banikarim et al., 2000; Dorn et al., 2009; Johnson, 1988; Klein & Litt, 1981; Negriff, Dorn, Hillman, & Huang, 2009; Rapkin et al., 2006; Wilson & Keye, 1989), Australia (Boyle, 1997; Hillen, Grbavac, Johnston, Straton, & Keogh, 1999; Nur Azurah et al., 2013; Parker, Sneddon, & Arbon, 2010), Finland (Teperi & Rimpelä, 1989), Wales (Fontana & Rees, 1982), and Scandinavia (Frisk, Widholm, & Hortling, 1965; Svanberg & Ulmsten, 1981; Widholm, 1979). Most studies recruited girls from educational institutions, whereas others obtained raw data collected from the national centre for health statistics, USA (Klein & Litt, 1981) or recruited from a gynaecology clinic (Nur Azurah et al., 2013), the community (Dorn et al., 2009; Rostami, 2007; Teperi & Rimpelä, 1989), a teen health centre (Dorn et al., 2009; Negriff et al., 2009), and school girls visiting an outpatient clinic for teenagers (Frisk et al., 1965).

The overall ages of participants ranged from 8 to 19 years. There was a large variation however in age range intervals between studies. For example, ages could range from 8-18 (Rapkin et al., 2006), 15-17 (Hillen et al., 1999), 17-18 (Teperi & Rimpelä, 1989), and 10-18 (Deo & Ghattargi, 2007). In some cases, participant age ranges were not reported (Banikarim et al., 2000; Chongpensuklert, Kaewrudee, Soontrapa, & Chuanchom, 2008; Dorn et al., 2009; Fontana & Rees, 1982; Goldstein-Ferber & Granot, 2006; Mohamed, 2012). The decision was made to include these studies in the review for the following reasons: recruitment was limited to secondary school girls only, and the mean age and standard deviation fell within the inclusion criteria. Two studies did not report the mean age or the age range of participants and the decision was made to include these studies based on the fact that the sample were recruited from secondary schools only. Nine of the included studies exceeded the age criteria to 19 years old (Amu & Bamidele, 2014; Dambhare, Wagh, & Dudhe, 2012; Lee, Chen, Lee, & Kaur, 2006; Nwankwo, Aniebue, & Aniebue, 2010; Parker et al., 2010; Santina, Wehbe, & Ziade, 2012; Wong, 2011; Wong & Khoo, 2010). Two further studies exceeded the age criteria (Svanberg & Ulmsten, 1981; Widholm, 1979) although data was provided separately for different participant age groups. The age at menarche also varied widely, overall ranging from 8 to 19 years. Some studies did not report menarcheal age of the participants (Boyle, 1997; Deo & Ghattargi, 2007; Fontana & Rees, 1982; Frisk et al., 1965; Klein & Litt, 1981; Negriff et al., 2009; Nur Azurah et al., 2013; Poureslami & Osati-Ashtiani, 2002; Strinić et al., 2003; Widholm, 1979; Wijesiri & Suresh, 2013; Wilson & Keye, 1989).

Girls reported a variety of symptoms that they experienced in addition to menstrual pain including breast pain/swelling, back pain, tired legs, cold sweats, dizziness, nausea, headaches, vomiting, diarrhoea, constipation, syncope, fainting, sweating, changes in appetite, fatigue, restlessness, constipation, fluid retention, mood change, abdominal bloating, acne, cravings, muscle stiffness, general aches and pains, edema, sleeplessness, flushing, and weakness. None of the included studies however, reported the incidence of all of these accompanying symptoms within a sample.

Of the studies that defined dysmenorrhea, a variety of different definitions were used. For example, some authors used a detailed definition which included the possible occurrence of accompanying symptoms in addition to menstrual pain (Chaudhuri & Singh, 2012; Eryilmaz, Ozdemir, & Pasinlioglu, 2010; Hillen et al., 1999; Johnson, 1988; Klein & Litt, 1981; Negriff et al., 2009; Pitangui et al., 2013; Poureslami & Osati-Ashtiani, 2002; Strinić et al., 2003). Other definitions sometimes included the need for the use of medications or impact on quality of life to define dysmenorrhea (Chongpensuklert et al., 2008; Goldstein-Ferber & Granot, 2006; Rapkin et al., 2006). In some cases, no definition of dysmenorrhea was provided (Boyle, 1997; Dambhare et al., 2012; Deo & Ghattargi, 2007; Frisk et al., 1965; Lee et al., 2006; Santina et al., 2012; Sanyal & Ray, 2008; Svanberg & Ulmsten, 1981; Widholm, 1979).

Overall, the prevalence of menstrual pain ranged from moderate, 25% (Nwankwo et al., 2010) to high, 93% (Parker et al., 2010). Of the studies that reported menstrual pain severity, most categorised pain as mild, moderate and severe (Banikarim et al., 2000; Chaudhuri & Singh, 2012; Chongpensuklert et al., 2008; El-Gilany, Badawi, & El-Fedawy, 2005; Klein & Litt, 1981; Lee et al., 2006; Mohamed, 2012; Parker et al., 2010; Pitangui et al., 2013; Teperi & Rimpelä, 1989; Unsal, Tozun, Ayranci, & Orsal, 2012; Vicdan et al., 1996; Wijesiri & Suresh, 2013; Wilson & Keye, 1989). The prevalence of mild pain ranged from 5% to 74.4%, moderate pain ranged from 30% to 62.3%, and severe pain ranged from 14% to 51.97%.

3.3.2 Dysmenorrhea and school functioning

A large proportion of studies reported the impact of dysmenorrhea on school functioning alone. Therefore, this section is dedicated to those 13 included studies (Alam et al., 2011; Boyle, 1997; Dambhare, Wagh, & Dudhe, 2012; Deo & Ghattargi, 2007; Klein & Litt, 1981; Lee, Chen, Lee, & Kaur, 2006; Nwankwo, Aniebue, & Aniebue, 2010; Rostami, 2007; Sanyal & Ray, 2008; Sule & Ukwenya, 2007; Vicdan et al., 1996; Widholm, 1979; Wilson & Keye, 1989). Specifically, the impact of dysmenorrhea on school absenteeism (Alam et al., 2011; Dambhare et al., 2012; Deo & Ghattargi, 2007; Klein & Litt, 1981; Lee et al., 2006; Nwankwo et al., 2010; Rostami, 2007; Sanyal

& Ray, 2008; Sule & Ukwenya, 2007; Vicdan et al., 1996; Widholm, 1979; Wilson & Keye, 1989) and academic performance (Alam et al., 2011; Boyle, 1997; Wilson & Keye, 1989) were investigated. Sample sizes ranged from 13,665 (Vicdan et al., 1996) to 88 (Wilson & Keye, 1989) and included adolescent girls aged between 10 and 20 years. The majority of studies used selfreport questionnaires (Alam et al., 2011; Boyle, 1997; Dambhare et al., 2012; Deo & Ghattargi, 2007; Lee et al., 2006; Nwankwo et al., 2010; Rostami, 2007; Sanyal & Ray, 2008; Sule & Ukwenya, 2007; Vicdan et al., 1996; Widholm, 1979; Wilson & Keye, 1989). One study collected data from the national health examination survey cycle III in the USA which measured school absenteeism through interviews with school personnel (Klein & Litt, 1981). Objective measures of academic performance included school grades (Boyle, 1997), and school reports over two semesters (Alam et al., 2011). One study, investigating self-reported academic performance, indicated that over half of girls (55%) felt menstrual pain negatively impacted on their school performance (Wilson & Keye, 1989). In contrast, Alam et al. (2011) used an objective measure of school performance and found no significant differences between those who did and did not report dysmenorrhea. When menstrual pain was correlated with individual school grades, significant negative correlations were found between the presence of pain and seven out of 18 subject grades (Boyle, 1997).

Participants reported medium to high rates of school absenteeism, ranging from 6.33% (Deo & Ghattargi, 2007) to 51% (Rostami, 2007), low to medium rates of ‘frequent absenteeism’ (1%25.6%) (Klein & Litt, 1981; Vicdan et al., 1996; Widholm, 1979), and three studies found that girls missed an average of 1-3 days of school due to dysmenorrhea (Alam et al., 2011; Deo & Ghattargi, 2007; Lee et al., 2006). School absenteeism due to menstrual pain differed with age (Sanyal & Ray, 2008), pain intensity (Klein & Litt, 1981; Lee et al., 2006) culture (Dambhare et al., 2012; Deo & Ghattargi, 2007), and ethnicity (Klein & Litt, 1981).

3.3.3 Psychological functioning

Numerous studies have found that dysmenorrhea was associated with impaired psychological or emotional functioning. This includes feeling mentally affected by the pain (Wijesiri & Suresh, 2013), feeling unhappy during menstruation (Rani et al., 2015), feeling nervous during menstruation (Poureslami & Osati-Ashtiani, 2002), perceived ability (Goldstein-Ferber & Granot, 2006), somatisation (Goldstein-Ferber & Granot, 2006; Rapkin et al., 2006), anxiety (Fontana & Rees, 1982; Frisk et al., 1965; Rapkin et al., 2006), neuroticism (Fontana & Rees, 1982), depressive symptoms (Frisk et al., 1965; Rapkin et al., 2006; Unsal et al., 2012), insomnia (Frisk et al., 1965), impaired concentration (Frisk et al., 1965), restlessness (Frisk et al., 1965), mood changes (Santina et al., 2012), negative menstrual experiences (Santina et al., 2012), and depression (Negriff et al., 2009), and what Frisk et al. (1965) described as “emotional instability” and “hysteroid reactions”. One study did not find that dysmenorrhea was associated with general reasoning (Fontana & Rees, 1982) and another found that menstrual pain was not associated with trait anxiety (Negriff et al., 2009).

3.3.4 Activities of daily living (ADL)

Many studies reported that girl’s ADL were limited by dysmenorrhea specifically, general activities (Amu & Bamidele, 2014; El-Gilany et al., 2005; Hillen et al., 1999; Pitangui et al., 2013; Strinić et al., 2003; Svanberg & Ulmsten, 1981), daily chores (Banikarim et al., 2000; El-Gilany et al., 2005), sports (Banikarim et al., 2000; Chongpensuklert et al., 2008; El-Gilany et al., 2005; Hillen et al., 1999; Liliwati et al., 2007; Parker et al., 2010; Svanberg & Ulmsten, 1981), physical functioning (Nur Azurah et al., 2013), lifting heavy objects (Rani et al., 2015), having to staying in bed (Chaudhuri & Singh, 2012; Strinić et al., 2003; Svanberg & Ulmsten, 1981) or at home (ElGilany et al., 2005), being less active (Chaudhuri & Singh, 2012; Johnson, 1988), casual paid work (Parker et al., 2010), sleep (Amu & Bamidele, 2014), and disturbance to reading (Amu & Bamidele, 2014) and recreational activities (Wong, 2011; Wong & Khoo, 2010). In many cases, increased negative impact of dysmenorrhea on ADL was associated with higher reported pain severity (ElGilany et al., 2005; Liliwati et al., 2007; Mohamed, 2012; Parker et al., 2010).

3.3.5 Social relationships and activities

Several of the included studies found that dysmenorrhea impacted on the girl’s social relationships. This included relationships with family (Eryilmaz et al., 2010; Frisk et al., 1965; Parker et al., 2010), relationships with friends (Eryilmaz et al., 2010; Parker et al., 2010), limitations to socialising/ social activities (Banikarim et al., 2000; Chaudhuri & Singh, 2012; Chongpensuklert et al., 2008; El-Gilany et al., 2005; Hillen et al., 1999; Mohamed, 2012; Parker et al., 2010), becoming reclusive/ shy (Poureslami & Osati-Ashtiani, 2002), sexual activity (Parker et al., 2010), and relationships with partner (Parker et al., 2010). Several studies showed that girls with more severe pain reported a more profound impact of dysmenorrhea on social relationships and activities. (El-Gilany et al., 2005; Eryilmaz et al., 2010; Mohamed, 2012; Parker et al., 2010) or duration (Eryilmaz et al., 2010). One study investigated whether dysmenorrhea had an impact on sexual activity and romantic relationships and found an association between increased pain severity and negative impacts on sexual activity and relationship with partner (Parker et al., 2010).

3.3.6 Academic performance

Many studies reported that menstrual pain had a negative impact on some aspect of academic performance (4.5-74%). Specifically, dysmenorrhea was associated with lack of focus on school content (Eryilmaz et al., 2010), missing exams (Eryilmaz et al., 2010), and limitations in class concentration (Chaudhuri & Singh, 2012; El-Gilany et al., 2005; Liliwati et al., 2007; Mohamed, 2012; Wong, 2011; Wong & Khoo, 2010), exam performance (Banikarim et al., 2000; Eryilmaz et al., 2010; Mohamed, 2012), class performance (Amu & Bamidele, 2014; Banikarim et al., 2000), class participation (Banikarim et al., 2000; Mohamed, 2012), homework (Banikarim et al., 2000; El-Gilany et al., 2005; Mohamed, 2012), grades (Banikarim et al., 2000; Boyle, 1997; Wong, 2011), school activities (Hillen et al., 1999), academic performance (Chaudhuri & Singh, 2012; Frisk et al., 1965; Wilson & Keye, 1989; Wong, 2011), completing school work (Parker et al., 2010) and improvement in exam performance (Fontana & Rees, 1982). School performance was measured objectively in three studies (Alam et al., 2011; Boyle, 1997; Fontana & Rees, 1982), otherwise relying on self-reported academic performance. Two studies comparing girls with and without dysmenorrhea symptoms, did not find any difference in school grades between groups (Alam et al., 2011; Fontana & Rees, 1982). One study found significant negative correlations between premenstrual and menstrual pain and grades in seven of 19 school subjects but not the others (Boyle, 1997). The studies that used objective measures of school performance were the only studies to find that dysmenorrhea did not impact on school performance. In many cases, the impact of dysmenorrhea on school performance increased with higher levels of pain severity (Chongpensuklert et al., 2008; Eryilmaz et al., 2010; Liliwati et al., 2007; Mohamed, 2012; Parker et al., 2010).

3.3.7 School absenteeism

The most reported impact of dysmenorrhea investigated by the included studies was school absenteeism. Absenteeism as a result of menstrual pain ranged from 1 (Widholm, 1979) to 51% (Rostami, 2007). Many studies reported that absenteeism increased with pain severity (Banikarim et al., 2000; Chongpensuklert et al., 2008; El-Gilany et al., 2005; Klein & Litt, 1981; Lee et al., 2006; Liliwati et al., 2007; Mohamed, 2012; Parker et al., 2010; Pitangui et al., 2013; Teperi & Rimpelä, 1989). Of those that reported the days of school missed due to dysmenorrhea, absenteeism ranged from individual missed classes (Banikarim et al., 2000) to 7 full school days (Poureslami & Osati-Ashtiani, 2002).

3.3.8 Quality assessment

As shown in appendix E, the studies produced a wide range of quality assessment scores. Out of a possible score of 17, overall risk of bias index ranged from 2 to 15. Specifically, quality of reporting scores ranged from 0 to 8, external validity and bias scores ranged from 1 to 6, and selection bias and power scores ranged from 0 to 2. This review therefore summarises the evidence of studies with a vast range of methodological rigour. Poor methodological rigour can result in biased results, which may, in turn, bias the conclusions formed in this narrative synthesis. Specific methodological limitations are discussed further in the discussion, along with recommendations to help improve the robustness of future research.

3.4 Discussion

This systematic review aimed to investigate, by collecting and synthesising the existing empirical literature, what impact primary and secondary dysmenorrhea has on the HRQoL of adolescents (<18 years old). Although research in this specific area is still in its infancy, some notable findings have emerged. Overall, girls reported that dysmenorrhea had a negative impact on all domains of HRQoL including physical, social, psychological and school functioning and wellbeing. Girls reported that dysmenorrhea had a negative impact on psychological functioning, ADL, social relationships and activities, academic performance, and school attendance. The overall evidence also shows that associations between dysmenorrhea and impaired HRQoL often increase with menstrual pain severity.

The current evidence indicates that adolescent dysmenorrhea is often associated with impaired HRQoL. As previously discussed, from a biopsychosocial perspective this relationship may be bi-directional and, although dysmenorrhea can affect HRQoL, psychological and social factors can also influence the overall experience of menstrual pain (Gatchel et al., 2007; Walker, 2008). For example, in Fontana and Rees' (1982) study, adolescents with recurrent menstrual pain reported higher levels of anxiety than adolescents that did not, which could be interpreted as a direct result of experiencing monthly menstrual pain. However, anxiety has been found to increase activity within the parahippocampal network in the brain resulting in increased pain perception (Ploghaus et al., 2001), suggesting that increased anxiety experienced among girls who get regular menstrual pain may also contribute to the girl's overall experience of pain. This may also help to explain why several studies found an inverse relationship between pain intensity and HRQoL (Banikarim et al., 2000; El-Gilany et al., 2005; Eryilmaz et al., 2010; Klein & Litt, 1981; Pitangui et al., 2013; Teperi & Rimpelä, 1989). These findings support empirical research investigating paediatric chronic pain and HRQoL which have found that lower levels of pain were associated with higher HRQoL scores (Gold et al., 2009). Despite the fact that biopsychosocial models of chronic pain are well established, just one of the reviewed studies developed a theoretical model of menstrual pain in their report (Wijesiri & Suresh, 2013).

The main, overall conclusion of this review is that dysmenorrhea has a profound impact on many aspects of HRQoL for adolescent girls. These findings were not unanimous however, as two studies found no difference in school grades between girls who did and did not experience regular menstrual pain (Alam et al., 2011; Fontana & Rees, 1982), although girls experiencing dysmenorrhea did show less improvement between the exams than those who did not experience menstrual pain (Fontana & Rees, 1982). Furthermore, two studies did not find dysmenorrhea to be associated with limitations in general reasoning (Fontana & Rees, 1982) or increased anxiety (Negriff et al., 2009). Finally, in contrast to the majority of evidence, which found medium to high rates of dysmenorrhea-related school absenteeism, two studies found either no differences in school absenteeism between girls with and without dysmenorrhea (Fontana & Rees, 1982), or that most girls did not miss school as a result of menstrual pain (Teperi & Rimpelä, 1989). Many important variations across and between the included studies could help explain these varying results. Specifically, differences in methodological rigour (as shown by the quality assessment scores), cultural factors, and the vast range of participant's chronological age and menarcheal age range.

There are several common limitations across and within the included studies. Firstly, one limitation in the strength of the evidence across studies is that most of the included studies (n=26) were conducted in a non-western cultural setting. In contrast with the studies from non-western cultures, many of the studies conducted in a western setting were outdated (Fontana & Rees, 1982; Frisk et al., 1965; Hillen et al., 1999; Johnson, 1988; Klein & Litt, 1981; Teperi & Rimpelä, 1989; Widholm, 1979; Wilson & Keye, 1989), highlighting a need for up-to-date research within these cultures. Specifically, although one study was conducted in Wales (Fontana & Rees, 1982), this study is over 20 years old and no studies investigating the impact of dysmenorrhea on the HRQoL of children and adolescents (<18 years) have yet been conducted in England. As previously discussed, numerous studies have found that menstrual attitudes and beliefs are culturally and socially constructed (Anson, 1999; Marván et al., 2003; McMaster et al., 1997). Premenstrual and menstrual symptom reporting also varies across ethnicities, cultures, and other factors related to up-bringing (Anson, 1999; McMaster et al., 1997; Van Den Akker et al., 1995) suggesting that ethnicity and culture are instrumental factors in pain perception and highlighting the importance of obtaining information about the impact of dysmenorrhea among adolescents from various cultures, religions, and locations. It should be noted that all but one of these findings (Marván et al., 2003) were collected from an adult sample however, findings from this review support cultural differences among young girls (<18 years). Differences in the impact of dysmenorrhea were explored in several studies between girls of different ethnicities (Klein & Litt, 1981; Wong & Khoo, 2010), religions (Goldstein-Ferber & Granot, 2006), cultures (Dambhare et al., 2012; Deo & Ghattargi, 2007) and age groups (Sanyal & Ray, 2008; Svanberg & Ulmsten, 1981; Teperi & Rimpelä, 1989; Widholm, 1979). Differences were found in school absenteeism, perceived ability, and somatization between groups, supporting theories that ethnicity can influence menstrual pain. The review findings show that a gap within the current literature exists for more up-to-date research with adolescents living in western cultures.

Although many of the studies that were not specifically investigating primary dysmenorrhea enquired about medical history (physician consultation and treatments used to relieve dysmenorrhea, very few reported whether participants had any underlying pelvic pathology (Frisk et al., 1965; Parker et al., 2010; Pitangui et al., 2013; Santina et al., 2012; Sanyal & Ray, 2008). Of those that did, there was no investigation into whether primary or secondary dysmenorrhea impacted on HRQoL differently. Several studies either included a definition of primary dysmenorrhea only, or specifically recruited girls with primary dysmenorrhea as opposed to secondary (Alam et al., 2011; Chaudhuri & Singh, 2012; Fontana & Rees, 1982; Negriff et al., 2009; Nwankwo et al., 2010; Rostami, 2007; Strinić et al., 2003; Svanberg & Ulmsten, 1981; Unsal et al., 2012; Wong, 2011). Therefore, additional concerns associated with the pelvic pathologies of secondary dysmenorrhea, such as endometriosis, which is associated with infertility (Ventolini & Horowitz, 2005), were not taken into account. Also, different treatment approaches for primary and secondary dysmenorrhea (Harel, 2006) may impact on the HRQoL of adolescent girls differently. In relation to the review question, conclusions are not able to be drawn on whether primary and secondary dysmenorrhea impacts differently on the HRQoL of young women.

Wide methodological variations in measurement were apparent throughout the included studies. As previously mentioned, various definitions of dysmenorrhea were used by authors. Less than half of the included studies reported the time interval to which the presence of dysmenorrhea was measured (Banikarim et al., 2000; El-Gilany et al., 2005; Eryilmaz et al., 2010; Mohamed, 2012; Negriff et al., 2009; Parker et al., 2010; Santina et al., 2012; Sanyal & Ray, 2008; Sule & Ukwenya, 2007). Of the few that did report a time interval, timing varied from experiencing pain in the previous three cycles or months (Banikarim et al., 2000; El-Gilany et al., 2005; Eryilmaz et al., 2010; Mohamed, 2012) to what participants experienced as a ‘usual’ period (Parker et al., 2010; Santina et al., 2012; Sule & Ukwenya, 2007). Lack of a definitive time interval that can be used across studies may therefore cause further difficulty when trying to compare the results of these studies. Also, very few studies reported the use of validated tools to measure all primary outcomes (Chaudhuri & Singh, 2012; Dorn et al., 2009; Goldstein-Ferber & Granot, 2006;

Negriff et al., 2009; Nur Azurah et al., 2013; Rapkin et al., 2006; Santina et al., 2012; Unsal et al., 2012; Wong, 2011; Wong & Khoo, 2010). Specifically, of the studies that categorised participants in terms of pain severity, very few reported the use of validated measures (Banikarim et al., 2000; Chaudhuri & Singh, 2012; Eryilmaz et al., 2010; Goldstein-Ferber & Granot, 2006; Liliwati et al., 2007; Mohamed, 2012; Unsal et al., 2012). Of those that did, measures of pain intensity included the Numerical Rating System (NRS) (Pitangui et al., 2013), Visual Analogue Scale for Pain (VASP) (Banikarim et al., 2000; Chaudhuri & Singh, 2012; Mohamed, 2012; Rostami, 2007; Unsal et al., 2012), Visual Analogue Faces Scale (Rani et al., 2014), Verbal Multidimensional Scoring System (Rostami, 2007), and Facial Pain Rating Scale (Eryilmaz et al., 2010). Due to the variations across the studies in terms of measures used and differences in the definitions of dysmenorrhea, it is difficult to establish the impact of dysmenorrhea on all domains of HRQoL.

All of the included studies were cross-sectional designs, three of which compared girls experiencing dysmenorrhea to ‘healthy’ controls (Alam et al., 2011; Fontana & Rees, 1982; Rapkin et al., 2006). Several studies also investigated the impact of pain severity on adolescent’s HRQoL. Others compared the impact of dysmenorrhea on participants of different ethnicities (Klein & Litt, 1981), religions (Goldstein-Ferber & Granot, 2006), cultures (Deo & Ghattargi, 2007; Rani et al., 2015) and age cohorts (Teperi & Rimpelä, 1989). Also, several studies compared the impact of dysmenorrhea to the impact of other menstrual problems (Nur Azurah et al., 2013) and premenstrual syndrome (PMS) (Wilson & Keye, 1989) on HRQoL. HRQoL was also compared between girls experiencing dysmenorrhea and previously published data of adolescents without dysmenorrhea, girls with cystic fibrosis, and girls with juvenile arthritis (Nur Azurah et al., 2013). As many of the included studies failed to compare HRQoL between adolescent girls with and without dysmenorrhea, I am unable to determine whether dysmenorrhea is the only reason for impaired HRQoL scores in adolescence. There are many factors associated with adolescence, other than menstrual pain, which can influence all aspects of quality of life. Adolescence is a critical period of development whereby young people are going through puberty, taking on new body shape, and developing new cognitive skills, independence from parents and a sense of personal identity (Christie & Viner, 2005). During this dynamic development into adulthood, several factors such as body image (McCreary, 2002; Smolak, 2004), school pressures, negative academic events (i.e. school underachievement), poor peer relations (Hart, Hodgkinson, Belcher, Hyman, & Cooley-Strickland, 2013; Wagner & Compas, 1990), and bullying (Levy et al., 2012) can have a negative impact on young people’s quality of life. Bullying in adolescence, which is highly prevalent (20-35%) whether as a victim, bully or both, is associated with limitations in QoL including depression, suicide attempts, substance use and unsafe sexual behaviour (Klomek, Marrocco, Kleinman, Schonfeld, & Gould, 2007; Levy et al., 2012; Litwiller & Brausch, 2013). There are therefore many aspects to an adolescent's life including social, psychological, academic, and physical events that may impact on HRQoL, but also that can be affected by menstrual pain. However, 13 out of the 41 included studies singularly investigated how dysmenorrhea impacts on school functioning, and in some cases, absenteeism only (Alam et al., 2011; Boyle, 1997; Dambhare et al., 2012; Deo & Ghattargi, 2007; Klein & Litt, 1981; Lee et al., 2006; Nwankwo et al., 2010; Rostami, 2007; Sanyal & Ray, 2008; Sule & Ukwenya, 2007; Vicdan et al., 1996; Widholm, 1979; Wilson & Keye, 1989). School functioning, although important, is not the only aspect of an adolescents life that can be impacted by pain. Finally, as previously mentioned, there was a wide range of age ranges and menarcheal ages reported across studies. Menarche is an important milestone for young women as it symbolises the start of womanhood (Deligeoroglou & Tsimaris, 2010). The severity of dysmenorrhea has previously been associated with several factors, including younger menarche (Gagua et al., 2012). In adolescence, the luteinizing hormone that causes ovulatory, regular menstruation has not matured. As a result, during the first 2-5 years of menarche, 50-80% of cycles are anovulatory. With the onset of ovulatory cycles, local prostaglandins are released which, as previously mentioned, is often thought to contribute to primary dysmenorrhea. Painful menstruation is therefore more common in the mid-late adolescent stages (Harel, 2006). Early menarche however, which can be influenced by environmental factors such as nutrition and climate (Delemarre-van de Waal, 1993), might therefore increase the likelihood of dysmenorrhea among younger-aged girls and increase the severity of pain. It is therefore important to report the menarcheal age of this population so that these factors can be taken into account.

The results of this synthesis should also be considered within the context of the methodological strengths and weaknesses of the review. Unlike previous reviews (Davis & Westhoff, 2001; Gagua et al., 2012; Harada, 2013; Ylikorkala & Dawood, 1978) which have focussed on the biomedical aspects of dysmenorrhea, this systematic review has taken a psychosocial approach towards adolescent menstrual pain. However, the evidence summarised from this review is based on a compilation of studies that vary considerably in methodological rigour. The limitations of, and descriptive natures of the included studies should therefore be considered when drawing conclusions (Akers, 2009). To account for this limitation however, the findings have been interpreted in a particularly critical manner, and suggestions have been made, based on these criticisms, for future research. Finally, as this was not a systematic review of interventions or randomised control trials, the quality assessment checklist was modified specifically for the purpose of the review which did not allow for comparison of study quality with other published reviews. Although the checklist used was not previously validated, it was piloted and peer reviewed before use.

In light if these findings and the limitations identified in terms of the included studies, recommendations for future research are indicated. Firstly, as only three of the included studies used a case-control design, future methodologically rigorous studies using an adequately matched control group of girls who do not experience menstrual pain might be helpful in determining whether differences in HRQoL between girls with and without dysmenorrhea exist. Due to cultural differences in pain perception and symptom reporting, and limited up-to-date studies investigating dysmenorrhea among western adolescents, the current literature may benefit from future research conducted in western cultures. In addition, the implementation of a single definition (including a time interval) of dysmenorrhea, and validated and age-appropriate pain severity, and HRQoL measures may benefit future reviews as this will allow comparison between, and more reliable findings. Reporting the average menarcheal age of the sample may also prove beneficial to future researchers as this may provide insight about who is more likely to be affected by dysmenorrhea. Future studies that differentiate between primary and secondary dysmenorrhea and compare their individual impact on adolescent HRQoL could provide a greater insight into menstrual pain and its effect on the lives of girls experiencing it. There is currently a lack of biopsychosocial, theoretical models of adolescent dysmenorrhea. Development of these models may help to increase awareness among healthcare professionals, parents, and young people about the overall experience of menstrual pain and, in turn, this increased understanding may eventually improve management and care.

In sum, this review provides an overview of the current literature investigating the impact of dysmenorrhea on adolescent HRQoL. The limitations in the literature so far highlight the necessity for further research in this area and give an indication of the ways in which research can move forward to develop a better understanding of this highly prevalent phenomenon that impacts on many aspects of young women’s lives.

Chapter 4 The methodological approaches to investigating adolescent dysmenorrhea and health-related quality of life.

4.1 Introduction

This chapter discusses the methodological approaches taken in this thesis and justifies the subsequent methods used to investigate the impact of dysmenorrhea on adolescent HRQoL. This chapter begins with a discussion about the major philosophies and paradigms of scientific research and justification for the broad critical realist stance that has been chosen to guide this research. The strengths and weaknesses of quantitative and qualitative research is then presented, followed by a rationale for taking a mixed methods approach. Finally, this chapter ends with an introduction and rationale for the specific quantitative and qualitative methods chosen for this thesis research to investigate adolescent dysmenorrhea.

4.2 Philosophy and Paradigms in Scientific Research

Before choosing a methodological approach, the philosophical underpinnings of scientific research need to be considered. A research paradigm encompasses the beliefs, assumptions, values and practices of a research community (Kuhn, 1962). Research paradigms are used to guide the development and delivery of research (Braun & Clarke, 2013; Guba, 1990). Which research paradigm to choose depends heavily on a researchers' philosophical stance which consists of their core beliefs and assumptions about the world. There are four main philosophical considerations which underpin scientific enquiry. These include: 1) whether or not a 'truth' is attainable (ontology), 2) if and how knowledge can be acquired (epistemology), 3) if and how a researchers' beliefs and values impact their approach to research (axiology) and 4) what methods are needed to acquire knowledge (methodology) (Guba, 1990). A research paradigm is chosen based on these four key areas of consideration and should therefore reflect the researchers' worldview (Guba, 1990) and guide all aspects of the research process (Teddlie & Tashakkori, 2009). This section summarises some of the most commonly discussed philosophical considerations in research.

4.2.1 Taking a Pragmatic approach

Pragmatism offers a resolution to the conflicting agendas of the post-positivist and constructivist philosophies by taking a mid-point stance (Ivankova, Creswell, & Stick, 2006; Morgan, 2014; Yardley & Bishop, 2008). This approach is characterised by the belief that research should be driven by the topic of enquiry. Those who take a pragmatist approach to research choose the methods that are best suited to answering the research question. Those who take this approach therefore do not limit their methodological options based on their philosophical stance. If this approach is taken, the methodology most likely to enhance understanding of the research problem will be chosen (Teddlie & Tashakkori, 2009; Yardley & Bishop, 2008; Yardley, Morrison, Bradbury, & Muller, 2015). Post-positive and constructive approaches favour quantitative and qualitative methods, respectively, viewing the two as incompatible (Yardley & Bishop, 2008). However, the pragmatist approach rejects the need to separate these two types of methods. Pragmitism therefore offers an opportunity to combine these two methodologies within research (Yardley & Bishop, 2008).

4.2.2 Two main paradigms: Post-Positivism and Constructivism

Each of the four main philosophies for obtaining knowledge and understanding through research (ontology, epistemology, axiology, and methodology) raise certain questions that challenge researchers to consider their particular ‘worldview’ (Guba, 1990). A researchers’ stance within the two main, contrasting, paradigms of research, post-positivism and constructivism, may be influenced by beliefs about ontology, epistemology, axiology and methodology (Feilzer, 2010). Post-positivist approaches to research are theory driven, derived from positivism from which traditional forms of research were based (Yardley & Bishop, 2008; Yardley & Bishop, 2008). This philosophical stance is characterised by a belief that a ‘truth’ is knowable, objective and separate from external influences and values, and accessible through the testing of hypotheses (Teddlie & Tashakkori, 2009). In contrast, researchers who take a constructivist stance emphasise the importance of social and cultural influences on perceived reality (Yardley & Bishop, 2008). The constructivist approach is characterised by beliefs including that there is no single ‘truth’, reality is ‘constructed’ and influenced by the researchers’ interpretation. From this philosophical stance, qualitative methodologies are often used to explore complex phenomena and understand individual beliefs and experiences (Bishop, 2015; Creswell, 2014; Ritchie, Lewis, Nicholls, & Ormston, 2013).

4.2.3 Critical Realism and this research

The critical realist approach, developed by Roy Bhaskar (Bhaskar, 2013) is another approach that acts as a compromise between the positivist and constructivist positions. Like pragmatism, critical realism is compatible with both qualitative and quantitative research methodologies and can facilitate communication and cooperation between the two (Greene, 2000; Mark & Henry). The critical realist approach acknowledges that, although it is possible to know the 'truth' about a phenomena, we can only really understand that truth through available discourses (Sayer, 1999). From this perspective, the researcher assumes that 'truth' is knowable (positivist perspective) while acknowledging the subjective and socially-constructed nature of that truth (constructivist perspective) (Braun & Clarke, 2013). Like pragmatism, the critical realist approach does not favour quantitative or qualitative approaches, serving as an optimal framework for conducting mixed-methods research (McEvoy & Richards, 2006). Critical realism is in agreement with the pragmatic approach that research methods should be primarily driven by the research question. From this perspective, research methods can be informed by one or more of a number of research paradigms (Greene, 2000; Maxwell, 1992).

However, unlike the pragmatic approach, the researcher is acknowledged as being qualitatively different from participants and that interpretations of the data are likely to be influenced by the researcher's unique perspective. In contrast to the pragmatic approach however, critical realists believe that pragmatism underestimates the actual influence of philosophical assumptions on research methods. From the critical realist perspective, considering this influence is particularly important when combining qualitative and quantitative approaches (Maxwell & Mittapalli, 2010). Critical realism is adopted with the aim of distinguishing between the world and our experience of it. It distinguishes the real (what naturally or socially exists), the actual, and the empirical (Bhaskar, 2013; Collier, 1994).

Therefore, a broad critical realist approach was chosen to investigate adolescent dysmenorrhea because it allows the researcher to obtain a window into the adolescent's reality, while taking into consideration the interpretive role of the researcher. This approach enabled the researcher in this thesis to acknowledge the context of the adolescents' unique world and incorporate the complexity and diversity of the participants' experiences into the analyses (Braun & Clarke, 2013). The critical realist philosophical approach underpinning this thesis justifies and encourages the use of both quantitative and qualitative methodologies in addressing the research aims (McEvoy & Richards, 2006).

4.3 Methodological considerations

Methodology is the approach taken to answering a proposed research question (Teddlie & Tashakkori, 2009). Historically, quantitative and qualitative approaches were considered separate and unable to be integrated. However, in the last 20 years, mixed methods research has started to be considered as the third research paradigm (Johnson & Onwuegbuzie, 2004). Mixed-methods research is research which combines elements of both quantitative and qualitative approaches, for the purpose of broadening and expanding understanding of a particular phenomenon (Johnson, Onwuegbuzie, & Turner, 2007).

It’s important to identify a clear rationale for why a mixed methods approach would be superior to using just one of those approaches, as researchers need a particular set of skills with which to conduct this type of research (Yardley & Bishop, 2008). In this thesis, a mixed methods research design was chosen for ‘development’, whereby the findings of one method help to inform the other method (Greene, Caracelli, and Graham (1989). This approach was considered as a way of combining the strengths of both quantitative and qualitative paradigms, while addressing the weaknesses of both. Mixed methods research is an attempt to legitimate the use of multiple approaches in answering research questions, rather than restricting or constraining a researchers’ choices. It is an expansive and creative form of research, not a limiting form of research (Johnson & Onwuegbuzie, 2004).

A mixed-methods approach was therefore adopted to investigate adolescent dysmenorrhea and HRQoL. The following section will consider: a) what are the contributions of both quantitative and qualitative methods to answering a research question, b) what a mixed-methods approach involves, c) the different ways in which they can be combined, and d) an outline of the specific mixed-methods design of the present research.

4.3.1 The contribution of both quantitative and qualitative methods

To understand how the two components complement each other in mixed methods research, it is important to understand the strengths and limitations of both (Johnson & Onwuegbuzie, 2004; Yardley & Bishop, 2008). This section will give a brief overview of the strengths and weaknesses of quantitative and qualitative methods, respectively.

Quantitative methods

Historically, quantitative methods have been considered the ‘gold standard’ approach to scientific research. Quantitative assumptions are often consistent with a positivist philosophy (Ritchie et al., 2013) whereby the ‘truth’ of a phenomenon can be scientifically proven, often mathematically. From this perspective, the researchers are encouraged to remain objective from the research process and outcomes. The belief that the ‘real’ or ‘true’ causes of social scientific outcomes can be determined reliably and validly are the foundation of this approach (Yardley & Bishop, 2008). Therefore, a ‘passive voice’ is often used when writing up quantitative research.

There are many strengths to using quantitative methods to investigate psychological phenomena, such as their ability to test and validate existing theories about how and why various types of phenomena occur (Johnson & Onwuegbuzie, 2004). Quantitative methods can also be used to test hypotheses that are generated before data are collected, and findings are often generalised. This testing can also be used to investigate the effectiveness of psychosocial interventions based on theory which can inform the development, improvement and further validation of interventions. Quantitative data collection is also particularly useful in childhood and adolescent pain research because it allows researchers to make predictions about chronic pain outcomes later in life [insert ref]. Randomised controlled trials (RCTs) are commonly used to investigate the effectiveness of interventions aiming to improve chronic pain outcomes among children and adolescents (Eccleston et al., 2004).

The research results often require little to no interpretation and subjectivity on the researchers’ part (e.g., effect size, statistical significance) (Ritchie et al., 2013). Unlike with a qualitative approach, quantitative research allows the investigator to control for potential confounding variables, allowing for a more focussed assessment of cause-and-effect relationships (Johnson & Onwuegbuzie, 2004). There are also some practical benefits to obtaining quantitative data, which is precise and numerical. Quantitative data are often relatively quick data to collect, on a very large scale, particularly since online surveys have become a popular way of collecting data. Data analysis is also relatively less time consuming (using statistical software) and much less laborious in comparison to many types of qualitative analysis (Creswell, 2014). Finally, historically quantitative results have had a much higher credibility with people in governments, schools, and policy makers (Johnson & Onwuegbuzie, 2004). Therefore, researchers may lean more towards conducting large, quantitative studies if their main objective is to be persuasive in making recommendations based on their research findings.

These benefits of adopting a quantitative approach to research highlight its usefulness as an appropriate method to investigate childhood and adolescent chronic pain. However, there are some limitations to this approach which may be addressed by use of other approaches. For example, when developing a quantitative survey, the researcher’s categories or set answers that are used may not reflect participants’ understandings (e.g., the type of words and phrases that are commonly used among the set population) and some key answers may be missing because the researchers may not fully understand the phenomena yet (Yardley & Bishop, 2008). This could lead to missing out on important information or phenomena occurring because of the focus on theory or hypothesis testing rather than on theory or hypothesis generation (confirmation bias) (Johnson & Onwuegbuzie, 2004). Without exploration of individual's experiences, any knowledge produced could be focussed on misinformed data which is too general to be applied to specific local situations, contexts, and populations (e.g., children and adolescents) (Yardley & Bishop, 2015).

Qualitative methods

There are important, fundamental differences between the qualitative and quantitative research paradigms. In contrast to quantitative research, the qualitative approach is consistent with a constructivist perspective and assumes that there is not one, but multiple versions of reality which are strongly associated with context (Braun & Clarke, 2013). Qualitative research acknowledges that an individual's reality will be different depending time and context. Qualitative research is value-bound and the researchers' beliefs, assumptions, attitudes and knowledge are all acknowledged as factors that may potentially influence the interpretation of research findings (Guba, 1990). Qualitative research is often written up using detailed and rich descriptions of experiences, thoughts and feelings (Ritchie, 2013).

There are many strengths of qualitative research that often can fill the gaps in understanding left by a quantitative paradigm alone. For example, rather than assuming knowledge and developing researcher-led questionnaires, qualitative data are based on the participants' own meaning (Braun and Clarke, 2013). The voices of the participants are obtained and often, they are able to lead the researcher to focus onto the topics that are most important to them. Qualitative methods are also useful for studying a phenomenon in-depth (Creswell, 2014). This enables researchers to explore and describe rare, complex phenomena without the need for large sample sizes. Qualitative research offers rich and compelling insights into the real worlds, experiences, and perspectives of participants in a way that is completely different to, but can be complementary to, the knowledge we can obtain through quantitative methods (Braun & Clarke, 2014). There is the ability, if a case-study approach is chosen, to provide individual case information (Johnson & Onwuegbuzie, 2004). Although statistical methods are not used, there is still the possibility to explore cross-case comparisons and analysis (e.g., comparing the findings from groups of girls to that of groups of boys), and this can be done in rich, detailed description (Johnson & Onwuegbuzie, 2004).

Unlike quantitative methodologies, qualitative data collection and analysis provide an in-depth understanding and description of people's personal experiences of a phenomenon (Braun and Clarke, 2013) which can be particularly useful for exploring phenomena such as pain, which is entirely a subjective and individual experience. In addition, context and time are considered in the analysis of qualitative data. Participants are often encouraged to consider the past, present and future in relation to their experiences, and in discussion often provide important contextual information. The researcher also considers the contextual and relational factors that may be associated with the data that has been collected. For example, in focus group interviews, there is a 'facilitator' and an 'observer' present. One of the roles of an observer is to note down contextual factors and how these might influence the data being collected (Krueger & Casey, 2014). Another strength of qualitative research is the 'inductive' nature of this type of research. Rather than theory-testing, theory is often generated. For example, in grounded theory, the data are used to generate inductively a tentative but explanatory theory about a phenomenon (Johnson & Onwuegbuzie, 2004). Qualitative research can determine how participants interpret psychological constructs to help us to better understand them, data is often collected in naturalistic settings, and qualitative researchers are responsive to changes that occur during the conduct of a study (especially during extended fieldwork) and can shift the focus of their research as a result (Braun & Clarke, 2013) .

In common with a quantitative approach, the qualitative paradigm has many strengths which makes it applicable to exploring the experiences of children and adolescents; however, there are some weakness to using these methods alone. The findings from qualitative research are not generalizable to large populations of people and people living in very different contexts (Johnson & Onwuegbuzie, 2004). Instead, qualitative researchers use the term 'transferability' which enables researchers to consider how findings may be transferred to different populations (Houghton, Casey, Shaw, & Murphy, 2013). It is also very difficult to make quantitative predictions and test hypotheses and theories using qualitative methodologies; however, this is usually not the aim of qualitative research (Creswell, 2014). Finally, there are also some practical limitations to consider in qualitative research, including the fact that it is extremely time- and labour- intensive. It generally takes much more time to collect data when compared to quantitative research and the data analysis process is often time consuming (Johnson & Onwuegbuzie, 2004).

By answering a research question with both qualitative and quantitative approaches, the bias that is inherent in data sources and methods can be reduced when combined with other data sources and methods, strengthening the reliability of the findings (Denzin, 1978). The richness and depth of qualitative data can be used to add meaning to, and provide some context to statistical results. In addition, statistical data can add precision to qualitative data. Combining qualitative and quantitative methods means utilising the strengths of both as well as enabling the researcher to answer a broader range of research questions. This approach may add insights and understanding of adolescent dysmenorrhea that might be missed when only a single method is used. Finally, this approach also allows researchers to develop more creative ways of collecting data and using various methods can often lead to richer, more in-depth data (Johnson & Onwuegbuzie, 2004).

4.3.2 Mixed-methods research in practice

There are various considerations that need to be made before conducting mixed methods research. There are generally four types of mixed methods research designs: sequential explanatory, whereby the quantitative phase is followed by a qualitative phase; sequential exploratory, whereby the qualitative phase is followed by a quantitative phase; embedded, whereby quantitative and qualitative phases are conducted simultaneously; and triangulation designs (Johnson & Onwuegbuzie, 2004). The design chosen as most appropriate for addressing the current research problem was sequential exploratory. This decision was driven by the aim of this research to develop a working model of adolescent dysmenorrhea. Research into adolescent dysmenorrhea is still in its infancy and so exploratory, qualitative research was first carried out to identify all possible factors that were associated with adolescent dysmenorrhea. These findings were then used to inform the development of a quantitative study investigating the psychosocial predictors of QoL outcomes among adolescents experiencing dysmenorrhea.

It’s important to consider in mixed methods research how each component will be weighted (Bryman, 2006). For this research, they were weighted equally; no priority was given to either qualitative or quantitative components. Another important consideration of mixed methods research is at which point do researchers synthesise the components? (Bishop, 2015; Morse & Niehaus, 2009). Synthesis can occur at several different stages: sampling, data collection, data analysis, or interpretation (Bishop, 2015; Creswell & Plano-Clark, 2011; Yardley & Bishop, 2015). There are several advantages to combining the findings of mixed methods research (Jick, 1979). This allows researchers to be more confident of their results because they have answered their research questions using more than one approach. For this thesis, the point of synthesis was during interpretation (Morse & Niehaus, 2009). Both components were conducted separately, followed by combined discussion and interpretation in the discussion chapter. The following section will describe the mixed methods used in this thesis.

4.4 Using mixed-methods research to investigate adolescent dysmenorrhea and HRQoL

4.4.1 Qualitative component

Semi-structured interviews

For the qualitative phase, in-depth, semi-structured interviews with adolescents and their mothers (two separate empirical studies; see chapter five and chapter six) were chosen to explore the impact of dysmenorrhea on all aspects of adolescents' lives. This method was ideally suited to experience-focussed research questions. Interviews are an optimal method for exploring thoughts, feelings, and behaviours about a topic that participants have a 'personal stake' in (Braun & Clarke, 2013). A semi-structured interview design, using open-ended questions was implemented to allow participants to discuss issues important to them. As adolescent dysmenorrhea is a relatively under-researched area, open-ended interviews were chosen as the method of data collection to broaden the possibility of addressing new, unanticipated topics (Braun & Clarke, 2013; Kortesluoma, Hentinen, & Nikkonen, 2003). Each interview followed an interview schedule (see full interview schedule in appendix G), developed by the researcher based on discussions with academic supervisors and previous research (Chen, Lin, Heitkemper, & Wu, 2006; DiCicco-Bloom & Crabtree, 2006; Sällfors & Hallberg, 2009). Prompts and probes (e.g., can you tell me more about that?) were used to encourage participants to clarify, expand, elaborate, and provide more detailed answers (Braun & Clarke, 2013). This qualitative phase of the research process was iterative, which allowed the researcher to focus interviews on areas that were most important to the participants. As data collection proceeded, an enhanced understanding of important issues led to interview guide alterations. For example, while collecting data from the adolescent girls, many girls expressed reluctance to stay over at friends' houses while menstruating, resulting in the addition of 'sleepovers' as a prompt when asking girls about the impact of dysmenorrhea on their social activities. This iterative, and very flexible research process allowed the interviewer to modify interview techniques based on the adolescents' individual and cognitive development stage (Faux, Walsh, & Deatrick, 1988). The interviewer sought to ask interview questions in a way that would be understandable to each participant. For example, when younger participants referred to their period-related pain as a 'tummy ache', the researcher mirrored the terms used by the girls to aid the understanding of questions, which was also conducive to building up rapport. Also, if participants asked for clarification or appeared to misunderstand, the researcher re-worded questions by simplifying the language used, expanding an explanation, and using appropriate examples.

Inductive thematic analysis

Braun and Clarke’s (2006) step-by-step guide to thematic analysis was chosen as the most appropriate way to analyse the qualitative findings in this thesis. Thematic analysis first began being used and coined as a ‘‘method’’ in the 1970s by a science historian Gerald Holton (Merton, 1975). Since then, many different variations of thematic analysis have appeared (e.g., Boyatzis, 1998; Guest, MacQueen, & Namey, 2012; Joffe, 2011) which locate thematic analysis within the realist/post positivist paradigms. Some thematic analysis approaches do so through, for instance, advocating the inclusion of measures like interrater reliability, which does not fit within the overall philosophy of qualitative research (Braun & Clarke, 2013). Until 2006, thematic analysis was often variably and inconsistently used, partly due to a lack of clear guidelines (Braun and Clarke, 2014). Thematic analysis became a well-known and widely used approach in the social and health sciences following the publication of Using thematic analysis in psychology in 2006 (Braun & Clarke, 2006). The authors provided clear step-by-step guidelines that enabled all researchers, even those new to qualitative methods, to systematically analyse qualitative data (Braun and Clarke, 2014). Also, this approach to thematic analysis was unlike other variations as it offered a theoretically flexible approach. This version of thematic analysis provides a robust, systematic framework for coding qualitative data, and for using that coding to identify patterns across the dataset in relation to the research question. The questions of what level patterns are sought at, and what interpretations are made of those patterns, are then more flexible decisions that the researcher is able to make. The Braun and Clarke (2014) guidelines were followed to guide the thematic analysis of data collected from adolescent girls and their mothers.

Although being widely used by social science researchers, thematic analysis is a fairly new analysis method compared to other pattern-based qualitative analysis approaches , including Grounded theory (Glaser & Strauss, 1965), , discourse/narrative approaches (Riessman & Speedy, 2007) and interpretative phenomenological analysis (IPA) (Tindall, 2009).

The use of a qualitative, descriptive approach such as thematic analysis was suitable to explore the current research question as this method employs a relatively low level of interpretation compared to methods such as grounded theory and IPA (Vaismoradi, Turunen, & Bondas, 2013). In the present study, the data-driven, thematic analysis enabled the adolescent girls to explain, in their own words, their experiences with dysmenorrhea. Braun and Clarke’s step-by-step approach to thematic analysis was chosen over grounded theory, as used in Sällfors, Hallberg, and Fasth (2001), for several additional reasons. Firstly, unlike thematic analysis, there are many different versions of and procedures for conducting grounded theory; choosing, rationalising, and conducting the appropriate form can be a considerably time-consuming and complex process. In addition, grounded theory was first developed in the field of sociology and so concerns are focussed more on social structures and processes rather than psychological ones (Braun & Clarke, 2013). Finally, to conduct grounded theory correctly the researcher should not engage in the relevant literature until data analysis is complete (Braun & Clarke, 2013). This was not possible as the present study followed on from the findings of a systematic review investigating the impact of dysmenorrhea on adolescent HRQoL (see chapter three). Thematic analysis, as opposed to another descriptive approach such as content analysis (Aziato, Dedey, & Clegg-Lamptey, 2014; Chen et al., 2006), was used so that the context of adolescent life would be considered as an important part of girls' experiences. Content analysis, a method of analysing qualitative data by quantifying certain aspects of it, can lead to dismissing context as it aims to quantify the occurrence of codes (Mayring, 2004). Quantification of qualitative accounts could result in missing important aspects of the data as there are a number of reasons why participants may discuss a particular topic frequently such as comfort with discussing that particular aspect of life (Vaismoradi et al., 2013). In contrast, thematic analysis focusses on aspects of the data that are important in terms of the research question and the participants. Thematic analysis was chosen rather than another popular pattern-based approach, IPA (Braun & Clarke, 2013), because the purpose of this research was to explore the experiences of dysmenorrhea across a heterogeneous sample of adolescent girls. IPA focuses on the lived experiences of either individuals or a very small group (Smith & Shinebourne, 2012) and was therefore not appropriate for answering the research questions posed in this thesis.

Finally, thematic analysis is a particularly flexible approach, giving the author freedom to position themselves within both essentialist and constructionist paradigms (Braun & Clarke, 2006). Researchers can use any methods of qualitative data collection to answer almost any type of research question before applying thematic analysis (Braun & Clarke, 2013).

4.4.2 Quantitative component

Psychosocial measures

Qualitative data were collected from adolescent girls and their mothers exploring the impact of dysmenorrhea on all aspects of adolescent girls' lives. The qualitative findings (chapter five and chapter six) highlighted the importance of psychosocial factors involved in adolescent girls' experience of dysmenorrhea above and beyond pain severity. Overall, from the interviews with adolescent girls and their mothers it was clear that adolescent dysmenorrhea had a profound impact on all aspects of their lives. Adolescent girls and their mothers discussed the emotional impact of dysmenorrhea (e.g., worrying and feeling tearful), catastrophic thoughts about its potential cause, girls' perceptions of normal bodily sensations (e.g., several girls were described as hypochondriacs) and differences in family functioning and communication around dysmenorrhea. These findings suggested that the HRQoL of adolescents experiencing dysmenorrhea may be influenced by psychosocial factors, rather than pain severity alone. This was used to inform the development of a quantitative survey to investigate the predictors of HRQoL outcomes among adolescent girls experiencing dysmenorrhea. Potential predictors of QoL entered into the initial model included pain severity, levels of depression and anxiety, pain catastrophizing, somatisation, and family functioning. The next sections detail the measures used in the survey:

Demographic information (age and school year) were collected at the start of the survey. A battery of the following questionnaires were then used to measure study variables (see appendix Q):

Menstrual Disorders of Teenagers Questionnaire (MDOT)

The Menstrual Disorders of Teenagers (MDOT) questionnaire (Parker, Sneddon, & Arbon, 2010) is used to obtain information about adolescents' menstrual characteristics including: regularity, duration and heaviness; menstruation-related school absence; dysmenorrhea, and the use and effectiveness of analgesia; other menstrual-related symptoms; interference of menstruation with life activities; and perceptions surrounding menstruation. The full questionnaire takes approximately 20 minutes to complete and was piloted with age appropriate adolescent girls (12-18 years) and questions modified based on their responses (Parker et al., 2010). For the purpose of this study, a subset of fifteen items from the MDOT questionnaire were used to obtain information about dysmenorrhea (e.g., pain severity) and menstrual cycles (including duration, regularity, and heaviness, use of analgesia, physical/emotional menstrual symptoms, and school absence) (Parker et al., 2010). A mixture of question types were used, including single and multiple response, rating scales, and true/false statements. The purpose of these questions were to provide contextual information about adolescent menstrual characteristics rather than provide a total score.

Visual Analogue Scale (VAS):

A recent systematic review of pain measures published in the Journal of Pain has recommended numerical pain rating scales such as the VAS for measuring pain in children and adolescents aged 8 years and above (Birnie et al., 2019). An 11-point Visual Analogue Scale (VAS) ranging from 0 (no pain) to 10 (worst possible pain) was used to measure the pain intensity of adolescents' 'usual' and 'most recent' period (McGrath, 1987). Self-report is considered the 'gold standard' of pain measurement ("Good Practice in Postoperative and Procedural Pain

Management, 2nd Edition," 2012). The VAS of pain severity is suitable for paediatric populations and has shown good reliability and validity in children aged 9-15 years old and convergent validity with other widely used pain scales (The Numerical Rating Scale of Pain) (r=.87) is excellent (von Baeyer et al., 2009). VAS scores were categorised as 0-3 (mild), 3.5-7 (moderate), 7.5-10 (severe) (Boonstra, Preuper, Balk, & Stewart, 2014).

Paediatric Quality of Life Inventory Version 4 (PedsQL 4.0)

The PedsQL was chosen over another commonly used adolescent quality of life scale the Minneapolis-Manchester Quality of Life Adolescent Questionnaire (MMQL) (Bhatia et al., 2002; Wu, 2006) due to its short completion time and consistency with the four WHO domains of QoL. The MMQL is much longer (46 items) and was specifically designed for adolescent survivors of cancer. This instrument also comprises seven quality of life domains (physical functioning, cognitive functioning, psychological functioning, body image, social functioning, intimate relations and outlook on life) which were not all necessary for answering this current research question. The PedsQL 4.0, a 23-item questionnaire measuring the core health dimensions outlined by the World Health Organization (WHO) (Varni, Seid, & Rode, 1999b) was used to measure adolescent qualtiy of life (QoL). Core dimensions include: physical functioning (8 items), emotional functioning (5 items), social functioning, and school functioning (5 items) (Varni, Burwinkle, Seid, & Skarr, 2003; Varni et al., 1999b). A 5-point response scale was used ranging from 0 (never a problem) to 4 (almost always a problem). Possible scores range from 0-92, with higher scores indicating poorer quality of life. The PedsQL 4.0 takes approximately 4 minutes to complete and is suitable for participants aged 8-18 years. Use of this generic HRQoL measure allows for benchmarking with both community and clinical samples from the existing literature (Varni, Seid, & Rode, 1999a). Internal reliability for self and proxy report scale total scores (.90) and internal reliability for all subscales (>.70) are good (Upton et al., 2005).

The State – Trait Anxiety Inventory (STAIC)

The STAIC was chosen as a way of measuring both state and trait anxiety, over other generic measures of children's anxiety such as the Revised Children's Manifest Anxiety Scale (RCMAS). Both measures have been shown to be effective in discriminating between children and adolescents with and without anxiety disorders and there is good convergent validity between the two scales (Seligman et al., 2004). The STAIC was chosen because previous research has found a 21% overlap between the RCMAS and the children's depression inventory (CDI) suggesting that some items are actually measuring negative affectivity rather than anxiety (Seligman et al., 2004). The 40-item STAIC measures anxiety symptoms in adolescents experienced over the past 2 weeks (Spielberger, 1983). The STAIC is made up of two scales measuring both state (how participants feel at the present time) and trait (how participants generally feel across different situations) anxiety. Both scales contain anxiety present (i.e. “I feel worried”) and anxiety absent (i.e. “I feel secure”) questions. Responses on the S-scale (state anxiety) range from 1- ‘not at all’ to 4- ‘very much so’. Responses on the T-scale (trait anxiety) range from 1- ‘almost never’ to 4- ‘almost always’. Total scores range from 20-80, with higher scores indicating higher levels of anxiety (Spielberger, 1983). The STAIC is suitable for participants aged 12 years and above. Test–retest reliability coefficients (0.31 to 0.86 and internal consistency (.86 to .95) range from good to excellent (Spielberger, 1983).

Children’s Depression Inventory (CDI) - Short Version

The CDI was chosen over other popular measures of psychological wellbeing including Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS) (Tennant et al., 2007) because, unlike the latter, the CDI has been widely used and tested with children and adolescents in recent research, commonly being used as a measure of depressive symptoms in clinical trials (Ahlen & Ghaderi, 2017; Sibinga et al., 2016). The CDI-short version, a 10-item self-report children’s depression inventory (CDI) (Kovacs, 1981) measured levels of depression in the adolescents over the past two weeks. Each item, representing a symptom of depression, is scored on a 3-point scale from 0 (no symptom) to 2 (severe form of the symptom). The CDI consists of six subscales including a) sadness, b) self-blame, c) loss of appetite, d) insomnia, e) interpersonal relationships, and f) school adjustment. Scores can range from 0 to 20 with higher scores indicating more depressive symptoms. The CDI is suitable for participants aged 7-17 years. The CDI has shown excellent reliability in community (.82-.84) and clinical samples (.85 -.81) (Masip, Amador-Campos, Gómez-Benito, & del Barrio Gándara, 2010).

The Children’s Somatization Inventory (CSI-24)

As the only known validated measure of children’s somatisation, the CSI-24 (Walker, Beck, Garber, & Lambert, 2009) was used to assess 24 nonspecific somatic symptoms experienced in the last 2-weeks (e.g., “weakness,” “dizziness”). Participants report how much they experienced each symptom during the last two weeks using a 5-point scale ranging from 0 (not at all) to 4 (a whole lot). Scores can range from 0 to 96. The total score is calculated from the sum of all answers and higher scores indicate higher somatisation levels. The CSI is appropriate for use in children and adolescents aged 8-17 years. The CSI has been found to have good concurrent validity, construct validity, and reliability coefficients (.87).

Children's Pain Catastrophizing Scale (PCS-C)

As the only known measure of children's pain catastrophizing, the 13- item PCS-C, an adaption of the adult version, measured catastrophic thinking about menstrual pain (Crombez et al., 2003). Participants in this study were asked to recall catastrophic thinking during their most recent menstruation. The PCS-C items describe different thoughts and feelings that adolescents might experience when they are in pain. Children rate how frequently they experience each of the thoughts and feelings using a 5-point Likert scale (0-not at all, to 4- extremely). The PCS-C yields a total score ranging from 0 to 52, with higher scores indicating more catastrophic thoughts. Each item is categorsied into three domains: helplessness (items 1, 2, 3,4, 5, and 12), magnification (items 6, 7, and 13), and rumination (items 8, 9, 10, and 11).The PCS-C is suitable for use with children and adolescents aged 8-17 years. The PCS-C has shown excellent validity (.87) and reliability (.88-.90) in both clinical and community samples of children and adolescents (Crombez et al., 2003).

Family Assessment Device (FAD-SF)

The Family Assessment Device (FAD) is a 53-item questionnaire used to measure family functioning (Epstein, Baldwin, & Bishop, 1983; Epstein, Bishop, & Levin, 1978). The FAD has 7 subscales including: 1) problem solving (5 items), 2) communication (6 items), 3) roles (8 items), 4) affective responsiveness (6 items), 5) affective involvement (7 items), 6) behaviour control (9 items), and 7) general functioning (12 items). The 'general functioning' subscale of the FAD was used to measure family functioning in this study. Participant responses ranged from 1- strongly agree to 4- strongly disagree, with higher scores indicating lower levels of family cohesion. The FAD can be completed by participants aged >12 years (Epstein et al., 1983; Epstein et al., 1978). The FAD has shown good reliability with samples of adolescents aged 12 years and older (> .70) (Bihum, Wamboldt, Gavin, & Wamboldt, 2002). Evidence from the literature has shown that the McMaster Family Assessment Device (FAD) is the most widely used family assessment measure (Sanderson et al., 2009), and that the use of the 'general functioning scale' alone is practical, reliable and valid (Hamilton & Carr, 2016).

Summary of quantitative data analysis

The data from the quantitative surveys were collected and analysed using multiple regression and mediation models (see chapter seven for details). Missing data were replaced using the Expectation Maximisation (EM) algorithm, an assumption of this method is that the data are missing randomly. Little's missing completely at random (MCAR) test was used to test this assumption. Data analysis of the EM imputed data set was conducted using IBM SPSS Version 24. Descriptive statistics were calculated for both categorical (frequencies and percentage) and continuous variables (mean and standard deviation). Assumptions were checked before continuing with multiple linear regression analysis including the normality of the data, the presence of any outliers, collinearity, and questionnaire reliability. The following variables were entered into a multiple regression model to predict the value of HRQoL outcomes among adolescents experiencing dysmenorrhea: 1) levels of anxiety and depression, 2) pain catastrophizing, 3) somatisation, 4) family functioning, and 5) pain severity (of both a usual and most recent period). The outcome of the analysis has been presented, in chapter seven as a correlation matrix, detailing the correlations between all variables entered into the model, followed by a 'model fit' including the standardised β, t value, and p values for each predictor value. Finally, mediation analysis was conducted using PROCESS (Model 4, Hayes, 2013), a MACRO of SPSS. The Preacher and Hayes' Bootstrapping method was chosen to investigate mediation.

Chapter summary

This research adopted a broadly critical realist approach to scientific enquiry. Like pragmatism, critical realism serves as a compromise between the positivist and constructivist positions. However, a critical realist approach was chosen to ensure that through the research process the impact of the researcher, who is viewed as qualitatively different to the participants, on the findings is considered. A mixed-methods approach to investigating adolescent dysmenorrhea was adopted with the aim of combining the strengths of each, while addressing the weaknesses of both. A sequential exploratory design was chosen whereby two qualitative studies exploring adolescent dysmenorrhea from the perspectives of girls (chapter five) and their mothers (chapter six) informed the development of a quantitative study investigating the predictors of QoL outcomes among adolescents living with dysmenorrhea (chapter seven). Through this sequential design, biopsychosocial factors associated with adolescent dysmenorrhea were identified and a working model of adolescent dysmenorrhea was developed.

Chapter 5 Exploring the Impact of Dysmenorrhea on the Lives of Adolescent Girls

5.1 Introduction

The need for up-to-date, methodologically rigorous research investigating the impact of dysmenorrhea on the lives of adolescents living in the UK was highlighted in chapter three. A scoping search indicated that, to date, just two studies have used qualitative methods to explore adolescent dysmenorrhea from the adolescents' perspective. Chapter five will begin by explaining why qualitative methods are an important tool to gain an in-depth understanding of paediatric chronic or recurrent pain. The two previous qualitative studies exploring the impact of dysmenorrhea on the lives of adolescent girls will then be reviewed and evaluated, followed by a review of the current qualitative research in the area of paediatric chronic pain of other aetiologies. An overall evaluation of the current literature will then be presented and gaps in current knowledge and understanding of this topic will be identified. Finally, the first empirical, qualitative study of this PhD thesis is presented.

The Qualitative Paradigm

Qualitative research provides the means to explore what happens to different groups of people experiencing the same, or different, phenomena. This is in contrast to quantitative research which is limited in its ability to describe those experiences in-depth and comment upon the complex interactions among the various factors that drive each individual's behaviour (Rich & Ginsburg, 1999). Qualitative research seeks to obtain in-depth, rich descriptions of individual experience, taking into account the context of the participant's world. Qualitative research is able to capture participants' perspectives in a closer, more detailed way than quantitative research which relies on distant, experimental methods (Stake, Denzin, & Lincoln, 2005).

Qualitative research is increasingly recognised as an important tool in pain research. Qualitative exploration enhances understanding of the biopsychosocial domains of pain experience and enables researchers to move forward in the development of theory in under-researched areas (Coyle & Tickoo, 2007; Mitchell & MacDonald, 2009). Research that focusses on the unique and subjective nature of pain adds to the growing body of literature which aims to understand the multifaceted experience of pain (Mitchell & MacDonald, 2009; Rich & Ginsburg, 1999). Qualitative data collection and analysis provide an in-depth understanding and description of personal experiences (Braun & Clarke, 2013) which can be particularly useful for exploring phenomena such as pain, which is entirely a subjective and individual experience. However, qualitative research with children is a relatively new concept in academia (Grover, 2004). Until relatively recently, most information obtained about young people with chronic illness and pain (published in medical journals) has been based on parent-reported quantitative data (Sällfors, Fasth, & Hallberg, 2002). Due to the subjective nature of pain, and the unique thoughts, feelings, and behaviours of young people, Sällfors et al. (2002) recommended that pain should be described by the young person directly. Childhood and adolescence are qualitatively different developmental stages to adulthood. Adolescence is a crucial period characterised by physical, psychological, and social upheaval and change (Rich & Ginsburg, 1999). When interpreting results from a quantitative study, adult researchers may overlook the adolescent point of view (Rich & Ginsburg, 1999). In contrast, qualitative researchers aim to ensure that areas of greatest concern to adolescents are explored by using open-ended questions and staying close to the original data set, so that the findings provide an adolescent-centred view (Rich & Ginsburg, 1999). Qualitative data collection methods often ensure that the voices of the participants are obtained and they are able to lead the researcher to focus onto the topics that are most important to them (Creswell, 2014). An important advantage of qualitative interviews is that it gives young people a platform from which to express their voice (Sällfors, Hallberg, & Fasth, 2001) and to describe, in their words, how pain impacts them as individuals within the context of their world, how they cope with pain, and what can be done to improve pain management.

Qualitative explorations of Adolescent Dysmenorrhea

A scoping review, in addition to the systematic review detailed in chapter three, identified two studies that have explored the experiences of adolescent girls living with dysmenorrhea (Aziato, Dedey, & Clegg-Lamptey, 2014; Chen, Lin, Heitkemper, & Wu, 2006). Data from these two studies were collected via focus group discussions with 23 Taiwanese adolescent girls aged 16-19 years (Chen et al., 2006) and in-depth interviews with 16 Ghanaian students aged 16-38 years from a secondary school and a university in Acca, Ghana (Aziato et al., 2014). The aims of these studies were to explore girls' bodily experiences, self-care strategies, and evaluations of those self-care strategies in relation to period-related pain (Chen et al., 2006) and the lived experience of dysmenorrhea (Aziato et al., 2014). Thematic content analysis and descriptive phenomenology were used to analyse the qualitative data, respectively.

The adolescents in Chen et al.'s (2006) study reported many accompanying symptoms (diarrhoea, constipation, lack of appetite, edema, fatigue, dizziness, and lower-back, upper leg and nipple pain), apart from pelvic pain, and the importance of those accompanying symptoms in influencing how they chose to self-manage dysmenorrhea. Emotional symptoms were also reported which included crying, emotional fluctuations, and seeking attention from family and friends who were often viewed as people with whom they could express their emotions. This was echoed in the theme ‘altered emotion and interaction’ from Aziato et al. ‘s paper (2014) where the girls expressed many negative emotions associated with pain, including feeling sad, angry, irritable, and depressed. The adolescents in Aziato et al.’s (2014) study also reported ‘activity intolerance’. In this theme, they described how dysmenorrhea hindered their activity. Girls reported needing assistance in walking and standing, and struggling to find a comfortable position to be in whilst experiencing severe pain. Some of the girls reported that they preferred to be alone rather than socialising when they were in pain. Similarly, the adolescents in Chen et al.’s (2006) study reported ways in which the girls self-managed dysmenorrhea such as reducing physical activity including bed rest, sleeping, not moving, school absence, avoiding swimming, avoiding exercise, and finding a comfortable position. The third theme in Aziato et al.’s (2014) study ‘altered sleep pattern’ showed that dysmenorrhea either resulted in loss of sleep, unusual sleeping positions (e.g., sleeping on the floor), or sleeping for longer periods. In the fourth theme ‘absenteeism and inattentiveness’, Aziato et al. (2014) reported that some girls were unable to attend school due to the severity of their pain while others who attended school struggled to concentrate on their work.

In contrast to Aziato et al.’s (2014) findings, other coping strategies employed by the adolescent girls were explored and reported in Chen et al.’s (2006) study. These included modifying diet (eating sweets, eating highly nutritious food, eating food with energy supplements, drinking hot beverages, and either increasing or decreasing fluid intake), using traditional Chinese herbal remedies suggested by their mothers (including traditional herbal medicine, herbal chicken soup, sesame oil chicken, Chinese wolfberry ginseng soup, Zhongjiang herbal soup, Xiaoya powder, dried longan stir-fried in sesame oil, and Baifeng pills), using medication (both prescribed and over-the-counter medications, and nutritional supplements), and using complementary therapies (acupressure, massage, aromatherapy, and heat therapy). Chen et al. (2006) concluded that, as adolescent girls are independent and responsible for their self-care, girls experiencing dysmenorrhea would benefit from effective, culturally appropriate education on beneficial self-care practices for dysmenorrhea. Although Chen et al. (2006) indicated that girls were asked to evaluate the self-care strategies used to manage dysmenorrhea, the outcome of this discussion was not reported. The authors discussed the efficacy of the various self-care strategies based on evidence from the existing literature rather than perceptions from the girls themselves. Based on Chen et al.’s (2006) conclusions that adolescents should be provided with effective information about dysmenorrhea management, it would have been beneficial to report on which methods the girls’ perceived as the most effective and comforting to them, and why. Also, although girls in this study reported a significant emotional aspect related to menstruation (e.g., crying and mood fluctuations) it was not reported whether this was as a result of menstrual pain or other factors associated with menstruation. Finally, focus groups are appropriate for collecting data about a topic that participants do not have a 'personal stake' in (Braun & Clarke, 2013). Therefore, this method of data collection may not be as appropriate for exploring adolescent dysmenorrhea compared to other, more personal methods such as individual interviews (Braun & Clarke, 2013).

From the qualitative studies summarised above, it is clear that adolescent dysmenorrhea had a negative impact on important aspects of girls' lives including school attendance, sleep and physical functioning. Aziato et al.'s (2014) report explored this impact further, indicating that adolescent dysmenorrhea had a profound impact on the girls' psychological functioning and perceptions of womanhood. In the fifth theme 'wishes and regrets', girls expressed regretting being a woman for having to experience regular pain, wished for early menopause, and some girls reported having suicidal thoughts when the pain was very severe. Finally, the last theme 'misconceptions' described fears of infertility for some students (Aziato et al., 2014). The findings showed that dysmenorrhea can be debilitating and the authors recommended enhanced education about period-related pain to address misconceptions and the negative emotions towards menstrual pain, particularly for those individuals that reported suicidal thoughts. Although Aziato et al. (2014) provided a detailed insight into the lived experience of dysmenorrhea, the broad age range of participants with no comparison between the different age groups limits the transferability of the findings. Adolescent girls in senior school may have responded very differently to the interview questions compared to university students (aged 20-30 years) and a thirty-eight year old PhD student. As research in this area is limited and only two studies have conducted qualitative research on adolescent dysmenorrhea, research on paediatric chronic pain of other aetiologies will now be summarised.

Qualitative explorations of Juvenile Chronic Arthritis

Several studies have used qualitative methods to explore the experiences of children and adolescents living with juvenile, chronic arthritis (Britton & Moore, 2002a; Sällfors et al., 2001; Sällfors et al., 2002; Sällfors & Hallberg, 2009). In two papers based on one study (Sällfors et al., 2001; Sällfors et al., 2002) the lived experience of juvenile chronic arthritis (JCA) was explored using qualitative, individual interviews (45-60 minutes) with 22 Swedish children (6-17 years; 16 girls; 6 boys). A purposive, open sampling technique was employed to recruit a heterogeneous group of children and explore a wide range of experiences. Interviews aimed to identify the strategies that children used to relieve their pain and included questions such as 'what do you do when you are in pain?', 'what do you think about when you're in pain?', and 'what can you do to reduce pain?' The core category that emerged was labelled 'making me different' which depicted psychosocial aspects of living with pain for these children and how pain made them feel different from their 'healthy' peers. Six categories of coping strategies were identified, including controlling strategies (planning, taking responsibility, taking command, doing your best) whereby the children described taking responsibility for their pain by prioritising activities and making daily decisions relating to their health. In some cases, children described participating in activities even when doing so would trigger pain, to be like their peers. Many children reported the use of avoidance strategies (ignoring, excluding, and withdrawing) and would cope with their pain by avoiding sports activities which could result in them feeling different from their peers and that they missed out on activities. Cognitive strategies such as positive thinking, talking to oneself, and wishful thinking were used by children who would tell themselves that they would not have to give up or that it was not important to join in with sports activities. Most children reported positive feelings about the use of medicines and compliance with the treatment (medicines, physiotherapy, and technical aids). Children also described their dependency on treatment to manage the pain, which also made many feel different to their peers. Children regularly sought social support (practical help, emotional support, professional support) in coping with their pain. Family members were important sources of support, love, confidence and empathy for all of the children. Children experiencing chronic pain often felt tired and time for recovery (rest, heat, relaxing leisure activities) had become very important for many of the children. Peer interactions were greatly affected by arthritis and being 'different' from their peers was a real source of worry and concern for the children. A second core category was identified from the findings, labelled 'oscillating between hope and despair'. Children described the pain controlling their lives and restricting their daily activities (including school activities such as physical education), and expressed feelings of frustration, powerlessness, and uncertainty about the future in relation to their disease. The stiffness caused by arthritis limited daily activities such as their ability to get out of bed in the morning. Fatigue as a result of pain also posed limitations to activities and the children felt that they could not live like their 'healthy' peers. Reactions from their peers were a significant concern to the children who felt that, due to the variation in symptom severity, their peers might not believe their pain. Many participants, who were part of a support group for children with rheumatic disease, expressed very positive feelings about such support groups. Feelings of dependency were also expressed in relation to medications and treatment for their pain. Many children felt that they could not turn down offers of support and help in case they were to need that same support in the future. Finally, the children's emotional reactions were labelled as powerlessness, frustration, distress, being left out, hopelessness, sadness, and aggression. Older children in particular felt very negatively about their disease and some stated that they 'wanted to die'. Daily life was consumed by feelings of worry and concern, often due to uncertainty about how severe the arthritis would be that day. These interviews showed that chronic pain had a profound impact on every aspect of daily life for the children and that everyday lives of these children differ significantly to that of healthy children. The authors suggested that professionals should listen to children's perspectives of their illness and give children more of an opportunity to describe their situation because only they can explain how they feel about their pain.

Other studies used a variety of methods to explore the impact of JCA on the lives of children and their families including survey data (for those using a mixed methods approach), semi-structured interviews and journals (Britton & Moore, 2002a; Sällfors & Hallberg, 2009). One study (Britton & Moore., 2002a) explored the lived experience of 46 children (aged 7-8 or 11-13 years; 13 boys and 33 girls) living in the UK. Each family were interviewed twice with a gap of eight weeks between. Children (>8 years old) were asked to write a diary called 'arthritis, my family and me' between each in-depth interview. Four families also made their own independent video diary with the same title. Ethnographic analysis (Gahan, Hannibal, & Hannibal, 1998; Miles & Huberman, 1994; Patton, 1990) of children's perspectives showed that many were reluctant to disclose their pain to family or peers, which the authors suggested, was due to children viewing pain as a normal part of their lives, especially those who developed arthritis from a young age. Many children reported that arthritis had a negative emotional impact; eliciting feelings of irritation, resentment and isolation due to feeling 'different' from their peers (Britton & Moore, 2002c). Some children reported feeling as though they were neither disabled, nor 'well' which increased their feelings of isolation because they did not fall into either category. The interviews identified that, for many children, the part of having arthritis that they felt most resentful about was feeling 'different' from their peers. Children described feeling as though they were neither 'well' nor 'disabled' because they spent some time as both.

Sällfors and Hallberg (2009) used both in-depth, individual interviews (approximately 60 minutes duration) and data from diaries to understand the day-to-day experiences of 18 Swedish female adolescents (14-17 years) with chronic arthritis. Interview questions were based on daily experiences with arthritis, and how it might affect the future. Six participants also kept diaries for 12 months focussing on the same topics as the interviews. The authors selected a heterogeneous group of girls based on age, duration of disease, family situation, and location to maximise the variation of experiences. Grounded theory (Glaser & Strauss, 1967) was used to analyse the data. Participant's main concern in relation to living with arthritis was identified as 'fitting into the prevailing teenage culture'. Girls expressed a desire to seem like a 'normal' teenager who was not restricted by arthritis. Girls described several ways in which they tried to be seen as 'normal' or to 'fit in' including 'mastering' their pain psychologically (being mentally prepared for pain), using social support by discussing their thoughts and feelings with others, living 'one day at a time', and 'fighting for health' (by adhering to treatment and managing their disease). The girls expressed feeling that they did not have control over their bodies and lives due to arthritis. They wanted to be physically active, participate in games, and do the same activities as their peers. One coping strategy was 'always being ready to change plans and make excuses' when they weren't able to take part in activities or social events. Girls also sought information on the best ways to manage their illness and pain. Girls reported worrying about if the pain was so severe that peers would not plan a shared activity. Social support was important to the girls in their struggles to fit into the prevailing teenage culture. The results showed that the girls tried to take control of the unpleasant consequences of pain and illness by living one day at a time which is a way of taking some control over the situation and dealing with the unpredictability of the illness.

Qualitative explorations of the experience of young people with chronic pain of various aetiologies

Several studies have used qualitative methods to explore the experiences of young people living with multiple types of chronic pain including musculoskeletal pain, JCA, chronic headaches (migraines; myofascial, vascular, tension, stress-related or other headache type), myofascial pain, functional neurovisceral pain disorder (functional bowel, uterine, bladder disorder), complex regional pain disorder or fibromyalgia (Jacobson et al., 2013; Meldrum, Tsao & Zeltzer, 2008; Meldrum, Tsao & Zeltzer, 2009). All three studies of children with multiple pain types used in-depth individual interviews to collect data; and two studies used grounded theory (Meldrum, Tsao & Zeltzer, 2008; Meldrum, Tsao & Zeltzer, 2009) and one thematic content analysis (Jacobson et al., 2013) to analyse the data. Similar to the reports from adolescents living with dysmenorrhea (Aziato et al., 2014; Chen et al., 2006), limitations in functioning were a commonly reported theme and children described that their pain interfered with their ability to attend school or take part in a favourite hobby/ activity (Meldrum, Tsao, & Zeltzer, 2008). Children reported that pain made them feel a number of negative emotions, including distress, sadness, anger, tiredness, worry, and resignation. Commonly, participants reported feeling annoyed or frustrated when they felt restricted by their pain. The authors identified three different ways in which the children were functioning with chronic pain. The most highly functioning children were categorised as 'adaptive', many of whom used distraction as a way of trying to reduce how much they focussed on pain. 'Adaptive' children were more likely to realise that focussing on pain would exacerbate it. 'Passive' children, who allowed the pain to take over their entire lives and dictate their level of daily functioning, were more likely to be overcome by the impact of pain, miss school, and report isolation. 'Stressed' children made attempts to continue functioning normally whist still focussing on the pain and were fairly high functioning despite high levels of pain-related anxiety. Many children felt isolated from their peers due to a lack of understanding about their condition.

Children also expressed concerns about their future such as whether their pain would interfere with their ability to go to college/ university and pursue future career plans. Three strategies for pain-related coping emerged which included ‘getting on with things’ where children would attempt to ignore the pain and continue with daily activities. ‘Getting on with things’ was a strategy used by all three groups of children (adaptive, passive, and stressed) although adaptive children incorporated distraction techniques in order to better manage daily activities. Adaptive children were unique in reporting the other two coping strategies including ‘planning ahead’ which included being organized and prepared for activities that might trigger pain, and ‘body awareness’ which included being more aware of bodily sensations and posture.

In a follow up study, Meldrum, Tsao, and Zeltzer (2009) identified four themes from their data from adolescents aged 10-17 years including not wanting to disclose pain to others, feeling isolated from peers, pain-associated activity limitations and concerns about how pain will impact life in the future. Many children reported that they decided to hide their pain from parents and peers to be seen as ‘normal’ and to reduce parental anxiety and stress. Several children felt that there was no purpose in disclosing their pain to anyone because there would be no benefit from it and they would not be able to relieve the pain. Pain also restricted many of the children’s goals and participation in daily activities. Narratives used by children included the ‘constant patient’ who believed that the pain could be cured when the right HCP or medication was discovered and therefore participated in many on-going treatments. The ‘invalid’ was a narrative characterised by children who felt defeated by their pain. The ‘weary soldier’ characterised the narratives of children who referred to life as an on-going struggle but coped with pain despite experiencing constant pain-related stress. The ‘stoic’ characterised the narratives of children who would mask their pain from others and continue with normal activities despite experiencing pain. The ‘positive thinker’ tended to use cognitive distraction techniques to cope with their pain, engage in their favourite hobbies, and seek help for their pain. Finally, the ‘decision maker’ characterised children who made independent decisions to change their lives for the better for example some children had developed from ‘weary soldier’ to making positive lifestyle choices and pain management decisions. Some children’s narratives changed over time and children were able to move from less effective coping narratives (e.g., the invalid) to more effective coping narratives (e.g. decision maker). This suggests that interventions can be used to improve children’s pain-related disability, pain perceptions and perspectives on how chronic pain impacts life. These studies highlight the fact that, although many children suffering with chronic pain have similar experiences, each child has their own unique story to tell.

Jacobson et al. (2013) conducted semi-structured, individual interviews with adolescents aged 8-18 years living with JCA or noninflamatory chronic pain. The original purpose of this study was to examine the content validity of the Patient-Reported Outcomes Measurement Information System (PROMIS) paediatric measure. The individual interviews aimed to explore the PROMIS domains (anger, anxiety, depressive symptoms, fatigue, pain interference, peer relationships, physical functioning). Similarly to other studies exploring childhood chronic pain, the children in this study reported negative emotions (feeling mad, sad, or upset) to specific triggers or events such as missing a social event due to their pain or having injections. Older children were able to better articulate differences between anger, anxiety, and depression and showed greater awareness of these emotions than the younger children. Children expressed that their chronic pain condition interfered with night time sleep and their ability to interact with peers, resulting in social withdrawal. Teenagers expressed preoccupation with managing social impressions e.g., not wanting to be judged as arthritic and trying not to act differently from their peers despite their chronic pain condition. Young teenagers (13-15) were concerned that, due to their pain condition, their friends could often "go overboard" with their sympathy, get nervous, *"might not wanna be around you"*, *"think bad of me"* for missing school, or *"thought I was boring"*. This highlights the importance of peer relationships and social perception to adolescents, and the limitations chronic pain can have in terms of their social world.

Medical Encounters in Paediatric Chronic Pain

Paediatric chronic pain patients often visit many health care professionals (HCPs), in search of diagnosis and treatment for their condition (Bennett, Huntsman, & Lilley, 2000; Dell'Api, Rennick, & Rosmus, 2007), although just one qualitative study has explored these encounters from the child's perspective. Dell'Api et al. (2007) aimed to understand how five children (10-17 years; two boys, three girls), recruited from a Canadian paediatric hospital, with chronic pain (located all over the body or the flank and renal, chest and abdominal, and leg area) perceived their interactions with HCPs to influence their pain experience. In-depth, semi-structured, individual interviews were used to collect data, with questions exploring experiences with HCPs, the information they took away from those experiences, and how HCP interactions influenced their pain experience. The transcripts were analysed using interpretive description based on an inductive approach (Thorne, Kirkham, & MacDonald-Emes, 1997). Observational field notes were also taken by interviewers. Line-by-line open-coding was applied and themes reflecting the HCP-child interactions emerged. The study describes how children felt disbelieved and misunderstood by HCPs which resulted in feeling abandoned and unsupported by the health care providers. Many children also felt that they were being 'dismissed' when their physicians referred them to a specialist and as if the doctors were 'wiping their hands clean'. All of the children described the search for understanding during which children would undergo multiple examinations, and treatment regimens. Many ineffective treatments trialled and conflicting information also left the patients feeling disappointed and that their treatments were ‘useless’. The findings also highlighted that four children had resorted to questioning whether they should continue to visit HCPs due to a combination of poor pain management, and lack of understanding on the part of both themselves and their HCP. Previous, negative HCP encounters also impacted on the children’s current experiences with HCP’s, leaving them with low expectations of these interactions. Children also reported that their perceptions of chronic pain had been influenced by HCP interactions. For example, due to a lack of explanation or understanding for the cause of their pain, children felt fearful for the future and often perceived their pain as either life-threatening or something they would have to deal with for the rest of their lives. Finally, as a result of poor pain management the children expressed a profound, negative impact on all aspects of their daily lives including school attendance, and participation in social or athletic activities. These interviews demonstrate that, among this sample, HCP interactions were an important factor in, and influenced many aspects of a child’s experience of chronic pain. The authors suggest that further knowledge of what influences the experience of paediatric chronic pain can be used to provide a foundation for HCPs to develop effective care for children and, hopefully, influence more positive experiences.

Limitations in the Current Literature

Although Dell'Api et al.’s (2007) findings indicate that HCP interactions can have a profound influence on a child’s experience of pain, of the nine qualitative studies reviewed, just one focussed on experiences with HCPs from the child’s perspective. The children in this study reported strong feelings in relation to their HCP encounters, with some children considering not accessing HCP care in the future due to previous negative experiences. It is therefore of critical importance to children’s pain experience, management, and care that they are able to discuss their HCP and treatment experiences. Also, five of the studies looked specifically at the impact of JCA on the lives of children and adolescents (Britton & Moore, 2002b; Britton & Moore, 2002; Sällfors et al., 2002; Sällfors et al., 2001). Moreover, the four remaining studies recruited children experiencing chronic pain of various aetiologies including migraine, functional bowel pain, fibromyalgia, and musculoskeletal pain. Therefore, despite the importance of using qualitative research to explore under-researched areas, condition-specific research in the area of paediatric chronic pain, from the child’s perspective, is particularly limited (Coyle & Tickoo, 2007; Mitchell & MacDonald, 2009). Qualitative research aims to give children and adolescents the opportunity to discuss areas of their lives and concerns that are most important to them. Although Jacobson et al. (2013) aimed to explore how children understood each of the PROMIS domains, in each interview they only explored up to four domains. Therefore, all of the children may not have had the opportunity to discuss the impact of their pain condition in terms of what is important to them and the findings may not represent the children's experiences of chronic pain as a whole. Meldrum et al. (2008) reported that they audiotaped and videotaped their interviews with the children and adolescents. They do not report why they have chosen to do this or what added benefit it may have had to the analysis. It is possible that adding 'video' to the qualitative interviews may have limited the quality of data that was obtained. Several recording devices may have served as a distraction to participants and made them feel more inhibited and self-aware. In-depth, open-ended qualitative interviews were used to explore the experiences, thoughts, feelings, and beliefs in many of the qualitative studies exploring the impact of paediatric chronic pain in the majority of the current studies. This is a powerful method for capturing the daily experiences of these children/ adolescents. Several methodologically strong studies used multiple methods of data collection (Britton & Moore, 2002b; Britton & Moore, 2002; Sällfors et al., 2002; Sällfors et al., 2001) including individual interviews, written diaries, and home-video diaries. Finally, Sällfors et al. (2001) purposively recruited a heterogeneous sample of children and adolescents (Sällfors et al., 2001) with JCA which allowed the authors to report on a wide range of experiences and improve the transferability of the findings. However, none of the reviewed studies conducted a subgroups analysis to compare and contrast accounts of chronic pain between children and adolescents of different ages, genders, or other demographic characteristics.

Dysmenorrhea

The current literature suggests that chronic pain has a profound negative impact on all aspects of life for young people. In addition to this, dysmenorrhea may pose other condition specific concerns. Although adolescent dysmenorrhea shares many similarities with other paediatric chronic pain disorders there are factors that make dysmenorrhea unique. For example, dysmenorrhea is a regular, cyclic pain associated with menstruation which is often perceived as a 'normal' part of womanhood. This therefore suggests the need for an exploration of the biopsychosocial factors associated with adolescent dysmenorrhea. This also opens up questions about whether the predictability of pain influences pain management, how girls prepare for pain, and whether the anticipation of monthly pain impacts on HRQoL. Also, chapter three highlighted the variety of unpleasant symptoms that can accompany dysmenorrhea including breast pain and swelling, diarrhoea, nausea, acne, and bloating. It is likely that these accompanying symptoms will also impact on the girls' quality of life and contribute to their experience of pain. This further supports the use of qualitative research which may help to untangle the girls' experiences of dysmenorrhea and accompanying symptoms. Finally, chapter three highlights that up to 93% of girls between the ages of 12 and 18 experience some form of period-related pain. It is therefore likely that young girls experiencing this pain will know others with dysmenorrhea. This is qualitatively different to many paediatric chronic pain disorders for example, approximately 9-15% of all children experience chronic abdominal pain (Sparks, Garin-Laflam, & Cravero, 2015). Finally, dysmenorrhea affects girls, not boys. Research has identified sex differences in how pain is perceived, reported, managed, and treated (Bartley & Fillingim, 2013). As a result, dysmenorrhea needs to be explored to identify exactly how menstrual pain impacts on HRQoL among adolescent girls, living in England.

In sum, the existing qualitative literature has highlighted the importance of peer relationships and social perception for young people experiencing chronic pain (Britton & Moore, 2002c; Jacobson et al., 2013; Meldrum et al., 2008; Mitchell & MacDonald, 2009; Sällfors et al., 2002; Sällfors et al., 2001) as children expressed deep concern and feelings of isolation at being perceived as ‘different’ from their peers. The majority of the current qualitative evidence is based on JCA, and just two studies, conducted in non-western cultures have explored adolescent dysmenorrhea. Although adolescent dysmenorrhea is characterised by recurrent pain, gender differences, the way in which menstruation (and in particular, menstrual pain) is perceived as a ‘normal’ bodily function, and the ‘taboo’ nature of menstruation as a topic means that adolescent dysmenorrhea should be explored separately to that of other chronic pain conditions. The current study therefore aims to address the gaps in existing literature by using qualitative interviews to give adolescent girls experiencing dysmenorrhea and living in the UK, a voice.

The aim of this research was to explore, using individual in-depth, semi-structured interviews, the impact of dysmenorrhea on the lives of adolescent girls aged 12-18 years. The study explored the following research question: How do adolescent girls (12-18 years) experience dysmenorrhea and how does it affect all aspects of their lives including physical, psychological, school and social functioning, and well-being?

5.2 Method

The methodological considerations are presented, in detail, in Chaper 4.

5.2.1 Study Design and Tools

A protocol (appendix G) was developed by the primary researcher (PL) and reviewed by Professor Sarah Creighton, a University College London Hospital paediatric gynaecologist with a special interest in adolescent dysmenorrhea. Based on feedback, modifications relating to a) accurate medical descriptions (specifically, aetiology of both primary and secondary dysmenorrhea), and b) recruitment strategies (specifically, advice on how to invite participants to engage in the study) were implemented into the final draft of the protocol.

Ethical approval for this study (ID: 12099; 12871) was obtained on 09.10.2014 by the University of Southampton Ethics Committee. Participants completed one interview which took place at the University of Southampton (interview room located on Chamberlain Road) (n=2) and participants' homes (n=18). The majority of participants reported preferring to be interviewed at home because they would not need to travel to the university. All young participants (<16 years) (n=9) were asked if they would like their parent/ guardian to wait nearby during their interviews. No participants wanted their parent present during the interviews.

In-depth, semi-structured interviews with adolescents were chosen to explore the impact of dysmenorrhea on all aspects of adolescents' lives. This method was ideally suited to experience-focussed research questions. Interviews are an optimal method for exploring thoughts, feelings, and behaviours about a topic that participants have a 'personal stake' in (Braun & Clarke, 2013). A semi-structured interview design, using open-ended questions was implemented to allow participants to discuss issues important to them. As adolescent dysmenorrhea is a relatively under-researched area, open-ended interviews were chosen as the method of data collection to broaden the possibility of addressing new, unanticipated topics (Braun & Clarke, 2013; Kortesluoma, Hentinen, & Nikkonen, 2003). Each interview followed an interview schedule (see full interview schedule in appendix G), developed by the researcher based on discussions with academic supervisors and previous research (Chen, Lin, Heitkemper, & Wu, 2006; DiCicco-Bloom & Crabtree, 2006; Sällfors & Hallberg, 2009). The interview questions were also developed based on a reflection of the key biopsychosocial models of paediatric chronic pain introduced in Chapter 2. Questions were chosen which explored the biological (e.g., regarding dysmenorrhea characteristics), psychological (e.g., regarding self-esteem and coping with dysmenorrhea) and social aspects (e.g., regarding social acitivites) of dysmenorrhea. Family systems theories suggests that families are an important context for understanding paediatric chronic pain (Chambers et al., 2002). Therefore, questions related to family functioning and dysmenorrhea were included in the interview guide. Prompts and probes (e.g., can you tell me more about that?) were used to encourage participants to clarify, expand, elaborate, and provide more detailed answers (Braun & Clarke, 2013). This qualitative phase of the research process was iterative, which allowed the researcher to focus interviews on areas that were most important to the participants. As data collection proceeded, an enhanced understanding of important issues led to interview guide alterations. For example, while collecting data from the adolescent girls, many girls expressed reluctance to stay over at friends' houses while menstruating, resulting in the addition of 'sleepovers' as a prompt when asking girls about the impact of dysmenorrhea on their social activities. This iterative, and very flexible research process allowed the interviewer to modify interview techniques based on the adolescents' individual and cognitive development stage (Faux, Walsh, & Deatrick, 1988). The interviewer sought to ask interview questions in a way that would be understandable to each participant. For example, when younger participants referred to their period-related pain as a ‘tummy ache’, the researcher mirrored the terms used by the girls to aid the understanding of questions, which was also conducive to building up rapport. Also, if participants asked for clarification or appeared to misunderstand, the researcher re-worded questions by simplifying the language used, expanding an explanation, and using appropriate examples. Once all interview topics had been covered, participants were thanked and asked whether they would like to add anything before the audio-recording stopped. When this question was posed, all but one participant reported that the interview guide had covered everything that they wished to discuss. Participant 19 (14 years) added information about toilet use at school as she felt she had more to say about this topic. All interviews were audiotaped and transcribed verbatim.

Table 1 Interview Guide

Topics	**Subject Prompts**
Overview of period pain	Menarche, pain onset, accompanying symptoms, pain development/ change, pain patterns, general health.
Pain management	Medical visits, examinations, causal attributions, treatments (and their efficacy), self-help strategies, future expectations.
Impact on QoL	School attendance and performance, daily activities, sibling relationships, hobbies/sports, friendships, social life, family life, self-esteem, future plans, social activities, coping, support available.

3.2.2 Participants

Twenty participants were recruited (see Table 2 for participant characteristics). Recruitment finished once data saturation, the point where additional data fails to generate new information (Morse, 1995; as cited in Braun & Clarke, 2013), had been achieved. A sufficient number of girls experiencing dysmenorrhea were recruited to analyse the impact of adolescent dysmenorrhea on all aspects of life.

From a historical point of view, adolescence starts with the commencement of puberty, and ends with transitions into marriage and parenthood (Feldman & Elliott, 1990; Patton et al., 2016). However, more recently the definition of when adolescence begins and ends is less consistent. Adolescence is now commonly defined based on the adoption of responsibilities and stereotypically 'adult' behaviours. This includes becoming employed and financially independent, in addition to forming serious personal relationships. To add more complexity, these typically 'adult' behaviours differ significantly depending on context and culture (Patton et al., 2016). For the purpose of the research in this thesis, the World Health Organization's (WHO) definition of adolescence as between the ages of 10 and 19 years was adopted. In this study, adolescent girls who were attending secondary school/ sixth form form (aged 12-18 years) were chosen as eligible for inclusion.

Inclusion criteria for this study included: a) female gender, b) aged 12-18 years old, c) have experienced period-related pelvic pain of varying severity d) for a minimum of 3 consecutive months (or 3 consecutive menstrual cycles), e) be fluent English speakers, and f) provide assent/consent where necessary.

Exclusion criteria for this study included: a) male gender, b) aged <12 years or >18 years, c) not fluent English speakers, d) unable to provide assent or comply with study procedures, e) diagnosed with learning difficulties, and f) diagnosed with a major psychiatric disorder.

5.2.2 Procedure

Purposive sampling was employed (Patton, 1990) so that a heterogeneous sample of girls experiencing dysmenorrhea in terms of age, length of time with dysmenorrhea, and pain severity were recruited. This was achieved by recruiting from a variety of sources including: a) One secondary (all-girl) school in Southampton, b) two local newspapers (Daily Echo, Hampshire Chronicle), c) a press release (from the University of Southampton), d) The Vulval Pain Society (VPS) and Pelvic Pain Support Network, e) the University of Southampton (via posters and SUSSED advert (to staff and students of the University of Southampton), f) local youth groups and community centres (Youth House Community Centre, West End Parish, Townhill park Community Centre, Young Southampton Facebook Group, Breakout Youth, The Garage Youth Centre, Fareham Youth Council, Hampshire Isle of White Army Cadet Force, Basingstoke Youth Movement) (via Facebook messages and posts, posters and leaflets), local 'mum' groups via Facebook messages and posts (Southampton mums buy and sell board), and through g) snowball sampling (whereby participants referred their friends, eligible potential participants, to the researchers information). Contact was made with a senior teacher at a local secondary school to ask permission to recruit female students aged 12-18 years (see information sent to local schools in appendix H). Once permission was granted, study posters were sent to school personnel for approval (appendix I). Once approved, posters were given to school personnel where they were placed around school buildings and noticeboards. The researchers contact details were provided on the poster and students were asked to contact the researcher's directly if they would like to participate.

All potential participants were given an information sheet (appendix J) tailored to their age and language abilities. Information sheets detailed all aspects of the study (PhD aims and study aims and methods), participation requirements (interview procedure), and information regarding right to withdraw and confidentiality (e.g., audio-recordings and any identifying information attached to data will be destroyed post transcription). Younger participants (<16 years old) provided written informed assent once fully informed parental consent for their participation was provided. Informed consent (adolescents aged 16-18 years) and assent (children aged <16 years) were obtained (appendix J) via a dated signature and kept at the University of Southampton in a locked filing cabinet.

5.2.3 Ethical Considerations

Before each interview, the researcher introduced herself and the study again, participants were thanked and reminded of their right to withdraw at any time, confidentiality unless they disclose that they or anyone else is in danger of harm, and that the interview will be recorded (recordings will be listened to by study researchers only). All participants were assured that there are no right or wrong answers and were asked if it was OK for the researcher to start the recording and the interview. At the end of the interview, once all topics from the interview schedule had been covered, participants were asked if they would like to add anything, thanked and the recording stopped. Participants were then debriefed. Finally, all participants were given the option of being entered into a raffle where the winner received a prize worth £20-£30. Twenty participants took part in the raffle. To ensure data protection, audio-recordings and transcripts were kept on a password protected computer. Adolescents experiencing recurrent pain (e.g., dysmenorrhea) are classified as a vulnerable group (Kortesluoma et al., 2003). Therefore, procedures were put in place to ensure their safety at all times.

5.2.4 Analysis

Inductive thematic analysis was used to analyse the data, using Braun and Clarke (2006)'s step-by-step guide. Immersion in the data began with transcribing the audiotaped interviews which were then read and re-read. Manual, open-coding was employed, based on sematic meaning in the data. Each code was mutually exclusive and all aspects of the data were given equal attention. As the analysis progressed, when the same concepts were identified, they were placed under the same label and as new concepts were identified in the data, the initial codes were revisited and refined. A credibility check was conducted whereby an academic supervisor (CL) reviewed random coded transcripts to ensure consistency. Once all of the data had been coded, all codes and extracts were revisited and potential patterns were searched for. Similar codes and extracts were then organised into categories. The researcher is viewed as 'active' and so, in contrast to many qualitative reports, themes did not simply emerge but were identified and developed by the active researcher. Potential themes were discussed by the research team and reviewed based on Patton's (1990) dual criteria for judging categories, based on whether themes appear to have internal homogeneity (consistency within each individual category) and external heterogeneity (each category was qualitatively different from the next). If themes did not meet these criteria, they were changed or the extracts within the theme were moved. Once the data had been analysed as a whole, a subgroup analysis was conducted. Themes, codes, and excerpts were compared between young teenagers (12-15 years) and older teenagers (16-18 years). A detailed paper trail recorded the development of the analysis from initial codes to the finalised themes. The final results describe all themes relating to how dysmenorrhea affects young women and how they cope with these affects. Verbatim quotes used in the results section of this paper were chosen as appropriate representations of each theme. Finally, Braun and Clarke's (2006) 15-point checklist of criteria for good thematic analysis was referred to during data collection, analysis, and write-up of the report.

5.3 Results

5.3.1 Introduction to results

Overall, twenty interviews lasting 15.32 to 42.51 minutes (M= 27.95 minutes) were transcribed verbatim and coded. One overarching theme titled 'Dysmenorrhea has a profound impact on all aspects of adolescent girls' lives" derived from inductive thematic analysis. Within this overarching theme, four key themes and seventeen subthemes were identified (see Table 3). To begin with, contextual information derived from the data regarding dysmenorrhea characteristics are presented. This is followed by the presentation of the key themes and subthemes. Verbatim quotations were selected from original transcripts to aid understanding of each of the themes and subthemes. Quotations have been used liberally throughout the text so that the experience of adolescent dysmenorrhea can be explained in the girls' own words.

Table 2 Participant demographic and menstrual characteristics

Characteristics	**Frequency (n)**	**Range (*M*age)**
Age (years)		12-18 (15)
12-15	9	
16-18	11	
Age at menarche (years)		10-16 (11.9)
10-11	9	
12-13	10	
14-16	1	

5.3.2 Descriptive presentation of contextual information

As shown in Table 2, menarcheal age ranged from 10-16 years. The onset of dysmenorrhea varied from menarche 'yeah, it was as soon as my, as soon as I started at like 11' (pp2, 17 years) to two years post menarche 'Errr I started getting it when I was about 13' (pp17, 14 years). Some of the girls described the pain as gradually 'building up' over time, whereas other girls reported that the pain had improved over time.

Pain was located in a number of areas including the 'lower abdomen', 'where your womb is', 'groin area', 'vaginal area', 'legs', 'thighs', 'lower back', 'bladder', 'just below my belly button', and 'everywhere'. Girls used a variety of ways to describe dysmenorrhea such as feeling 'uneasy', 'harsh squeezing', 'cramps', 'throbbing and aching', 'twisting', 'sharp pains', 'churning', 'pulling', 'stabbing', 'uncomfortable', and feeling like they 'needed to curl up into a ball'.

The frequency of pain varied between girls, some experienced pain every month whereas others reported patterns of pain 'it normally goes from, I'd say, two months good then two months really bad pain'. The duration of pain generally lasted from 'a few hours' to an entire week per menstrual period. Many girls reported that pain intensity would vary between periods 'I think it depends you know, sometimes it can be more painful but there's other times when the first few days it'll be bad but I can cope with it'. Girls commonly reported greatest pain intensity at the beginning of menstruation when menstrual flow was at its heaviest. In addition, numerous accompanying symptoms were reported including heavy menstrual flow, loose bowels, mood swings, bloating, headaches/migraines, acne, nausea, vomiting, loss of appetite, fatigue, muscle aches, hunger, breast pain, dry hair and skin, body odour, back ache, sweating, dizziness, and feeling 'ill' or 'rubbish'. Just three girls reported no accompanying symptoms.

Nine girls had been prescribed medical treatment to help relieve their pain. Of those who reported using the oral contraceptive pill (OCP), the majority reported that it had been very effective in regulating their periods and relieving menstrual pain. For some girls, taking the OCP had controlled the pain to such an extent that additional medications such as paracetamol which would previously had only partially provided relief, were now effective in controlling remaining pain:

> *"Err now definitely, now if I've got the pain I'll just take a paracetamol or codeine so I can control it fine now but previously not at all"* (pp1, 17 years)

However, this was not the case for all girls as one reported that, although the OCP improved menstrual regularity, the intensity of dysmenorrhea increased:

> *"the pains with it were quite bad and so I went on the pill for it cause they were quite irregular as well and it made them more regular but more heavy and more painful"* (pp14, 17 years)

Finally, n=3 girls had undergone investigation into a possible pelvic pathology. Overall, these girls reported feeling embarrassed or frightened during health care appointments but felt that the need to relieve the pain was more important:

> *"I think I'd be pretty frightened you know, a hospital for a younger person is a frightening place but at the same time, I felt like I'd finally gotten through…I felt like they were paying more attention to it and I felt like I would get a breakthrough and the hospital appointments were what led me to be put on the contraceptive pill which did in the end make things better- so they were quite a positive thing."* (pp1, 17 years)

Overview of themes

Within the overarching theme 'dysmenorrhea had a profound impact on all aspects of adolescent girls' lives', from the inductive thematic analysis, four key themes were identified: 1)

Managing period pain; 2) Period pain is restrictive; 3) Negative emotions associated with dysmenorrhea and accompanying symptoms; 4) The complexities of managing relationships while experiencing period pain and the complexities of managing relationships while experiencing period pain (see Table 3). The following section presents these themes and their subsequent subthemes:

Table 3 Table of themes and their associated subthemes.

Theme	**Subthemes**
Managing period pain	- Influences on help-seeking behaviours - The integral role of mum in managing dysmenorrhea - Misconceptions about the oral contraceptive pill - Interest in holistic pain management approaches - The experience of pain changes over time
Period pain is restrictive	- Period pain negative effects physical functioning - Difficulty performing usual activities - Weighing up the consequences of being absent from school versus attending while in pain - Reluctance to engage in PE while menstruating
Negative emotions associated with dysmenorrhea and accompanying symptoms	- I resent feeling like this - Anxiety, helplessness and pain-catastrophising - Focussing on the pain - Feeling self-conscious
The complexities of managing relationships while experiencing period pain	- Conflicts and negotiations with school staff - Tensions between family members during menstruation amplified by pain - Dysmenorrhea can have a positive impact on future family functioning - Period pain, social activities and friendships

5.3.3 Theme One: Managing period pain

Managing period pain is the first theme that identifies the many strategies used by the adolescents in this study to manage their monthly pain. This theme outlines the factors that influence whether or not adolescents sought support from others; the importance of mothers in helping them to cope with their pain; misconceptions about the use of the contraceptive pill which influences its use with pain management; and how the way in which period pain is managed, and therefore experienced, changes over time.

Influences on adolescents' help-seeking behaviours

The majority of adolescent dysmenorrhea is self-managed. For the participants in this study, there were various sources of support available from which girls were able to seek help for their pain. These included relatives, friends, boyfriends, health care professionals, and school staff. However, girls displayed clear preferences for whom they would seek support from.

Help-seeking for period pain was influenced by the girls' perceptions of gender and whether or not menstruation was considered a taboo topic. Gender played a key role in the girls' help-seeking behaviours, all of whom preferred to discuss menstrual issues including dysmenorrhea with women than men. This was because they felt as though women were able to relate to their issues and therefore empathise with them:

> *"Yeah, I prefer to talk to a woman. Just because of the relatability. I know that they would understand"* (pp6, 16 years)

> *"Err no, so it really, they (boys) don't really get it and they're a bit like disgusted by it like that's what makes them go away (laughs). They're just like 'ohh OK, ergh' (laughs)"* (pp11, 16 years)

Menstruation is still a relatively 'taboo' topic that many adolescent girls often feel too shy to discuss. Previous research has shown that approximately 80% of adolescent girls with problematic menstrual symptoms do not seek professional medical advice. The girls in this study indicated that they struggled to speak to a male doctor about menstruation. Many explained how they would not talk to a man about period pain because it would be *'awkward'* and they just *'wouldn't understand'*. These factors inhibited girls seeking menstrual-related support from their dads too:

> *"Oh god no, I'd never go to my dad. That's too awkward. He don't get periods, he don't know"* (pp17, 14 years)

This gender preference around the discussion of menstruation did not extend to romantic relationships. This is possibly explained by the importance placed on peer and romantic partners during the adolescent period. The girls who reported having a boyfriend at the time of interview (n= 4) had discussed dysmenorrhea with them and described their boyfriends' response as understanding and supportive. Boyfriends were a key source of social support to the girls, helping them to cope with the pain by using distraction techniques such as *'sending me YouTube videos'* and *'telling me to go and play with my cats'* (pp2, 17 years).

In addition to the gender of the health care professional, girls described other barriers to seeking medical help for dysmenorrhea. Overall, 12 girls had not sought help from HCPs for their pain; the barriers to doing so included: the normalisation of period pain (*'it's not something you go to the doctors for'*), the pain not being severe enough, believing that the doctor would not be able to relieve their pain, unsuccessful previous experiences, and unwillingness to take medication:

> *"I haven't really thought about it but I don't know what they'd do, it's just period pain so I don't know if they can do anything about it."* (pp16, 14 years)

> *"Um, I haven't' really been before as I've not started long ago but it's like pain that all of us will get so it's not that, not something I've got, not something that isn't, something that's unusual so I haven't been to the doctors about anything."* (pp19, 14 years)

> *"Again, similarly with the doctors- it was frustrating 'cause they were kind of grouping everybody together so rather than looking on an individual basis how it's affecting one individual they should be a bit more considerate I think."* (pp1, 17 years)

> *"erm at first they were really quite annoying and they said oh you just need to eat well and do loads of exercise and drink loads of water and I thought OK fair enough (laughs) and then I went 3 more times I think during the course of the year and they said the same thing again and again."* (pp2, 17 years)

Interestingly, several of the girls reported feeling averse to taking medications that were *'unnatural to the body'*. Other girls disliked swallowing tablets even if they knew it would help to relieve the pain. These girls reported that they would rather experience pain than ingest an analgesic:

> *"I'm not a big fan of taking medication um, I don't know like, I'm like 'it'll go away, it'll go away' so I kind of just leave it to settle yeah and…."* (pp9, 15 years)

> *"I don't know I just don't really take tablets for anything and just deal with the pain and yeah get through it…it's just swallowing the tablet"* (pp19, 14 years)

Generally, the majority of girls did not view teachers and other school staff as key sources of social support. Although the girls described times when they had sought help with period pain at school, they perceived the staff as unsupportive. In response to their help-seeking, school staff were often described as *'rude'* and *'unhelpful'*.

> *"Well, because obviously every woman gets a period they've, they've obviously had an easy time with periods and they, they don't know how I get and if you say I don't feel very well they say 'oh every woman gets it' and they kind of take you back to class and say 'you'll be alright' and everything erm, and they don't really make you feel comfortable and erm like that you can take a break"* (pp3, 13 years)

Finally, age also influenced whether girls could seek help and support from their peers. In contrast to older adolescents, younger girls reported that some peers hadn't yet reached menarche which limited the number of peers that could empathise with them and their social support network. This suggests that social support from peers may increase as girls' progress through adolescence:

> *'two of my other friends haven't started so I guess they don't understand as much as my two friends that have but they do know that I get it bad'* (pp3, 13 years).

The integral role of mum in managing dysmenorrhea

As has been found from previous work, the girls in this study described their mothers were the key caregiver in managing their menstrual symptoms. Mums were their primary, and sometimes only, source of support when experiencing menstrual pain:

> *"I wouldn't get out of bed. It was um 'mum bring me soup, bring me my hot water bottle, and dose me up on medication because I don't want to feel the pain"* (pp15, 16 years)
>
> *"well she'll (mum) let me stay off and she'll make me a hot water bottle and things like that and just sympathise really"* (pp17, 16 years)

The salience of the mothers' role in helping them to manage their pain was highlighted in most of the adolescent interviews. Girls with severe dysmenorrhea were aware of the caregiver burden placed on their mother. For example, some expressed guilt that their mums were occasionally absent from their jobs to stay at home with their daughter or for period-pain related medical appointments:

> *"Err not in a negative way, I mean aside from maybe mum having to take time off work to take me to hospital or doctors, or if I was in pain she wouldn't like to leave me alone so she probably had about the same amount of time off of work as I did for my school."* (pp1, 17 years)

> *"Erm, her employers were fine with it, but I do think she had the worry in the back of her mind of either letting them down of missing out on the money…I still think it played on her mind a bit but moreso worried about the pain than missing work."* (pp1, 17 years)

Girls talked about the impact they had on their mother's sleep. Some would wake them up in the middle of the night for comfort and pain relief:

> *"And also it probably affects my mum in the fact that I wake her up in the night because it's so painful, I need her to get me stuff."* (pp5, 16 years)

> *"But then it's probably not made it, you know, if I'm keeping her up at night that makes her stressed."* (pp5, 16 years)

Misconceptions about the oral contraceptive pill: *'I thought it was for contraceptive use only'*

Although the OCP is a widely used and effective treatment for primary dysmenorrhea, many of the girls displayed misconceptions surrounding the OCP, which acted as barriers to treatment. Many of the girls shared a belief that the OCP was used for contraceptive use only and were surprised to find it could help relieve period pain. This could therefore act as another explanation for why adolescent dysmenorrhea is poorly managed:

> *"Err well, I was talking to, well (friend)…and I was like oh how are you so alright cause I was really not, has everything gotten better, and she told me that she's gone on because of something…I was really confused because I thought that was only for birth control and she was like no it's not because it controls erm your hormones as well."* (pp2, 17 years)

> *"Erm well I was a little bit shocked because I thought oh I thought that was for contraceptive use only"* (pp7, 16 years)

Even when girls knew that the OCP could be a 'long-term solution for the pain', their mothers' perceptions of the OCP also acted as a barrier for treatment. For many girls, disclosing this form of treatment to mothers was a serious cause for concern:

> *"Well I never really told her… she was like cleaning my room and putting stuff away in my drawers and stuff and she just came and said what are these and I was like they're for my periods and she was like why, when did this happen and I was like a little while ago and she was like why didn't you tell me about it and I was like I didn't want you to be cross with me"* (pp14, 17 years)

The association between the OCP and sexual activity made girls feel anxious about disclosing the use of the OCP to mothers and peers. The stigma surrounding the OCP at a young age caused some girls to either hide or avoid this treatment:

> *"I didn't want her to think I was sleeping around or anything so yeah."* (pp14, 17 years)

> *"Definitely cause of my age…if I went into school and people knowing like if you say oh I'm on the pill, it doesn't sound very…it doesn't sound very nice (laughs). People generally relate it to pregnancy and sex erm definitely people in my year, some of the guys are more immature, whereas the girls understand obviously, they definitely will link it to 'sluttyness' like if that's a word."* (pp18, 13 years)

Interest in holistic pain management approaches

All participants reported using self-care techniques and/or treatments to relieve their pain such as a variety of distraction techniques including television, pets, hobbies, exercise, school work, sleep, and social activities to take their mind off of the pain:

> *"I try and just kind of like move my mind somewhere else because it is painful, but I try to take it away from that situation. Usually probably me just lying on my bed, on my laptop just watching videos but obviously sometimes you have to do homework or something like that so…"* (pp9, 15 years)

Also, some unusual home remedies were passed on through peers and mums:

> *"Or we, we tried little home remedies that we heard about like, something like apples- obviously didn't relieve it and their probably only old wives tales but we thought we would try our best. Oh we heard about heating a cabbage leaf and pressing it to the area was supposed to help."* (pp1, 17 years)

Other self-care methods included placing hot water bottles to the painful area, keeping warm, hot drinks (e.g., tea, hot chocolate), hot baths, exercise, over-the-counter medications (e.g., ibuprofen and paracetamol), diet changes (e.g., healthier eating), emptying bowels, relaxation techniques (e.g., deep breathing, yoga), and finding a comfortable position to rest in. Several girls reported that preparation and planning the self-care methods helped them to cope with the pain during their daily life and activities by enabling them to elicit some control:

> *"Um then I'll make sure I have some in my bag and I'll make sure I have tablets …if I know that I'm gonna have it on the day specifically, then I'll try and take tablets before so then maybe the pain will like go away before it even comes so I try to plan ahead thinking when I'm gonna come on and yeah…"* (pp19, 14 years)

The experience of pain changes over time

The older adolescent girls in this study were more effective at managing their pain over time. Often the girls would describe dysmenorrhea as more intense when they were younger and less experienced. Throughout adolescence, they had learned various pain coping and management strategies which enabled them to better relieve or tolerate it:

> *"it was worse yeah to begin with because, well partly because you're not used to it as well so it seems like so much worse than it actually is"* (pp4, 16 years)

Over time, the girls had learnt that panic and anxiety were associated with increased pain severity. As a result, by managing their emotional response to the pain, they were better equipped to accept and manage the pain:

> *"Obviously I was quite young, I've got a better pain resistance now but when I was younger you know I'd be in tears and panicking, you know I couldn't cope very well with it, at all."* (pp1, 17 years)

In addition, some of the girls who were newer to menstrual cycles believed that they would better cope with the pain with time:

> "Erm I think I'll be able to deal with it better as time goes on because obviously, I've only had periods for like a year, a year and a half so I'm hoping that the more time goes on, I'll get used to it a bit more" (pp7, 16 years)

5.3.4 Theme Two: Period Pain is restrictive

The restrictive nature of dysmenorrhea is emphasised by the girls in this study who are at varying stages of adolescence, a time when autonomy is of growing importance. The second theme identified in this analysis is 'period pain is restrictive'. This theme that identifies the various ways in which dysmenorrhea was perceived as restrictive by the adolescents in this study. . This theme outlines how the adolescent girls perceived dysmenorrhea to have a profound impact on their physical functioning (e.g., standing, walking) and ability to engage with their usual daily activities. This theme also explains how adolescent girls weigh up the potential consequences between either being absent from school or attending with pain (and risking being sent home), and the almost universal reluctance to engage in PE.

Period pain negatively impacts physical functioning

The majority of participants reported a physical impact of pain on their lives such as movement restrictions, loss of appetite, and sleep disruption as a result of pain. Almost all of the girls reported some movement restriction resulting from period pain including walking, standing, trying to find a comfortable position, and being *'stuck on the toilet all day'*:

> *"Errr it's hard to move when you've got, it's quite uncomfortable cause you're trying to find a good position to be in and, you never really can so you end up trying to kind of pull your legs up to you trying….To try and secure it I guess"* (pp3, 13 years)

> *"And I couldn't move and I had really bad pains. My mum had to sort of help me up the stairs because I couldn't move"* (pp16, 14 years)

These movement restrictions limited some of the girls' ability to perform basic daily activities such as walk to school:

> *"Um, if I, lots of times I've come on when I'm getting ready for school so like if I'm walking to school so I don't, I try to like just crunch down when I walk so it makes me walk awkward you know and people think why is she walking like that"* (pp19, 14 years)

> *"normally I walk to school, every day my friend, me and my friend walk to school together… and if I have got period pains, I'll probably ask mum to take me to school so I won't do that"* (pp3, 13 years)

Dysmenorrhea was described as either directly or indirectly impacting on girls' appetite. Appetite was directly impacted as a menstrual symptom accompanying menstruation. Indirectly, the pain limited their ability to eat either by impacting their mood or by physically restricting their ability to walk to the kitchen and make food:

> *"Not particularly, sometimes I wouldn't eat because I wouldn't feel in the mood to eat, I'd be uncomfortable but that didn't bring too much but in the end I'd make myself eat so I didn't miss out on food (laughs)"* (pp1, 17 years)

Many girls reported sleep disturbances as a result of period pain which, in turn, impacted their emotional and cognitive functioning which was already impaired due to pain. The girls frequently discussed the negative impact of sleep disruption to their daily life:

> *"Yeah I lose a lot of sleep. It makes me tired, probably a bit ratty."* (pp5, 16 years)

> *"Probably sleeping, probably, go to bed, having to change your sheets every night, that sucks especially because your mum has to do it…you get lack of sleep, just rolling around in the night but other than that…"* (pp18, 13 years)

Difficulty performing usual activities

The girls reported numerous daily activities that were limited by period pain such as walking around the home, going outside, part-time work, and household chores:

> *"Anything like, I'd be laid out on the sofa and I wouldn't be able to move so I wouldn't be able to get up and walk around the house to tidy my bedroom"* (pp1, 17 years)

> *"Yeah I do help out and then if my mum knows I'm in pain she'll let me just sit down and watch TV but then if it's not much pain I'll still try and help if I can"* (pp19, 14 years)

The girls' accounts varied in terms of hobbies and exercise as some reported that they were unable to engage in sports team practice as often: *"Yeah I won't go rowing if it's too heavy and too painful"* (pp5, 16 years). Other girls felt that their hobby helped them to 'keep busy' and serve as a distraction from the pain: *"Erm netball it doesn't affect anything cause I kind of forget about it when I'm playing netball"* (pp10, 14 years)

Some of the girls had learnt how to incorporate pain management techniques into their daily lives which enabled them to engage in more activities. For example, distraction techniques, often described as 'trying not to think about it', were viewed by many as a helpful pain management technique:

> *"Erm it's usually like, it's, it's quite painful but it's not, it doesn't stop me from doing things that I want to do."* (pp6, 16 years)

Weighing up the consequences of being absent from school versus attending whilst experiencing pain

The salience of school was emphasised by all of the girls. The impact of period-related pain on all aspects of school life, including attendance, concentration, academic performance, and physical education (PE) was discussed by the girls more than any other aspect of their lives. The impact of period pain on their ability to engage in school was profound for most and a cause for great anxiety and stress.

Eleven of the 20 girls had been absent from school due to period-related pain. Eight of those eleven reported regular absence for period-related pain:

> *"Erm pretty much it was every year my attendance would be about 70% which obviously isn't great, if you think that's 30% of the school year…There would be the odd few days when I might have had a hospital appointment or I might have felt a little unwell myself but the majority of it was period pains."* (pp1, 17 years)

> *"last year I know that I did have every 2 of 3 periods I'd have at least 2 days off or something like that"* (pp3, 13 years)

For many girls, school absence was due to a combination of period-related pain and other accompanying symptoms such as heavy menstrual flow and fatigue:

> *"I think it's both, sort of both at once like usually if it, so if I'm feeling tired I will most, most likely go into school but then if there is pain as well, I will stay off school sort of thing."* (pp4, 16 years)

Despite the desire to go into school, the majority of girls had to take some time off of school:

> *"obviously at the time you'd think yay no school but I literally would have done anything to go to school that week because it was so bad…like I couldn't even walk, like it was horrible like so because of that I had to miss quite a bit of school every month because I couldn't always make it."* (pp2, 17 years)

For some girls, regular period pain-related school absences caused 'problems' with the school:

> *"Um well my attendance is, OK at the moment but it has been below 80% you know like the guidelines are 90% or something so I did get letters home but we have explained to them, I have got doctors reasons why you know so yeah…."* (pp5, 16 years)

> *"oh no they weren't very happy cause, obviously cause of my absence, my attendance obviously went down and every single year they'd be like (name), you can do better this year and I would just be like yeah I try but I can't help it, you don't understand… but a week, I know it's a bit much but you can't really help it if you're you know, struggling."* (pp2, 17 years)

Parental responses to school absence for menstrual-related pelvic pain differed, and often seemed to influence whether or not girls would take time off. For example, one girl reported that she would not even consider asking for a day off for period pain because she is aware that her mum's response would be no:

> *"No I haven't, my mum wouldn't let me, no (laughs). No I've never tried but I know because obviously I've got some friends who have taken time off school and, and I, I've told my mum, I've been like oh so and so's off school because they've got period pain and then she's been like 'that's ridiculous, you'd never take time off school' so I'm like OK mum, you don't know what they're going through (laughs)"* (pp8, 17 years)

The more rebellious girls refused to go into school with period pain even if their parents did not willingly allow their daughters to be absent:

> *"Not really but there's not a lot they can do about it if I'm in bed and like I'm not getting out of bed, I'm not going, there's not a lot they could do. I'd usually lay in till dad had gone to work and then be like 'mummy I'm so ill' (laughs)"* (pp14, 17 years)

When they did manage to go into school, many girls described instances where they were sent home due to severe pain. This was often also a source of stress however, as several girls recalled times when they were not permitted to leave and resorted to calling their mother to be picked up, without permission from the school:

> *"Erm, well, if I'm at school I'll ring or text mum and tell her because we've had problems with my school about sending me home because they say oh every girl gets it um so you need to deal with it erm"* (pp3, 13 years)

> *"I have once when I couldn't like deal with it and then I had to go outside and have fresh air and I was feeling quite sick and then I was trying to text my dad to pick me up and then*

> *normally when my dad, when he came to pick me up he had to say a lie to the school because they normally don't allow people to go home so my dad took me home and then I took the day off school"* (pp19, 14 years)

Attendance did not necessarily negate the negative impact that dysmenorrhea would have on school performance. Girls explained that whether they went to school or not, they perceived their academic performance to be compromised. In support of this, girls reported that they were unable to concentrate on their school work because all of their attention was focussed on the pain and how to stop it:

> *"And so when I'm in class then I try to ignore it but then I can't do the work when I do have it yeah I find it really difficult."* (pp19, 14 years)

Unsurprisingly due to school absence and limited concentration each month, girls perceived dysmenorrhea to have had a negative impact on their academic performance:

> *"obviously it impacts on like your school and everything that you're working with, cause it was sort of GCSE sort of time so it was like I couldn't really afford to miss days off school and stuff so it was like just getting me behind with school and stuff"* (pp14, 17 years)

> *"No I didn't do as well as I was meant to do at GCSEs, I don't know if that was the cause or, I sort of didn't revise as much as I should have, yeah I ended up getting loads of C's when I was predicted As and Bs. I did miss a lot of school at the time and I think I'm fine now because I can go in now."* (pp2, 17 years)

Girls have reported feeling worried and anxious about the impact of their period pain on their school grades:

> *"Definitely sometimes, especially if it's, you know you have to do this or it depends on your grade for next year which is something that we're doing at the moment and it's just a bit panicky. So… a lot of pressure"* (pp18, 13 years)

> *"But, cause I've got my GCSEs coming up, starting this year and I'm starting the main subjects and this year I'm starting to think, cause I have quite a lot of time off school for my periods and, I'll be missing out on a lot of lessons and work and things so yeah (pause)"* (pp3, 13 years)

Finally, age influenced the girls' perceived consequences of school absence. Some of the older girls reported that they were more concerned about missing school because school became more important throughout the years.

> *"At the time when you were in high school it didn't really matter because it wasn't anything really important that we were doing anyway"* (pp2, 17 years)

> *"But it was really helpful that I went on the pill just before A levels because if I had taken days off I would have honestly failed"* (pp2, 17 years)

Reluctance to engage in physical education (PE) while menstruating:

The girls in this study perceived period pain to have a profound impact on their ability to engage in physical education (PE). In particular, the girls who reported severe mobility restrictions due to pain found it really difficult to engage in PE, despite persistent attempts by PE staff to engage them. These findings support previous findings that girls' physical activity levels drop dramatically during adolescence, while boys remain largely unchanged (Brodersen, Steptoe, Boniface, & Wardle, 2007). These findings provide some explanation for this gender-specific reduction in physical activity:

> *"It didn't really affect me because if they told me to do it, I'd sit myself on the side anyway because I really didn't feel like doing it or if they told me you know, everybody goes through it, I'd just take myself off to the office because you know, I could barely walk along let alone do a sport so…"* (pp1, 17 years)

For the majority of the girls, their motivation to engage in physical activity was limited. When they did take part while experiencing period pain, they described their engagement in the activity as minimal:

> *"I just wouldn't, cause, like I wouldn't want to make the effort to have to go and do that so I'll the, I'll do the PE but I wouldn't put in any effort, I'll just kind of…. (laughs)… yeah."* (pp4, 16 years)

For some, although the impact that PE on pain severity was expected to be negative, their motivation to enthusiastically engage increased during the physical activity. As a result, the girls reported some pain relief. Potential explanations for this include that the activity acted as a distraction from focusing on the pain or that the exercise directly reduced pain severity (exercise-induced hypoalgesia, EIH) (Koltyn et al., 2014).

> *"It wasn't appealing so I didn't want to do it but then, thinking about doing it and then doing it- you don't want to do it but then after you do it you feel better but it's just that first bit where you're like it hurts then later on you're like 'I feel better'."* (pp14, 16 years)

5.3.5 Theme Three: Negative emotions associated with dysmenorrhea and accompanying symptoms

Dysmenorrhea is perceived by adolescent girls as an unpleasant, unwanted phenomena that is associated with negative emotions. The third theme in this report titled 'negative emotions associated with dysmenorrhea and accompanying symptoms' outlines how the girls perceived period pain and how it made them feel. This includes feeling resentful towards other girls who do not experience dysmenorrhea; feelings of anxiety and helplessness, their experiences of catastrophizing about the cause of their pain, and feeling self-conscious and unattractive while menstruating.

<u>I resent feeling like this</u>

Peer relationships and feelings of belonging and commonality with peers are uniquely important during adolescence, with peers often contributing more to adolescent social development than families (Patton et al., 2016; Somerville, 2013). Therefore, it is unsurprising that for these adolescents, feeling *'different'* to their peers who did not experience dysmenorrhea was distressing. In addition, several of the participants described feeling annoyed and frustrated that other girls did not experience the same level of pain:

> *"Well it just makes me feel a bit rubbish because like other people might not get pain and stuff and it just annoys me that other people might not be getting pain and I am."* (pp12, 12 years)

> *"It does really I guess cause I often think oh why'd I have to go through all this and it's like what have I done, why have I gotta do this (laughs) so it's a bit annoying (laughs)."* (pp3, 13 years)

Resentment also stemmed from frustrations with having to deal with the pain in combination with other adolescent pressures. Juggling multiple school, extra-curricular, social and familial responsibilities alongside monthly pain was a source of persistent worry and anxiety:

> *"More than hurting, it's annoying cause I can't concentrate on other things cause [it's] constantly there. So (laughs) yeah….Errrm well it does, it sort of, when I have got it, it just winds me up sometimes, like I've got to deal with all of this"* (pp3, 13 years)

> *"Erm I think it's sort of a mixture because before when I didn't have any pain I was still quite moody but not as irritable but when you're sort of concentrating on the pain, other things that you have to concentrate on are just annoying."* (pp11, 16 years)

One participant identified as gender fluid and expressed feeling frustrated by menstrual pain as it served as a reminder of her female anatomy:

> *"Yeah, yeah, I dunno. Kind of like well, I, I identify as gender fluid so it kind of, yeah it, yeah when I'm feeling like more masculine it does remind me that… it's like this."* (pp20, 13 years)

> *"Mmm yeah just, kind of like, I feel more kind of masculine most of the time like more, more often than not I feel masculine so like kind of it does kind of remind me like that… that kind of stuff is going on in my body yeah."* (pp20, 13 years)

Anxiety, helplessness and pain catastrophising

Many negative feelings were expressed when discussing period pain and its impact on the lives of the girls. In particular, descriptions of anxiety and helplessness were present in their accounts of their pain.

> *"I came on my period and that pain coming back to my body was such a shock that it actually sent me into a panic attack cause I was in the middle of a class"* (pp1, 17 years)

> *"Yeah, it would come back so bad like honestly I could not stop crying when I was on like the first couple of times it was horrible"* (pp2, 17 years)

These feelings of panic and anxiety were sometimes triggered by a lack of understanding and fear that there might be an unknown cause of pain:

> *"I was really like, a bit scared, I was kind of like, cause it was hurting and you're like, you're kind of like why does this happen? And obviously now I, I kinda know it's fine but obviously you don't really get told about the pain, you get told that you have pain but you don't get told why it's like that and it just makes you a bit scared that you don't know, you've never experienced that sort of pain before."* (pp4, 16 years)

Some girls reported that a greater understanding of period pain had helped them to cope with the pain better:

> *"Well just like I know what to expect and I kind of like I, I understand what's happening better and I know how I'll react to certain things and I'm more comfortable with it."* (pp6, 16 years)

The majority of girls knew very little about period pain including whether or not it was a *'normal'* phenomenon, whether there was something abnormal about their bodies, and what the causes of period pain were. Several girls wanted to have been given pain-related information before they reached menarche.

> *"I don't know this is normal with everyone but I used to get loads of cramps when I was on my period like"* (pp2, 17 years)

Almost all of the girls also were not sure why women differed in the amount of period pain they experienced, often comparing themselves to their friends and female relatives:

> *"Not directly about mine but I know like about menstrual cycle and all about that. I know what it all is about but I don't really understand how one person gets it more like erm heavier and more painful than someone who gets it like really light and like easy. Yeah…"* (pp3, 13 years)

> *"Errr, probably just annoying like why do I get this pain and none of my friends get this"* (pp5, 16 years)

All but one girl (pp20, 13 years) reported that they had not received any period pain-related information from school:

> *"We've had sex education but then they never mentioned period pains and cramps or anything like that which is quite unexpected so, I think yeah they mentioned what there is to use but they never mentioned the cramps and things like that."* (pp9, 15 years)

Many of the girls felt that they would have benefited from an increased understanding about period-related pain:

> *"Yeah, if they did teach us it cause like some people do suffer badly so I think we all want to know why"* (pp16, 14 years)

> *"Yeah I would cause then you'd know more what to do about it like where erm know more what to take and stuff like if there's any other pills you could be taking errm it's just more of an understanding about what's happening in your own body as well erm so I guess that would be nice (laughs)"* (pp18, 13 years)

In addition to a limited understanding about period-related pain, several girls reported concerns about period pain-related information that they had received from peers:

> *"The one thing that's been on my mind is that there's this thing inside you or something that, when you period or whatever, and obviously that's not good, cause one of my friends told me and I said I don't think that sounds right… it's just been on my mind since and I don't know if it's true or not so I've just been thinking about cause it's a weird thing to bring up"* (pp16, 14 years)

Focussing on the pain

If managed poorly, chronic pain can become the focus of an individual's life. In this study, many of the girls found it difficult to draw their attention away from the pain they were experiencing and concentrate on anything else. Girls became detached from life interests while they were menstruating and pain dominated their attention:

> *"That's all you can really focus on."* (pp2, 17 years)

> *"You kind of feel detached from the things that you're interested in and you just want to sit and focus on finding a position you're comfortable in and then try and get rid of the pain. That's all it's focused on, everything around that."* (pp1, 17 years)

> *"I would feel a bit detached every couple of months or so and just avoid everything erm"* (pp14, 17 years)

For some girls, before the period and pain had even began, their focus would be drawn to the anticipation of the pain. This caused a significant amount of stress and anxiety in the days leading up to their period:

> *"Every month I would get worried that I would come on and then every time I would get stomach pains I would think oh I'll come on now and then yeah…"* (pp19, 14 years)

> *"I try and put it aside but then it does affect you because you're constantly kind of aware that you've got that and kind of nervous inside and especially when it comes around that time of the month, I always get a bit (pulls face) just in case."* (pp9, 15 years)

For these girls, the prospect of pain became such a major concern that they would avoid engaging in any activity beforehand:

> *"I feel quite anxious about it, erm quite reluctant to do things so if someone's like "do you want to go for a day out" then I'm kind of like mmm I might not… so I kind of already mentally decide for that week."* (pp7, 16 years)

Feeling self-conscious

Girls experienced heightened self-conscious thoughts and feelings while menstruating, although this was primarily caused by the accompanying symptoms rather than dysmenorrhea. Girls cited reasons for feeling self-conscious including feeling unclean, particularly when worrying about leaking menstruation through their clothes:

> *"Yeah it just felt kind of, you feel a bit gross really and you just don't wanna go out and you feel like, and, embarrassed because it's like there and you're just, like if it's light it's kind of as if it's not there and you don't worry about it as much but then if it's heavy you just feel embarrassed really."* (pp4, 16 years)

> *"I just feel a bit more self-conscious…like when ya, when you've been sitting down for a while and then you stand up you're just like, oh just in case a bit comes out when you stand up and then you look and it's like, like at school I tend to keep my coat with me so I put my coat on cause it's long and it goes down to there and then I feel fine if I've got that on."* (pp10, 14 years)

In addition, adolescents during this time were more attuned to physical changes including acne, bloating, and body odour. Adolescents typically feel more self-conscious than individuals at other developmental stages. Therefore, monthly and unpleasant physical changes were a cause of great concern to the girls, who often described feeling 'ugly' and 'gross' during this time:

> "Yeah, I definitely think I'm more ugly which sounds really weird… it just generally doesn't make me feel good. It makes me feel like, like I'll get ready and I'll like try and it just wouldn't be worth it but erm yeah that's all I can really think of." (pp18, 13 years)

> "Yeah, definitely. You know you, ergh, you feel like really, just really self-conscious, really , and obviously when you're on your period you're really like meant to you bloat around a bit so you feel bigger and then you look at yourself and then you get upset about it (laughs) yeah…" (pp4, 16 years)

5.3.6 Theme Four: The complexities of managing relationships while experiencing period pain

Adolescence is a period of transition from childhood to adulthood during which relationships with family, authority figures and peers are changing and becoming increasingly important. Adolescents typically spend more time with peers and develop an autonomous identity, separate from that of their family. Adolescents are more likely than any other developmental stage to behave impulsively and engage in increased risk-taking behaviours (Casey, Getz, & Galvan, 2008). As a result, relationships with family members and authority figures (e.g., teachers) can be strained. This section explores how the participants in this study navigate important relationships with school staff, family members, and their peers while experiencing dysmenorrhea.

Conflicts and negotiations with school staff

The majority of the girls reported tensions between themselves and school staff. Tensions were particularly prominent with PE staff. The girls perceived their interactions with PE staff in a negative light. A similar story was recounted across interviews whereby PE teachers would ‘unfairly’ try to encourage engagement in exercise despite (sometimes very severe) pain. The student/teacher relationship became increasingly frayed over time through repeated cycles of miscommunications about PE attendance, punishment (detention) for non-attendance and subsequent feelings of resentment:

> *“That probably made it worse cause they probably thought I was being you know, a disobedient student or disrespectful when in actual fact it was just how I felt in myself, I couldn’t do those things.”* (pp1, 17 years)

> *“A lot of teachers like, if I say I don’t wanna do PE for instance, they’ll say oh well every girl gets it and em say that I’ll get a detention if I use that as an excuse next time”* (pp3, 13 years)

In addition to PE staff, tensions with other teachers were evident from discussions of rules surrounding toilet breaks. The overriding feeling was that school staff were not appropriately sympathetic. Many girls had received detention for going to the toilet during classes despite telling the teacher that they needed to go for period-related reasons:

> *“but then at this age like it annoys you a bit when like teachers, if you need to go to the toilet, they’ll be like you need to come back for a 20 minute detention and if we say something then they still won’t allow you”* (pp19, 14 years)

Girls also reported feeling that the school office personnel were not supportive and did not understand that some girls experience severe period pain:

> *"Um normally I think they don't allow it because every girl in the school has probably started already so they think that because every girl's for it, it's not an excuse for us to take it, to go home so like they don't allow and the only thing they let you do is stay in the first aid and just have a hot water bottle for like 10 minutes and then they'll send you back to class so they don't do much about it"* (pp19, 14 years)

> *"or if you went to the medical room they would say everyone goes through the same thing and we can't be sending people home and because of that they weren't considerate of the fact that maybe things were different for different individuals"* (pp1, 17 years)

Tensions between family members during menstruation amplified by pain

Family functioning around menstruation and dysmenorrhea became a key topic of discussion among the girls. Family functioning is often poorer in families with a child or adolescent experiencing chronic or recurrent pain. The girls in this study were self-aware about how dysmenorrhea had caused tensions within the family unit. Pain negatively affected their mood which had consequently caused some tensions between different family members. Tensions particularly occurred with other female family members who were also experiencing menstrual symptoms:

> *"All the time like cause obviously we all have different menstrual cycles so we're all moody at different times …we''ll all have periods at different times and we'll all end up arguing at different times because we're all moody um then you'll have mum will start crying and then a week later we'll have the other one crying feeling that no one loves me"* (pp15, 16 years)

> *"It definitely makes it worse…like if I know my mum's upset or she's tired and I've shouted at her, I definitely feel really guilty afterwards, which makes me feel bad and we apologise after to each other and it's all just going round in circles cause the next day it'd be the same, get angry and then she'd be tired and it just makes you feel really like sick of it"* (pp18, 13 years)

The girls often found it difficult to express their need to be alone while on their period to their family. Although many felt that they had made their desire to be alone when they were experiencing period pain clear, they felt frustrated when family members did not understand that. This often led to negotiations around family-based time and chore participation:

> *"When I'm on and I get really moody I'm just like no just leave me alone for a bit. She (mum) doesn't really get that sometimes, but sometimes she does leave me alone."* (pp2, 17 years)

> *"I'll just completely ignore my dad and with my mum I sometimes snap because I don't really want to talk to anyone at the time and then my dad doesn't really understand anything so he'll be like oh can you do this and can you do that and I'll be like I'll do it later and then I'll tell my mum and then she'll do it so most of the time I'll try and be alone."* (pp19, 14 years)

Many expressed sympathy for their dad when menstrual-related mood changes led to tension and conflict in the household. Dads were viewed as naïve and helpless on this topic:

> *"Everyone's just like on edge, like you just do one thing and everyone's off it and my dad's just sitting in the corner like oh and he just waits for it to blow over until it's over (laughs)"* (pp11, 16 years)

Dysmenorrhea can have a positive impact on future family functioning

Although much of the impact of dysmenorrhea on adolescent girls' lives was negative, a novel finding from this study is that some girls perceived dysmenorrhea to have a positive impact on family functioning. Interestingly, several girls reported that their parents' had learned parental pain responses and coping strategies from their experiences with their period-related pain. They felt that this had therefore made them better prepared when coping with, and supporting their younger siblings with menstrual-related pain and accompanying symptoms:

> *"Erm but no not in a negative way I mean there weren't any fights or and everyone were pretty supportive and I feel like in a way, because obviously parents learn with their first child, mum and dad have learnt with all the experiences that I had and so maybe, hopefully it helps them to cope better with (sister) if hers continue to be bad."* (pp1, 17 years)

Girls also perceived a benefit to family communication between family members. Being forced to discuss a taboo and embarrassing personal matter had made the family more comfortable when discussing other sensitive personal issues:

> *"Err I don't think so just probably, it's probably improved in the fact that I can tell them more stuff about it"* (pp5, 16 years)

Period pain, social activities and friendships

The girls perceived that the most important social impact of menstrual symptoms was on their ability to attend social events. For example, they were more reluctant to sleepover at a friend's house due to concerns about anticipated sleep disturbance, menstrual leakage, feeling 'awkward' about going to the toilet in someone else's house, and simply feeling 'rubbish':

> *"it does make me unwilling to go round friends, if I wake up in the night I'd be scared and especially leaking and, you know getting the pain- a lot of my close friends, they'd just get me a hot water bottle."* (pp5, 16 years)

> *"Erm I probably wouldn't go to a sleepover if I was on my period I don't think… Erm I dunno just like going to the toilet would be more awkward and I don't know, it depends on the friends, there's like one or two friends that I might but most friends I probably wouldn't."* (pp10, 14 years)

Given the importance of social events in adolescence, cancelling plans with friends due to period pain was an unpleasant experience that sometimes led to distress:

> *"Yes, erm I made some plans the other day with one of my friends and I came on really bad and I had to cancel because I was so bad and I just couldn't…."* (pp16, 14 years)

They expressed deep regret for cancelling plans with friends and found it difficult to communicate the reason for doing so:

> *"Just having to think of excuses and not do stuff rather than just be like it's a period. I, I just kind of find it easier to say that rather than saying oh it's really difficult I really struggle because I don't want to particularly worry about it or think about it."* (pp7, 16 years)

> *"Yeah, I'll either just say like I'm not feeling well or just say I don't want to go."* (pp6, 16 years)

Many of the girls felt upset and sometimes guilty for disappointing their friends when they had to cancel plans. However, peers were described as understanding and empathetic for the most part:

> *"there were a few times when everyone was getting together and like 'why aren't you coming' and I just don't feel like it and it's like well 'just come out, you'll feel like it after' and no I won't, I won't and it was like, it just put a bit of tension in it cause like they thought you weren't doing it because you didn't want to rather than because you didn't want to because you were in pain sort of thing."* (pp14, 17 years)

> *"Well she was a bit disappointed but then we just made plans to do something else so.. it was alright"* (pp13, 14 years)

> *"Well if it was (friend), she would completely understand, she'd say that's fine, as long as you feel better and then some, some other friends were like OK nevermind"* (pp2, 17 years)

Some girls reported changed peer interactions as a result of period pain, which the girls perceived to be due to mood alterations and feeling *'snappy'*, *'quiet'*, or *'angry'* when in pain. These negative emotions led the girls to communicate with the friends in a more aggressive way than they normally would:

> *"Because, I kind of have a short temper with people and I'm just like don't touch me, go away, and don't talk to me so yeah…"* (pp3, 13 years)

> *"No not really cause I'm not a very, not a confident person, but because I know myself very well then it's like if I'm on it I'm kind of a bit shy if you know what I mean and my friends are like why are you so quiet and I'm like oh no reason."* (pp9, 15 years)

5.4 Discussion

5.4.1 Overview of main findings

This study aimed to explore the impact of dysmenorrhea on the lives of adolescent girls. A heterogeneous sample of younger (12-15 years; n=9) and older (16-18 years; n=11) adolescents experiencing menstrual pain of varying intensity were interviewed. Overall, based on the adolescents' reports, dysmenorrhea appeared to have a profound, negative impact on all aspects of the girls' lives, including physical, psychological, social and school functioning, and well-being. Four main themes were identified from the thematic analysis: 1) Managing period pain; 2) Period pain is restrictive; 3) Negative emotions associated with dysmenorrhea and its accompanying symptoms; and 4) The complexities of managing relationships while experiencing period pain. The following text will begin by outlining the key findings in relation to the previous literature and discussion around what the findings mean in relation to theory. Finally, strengths and limitations of the current study and implications for future research and real-world application will be discussed.

5.4.2 Managing period pain

Adolescence is a time of considerable behavioural, cognitive, and physiological development whereby new behaviours which may last into adulthood can easily be learned (Blakemore, 2019; Blakemore & Choudhury, 2006). These are foundational years whereby much of an individuals' health behaviours are decided (Lloyd, 2007; Patton et al., 2016). As highlighted in chapter 3, the way in which adolescents manage their menstrual pain during adolescence may have a long-lasting impact on the way in which they manage dysmenorrhea and any future instances of chronic or recurrent pain. It is therefore crucial to understand how adolescents are managing dysmenorrhea. This study has identified some key influences on how adolescents manage their period-related pain. For example, help-seeking behaviours for period pain seemed to be heavily influenced by gender and whether or not girls perceived menstruation to be 'taboo'. Gender played a key role in the girls' help-seeking behaviours, all of whom preferred to discuss menstrual issues including dysmenorrhea with women rather than men. Many of the girls in this study felt too embarrassed to talk to a man about menstruation, indicating that the topic is still relatively taboo. This finding seems to be specific to dysmenorrhea, as many of the girls reported that they wouldn't seek help from fathers or male friends because men/boys were unable to relate to this specific type of pain. Despite this specificity to dysmenorrhea, this specific finding was not reported in other qualitative studies exploring adolescent dysmenorrhea (Aziato et al., 2006; Chen et al., 2014). However, this is consistant with findings that secrecy and stigma still surround menstruation for many adult women (Repta & Carke, 2013) This clear gender preference may serve to explain another key finding of this study that mothers played an integral role in helping their daughters manage dysmenorrhea. Mothers were often cited as the girls' primary source of emotional and practical support while they were experiencing period pain. Adolescents reported a heavy reliance on their mothers while experiencing dysmenorrhea.

Consistent with Aziato et al.'s (2006) findings, girls in this study reported varying pain onset around menstruation (e.g., pain begins before or after bleeding starts), and varied intensity across the menstrual period. Girls in the current study reported using a variety of pharmacological and non-pharmacological pain management strategies. Chen et al., (2006) focussed on treatments and self-care strategies of girls with dysmenorrhea. The interview questions for this study explored the impact of dysmenorrhea on every aspect of girls' lives, beyond focussing on treatment strategies. This study supported Cheng et al.'s (2006) findings that girls used hot drinks to relieve menstrual pain although the current study expands this by reporting many other 'keeping warm' methods of pain relief including hot water bottles, hair dryers, and blankets. This supports Campbell and McGrath's (1999) findings that girls use non pharmacological methods such as heat and rest to relieve their menstrual pain. In contrast to Cheng et al.'s (2006) sample, no girls in the current study reported using complementary and alternative medicine (CAMs) or Chinese herbal remedies. However, the girls did discuss their interest in holistic treatments for their period pain. Chen et al., (2006) did not explore how girls felt about taking medication which may have impacted their use of effective treatments, overall management of the pain and, in turn, the impact of the pain on quality of life. The current study found that many girls are reluctant to either swallow tablets or ingest what they perceive to be ‘unnatural’ substances into their bodies. The reluctance to take medications resulted in several girls avoiding medical treatment. For the girls using the OCP or other long-acting contraceptives to treat dysmenorrhea, these methods were reported as more effective than previously trialled analgesics. For the girls in the current study who were not using the OCP to relieve their period pain, they reported feeling concerned due to the possible stigma related to it. The girls were concerned that taking the contraceptive pill might label them as being sexually active and this might have negative consequences for them in relation to how others perceived them. Girls’ reluctance to ingest pharmacological analgesic medications and misconceptions about the OCP could, perhaps, help to explain Campbell and McGrath’s (1999) findings that most girls rely on ineffective, nonpharmacological treatments to relieve their pain.

Many of the girls in this study used distraction techniques to manage their pain such as watching TV, engaging in hobbies, and listening to music. This is similar to reports from children with CP of various aetiologies. For example, in Meldrum et al.’s (2009) study, children who used distraction techniques were described as ‘positive thinkers’. Several of the girls in this study made associations between their ability to tolerate and cope with other sources of pain (e.g., injections) and their ability to cope with period pain. This evidence supports previous studies that have found that levels of somatization and perceived ability to cope with pain significantly predicted pain intensity (Goldstein-Ferber & Granot, 2006).

Expanding on previous findings (Aziato et al., 2006; Chen et al., 2014), the girls in this study described their experiences with the health care system. The girls reported negative feelings towards HCPs including feeling dismissed by their GPs when reporting period pain. For example, several girls felt disappointed when told that they would simply ‘grow out’ of their pain. The overriding feeling expressed by girls seeking help from HCPs was the need to relieve their symptoms despite feelings of embarrassment or fear. These findings expand on the previous literature which had not explored girls’ experiences with the health care system (e.g., consultations, and internal investigations) in relation to dysmenorrhea.

Also importantly, the girls reported a very limited understanding of period-related pain in terms of its causes and pain-management. Most of the girls reported that they were not initially aware that they could improve symptoms with the OCP. Just one girl reported pain-related information being provided to her at school. As a result, misconceptions about the cause of pain and uncertainty about whether or not period pain is ‘normal’ were expressed by many girls. Also, subgroup analyses showed that older adolescents (16-18 years), in contrast to the younger girls, reported concerns about how dysmenorrhea would impact on their attendance when they finished school and were employed. Overall, the evidence from this sample suggests that dysmenorrhea has a profound impact on the lives of young girls at an important stage of their development and transition from children to adult women. These findings are novel in that previous research has not yet explored girls’ knowledge of pain, its causes, and pain management strategies. This study is the first to identify that adolescent girls in the UK are not prepared for period-related pain, which often results in misconceptions about the causes of pain, limited knowledge about appropriate treatment, and in some cases anxiety about a potential pathological cause of pain.

5.4.3 Period pain is restrictive

The restrictive nature of dysmenorrhea was highlighted by the adolescent girls in this study who perceived dysmenorrhea to have an often profound negative impact on their physical functioning (e.g., standing, walking) and ability to engage with their usual daily activities. The girls’ frustrations with the restrictive nature of their monthly pain is unsurprising considering that adolescence is a transition from childhood (being heavily reliant on parental support) to adulthood through increasing autonomy and independence (Patton et al., 2016). For many of the girls in this study, they relied heavily on their mothers’ support when experiencing period pain. In addition, girls reported restrictions on their ability to engage with school. School is also of significant importance during adolescence because this is the time when the foundations for an individual’s future career are being formed (Lloyd, 2007; Patton et al., 2016). Many of the girls in this study were regularly required to weigh up the possible consequences of attending school in pain or being absent. This is consistent with previous research presented in chapter three of this thesis whereby dysmenorrhea limited girls’ school functioning. In discussing the impact of dysmenorrhea on school functioning, the current study expanded the previous literature by focussing on PE and teacher/school staff interactions as separate subthemes. PE was a profound concern for most of the girls as many experienced movement restrictions as a result of pain. In addition, tense teacher-pupil interactions were reported either when girls could not engage in PE, or needed to use the toilet during a lesson. The findings of this study support Aziato et al.’s (2014) suggestion that more education is required concerning period related pain for young girls. Many of the girls in this study reported a desire to have known more about period pain before they had reached menarche.

5.4.4 Negative emotions associated with dysmenorrhea

The current study showed that dysmenorrhea, and accompanying symptoms, had a profound, negative impact on the girls' psychological functioning. Girls reported that both pain and accompanying hormonal symptoms were responsible for feelings of emotional distress. Chen et al., (2006) did not report whether or not emotional symptoms (e.g., crying) were a result of pain or accompanying symptoms (e.g., hormone fluctuations). Many girls in this study reported that their hormones fluctuated causing mood changes during menstruation but that pain also resulted in crying, and feelings of irritability. The experience of pain alone induced negative emotions for many of the girls. In addition, some reported that the pain felt more severe when they had already felt upset or anxious before its onset. This supports a biopsychosocial model of dysmenorrhea in which pain can cause negative emotions while negative affect can exacerbate existing pain.

In contrast with Aziato et al.'s (2014) study where participants feared the impact of period pain on fertility and believed that they might be rendered childless, none of the girls in the present study reported fears about fertility. An important difference between the current study and Aziato et al. (2014) could help explain this contrast in findings. The age ranges between the two studies varied considerably. Girls who were aged 12-18 years in the present study may not have been considering the future yet in terms of children. Women were aged up to 38 years in Aziato et al.'s (2014) study and so were more likely to be at a stage in life where these concerns were relevant to them. Also, no participants in this study wished for early menopause as participants did in Aziato et al.'s (2014) study although this may also be due to the differences in age range between the two studies. Many of the adolescent girls in this study reported feeling anxious and helpless in relation to their menstrual pain. For example, some of the girls perceived themselves as being unable to cope with the pain. In addition, many girls described a type of 'catastrophizing' thoughts in relation to their pain. Catastrophizing is a pain specific psychosocial construct comprised of negative cognitive and emotional processes such as helplessness, pessimism, rumination about pain-related symptoms, and magnification of pain reports (Edwards, Cahalan et al. 2011). For example, many girls described the pain as becoming the main focus of their lives and some were concerned that menstrual pain was not 'normal' and feared that there might be a more sinister, pathological cause. Previous research suggests that pain catastrophizing can influence the development, maintenance, and magnification of chronic pain (Gatchel et al., 2007). Evidence from the wider paediatric chronic pain literature indicates that pain catastrophizing is one of many psychosocial factors that have been associated with increased somatic complaints, pain severity, disability, anxiety, and depression in clinical and community samples of children (Crombez et al., 2003; Eccleston et al., 2004). It is well established in the literature that anticipation and fear of pain can actually be more disabling than the pain itself, predicting emotional distress and physical disability (Crombez, Vlaeyen et al. 1999, Vlaeyen & Linton, 2000).

5.4.5 The complexities of managing relationships while experiencing period pain.

Peer influence becomes increasingly important during adolescence. Adolescents display an increased sensitivity to the presence of their peers, viewing the impact of their behaviours to their social reputation as highly important (Patton et al., 2016; Somerville, 2013). Research has shown that adolescents value their relationships and time with their peers over and above that of their family (Patton et al., 2016). Therefore, it is not surprising that the adolescent in this study found it particularly upsetting and frustrating that dysmenorrhea had a negative impact on their social activities and friendships. The girls reported a reluctance to go to sleepovers, having to cancel plans with peers, and altered peer interactions due to feeling irritated by pain. This expands the findings from quantitative studies reporting that period pain affect girls' relationships with friends and limited their ability to engage in social activities (Eryilmaz et al., 2010; Mohamed, 2012; Parker et al., 2010). The in-depth interview methodology used in this study enabled the researcher to expand on these findings by exploring girls' experiences further. For adolescents, peer influences on health and wellbeing are greater than at any other time in the life course (Resnick, Catalano, Sawyer, Viner, & Patton, 2012; Steinberg & Monahan, 2007). The girls in this study also reported feeling a sense of resentment towards other girls who do not experience period pain (e.g., 'why do I have to put up with this'), a concern previously not discussed or reported in the literature. This is somewhat comparable to previous findings from qualitative research with children and adolescents with JCA who felt 'different' from their 'healthy' peers (Britton & Moore, 2002).

Consistent with Sallfors et al.'s (2001; 2002) study, girls in the current study felt that their pain was not always believed. Children with juvenile arthritis reported this because of their varying symptoms, although girls in the current study felt that school staff and HCPs who had not suffered with menstrual pain did not understand individual differences in its severity. It should be noted however, that, as mentioned previously, dysmenorrhea differs greatly from other forms of paediatric chronic pain.

Interestingly and in contrast to previous findings, dysmenorrhea had some positive impact on family functioning for a minority of the girls. These girls reported improved communication about personal issues such as menstruation and that their parents had an improved set of resources and experience in dealing with menstrual issues which might be beneficial for younger sisters. This is a very interesting finding as, from a positive psychology perspective; these families have displayed resistance to some of the negative impacts of menstrual pain and, in some cases, flourished by having a positive outcome from the experience (Sturgeon & Zautra, 2010). The Broaden and Build Theory provides a rationale for this by explaining that positive emotions can strengthen an individual’s ability and efforts to cope with a stressor such as chronic pain (Fredrickson, 1998). Several positive characteristics of personality have been found to be associated with resilience in individuals with other types of chronic pain including optimism and pain acceptance (Smith & Zautra, 2008).

Another interesting and novel finding was the importance that girls placed on their interactions with teachers and school personnel regarding period-related pain. These interactions had the ability to make girls feel disbelieved, frustrated, and misunderstood. Many of the girls discussed their need to go to the toilet more frequently during menstruation and tense interactions that occurred between student and teacher when girls needed to use the toilet during a school lesson. In addition, almost all of the girls did not want to engage in PE while menstruating because of pain, heavy flow, and generally feeling unclean and this also had a negative impact on students’ relationships with PE staff. Previously, this has not been discussed in the literature despite the girls in this study reporting these school interactions as a significant barrier to personal hygiene and pain management. In addition, the current findings suggest that other aspects of physical functioning, apart from PE, were negatively impacted by dysmenorrhea including sleep disturbances and movement restrictions, supporting previous research (Chaudhuri & Singh, 2012; Nur Azurah et al., 2013; Strinic et al., 2003).

From a self-determination theory (SDT) (Deci & Ryan, 2008) perspective, these findings indicate that dysmenorrhea has had a profound, often negative impact on the adolescents’ three innate psychological needs. The SDT framework, similarly to the perspective of positive psychology, presents ways in which individuals’ can achieve personal growth and flourishing (Deci & Vansteenkiste, 2004). Specifically, SDT (Deci & Ryan, 2008) is a theory of human emotion that concerns an individual’s innate psychological needs which include competence, autonomy, and psychological relatedness. This theory posits that individuals seek to become skilled at particular things (competence). When individuals feel that they have the skills needed to succeed, they are more likely to take actions that will help them to achieve their goals. These findings indicate that adolescent dysmenorrhea has had a profound impact on the adolescents’ feelings of competence.

Dysmenorrhea limited their ability to carry out basic physical activities (e.g., walking, standing), concentrate on their school work and homework, and engage in their regular activities. The girls also described how much their reliance on their mothers increased during this time which often elicited feelings of guilt. SDT also posits that individuals also generally have the need to feel related to others (relatedness). This is the desire to want to interact, be connected to, and experience caring for others. Adolescent dysmenorrhea also had a profound impact on girls' feelings of relatedness. This has been shown through reports of increased tensions and conflict with family members, school staff, and friends while menstruating. Finally, individuals need to feel in control of their own destiny (autonomy), to be causal agents of one's own life. The extent to which dysmenorrhea has impacted on the girls' autonomy is highlighted by their expressions of helplessness in relation to their period pain. From this perspective, on a monthly basis, these adolescents' universal needs are being challenged.

This study expands on the conclusions drawn from the systematic review (chapter three). The findings, along with the findings from the systematic review, support key aspects of Palermo's (2012) conceptual model for understanding paediatric chronic pain and disability. Specifically, these findings suggest that there is an interrelationship between the biological (e.g., menstrual pain and associated symptoms), psychological (e.g., cognitions around dysmenorrhea and negative emotions) and social factors (e.g., impact on relationships with friends, family and school staff) associated with adolescent dysmenorrhea. The findings suggest that adolescent dysmenorrhea has a profound, negative impact on all aspects of HRQoL including physical, psychological, social and school functioning. The findings so far highlight a number of biopsychosocial factors that might be important in predicting quality of life outcomes among adolescent girls experiencing dysmenorrhea. These include perceptions about the severity of pain, pain management and coping, psychological functioning (e.g., anxiety and other negative emotions), and misconceptions about the cause of dysmenorrhea that can lead to pain catastrophizing. See Figure 2 presenting a map of the main findings from chapter three and how this expands on the main findings from chapter two.

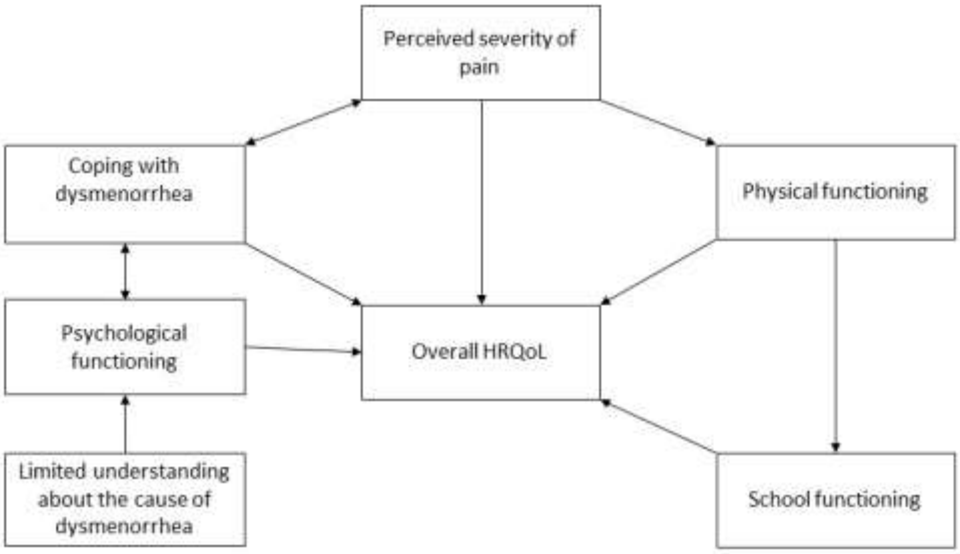


Figure 2 Map showing possible factors related to HRQoL outcomes among adolescents experiencing dysmenorrhea.

5.4.6 Strengths and limitations

A particular benefit of the current methodology adopted is that the data-driven approach to thematic analysis provided an adolescent-centred perspective on the phenomenon. The girls were given a voice to describe, in their own words, how dysmenorrhea has impacted every aspect of their lives and how they cope with and manage their pain. However, when interpreting the findings it should be considered that the adult researcher may have had some influence on the study outcomes, given that all qualitative analysis requires some level of interpretation. In an attempt to limit the researcher’s influence on the results, verbatim quotes have been used liberally throughout the results. The qualitative, explorative approach used has provided an in-depth insight into the lived experience of adolescent dysmenorrhea directly from the perspectives of the girls experiencing it. In-depth interviews and thematic analysis enabled the researcher to capture the girls’ experiences and take into account the context of their unique worlds. This method has allowed previously un-researched information to be identified which has enabled research on this topic to expand and move forward based on evidence provided directly from girls who lived with regular menstrual pain.

5.4.7 Implications and future research

As the data has produced many novel and interesting findings, several implications of this report are suggested in terms of future research and application. One of the key findings from this study was that girls preferred to talk to girls or women, rather than boys or men, about menstruation. The findings suggest that there is some secrecy surrounding menstrutation. In addition, some of the girls had not used the OCP due to possible stigma related to it, despite being aware that it might help to relieve some of their menstrual symptoms. Future research could therefore benefit from exploring this secrecy and stigma further. Future interventions could consider developing ways of helping all adolescents to feel comfortable discussing dysmenorrhea and the OCP. Information aimed towards for parents and daughters about the OCP could aim to reduce the stigma attached to using the OCP and its association with sexual activity. Increasing the proportion of girls and parents aware that OCP can be used to regulate periods and relieve menstrual pain could give girls and their mothers the opportunity to make an educated decision about its use. A source of worry and anxiety for many of the girls was missing out on social activities such as sleepovers during menstruation. Future research and interventions could benefit from finding out ways to improve adolescents' comfort in engaging with these types of activities when menstruating. From the SDT perspective, the need for competence, relatedness and autonomy are key psychological needs (Deci & Ryan, 2008). These findings suggest that adolescent dysmenorrhea challenges these needs. Therefore, future research could benefit from investigating ways in which the negative impact of dysmenorrhea on these key psychological needs might be improved. Possible approaches might be to engage adolescents in dysmenorrhea-related problem solving and decision making (Caruso et al., 2019).

As stated above, girls in this study reported negative feelings towards pharmacological treatment for period pain. Future research and interventions could target these negative beliefs and attitudes which may improve trials of, and adherence to treatments (analgesic and contraceptive) and in-turn reduce the impact of dysmenorrhea on HRQoL. Also, all of the girls expressed a very limited understanding of period-related pain which often resulted in misconceptions about its causes and confusion about treatment. Future interventions could also focus on improving girls' understanding of pain including coping strategies, medications available, and the aetiology of dysmenorrhea. Platforms for doing so could include school-based and social-media interventions. Early understanding of pain during menstruation and information about how to relieve it could reduce the 'shock' factor that some girls reported at pain onset, the resulting ctastrophising thoughts associated with it, and the time taken to find an effective coping pain strategy.

Roorda, Koomen, Spilt, and Oort (2011) found that student-teacher relationships are associated with both student engagement and achievement in primary and secondary school children and adolescents. Positive teacher-student relationships were significantly associated with higher levels of student engagement and achievement whereas negative relationships were significantly associated with lower levels of student engagement and achievement. Therefore, as many girls in this study emphasised the importance of their interactions with school staff and personnel in their pain experience, future research could benefit from investigating whether negative teacher-student interactions regarding period-related pain has an impact on girls' school engagement and achievement. Finally, as some girls reported a positive impact of dysmenorrhea on family functioning, future research could benefit from investigating the associations between positive personality characteristics, positive emotions, and coping with dysmenorrhea and inform the development of effective, evidence based interventions aiming to improve HRQoL.

In sum, this qualitative study provides an in-depth exploration of the impact of dysmenorrhea on the lives of young girls (12-18 years) living here in the UK. This study was conducted to address the limitations in the previous research highlighted in chapter three. There were many novel findings from the girls' transcripts which have been highlighted and discussed in-depth. Suggestions were made for future research and interventions which should aim to expand on these initial findings and address issues that cause worry, concern, and anxiety to girls who experience dysmenorrhea.

Chapter 6 Maternal Perceptions of Adolescent Dysmenorrhea and its Impact on Family Functioning

6.1 Introduction

To-date, no research has investigated the impact of parenting an adolescent experiencing dysmenorrhea. Therefore, the chronic pain literature on parenting a child with chronic pain of other aetiologies has been reviewed to inform our understanding of how parents respond to dysmenorrhea. There is limited research investigating the impact of parenting a child or adolescent with a chronic or recurrent pain condition. The available literature shows that childhood chronic pain conditions have a profound, negative impact on parent's psychological and emotional functioning (Palermo & Eccleston, 2009). Despite the high prevalence of adolescent dysmenorrhea and reports from girls that dysmenorrhea has a profound impact on their family relationships (see chapter three), no studies to-date have investigated the impact of adolescent dysmenorrhea on the family. This chapter will begin with a brief overview of quantitative literature investigating the impact of parenting a child with chronic pain, followed by a summary of nine qualitative studies exploring the experience of parenting a child with various chronic pain disorders (including juvenile chronic arthritis, chronic abdominal pain, musculoskeletal pain, and neuropathic pain). An evaluation of the current literature will then be presented, followed by a summary and rationale for the current study. The second empirical study of this thesis will then be presented in detail. The methodology shares similarities with the methods in Chapter five and will therefore be presented as a simplified version to avoid unnecessary repetition. Finally, the results will be presented followed by a discussion of the findings in relation to previous literature, theory, and clinical and research implications.

Becoming a parent and caring for a 'healthy' child is a significant event that changes every aspect of a person's life. Parenting a child with a chronic or recurrent pain disorder poses many additional challenges to an already incredibly demanding role (Palermo & Eccleston, 2009). The association between the family and paediatric chronic pain is complex and bidirectional in nature. Previous research has shown that paediatric chronic pain can have a profound impact on family life, including parental burden, stress, and emotional impact (Hunfeld et al., 2001). In addition, parental characteristics are associated with the experience of paediatric chronic pain. These parental factors include parenting style and pain responses (Connelly, Bromberg, Anthony, Gil, & Schanberg, 2017), psychological functioning (Campo et al., 2007) and parental chronic pain (Campo et al., 2007). Palermo and Eccleston (2009) reviewed studies which focussed specifically on investigating the impact of parenting a child with chronic pain, and how parent functioning impacts the child's experience of, and adjustment to living with chronic pain. The review showed that caring for a child/ adolescent with chronic pain is associated with high rates of parental stress, anxiety, and depressive symptoms (Campo et al., 2007; Eccleston, Crombez, Scotford, Clinch, & Connell, 2004; Jordan, Eccleston, & Crombez, 2008). They also found that high levels of parental distress were associated with elevated child-reported pain (Ross et al., 1993) and disability (Logan & Scharff, 2005). There are both complex interactional processes and individual factors that predict children's and parent's emotional, cognitive, and behavioural responses to pain which influences the child's overall functioning (Palermo & Chambers, 2005; Palermo et al., 2014).To explain the associations between parental distress and children's experience of pain, Logan, Simons, and Carpino (2012) investigated the relationship between parental cognitive (pain catastrophizing) and behavioural (protective) responses to pain and school functioning in children with chronic pain. They recruited 350 children and adolescents aged 8-17 years, diagnosed with neuropathic pain (34.3%), musculoskeletal pain (30.8%), back/neck pain (14.1%), chronic abdominal pain (8.9%), gynaecological/genitourinary pain (5.8%), headache (2.0%), and other pain (4.0%). They found that parental pain- catastrophizing was associated with pain-related interference with school functioning, and that this association was fully mediated by parents' protective responses to their child's pain. The authors suggested that this mediation may have occurred because overly protective parents are more likely to react to their child's pain with concern and sympathy (pain catastrophizing) than parents who are not overly protective. Therefore, parents who feel overly protective towards their children and catastrophize their child's pain complaints are more likely to allow their child to abstain from school when experiencing pain, increasing pain-related disability and reinforcing pain behaviours. The integrative model of parent and family factors in paediatric chronic pain and associated disability (Palermo & Chambers, 2005) demonstrates the complex nature of the relationship between family factors and childhood pain. This model highlights the reciprocal influence of the pain itself and its accompanying levels of disability, as well as child and/or parental factors (e.g. child age, gender, parental pain history), in interacting with the family at all three levels: individual, dyadic and family. In addition, Palermo's (2012) multifactorial model of parent factors in paediatric chronic pain posits that three main parenting factors are interrelated and associated with paediatric chronic pain and physical and psychological functioning. These included parental chronic pain (pain frequency, location of pain, pain intensity and chronic pain status), physical function (pain interference and physical function) and psychological factors (catastrophising, anxiety and levels of depression) (Cordts et al., 2019).

Despite the evident impact of childhood pain on parental psychological and emotional functioning, and the association between poor parental functioning and the child's adjustment to chronic pain, no studies have used qualitative methods to explore the experiences of parenting an adolescent experiencing period-related pain. Just nine studies have adopted qualitative methods to explore the impact of childhood chronic pain on parents lives (Palermo & Eccleston, 2009) which will now be summarised.

Parenting a child with juvenile chronic arthritis (JCA)

Of these qualitative studies, three explored the experiences of family members of children and adolescents living with Juvenile Chronic Arthritis (JCA) (Britton & Moore, 2002; 2002b; McNeill, 2004; Waite-Jones & Madill, 2008). Two studies collected data from fathers (McNeill, 2004; Waite-Jones & Madill, 2008) and one from a variety of family members (siblings, mothers and fathers) using in-depth interviews (Britton & Moore, 2002;2002b; McNeill, 2004; Waite-Jones & Madill, 2008) and video diaries (Britton & Moore, 2002;2002b). Findings from multiple family members (Britton & Moore, 2002; 2002b) were split into two groups, the first consisting of JCA-specific elements such as symptom fluctuation, the global influence of pain, the "well" appearance of JCA children, and the wide-ranging impact of various symptoms. The second group encompassed general experiences of 'caring' for the child, including having to navigate health, social, and educational systems, hard work to deliver care and treatment, enforced adjustments to family roles, relationships and expectations, social estrangement, and continuing chronic sorrow. Many families reported difficulty in obtaining a diagnosis for JCA, and that this difficulty caused them to feel continued anxiety and frustration when dealing with HCPs later on. Parents also felt shock when their child was diagnosed with JCA as they had only associated the disease with older people and reported feeling frustrated when other people made that same misconception. Parents also reported feeling that others did not understand their child's illness because children looked generally healthy. Finally, family members reported that daily therapy at home for JCA made them feel exhausted and limited the amount of time they could spend with other family members and engaging in leisure activities. They concluded that many families have intense feelings about early JCA experiences which can impact how they cope and feel about the disease later on. When exploring the differences in reports between different family members, Britton and Moore (2002) found that many siblings often worried about their sibling with arthritis and felt that, as their parents had to spend time managing JCA, there was less time available for the family to spend time together. Younger siblings had wondered when they would develop JCA and have to go to see the doctor, and older siblings had considered what life would be like if they developed arthritis too. Parents reported that siblings had become more considerate to others as a result of having a brother or sister with JCA. Some parents also perceived that siblings would compete for parental attention because they felt ‘left out’ as a result of JCA. Mothers felt that due to caring for their child with arthritis, they had less energy and time to engage in family leisure activities and many were concerned about having less time with other siblings. Many of the mothers reported that they had to focus their entire life to on being a carer for their child with JCA, felt exhausted as a result of the extra work and helpless when they could not relieve their child’s pain.

Although Britton and Moore (2002) indicated that mothers were often the primary carer for children with JCA and more mothers than fathers reported continued feelings of sorrow and despair, the two studies focussing on father’s experiences of parenting a child of adolescent with JCA (McNeill, 2004; Waite-Jones & Madill, 2008) contradict this. Both studies found that fathers reported experiencing negative emotions including Fathers expressed negative feelings when talking about their child’s pain, including guilt, anger, anxiety, sadness and feeling helpless due to being unable to relieve their pain. Fathers in McNeill’s (2004) study felt the need to be strong for their family and, as a result, disguised and suppressed the strong emotions felt in response to their child’s condition. Coping strategies used by fathers included prayer, exercise, distraction, and in some cases support from extended friends and family. Most fathers regarded their partner or wife as their primary source of social support; however, in times of high family stress they tried not to burden their partners or wives by expressing their emotions. Fathers also reported a positive outcome of parenting a child with JCA as they felt their parent-child relationship had become more meaningful as a result. Waite-Jones and Madill (2008) identified five themes: a) comparison, b) loss, c) constraints, d) concealment, and e) social and emotional adjustment. Fathers compared their families to other ‘normal’ families who were not caring for a child with JCA, perceiving that other families were fortunate. Fathers also reported feeling misunderstood by their peers who they perceived as not able to understand the impact that their child’s JCA has on the life of the family. Many fathers felt that, due to their child’s condition, they could not fulfil their role as ‘protector and provider’ adequately. A sense of loss of their ‘normal’ family life was also commonly reported by fathers which often resulted in negative feelings such as frustration, tension, and in some cases conflict between themselves and their partner. Some fathers reported that they had to come to terms with the loss of their ‘ideal’ child, family life, and future plans due to JCA. Fathers of sons expressed a desire for their sons to be physically strong and able and felt an additional sense of loss for the shared activities that they had planned to take part in prior to the development of their son’s condition. Many fathers reported having difficulty communicating with their child with JCA particularly in comparison with mothers’ who, they expressed, shared a deep connection with the children surrounding the child’s care. Most fathers described the mothers as being the ‘key information holder’ regarding their child’s condition. Fathers responded to the difficulties associated with parenting a child with JCA by concealing their feelings, and using coping strategies such as distraction or denial. Fathers continued to engage in a social life outside of the family, which they used as a distraction from the impact that their child's JCA had on their lives. Finally, many fathers described how their wife was the main source of social support for them and, as mothers took the lead role in the child's care, helped them to cope and maintain a relationship with their child.

Parenting children with various chronic pain conditions

Other studies have explored the experiences of parenting children with multiple chronic pain conditions including chronic arthritis, idiopathic musculoskeletal pain syndrome, headache, migraine, or recurrent abdominal pain (Bennett et al., 2007), chronic knee, abdominal, or back pain (Carter, 2002), idiopathic pain syndrome, complex regional pain syndrome, diffuse pain syndrome, rheumatoid factor positive arthritis, or mixed connective tissue disease (Jordan, Eccleston & Osborn, 2007), and musculoskeletal or neuropathic pain (Maciver, Jones & Nicol, 2010). Both mothers and fathers were recruited for all studies and data was collected via questionnaire (using open questions) (Bennett et al., 2000), in-depth interviews (Carter, 2002; Maciver et al., 2010), journal writing (Carter, 2002), and focus groups (Jordan et al., 2007). Many of the parents in these studies described the burden of taking time off of their own employment, travelling to treatment, and financial expenses as a result of their child's pain, and feeling that these costs deprived the rest of the family of time and attention. Parents also felt concerned about their children taking even more time off of school for medical appointments (Bennett et al., 2000). The parents in Carter's (2002) study felt that, as they could not relieve their child's pain, they directed all of their efforts to enhancing family life and protecting their family from the impact of pain. Parents focussed less on the child's pain and more on the frustrations they encountered with medical professionals and in daily life with pain. Parents reported feeling 'let down' by HCPs and feeling frustrated, hopeless, and disappointed in their lack of diagnosis (Carter, 2002). This was echoed in another study which found that parents felt distress when they were unable to identify a cause for their child's pain and reported relief after receiving a diagnosis (Jordan et al., 2007). They also felt disbelieved before their child's diagnosis and felt intense societal pressure to have a reason for why their child was experiencing chronic pain. Feeling helpless was often rooted in not being able to relieve their child's pain, not knowing what would happen next relating to their child's condition and uncertainty about how the pain would affect their child's future. Families in Carter's (2002) study reported that, as they did not have a diagnosis, they felt unsure of how to manage the problem because they didn't know what they were trying to manage. They also reported feeling disbelieved by HCPs, and explained that trying to convince HCPs that the pain was real was very problematic for them. Families felt ‘worn down’ by experiences with HCPs and frustrated at the lack of communication between different HCPs.

Parents also reflected on how their lives had changed as a result of their child developing chronic pain. In Maciver et al.’s (2010) study, parents reported how their ‘role’ as a mother or father had changed since their child developed pain and they struggled to know what would be an appropriate response to their child when in pain. All parents felt extremely distressed when their child first started experiencing pain and over time, this distress often reduced as parents learnt how to cope with their child’s pain. Many parents reported feeling helpless when they were unable to relieve their child’s pain as they believed that their role as a parent was to make their child feel better even though they were unable to do so. Parents were often particularly vigilant to any signs that their children were in pain and catastrophized the possible cause of that pain. Parents also described feeling exhausted as a result of the extra care and demands of parenting a child with chronic pain. In Jordan et al.’s (2007) study parents reported significant changes in their relationships. For example, their relationship with the adolescent often changed whether it be a positive change (feeling that their relationship had improved following the shared experience) or less positive (one mother described her daughter as becoming overly dependent). Parents commonly reported that their life was limited by their child’s pain, often having to change and reorganise parts of their lives to accommodate the condition. Bennett et al. (2000) suggested that further research should be conducted to explore other areas of child and family functioning such as emotional distress associated with chronic pain in children and parent’s (individual and couples’ stress), siblings, and extended family.

Parenting a child with chronic/recurrent abdominal pain

van Tilburg et al. (2006) recruited 15 parents of children diagnosed with recurrent abdominal pain to explore their worries and fears related to their child’s pain. They also aimed to explore associations between parental responses to their child’s pain complaints and the child’s illness behaviour. Thematic analysis was applied to the data which showed that many parents were uncertain about the cause of their child’s pain which resulted in fear that their child might have a serious underlying disease. As a result, parents expressed a longing to resolve their child’s pain through obtaining a diagnosis which, they hoped, would lead to effective treatment and management of the condition. Parents commonly reported that they felt helpless as they were unaware of how to relieve their child’s pain despite being eager to reduce their suffering. van Tilburg et al. (2006) concluded that parents reinforce illness behaviour by responding sympathetically to their child’s complaints of pain as a result of the uncertainty, fears, and worries felt by parents when their child experiences recurrent abdominal pain.

The use of qualitative methods, particularly semi-structured interviews, has allowed authors to collect detailed, in-depth data about perspectives of parents and siblings of children with chronic pain, in their own words. Several limitations of the qualitative literature were considered in the development stages of the current study. For example, one study simply implemented two open-ended questions in their descriptive questionnaire study (Bennett et al., 2000).

Although Bennett et al. (2000) provided a brief overview of parents' experiences, the authors did not obtain a very detailed insight into those experiences and the majority of questions did not allow parents to describe their experiences in their own words. Due to the exploratory nature of research in this area, qualitative, in-depth data collection methods are an appropriate means of exploring the experiences of parents. Also, despite the fact that mothers are usually the primary carer for children suffering from chronic pain conditions (Britton & Moore, 2002b; Britton & Moore, 2002; McNeill, 2004; Waite-Jones & Madill, 2008), two of the nine qualitative studies focussed on the experiences of fathers (McNeill, 2004; Waite-Jones & Madill, 2008). Although a growing body of research is developing in this area, the qualitative research is limited, being primarily focussed on interactions with HCPs (Carter, 2002), inflammatory pain conditions such as JCA (Britton & Moore, 2002b; Britton & Moore, 2002; McNeill, 2004; Waite- Jones & Madill, 2008), or in recruiting a heterogeneous sample of various chronic pain conditions (Bennett et al., 2000; Carter, 2002; Jordan et al., 2007; Maciver et al., 2010). Only one study has specifically explored the impact of parenting a child with recurrent abdominal pain and no studies have yet explored the impact of parenting a child with period-related pain. Finally, all of the nine studies recruited a clinical sample of parents of young people diagnosed with chronic pain conditions (Bennett et al., 2000; Britton & Moore, 2002b; McNeill, 2004; Waite-Jones & Madill, 2008). Because many girls self-manage their menstrual pain (Harel, 2006), findings from clinical samples of young people with other chronic pain conditions are not transferable to girls experiencing period-related pain.

Current evidence shows that the profound, negative impact of childhood chronic/ recurrent pain spreads out beyond the child and affects many aspects of family life. In addition to the impact of parenting a child with chronic pain, there are specific factors related to parenting a child with dysmenorrhea that require further exploration. Firstly, menarche is an important milestone for many girls as it symbolises reproductive maturity (fertility) and the transition from childhood to womanhood. Therefore, both primary and secondary dysmenorrhea could generate additional concerns related to exploratory or treatment regimens (e.g., use of the contraceptive pill or pelvic examinations) and symptomology (e.g., concerns about possibility of future infertility) (Harel, 2006). As mentioned previously, if medical investigations are carried out to identify a possible pathology (e.g., endometriosis), mothers may be present during their daughter's pelvic examination (Song & Advincula, 2005), yet no qualitative research has explored the thoughts and feelings of mothers in this situation and the impact of adolescent dysmenorrhea on family life has yet to be explored.

In sum, Palermo and Eccleston's (2009) review indicates that very few studies have investigated parents' experiences of childhood chronic pain and even fewer have used qualitative methods to do so. There is still little understanding of parents' needs, the impact of their child's pain on their lives, and the relationship between their behaviours and the child's pain and disability. Understanding in this area is critical to supplying the best possible care for families with a child experiencing chronic/ recurrent pain. Future research in this area can be used to inform interventions to improve quality of life for both children and their families. No studies have used qualitative methods to investigate the impact of parenting a child with dysmenorrhea. Therefore, to address this gap, the current study explored the following research question: How do mothers experience parenting a child with dysmenorrhea and how does dysmenorrhea impact upon them as individuals, the family unit, and the parental couple, where relevant.

6.2 Method

6.2.1 Study Design and Tools

As described in chapter five, the researcher developed a protocol for this study, which was then reviewed (appendix G). Ethical approval for this study (ID: 12099) was obtained on 09.10.2014 from the University of Southampton Ethics Committee. Participants completed one in-depth, individual interview which took place at the University of Southampton (n=2), participants' own homes (n=13), or over the telephone (n=5) based on the preference and convenience of the participant.

An open-ended semi-structured interview design was implemented to allow participants to discuss issues important to them. Each interview followed an interview schedule (appendix L) (see Table 4), developed by the researcher based on discussions with academic supervisors and previous research (DiCicco-Bloom & Crabtree, 2006). The interview questions were also developed based on a reflection of the key family-based biopsychosocial models introduced in Chapter 2. Parental characteristics are posited to be important in understanding adolescent pain including parenting style and parental psychological functioning (Connelly et al., 2017; Campo et al., 2007). For example, the researcher was interested in exploring ways in which mothers perceived and responded to adolescent dysmenorrhea. Family systems theories suggest that paediatric chronic pain can negatively influence a parents' emotional well-being which can impact on a child's chronic pain outcomes. Therefore, the way in which adolescent dysmenorrhea impact on mothers' well-being was explored in the interview.

Prompts and probes (e.g., could you clarify what you mean by that please?) were used to encourage participants to clarify, expand, and provide more detailed answers (Braun & Clarke, 2013). Once all interview topics had been covered, participants were thanked and asked whether they would like to add anything before the audio-recording stopped. All interviews were audiotaped and transcribed verbatim.

6.2.2 Participants

Twenty mothers (aged 36-56) of girls experiencing dysmenorrhea (aged 12-18) were recruited (see Table 5 for participant characteristics) for this sample. Recruitment finished once data saturation, the point where additional data fails to generate new information (Morse, 1995; as cited in Braun & Clarke, 2013), had been achieved. A sufficient number of mothers were recruited to analyse the impact of adolescent dysmenorrhea on all aspects of family life.

Inclusion criteria for this study included: a) aged >18 years, b) be a biological or adoptive mother of a girl who experiences dysmenorrhea aged 12-18, c) speak fluent English, d) be able to provide consent, and e) be able to comply with all study procedures.

Exclusion criteria for this study included: a) aged <18 years, b) are unable to give consent, c) diagnosed with any major cognitive impairments, d) diagnosed with a major psychiatric disorder, e) are foster or step parent of the girl experiencing dysmenorrhea.

Table 4 Interview Guide with Mothers

Questions	Topics
So, if it's OK, can you tell me a bit about yourself please?	Age, occupation, family situation and living arrangements, hobbies.
Can you tell me a bit about the period-pain that your daughter experiences?	Menarche (did the pain start at the same time?), accompanying symptoms, pain development/ change, patterns, general health.
Can you please tell me about any treatments for period pain that your daughter has had?	Medical visits, examinations, causal attributions, treatments (and their efficacy), self-help strategies, future expectations.

How does period-pain affect your daughter's life?	School attendance and performance, daily activities, sibling relationships, hobbies/sports, friendships, social life, family life, self-esteem, future plans, social, coping, support available.
How does your daughter's period-pain affect your life?	Social life, activities of daily living, occupation, family activities, relationships between family members, stress levels, coping strategies.
Is there anything that we haven't talked about today that you would like to talk about in this interview?	

Table 5 Participant Characteristics

	Frequency (n)	**Range (*M*age)**
Participant age (years)	-	36-56 (47.6)
Family Situation		
Married	17	
Living with Partner	1	
Single-Parent Household	2	
Daughters (n=23)		12-18 (15.13)
Daughter age (years)		
12-15	11	
16-18	12	
		10-15 (12.39)
Age at menarche (years)		
10-11	7	
12-13	13	
14-15	3	

6.2.3 Procedures

Purposive sampling was employed (Patton, 1990) so that we interviewed a heterogeneous sample of mothers in terms of daughters' age, severity of period-related pain, and family situation. This was achieved by recruiting from a variety of sources including: a) two secondary schools, b) two local newspapers (Daily Echo, Hampshire Chronicle), c) a press release (from the University of Southampton), d) an advert to the members of the Vulval Pain Society (VPS) and Pelvic Pain Support Network, e) the University of Southampton (via posters and SUSSED advert), f) local youth groups (jujitsu and dance groups and after-school youth clubs) and community centres (via posters and leaflets), and through g) snowball sampling (see further recruitment procedures in chapter five).

All potential participants were given an information sheet (appendix M). Information sheets detailed all aspects of the study, participation requirements, and information regarding right to withdraw and confidentiality. Informed consent was obtained via a dated signature and kept at the University of Southampton. Before each interview, the researcher introduced herself and the study again, participants were thanked and reminded of their right to withdraw, confidentiality and that the interview will be recorded. All participants were assured that there are no right or wrong answers and were asked if it was OK for the researcher to start the recording and the interview. At the end of the interview, once all topics from the interview schedule had been covered, participants were asked if they would like to add anything, thanked and the recording stopped. Participants were then debriefed. Finally, all participants were given the option of being entered into a raffle where the winner received a prize worth £20-£30. All participants took part in the raffle. To ensure data protection, audio-recordings were kept on a password-protected computer.

6.2.4 Method of data analysis

Although the adolescent and mother interviews were carried out at the same time, the data were collected, analysed, written-up and presented separately. This reflects the importance of family functioning in paediatric chronic pain highlighted in the biopsychosocial models introduced in Chapter 2. The developmental, family-based biopsychosocial theories of paediatric chronic pain (e.g., operant-behavioural theories) (Fordyce, Shelton, & Dundore, 1982) consider individual parental factors and family functioning (e.g., the McMaster model of family functioning) (Epstein, Bishop, & Levin, 1978) to be important infleunces on chronic pain outcomes. Therefore, to explore, in-depth, maternal experiences of adolescent dysmenorrhea, these data were analysed and written-up separately. Inductive thematic analysis was used to identify and report themes within the data (Braun & Clarke, 2006; Vaismoradi, Turunen, & Bondas, 2013) from a broadly critical realist perspective. Braun and Clarke's (2006) step-by-step approach to thematic analysis was followed. See Chapters 4 and 5 for further details. Once the data had been analysed as a whole, subgroup analyses were conducted. The first subgroup analysis explored the differences and similarities in parenting a girl with dysmenorrhea in early (13-15 years) and late (16-18 years) adolescence. A detailed paper trail recorded the development of the analysis from initial codes to the finalised themes. The final results describe all themes relating to how parenting an adolescent with dysmenorrhea affects the life of the family from the mothers perspectives. Quotes used in the results section of this paper were chosen as appropriate representations of each theme.

6.3 Results

6.3.1 Introduction to findings

Overall, twenty interviews lasting between 16.41 and 107.51 minutes (M= 37.71 minutes) were transcribed verbatim and coded. Thematic analysis produced one overarching theme titled 'maternal experiences of parenting a daughter with dysmenorrhea'. Within the overarching theme, the inductive thematic analysis generated three key themes: 1) Differeces in maternal responses to adolescent dysmenorrhea, 2) The importance of family functioning and communication, and 3) The primary caregiver for issues related to menstruation. This section presents details of each of the three key themes and eleven subthemes (see Table 6). Verbatim quotations were selected from original transcripts to provide examples and context to themes and subthemes and provide an insight into mothers' experiences, in their own words.

Table 6 Table of themes and their associated subthemes.

Theme	Subthemes
Differences in maternal responses to adolescent dysmenorrhean	- Perceived impact of dysmenorrhea on daughters' QoL - Maternal perceptions of the psychological factors associated with dysmenorrhea severity - Encouraging daughters to 'get on with it' - Maternal catastropising and empathetic responses

	- They should not call that pill a ‘contraceptive’ pill
The importance of family functioning and communication	- Women in the family support eachother - Still a taboo: secrecy around menstruation - A monthly impact on family life
The primary caregiver for issues related to menstruation	- The daily burden of the primary caregiver - Constantly being on ‘high alert’: the emotional impact of parenting an adolescent experiencing dysmenorrhea - When maternal menopause coincides with adolescent dysmenorrhea

6.3.2 Theme One: Differences in maternal responses to adolescent dysmenorrhea

All mothers wanted to help their daughters to cope with dysmenorrhea. There was agreement across interviews regarding the importance of daughters being able to cope well with dysmenorrhea because they would experience it for, potentially, all of their fertile life. Although they had the same goal, this theme highlights key differences in mothers’ responses to their daughters’ pain. Some mothers would encourage their daughters to engage in their usual daily activities despite their pain. Others would take a more sympathetic approach, permitting the avoidance of activities including school absence

Perceived impact of dysmenorrhea on daughters’ QoL

The majority of mothers believed that period-related symptoms negatively impacted many aspects of their daughters’ quality of life (QoL) (e.g. sleep, appetite, ability to socialise with friends, go swimming, or attend school). Many felt that pain severity and disability were one and the same. For example, one mother perceived her daughter’s period pain to be very severe because her physical and school functioning was severely limited by pain. Several mothers hadn’t considered there may be other psychosocial factors contributing to her daughters’ disability:

> *“She was having time out of, from school, quite a lot of time erm and also her night’s sleep would be interrupted because she’d be in pain. Um, I found her quite a few times crawling on the floor where she was in so much pain…When she was in a lot of pain, she had a real*

> *bad pain then she wouldn't feel like doing anything, I don't think she would pick up a book, she wouldn't, she wouldn't go up to her room and, and sit and do a bit of writing she'd just want to be on the settee and just focus on getting rid of the pain um so yeah, I suppose it would affect, it would affect it."* (Mother 1, daughter 17yrs).

Several mothers however, particularly those who considered their daughters' pain to be mild, felt that dysmenorrhea did not have a significant impact on their lives. These mothers felt that their daughters managed their period pain and its accompanying symptoms effectively:

> *"No, she's as I say she, she manages it well herself and as I say the things that I thought it would impact would be her sporting activities and things that you know, you've got exercise and all that kind of thing but she seems to be OK in doing that and you know we, we've been away, we've stayed, we go down to my mums a lot so um, you know she's had to deal with it when we're down there and I don't think it would stop her from going".* (Mother 7, daughter 14 years)

Maternal perceptions of the psychological factors associated with dysmenorrhea severity

Some mothers however, did consider the psychosocial factors associated with pain and disability. For example, adolescent girls' functioning was often perceived to be limited by dysmenorrhea because they naturally had a *'low pain tolerance'*. This was frequently highlighted in comparison to their own, with adolescents often being perceived as *'hypochondriacs'*. A girl's inability to cope with other generic illnesses or pain was often used to explain why they were severely affected by period pain:

> *"Um, she, she's always been a bit of a hypochondriac erm in illnesses and things like that and erm I dunno why she's like that in pain because I can tolerate quite a bit of pain and so can my husband but um, I don't know whether it's an only child thing, wanting a bit more comfort, I'm not really quite sure. But it's really hard to ascertain when she really is in pain you know, if you said to her, she would say oh 10 out of 10 my pain is really bad but I would probably only be about a 5 or a 6 out of 10 for that."* (Mother 3, daughter 16 yrs)

From the adolescent perspective (chapter five), daughters explained that they gradually learned how to cope with the pain over time. Therefore, mothers may have had more experience with dysmenorrhea to develop pain management strategies.

Several mothers were perceptive to how their daughters' feelings of anxiety and anticipation of monthly pain exacerbated the negative impact of dysmenorrhea on their daughters' QoL:

> *"She worries very much about the pain starting, she worries about erm being, they're quite heavy so she worries about the physical signs of a period being there and it stops her from doing things that she would ordinarily do. I mean she's having time off school, and she refuses to leave the house and she refuses to visit anyone so it's all built up around that."* (Mother 5, daughter 16 yrs)

Almost all mothers felt that period pain and related symptoms had a negative impact on their daughters' emotional functioning:

> *"It just makes her a bit more whiney and a bit more difficult and you can give her a million pounds and it wouldn't be good enough."* (Mother 10, daughter 15 yrs)

In agreement with the adolescent data (chapter five), the mothers felt that period pain had a severe negative impact on girls' school functioning. In addition, school staff were considered unsympathetic which exacerbated the problem:

> *"I mean this month's been dreadful, when you phoned, when we spoke, she literally, she had 3 days off school this month because she couldn't get out of bed and it's debilitating for her erm and it's sort of interrupting her learning but we find it's very difficult for the school because they don't understand."* (Mother 11, daughter 14 yrs)

Encouraging daughters to 'get on with it'

Although mothers had the same goal as eachother, there were clear differences in how mothers in this study described the ways in which they responded to dysmenorrhea. Some focussed on encouragement whereby they encouraged their daughters to 'get on with it' and carry on with their daily activities. In contrast, other mothers focussed on being sympathetic and nursing their daughters through the pain. This subtheme focusses on mothers who encouraged their daughters to 'get on with it' as an approach to helping them cope with their pain.

Many daughters had not sought out medical help from a HCP for their period pain which was partly due to some mothers not considering the pain severe enough to warrant medical attention:

> *"No she hasn't. I don't think there's been any need to because with period cramps you just gotta get through it haven't ya so I just give her as much as I can to help her through it and that seems to like you know, do her really. She's never been on the floor or screaming or… I'd have her straight to the doctors. She's just had the usual cramp pains."* (Mother 18, 17 years)

The more pragmatic, encouraging mothers did not want to respond to their daughter's pain in a way that was too sympathetic and did not view it as a reasonable excuse to take a day's absence from school:

> *"I say to her it's one of those things babe, you're gonna have it until your possibly in your late 50's, you gotta get on with it you know."* (Mother 12, daughter 14 yrs)
>
> *"She tries to get a day off school erm but that's about it. It doesn't happen so (laughs)… 'Oh it's just so bad and it hurts everywhere', just the general sort of symptoms and it's just like well you got it for the rest of your life so tough. Got it for a long time yet anyway".* (Mother 14, daughter 13 yrs)

Many mothers who chose this approach did so with the aim of teaching their daughters to be self-sufficient and independent, rather than relying on others for comfort:

> *"Erm and then (youngest daughter) would lie on the bed and feel sorry for herself and I said 'have you had paracetamol?' errr no, she would say no and oh let's go get some paracetamol, go get yourself some paracetamol, I don't want them to be the sort that, you know relies on somebody else as if it's this big deal so very early on I didn't pander to it"* (Mother 6, daughters 15 and 17 yrs)

In addition, several mothers also tried to limit the amount of analgesics that daughters took for their pain because they did not want them to become reliant on medication:

> *"To be honest I did say to her I didn't want her to take too much pain relief because neurofen is quite strong and as children they didn't take much pain relief because I was lucky, they weren't sickly kids and I didn't want her to become dependent on it every month so I said only take it if it's really really painful."* (Mother 13, daughter 17 yrs)

Finally, one mother described how she tried to be a model for her daughter by going to work even when she is ill:

> *"I think because I'm a get on with it person and I don't um, I feel sorry for them if they're generally ill or anything like that but um I, I never make a fuss about these things so there's no fuss need. If she says she's got a sore tummy, I just say oh take a couple of paracetamol um but they see me going into work no matter how rotten I feel and err I'm not much of one to make a big deal about stuff like that."* (Mother 15, daughter 16 yrs)

Maternal catastrophising and protectiveness

In contrast, some mothers were incredibly sympathetic to their daughters' pain, almost nursing them through the process each month. These mothers expressed distress at seeing their daughter in pain, which elicited sympathetic and protective responses:

> *"Sitting with them just holding their- when they were really bad just holding their hand, stroking their face like a mother would do you know or erm yeah.... I just felt as a mums point of view, I, I felt that I just, because you don't like seeing your daughter like that, you hate it, you wanna take it away and why should they go through that"* (Mother 1, daughters 13 & 17yrs)

These empathetic responses were also elicited by mothers own difficult experiences with dysmenorrhea. These mothers drew on their own experiences to help their daughters to cope with their pain. These same mothers allowed their daughters to be absent from school or PE lessons because their own adolescent experiences of school or PE during their period were very negative. These responses therefore enabled their daughter's avoidant pain behaviours:

> *"Yeah, I tend to just go into um, you just over drive really and you just go right, OK this is what I needed when I was that age and so it would be the heat packs to put on the tummy or hot water bottle or um sometimes we actually use the cold pack because I think to myself well if it's cold, it might reduce whatever the inflammation is inside"* (Mother 11, daughter 14 yrs)

> *"You know, I mean I remember being like that and thinking 'oh god I've now got to try to, you've got dressed for school, now I've got to get undressed to get into my PE stuff an I've got to wear a silly little skirt and pair of shorts, and everybody's going to see' and I always remember that horrible feeling and I just don't want her to go through that. That's, you know, I say it's fine if you don't want to do it, don't do it."* (Mother 11, daughter 14 yrs)

Although daughters' menstrual and pain-related mood changes caused a great deal of frustration, many mothers were able to empathise with how their daughters were feeling which reduced the negative impact on their interactions with daughters:

> *"Oh well I can kind of relate to how she's feeling so I think you know ah she just needs cheering up and a bit of a cuddle so I suppose I am more lenient with her around that sort of time."* (Mother 14, daughter 13 yrs)

These empathetic responses, in some cases, led to pain catastrophizing among some mothers. For example, some mothers reported deep concerns that their daughters' period-related pain and accompanying symptoms (e.g., heavy blood flow) had an underlying pathological cause:

> *"I'm no doctor and maybe you think we're all made up the same way so surely why do people work that way when they're losing so much blood erm, I've seen her sit on the toilet and not be able to get off, not being crude or anything…Erm you know and think that can't be normal but when you're going to see the doctor you think well that's their profession so, you know you take what they say but knowing all what's happened now, I do feel maybe yeah they should investigate and try and find out why, why this happens…."* (Mother 1, daughter 13 yrs)

These fears that their daughters' period pain had an underlying pathological cause was a great source of stress among mothers who wondered whether or not to take their daughter to hospital:

> *"Quite a few times I've had to come and pick her up from school where she is in real pain to the extent when I think well I'm worried, I'll go take you down to the walk-in clinic or the A & E when actually all she wants to do is come home and go to bed. So it's quite hard to actually find out where her pain threshold actually does lie."* (Mother 3, daughter 16 yrs)

<u>They should not call that pill a 'contraceptive' pill</u>

Like the reports from adolescent girls, mothers varied in how they the viewed the oral contraceptive pill (OCP) as a treatment option for period pain. Reasons for negative perceptions of the OCP were either due to concerns about health risks or its association with sexual activity and the stigma attached to that while their daughters were still below the age of 18:

> *"Personally I didn't want her to go on the pill because I thought it was far too young to interfere with your body's system at that age"* (Mother 10, 14yrs daughter).

> *"I was, as I said, I was a little bit… don't get me wrong, with the pill, it helps the period pains. This is one of the reasons when I was younger that I went on it but also with the pill, you advertise it too much comes the little bit of a stigma that goes with it. Erm and I was a little bit po-faced about it. A little bit 'don't make it too obvious to people' that you're on the pill because… "well I'm only taking it for my periods mum", she's got the right attitude. I was the one who was a little bit please don't advertise the fact that you take it because it could be said innocently to one girl, she could have a conversation with someone else, and it could go round that you're a little bit of an easy…that's my, perhaps I was a bit of a prude but that's my thing. And I think my husband felt a little bit that was as well although he said*

> *brilliant within two months; you could see a change in her, completely brilliant."* (Mother 12, daughter 14 yrs)

One mother reported profound concern about continuous use of OCPs:

> *"I've gotta be honest, I'd rather her have a week off (the pill), 3 weeks on, one week off because I think you're having a period for a reason. What happens to what doesn't come out? Do you see what I mean? I'm a little bit worried about that. Um, and I think coming up to 15, 16 I will be talking to the doctor and I will be saying to him can you suggest something else because I think a lady has a period for a reason. Your body's got to disperse that somewhere so… what happens? I'm a little bit concerned."* (Mother 12, daughter 14 yrs)

The majority of mothers suggested that a way to reduce the stigma of the OCP would be to change the name. They felt that the use of the word 'contraceptive' in OCP gave a false impression of its use:

> *"Yeah, I wish they wouldn't call it a contraceptive pill because then like she said she had a lecture from a male doctor who's kind of like, I, you can feel by the way he was talking to her that she was purely, it was is it because the sex, are you using it as a sex and she said no sort of thing and she said I don't like to be lectured on STI's and you know, and being careful and things like that she says I know all that stuff but I'm on this tablet for purely for my periods you know and she was, she felt really, I don't see why they should call, they should not call that pill a contraceptive pill, it should be a pill for period pain, pill for periods, you know it should be separated yeah."* (Mother 2, daughter 16 yrs)

Several of the mothers in this study however, would not allow these negative perceptions to act as a barrier to their daughter seeking effective treatment for dysmenorrhea. Many felt that the menstrual benefits of using the OCP outweighed the costs:

> *"Well obviously, a little portion of me felt, my god, my daughter of this age going on the pill, on the contraceptive pill. But then I told myself well she's not going on it for 'that' reason, it's solely you know, me as a mother , I wanna help my daughter and being as I went through it myself, I know that it was the right thing at that time to help me and hopefully it would be for her so yeah, I didn't care, and obviously she had to know how to take it and it was important to know how to take it right, we had a chat over it and, and she was OK, she, she just wanted to help herself, do something you know, so yeah she was OK about it. I don't think she told anybody, she was, school friends so…. (laughs)."* (Mother 1, daughter 17 yrs)

6.3.3 Theme Two: The importance of family functioning and communication

All of the women in this study emphasised the importance of good family functioning to them, particularly while daughters were experiencing dysmenorrhea. This is outlined in theme two where, in accordance with adolescents' reports in Chapter 5, communication was heavily influenced by gender. Mothers highlighted how important it was for women in the family to support each other in relation to menstruation and dysmenorrhea. However, some mothers discussed how menstruation and dysmenorrhea were still taboo subjects for their daughters, who did not willingly bring up the topic with them and kept some level of secrecy around menstruation. Finally, although communication around menstruation differed across families, many mothers explained that their daughters' dysmenorrhea had a profound monthly impact on family activities and overall functioning.

Women in the family support each other

All mothers described the way in which women in the family discussed and supported each other with menstruation. This was perceived as integral support for coping with dysmenorrhea related difficulties. Men were often left out of this conversation, which echoes the adolescent reports in Chapter 5. Their daughters preferred to communicate with female family members and friends about their period-related issues:

> *"Yeah I've always, always talked. I mean she will ask me erm anything related to women's stuff, any, she will come to me and speak to me about things so I know that if she was worried about anything she would come and tell me."* (Mother 10, daughter 15 yrs)

In particular, older sisters were viewed as a positive source of social support. This also shared the caregiver burden as mothers were often the primary caregiver in matters of menstruation:

> *"Erm, yeah she did, I think it helped that she's got her sisters as well before her, knowing what to expect in that sense but yeah, yes she let me know. You know when it's the initial when it's just spotting isn't it so you're not too sure and it, it goes from there so it's very open, lovely relationship."* (Mother 19, daughter 16 yrs)

> *"Yeah, oh yeah and if she's got problems and she goes to visit (her sisters) and she has a period, they've always got spare knickers and sanitary towels (laughs) you know what I mean so if she's got like that, she can go to a safe place when she knows that she, it's not erm, there's always err a mechanism there to, oh if I have a period then I don't have to*

> *worry cause my sisters have got all their spare, spare knickers and sanitary towels cause she doesn't like to go out when she's got her period."* (Mother 2, daughter 16 yrs)

Daughters were reluctant to discuss menstruation with their fathers, who were often described as naive regarding menstrual-related symptoms and issues. In a similar way as in the messages from the adolescent data (chapter five), mothers seemed to pity fathers in relation to menstrual tensions in the household:

> *"If they're snappy he (their dad) just doesn't get it , he just thinks they're being naughty so yeah, it is, he's not as good (laughs)."* (Mother 8, daughters 12 + 16 yrs)

Despite sisters and other family members being involved in discussion around menstruation, it was viewed as the role of the mother to pass down her valuable information to their daughters to prepare their daughters for menarche. They described the various pieces of advice they passed down to their daughters:

> *"It's, it's not the end of the world, it can make you feel a bit grotty, it can make you feel a bit tired, a bit icky, but it happens to every woman and it's part of being a woman and part of life and in a way it's great because when it happens it means you can go on in the future and have children. So it's just your body doing what it's meant to do."* (Mother 10, daughter 15 yrs)

> *"I'd told her all about what was going to happen, much to her disgust when she was about 10 or 11 um and she just sort of started and was just fine with it, I think 'cause we've always been quite open."* (Mother 8, daughters 12 + 16 yrs)

Still a taboo: secrecy around menstruation

Menstruation is still a taboo subject among many adolescents, which was reflected in mothers' reports. Although some mothers were able to have honest, open discussion around menstruation, some girls were described as being 'private' and reluctant to discuss menstruation directly:

> *"Yeah so erm, she (youngest daughter) would say 'oh I've got, got really bad period pain' whereas (eldest daughter) would say 'I don't feel very well'."* (Mother 6, daughters 15 &17yrs).

One mother explained that her daughter was not actually willing to discuss menstruation with her verbally when she reached menarche. This mother therefore decided to distribute the important information about menstruation to her daughter using a letter:

> *"Well my daughter started her periods when she was only 10 years old. She never told us, to be honest she still doesn't really talk about it. She's quite a sort of private person so I knew that she wouldn't anyway erm. I just you know, you find evidence in the laundry basket and stuff so I did try and broach the conversation, she just didn't want to talk about it erm so I just wrote her a letter and left it on her bed and sort of said you know, it's totally normal. I knew she knew all about it because we had tried to speak about it in the past and I knew she had the things at school and everything so I just left her a letter explaining it and saying to her how often it would happen and what was likely to happen and just about sanitary towels and stuff. And I just said that you know left the lines of communication open that you know it was fine if she didn't want to talk about it or feel the need to but if she ever did she, she could always come and ask us anything."* (Mother 18, daughter 17 yrs)

Some daughters were seen to be in denial about reaching menarche. They were perceived to be completely unprepared for menstruation yet unwilling to discuss it, despite their mothers' advice:

> *"She was completely unprepared even though we spoke about it because she said it never ever was gonna happen to her. And absolutely hated every minute of it and nobody's allowed to know (laughs) still"* (Mother 14, daughter 13 yrs)

Mothers did not generally understand their daughters' reluctance to use tampons, which were often viewed as a more convenient form of sanitary wear. Mothers described their daughters' embarrassment when this subject was raised:

"Well the swimming certainly you know, that, that's the big issue, and I say shall we go swimming and they say oh no, no, no, no and you worry about what they think about swimming now so it wasn't necessarily a hobbie but it was something we would do on Sunday mornings or and you know I said there's other things you can use you know- 'no I'm not using tampons' and things like that so they're a bit scared you know and no I've done the gentle gentle 'would you want me to show you what to do?' and of course there's a huge embarrassment around that so initially it was you know you got the shout in the toilet 'mum can you help me' and thought oh OK I know what that's about. It's another ball game you know standing at the sink with your mother" (Mother 6, daughters 17 and 15 yrs)

A monthly impact on family communication life

Although levels of communication around menstruation differed between families, the majority of mothers described how menstrual and pre-menstrual symptoms had a profound, negative impact on family communication and activities. Mothers felt frustrated that daughters were not willing to socialise and engage with the family while experiencing period pain. Daughters were viewed as unsociable as they would often retreated to their bedrooms instead of spending time with their family:

> *"She's not interested in going out or doing anything like that, she's quite happy to stay in her room and play on her playstation. Well I just go out on my own now, I take no notice. You can't make somebody do something they don't want to do can you, especially if they're pre-menstrual. I just open the door ajar, throw some food in and run out (laughs)"* (Mother 16, daughter 16 yrs)

There were also many situations where daughters would not attend family events or activities during their period due to pain or accompanying symptoms. This caused additional frustration among mothers who, as the primary caregiver, would also miss out:

> *"There's nothing you can do. So it's just leave her behind and I feel guilty, or we go out and try and cajole her along and she just doesn't cope so it, it's having a big impact…. it's quite frustrating because we've had to erm go back to her being quite small where we have to have always one person at home rather than two so if it's an important social event, he'll often go on his own. Sometimes I'm quite glad of it if it's family and I don't want to go (laughs) but at Christmas for example, he had to go to his parent because (daughter) refused to go which is highly unsual because all the family were there which is unusual and I had to go to places on my own as well and it becomes frustrating."* (Mother 5, daughter 16 yrs)

Tensions and conflict often arose at the time of menstruation due to hormonal fluctuations, pain-related mood changes, and menstrual 'syncing' between female family members. Mothers often described themselves as the 'peacekeeper' of their family:

> *"She usually just texts me from her bed and say, I've got a really sore tummy, bad tummy can you bring us some tablets and I run up and down the stairs like a slave to her basically cause it's just easier. My husbands like /get her to come down and do it her bloody self' and I know but it's just easier because it's just, she wouldn't come down, she would just lie there in pain all night rather than help herself and then if she did come down it would be like 'oh you just let us lie there in pain, you wouldn't get us a drink or anything' and then it just ends up snapping back at her and then it all just kicks off. It's just easier to go up with the tablets and the weatie and keep the peace basically. That's just what you end up doing all the time, keeping the peace."* (Mother 18, daughter 17 yrs)

However, the role of the peacekeeper was often a difficult one. Although mothers generally wanted to be sympathetic to their daughter's mood changes and complaints of menstrual pain, they often found it difficult to do so, particularly with the addition of other life stresses (work, financial or family difficulties):

> *"But sometimes if I'm you know, quite stressed from work you know I'd probably, I'm not as patient as I might be so I'll have a go at her for being difficult or you know, yes probably (inaudible) because she's not a difficult child you know but um, yeah. So yeah it can create a bit of difficulty in the family erm in the sense that I'm more likely to get annoyed with her if she's just being difficult you know like sometimes if you're trying to get off to work and she's moaning about not feeling great you know you probably maybe don't give her the time that you should"* (Mother 9, daughter 14 yrs)

Finally, although family tensions frequently arose as a result of menstrual symptoms, many mothers saw these as normal tensions and stress that are parts of 'normal' family life:

> *"I think it always does if you're having a bit of family stress and family tensions of course it does but not in that I would say it causes stress within a relationship, I think these are completely normal stresses rather than anything to be of concern."* (Mother 17, daughter 15 yrs)

6.3.4 Theme Three: The primary caregiver for issues related to menstruation

As reported by adolescent girls in Chapter 5, mothers also described themselves as the primary caregiver for addressing any issues related to their daughters' menstruation. In this theme, mothers describe this role as a practical and emotional 'burden'. Some mothers emphasise the difficulty of going through the menopause while their daughters are experiencing negative emotions associated with dysmenorrhea and associated hormonal fluctuations.

<u>The daily burden of the primary caregiver</u>

In chapter five, adolescent girls described their mothers as the primary caregiver, particularly when it comes to menstrual matters. They reflected on the burden of caretaking responsibilities on their mothers' quality of life. The data from interviews with mothers indicated similar findings. Mothers described themselves as the main caregiver regarding menstrual issues. Their daughters' period pain had a negative impact on their lives.

> *"Um, they're probably a bit more grumpy when I ask them to do anything like if I say it's 'oh no it's always me, it's never her' you know they get really grumpy about that"* (Mother 8, daughters 15 and 17yrs)

Parenting a daughter with dysmenorrhea had a negative impact on employment and financial stability, for mothers (e.g., having to take absence from work when girls had days off school). In addition, mothers had to deal with difficult interactions with school staff, and sleep disturbances (being woken up in the night) which in turn had a negative impact on daily functioning:

> *"Yes she did, yeah erm because obviously when they're still at school, obviously erm if they get up and they've had a rough night or you know, or if I've been up in the night a lot, which I was with her, sometimes obviously you can't just send them straight back to bed. It would be sitting up, because obviously she was still quite young then erm and you don't wanna keep them on their own and say to them oh just go back to bed or whatever, shove a couple of tablets down them a and say go back to bed, I wanted to sit with her and make sure she was alright and you know, till she felt comfortable to go back to bed"* (Mother 1, daughter 17 yrs)

Mothers of daughters with severe period pain described being on constant high alert when their daughters were menstruating. Mothers described receiving texts while they were at work from daughters who were in pain and felt unable to discuss it with teachers who were not perceived as sympathetic. Parents would ensure that daughters were provided with analgesics and sanitary wear, be prepared to leave work if necessary to collect her, and check their mobile phones frequently:

> *"I keep my mobile phone next to me 'cause I know there's a possibility of her fainting or she'll be doubled over in pain or she's got no sympathy from her teachers obviously and they don't understand and she doesn't want everybody to know because there's boys in the class that makes it embarrassing um. You know and it's, yeah I'm on high alert basically. Strange, strange feeling. And also dad's on high alert as well because he knows how she gets and obviously it's his little girl and he worries as well so he tends to be 'well let me know if you need me to get her, which he has had to do in the past because, with my work sometimes-if I've got to deliver for a funeral then I'm out and erm if I'm sorting the stuff and it's (location) I have to go to and he is working in say (location), he would go and get her you know."* (Mother 11, daughter 14 yrs)

However, in agreement with adolescent perceptions of improved pain management over time, some mothers felt that their daughters coped better with dysmenorrhea as they got older, gradually lifting the caretaking burden from them. They described how their daughters had learnt how to cope with their period pain and accompanying symptoms:

> *"To be honest she kind of manages it herself now. Um she's 16 now so it's, she doesn't come and tell you these things you know you just notice"* (Mother 15, daughter 16 yrs)

<u>Constantly on 'high alert': The emotional impact of parenting an adolescent experiencing dysmenorrhea</u>

The burden of being the primary caregiver in relation to dysmenorrhea was immense for some mothers. They reported that their daughters' period pain had a profound, negative impact on aspects of their emotional functioning and elicited feelings of frustration, anxiety, and stress. They felt distressed to see their daughter in pain, particularly when it was directly effecting their daughters' QoL. Mothers reported feeling anxious while anticipating their daughter' period and feeling helpless when the pain began:

> *"yeah it does, it makes me worry a lot and I worry for the younger one as well and you just think oh it's coming, I wish I could do more to help them but I'm not entirely sure what I can do though. I can only do what I know I can do and what helped me. Well try to help me you know. But you do worry, you can't help it. As a parent you do worry anyway with them being ill but when that's coming round you're waiting for the phone call from the school or the phone call from the friend to say she's not very well on the way home or your mum to phone and say I had to come and get her today."* (Mother 11, daughter 14 yrs)

The negative impact that menstrual-related symptoms had on family relationships was also an important source of stress and concern for many mothers:

> *"We don't fight very much at all so when it does happen it's quite distressing"* (Mother 4, daughter 16 yrs).

As the primary caregiver, many mothers felt that their daughters' menstrual and pain-related frustrations were targeted towards them as opposed to other family members or friends. This caused mothers to feel particularly stressed although many had learnt not to take these frustrations personally:

> *"It's horrible, horrible. When she's feeling really rotten and really miserable then it'll be vented, especially at me erm and that's the way it is but we're so used to it now we just get*

> *on with it. We don't fight against it. Erm yeah just try not to take it personally anymore like we used to."* (Mother 10, daughter 15 yrs)

Many mothers described how their daughters' mood can change rapidly which caused mothers a great deal of stress. Several mothers reported feeling as though they were walking on egg shells during their daughters' time of the month:

> *"Everything can be lovely and then she'll just snap and kick off and everybody's arguing and fighting and it's not fun. I'm praying she goes away to uni! It's absolutely soul destroying I hate it. When it's like that, if I had my life again I would not have children. It's too hard work when she's like that, you're walking on egg shells and you never know. It's nothing that's the trigger, it can be anything."* (Mother 18, daughter 17 yrs)

Finally, interactions with school staff were also a source of considerable stress for many mothers whose daughter had been regularly absent from school or who needed to collect their daughter due to pain or accompanying menstrual symptoms. Mothers often perceived the school staff as not being sympathetic or understanding of their daughters' menstrual pain:

> *"I don't think the school, as far as girls are concerned with their periods, I don't think their educated, I don't think they're sympathetic enough. I mean I know there might be some girls who go in and say no I don't wanna do PE, can I have the time off, you know there might be some girls out there that do that, but there are those who are truly suffering like my daughter and that would affect her life because there would be certain teachers that she wouldn't want to tell because they give them grief, you know they just turn around and say like well that's not good enough, that's not a reason not to be joining in PE or that's not a reason to have time off school. And that would make me angry, that would make me so angry because there was one incidence where I actually spoke to- my daughter was in school and because she didn't want to tell the teachers she texted me to say I've got pains, I'm in real bad pain, erm cause what they do at the school, if they're not well, they have to go to the office and the office ask them what's wrong and if it's a period pain, they'll say to them go back to class"* (Mother 1, daughter 13 and 17 yrs)

> *"The actual nurse has got very little sympathy at the school and the teachers don't. They see it as you're a blot on their books because she's having time off. Um, not that she's really fallen behind or anything but it does you know, like this week it was 3 days that she had off and it was just, what can you do? You can't send her to school if she's got such bad diarrhoea you know she can't get off the toilet. I'm pretty sure they wouldn't like that in their class and we have known to have a phone call to come and get her because she's*

> *fainted. So then they get funny because "oh if she's not well then you shouldn't have sent her to school" so we're caught in a catch 22 with them so and even worse with the PE teachers. Cause they just really do not understand and they don't care. That's how it comes across, they don't care. You know and unfortunately she's been unlucky to have such severe period pain and you know symptoms with it. But yeah, we find it very difficult with the school, like I say very little empathy and very little sympathy. They really don't understand."* (Mother 11, daughter 14 yrs)

When maternal menopause coincides with adolescent dysmenorrhea

Finally, the mothers who were going through the menopause reported that this made it more difficult for them to be understanding when their daughters were experiencing dysmenorrhea. They reported that the combination of daughters' period pain-related mood changes (e.g., frustration, tiredness, short-tempered), daughters' pubescent hormonal fluctuations and maternal menopausal symptoms were often viewed as a source of profound difficulty and tension among household members:

> *"Um, I'm there for her and she knows that um but obviously like I said before I'm having a tough time with the menopause so I can be a bit ratty as well… I don't have periods anymore but I know I've been a bit ratty to her and a bit short um so yeah it's kind of had a knock on effect onto how I am with her"* (Mother 12, daughter17 yrs)

> *"I, I can't repeat a lot of it (laughs) of what she said but um, she, she, she was just very very difficult. Very very volatile. More volatile than she's ever been and I was very erm, what's the word… sensitive cause I too was going through it and didn't really need anyone shouting at me when I was trying to hold it all together"* (Mother 10, daughter 15 yrs)

6.4 Discussion

6.4.1 Overview of Main Findings

This study aimed to explore maternal perceptions of how adolescent dysmenorrhea impacts on family functioning. A heterogeneous sample of 20 mothers of 23 younger (12-15 years; n=11) and older (16-18 years; n=12) adolescents experiencing menstrual pain of varying intensity were recruited. Overall, dysmenorrhea had a profound, negative impact on many aspects of family functioning including mothers' emotional functioning, relationships between family members, and family daily life. Three major themes were identified from the thematic analysis including: 1) differences in maternal responses to adolescent dysmenorrhea; 2) the importance of family functioning and communication; and 3) the primary caregiver for issues related to menstruation. In light of previous findings, this study expands on the conclusions drawn from the systematic review (chapter three) indicating that family functioning is negatively affected by adolescent dysmenorrhea. See Figure 3 for a map of how the findings from this study have added to those of chapter three. The following text will begin by outlining the key findings in relation to the previous literature. Strengths and limitations of the current study and, finally, implications for future research and real-world application will be discussed.

6.4.2 Differences in maternal responses to adolescent dysmenorrhea

All mothers in this study wanted to support their daughters' to be able to cope with dysmenorrhea however, they varied in how they felt they could best support their daughters. Specifically, mothers' responses to their daughter's pain seemed to fall into two distinct categories. Some mothers would encourage their daughters to engage in their usual daily activities despite their pain. In contrast, others would take a more sympathetic and protective approach, permitting the avoidance of activities including school absence. Previous research into the operant model of pain posits that parental responses to a child's pain can either negatively or positively reinforce increased pain behaviours (e.g., taking time off of school) (Turk et al., 1987). Mothers who encouraged their daughters to engage with their usual activities, despite pain, actively chose not to respond to their daughter's pain in a way that was too sympathetic and did not permit school absence. Many mothers who chose this approach did so with the aim of supporting their daughters to be self-sufficient and independent, rather than relying on others for comfort. In contrast, other mothers who were sympathetic to their daughters' pain would comfort their daughters and provide them with practical and emotional support while they were experiencing pain. From the operant model of pain perspective, these mothers were more likely to permit the avoidance of activities while daughters were menstruating. These mothers expressed distress at seeing their daughter in pain, which may have elicited what could be seen as 'over protective' responses (Caruso, Grolnick, Rabner, & Lebel, 2019).

From a social learning theory perspective, through observation and modelling, children often learn to catastrophise about pain from their parents. Paediatric pain catastrophising is also related to maladaptive coping strategies, including the avoidance of activities such as school (Simons, Sieberg, Carpino, Logan, & Berde, 2011). This may be because adolescent girls may then adopt these pain-related catastrophic thoughts as their own. This is supported by the findings in this study. In some cases, the mothers in this study who were more sympathetic than encouraging, also reported instances of pain catastrophizing. This included concerns that their daughters' period-related pain and accompanying symptoms (e.g., heavy blood flow) had a sinister underlying pathological cause. Previous research has suggested that both positive (provision of emotional support) and negative (punishing) parental responses (Vervoort, Eccleston, Goubert, Buysse, & Crombez, 2010) to their children's pain has been associated with children pain catastrophizing themselves which is associated with greater pain and disability (Sullivan et al., 1995). Pain catastrophizing was not unique to the mothers' reports, this was also found in the adolescent interviews in chapter 5. Both mothers and adolescents reported concern and confusion about certain menstrual-related issues including whether or not severe dysmenorrhea indicated underlying pathological cause.

Self-determination theory (SDT) (Deci & Ryan, 2008) (introduced in Chapter 2) can also provide a framework that would facilitate further understanding of adolescent dysmenorrhea self-management. SDT might be able to provide an explanation for pain behaviours and how family responses could support adolescents to cope with dysmenorrhea. From an SDT perspective (Deci & Ryan, 2008), there are various types of motivation for engaging in health behaviours such as effective pain management. These are: 1) external regulation whereby children might adhere to treatment regimen to avoid disappointing parents, 2) introjected regulation where a child might enact a behaviour to avoid punishment, 3) introjected regulation where a child might adhere to treatment to gain approval or avoid guilt and, 4) identified regulation (the most autonomous form of regulation) whereby individuals engage in behaviour out of personal value or perceived importance. SDT posits that individuals' behaviours become increasingly self-regulated through the process of internalisation, during which individuals move from regulating their behaviour due to external factors to more autonomous regulation. Internalisation can be facilitated by parental responses to pain by, for example, engaging children and adolescents in problem-solving and decision making. Interestingly, none of the mothers in this study reported engaging their adolescents in problem-solving or decision making. As mentioned above, some mothers displayed an 'overprotectiveness' in relation to their daughter's dysmenorrhea. From an SDT perspective, parental protectiveness has been linked to psychological reactance (resulting in rebellious/defensive behaviours) in adolescent community and clinical samples. Therefore, it is important for children experiencing chronic pain to take an active role in managing their health. Early management and engagement with treatment and health behaviours (such as medication adherence, good nutrition, and exercise) sets the stage for good pain management into adulthood (Antonaci et al., 2014).

Additionally, many mothers (as with adolescents) were not aware that the OCP could be used to reduce period pain. Of those mothers who were aware, several had negative feelings about their daughters using the OCP due to concerns about a) health-risks including future development of cancer, b) the stigma attached to the use of the contraceptive pill, and c) concern about what happens to the uterine lining during continuous OCP use. Despite these concerns, many mothers accepted the use of the OCP as a treatment for dysmenorrhea because they did not want to see their daughter suffer. This is a novel finding as the previous literature has only focussed on paediatric chronic pain for which the OCP is not a common treatment.

6.4.3 The importance of family functioning and communication

The McMaster model of family functioning (Epstein, Bishop, & Levin, 1978) emphasizes the importance of considering an individuals’ behaviour within the context of their family situations. From the perspective of family systems models such as this, an adolescent’s response to dysmenorrhea needs to be considered within the context of the family environment. Family functioning is usually assessed in five areas: family organisation, cohesion, communication, affective environment, and problem solving (Liossi & Howard, 2016). From the mothers’ reports, adolescent dysmenorrhea seemed to have a negative impact on each of these areas. They reported conflict and disagreement arising, adolescents avoiding spending time with the family and not attending events, feelings of frustration and tensions among family members, and varying levels of communication regarding dysmenorrhea. Although all mothers knew that their daughter had started their periods and experienced some form of dysmenorrhea, family communication about menstruation and period pain varied across all mothers’ reports with some adolescents being described as secretive. Many adolescents and children experiencing chronic pain report disturbances in family functioning, which is also associated with worse physical and psychological functioning. Previous research has found significant differences in family functioning between families with children/adolescents with and without chronic pain. Specifically, poorer family functioning was associated with increased disability and an increased likelihood that chronic pain would continue throughout childhood and adolescence, and into adulthood (Wickrama, Conger, Wallace, & Elder Jr, 2003). Reports from the mothers in this study were consistent with the findings from Chapter 5 that adolescent help-seeking behaviours for period pain was heavily influenced by gender of the help provider and whether or not girls perceived menstruation to be ‘taboo’. The mothers echoed that gender played a key role by emphasising the importance of women family members supporting each other through menstruation. This novel finding highlights a key difference between parenting an adolescent experiencing dysmenorrhea compared to another type of chronic pain.

Also in support of findings from adolescent qualitative data (see chapter five), mothers perceived dysmenorrhea to have a profound, negative impact on many aspects of the girls lives. Specifically, mothers discussed the impact of pain on their daughters’ interaction with family members and ability to engage in with family activities. Interestingly, adolescent reports (chapter five) indicate that many girls prefer to be alone when they are menstruating due to both pain and accompanying symptoms (e.g., mood fluctuations, heavy flow, fatigue). Adolescent reports of feeling fatigued and wanting to be alone explain mothers' reports of their daughters disappearing off to their bedroom.

6.4.4 Mothers as the primary caregiver for issues related to menstruation

Although adolescence usually signifies a transition towards independence away from the family (Palermo et al., 2014; Sameroff, 2010), mothers felt that they were heavily relied upon when it comes to their daughters' menstrual-related issues. There are clearly competing needs for autonomy during adolescence and the dependence that occurs as a result of pain in the findings from both this study and the adolescent reports. This reflects previous findings that there is often difficulty balancing independence and parental support in adolescent chronic pain (Evans, Meldrum, Tsao, Frayant, & Zaltzer, 2010). In this study, the reliance had a profound, negative impact on many aspects of mothers' quality of life, particularly their emotional functioning. In accordance with the conclusions of Palermo and Eccleston's (2009) review investigating the impact of parenting a child with chronic pain, mothers of adolescents experiencing dysmenorrhea reported elevated levels of stress and anxiety as a result of their daughter's menstrual and pain-related symptoms. Mothers felt that these negative emotions were resulting from a) daughters' pain-related complaints, b) missing out on family events or activities to stay home with their daughter, c) concerns about a potential pathological cause for the pain, and d) because a combination of hormone fluctuations, pain, and accompanying symptoms had caused their daughters' moods to fluctuate. Similar to parent reports in the qualitative adolescent chronic pain literature (Jordan et al., 2007), many mothers reported feeling helpless when their daughter was in pain (van Tilburg et al., 2006). Mothers felt that, as time since menarche progressed, theirs and their daughters' ability to manage dysmenorrhea improved. Daughters' improved ability to cope with dysmenorrhea reduced monthly stress experienced by mothers and other family members. Similarly, reduced parental distress associated with improved child pain coping has also been reported in the general paediatric chronic pain literature. Maciver et al. (2010) found that over time parental distress reduced as parents learnt how to cope with their child's pain. Therefore, these findings suggest that adolescent dysmenorrhea has a negative impact on mothers' emotional functioning. However, parental distress could possibly be improved by improving how girls manage their periods and dysmenorrhea.

These findings also expand on findings presented in theme 1 (differences in maternal responses to adolescent dysmenorrhea). In the previous theme it is described how parents who report increased pain catastrophizing thoughts and protective behaviours maybe more likely to reinforce pain behaviours by permitting the avoidance of activities (e.g., school absence) . Parental catastrophizing and protective behaviours are also associated with overall school impairment (Levy et al., 2012). These findings support the use of the Social Learning Theory to explain the association between parent responses and child pain-related functioning. Parents experiencing negative pain related thoughts are more likely to feel protective over their child, respond with sympathy and agree to let their daughter take absence from school which reinforces their child’s pain-related behaviours (Levy, 2007). Family systems theories describe families as a ‘fully interactive collection of subsystems, where changes in one system influence changes in all others’ (Guite, Russell, Homan, Tepe, & Williams, 2018). For example, a child’s chronic pain condition may negatively influence a parent’s mental health which, in turn may influence parent-child communication and the child’s overall chronic pain outcomes. For example, parental anxiety and distress related to their daughter’s pain may lead to pain catastrophizing and associated overprotective behaviours that include permitting avoidance of activities.

In addition, overly protective parents who catastrophize are more likely to interpret teachers’ as unsympathetic or disbelieving (Logan et al., 2012). Interestingly, mothers in the current study who were very sympathetic of their daughter’s pain described school staff members as uncaring or non-empathetic. However, reports from adolescents in chapter five indicate that interactions between adolescents with dysmenorrhea and school staff were often difficult. Many of the girls reported that teachers would not let them a) use the toilet at certain points in the school day, b) take paracetamol to relieve their pain, or c) visit the school nurse and would not accept dysmenorrhea as an excuse to be absent from school or PE lessons. Therefore, reports from mothers about unsympathetic school staff may also be related to reports from adolescents when disagreements about menstrual issues occur.

There are both similarities and differences between the findings of this study and the literature investigating parents’ experiences of JCA. Britton and Moore (2002) found that parents of children with JCA raised concerns about what other parents and people might think about their child’s illness because from an outsider looking in, their child appeared healthy. Interestingly, this issue was also raised by mothers in this study. Mothers reported feeling as though school staff did not understand their daughters’ pain because they appeared healthy and menstruation is considered a ‘normal’ event. In contrast to mothers of daughters with dysmenorrhea, parents of children with JCA described their feelings of relief when their child was diagnosed with JCA. No mothers in the current study reported that their daughters received a diagnosis, although several were concerned about the possibility of an underlying cause. Also, mothers of children with JCA reported feeling as though they did not spend enough time with their other children as much of their caregiving was focussed on the child with JCA. However, mothers in the current study did not report this. In contrast, mothers reported elevated levels of distress as a result of increased sibling conflict which arose from menstrual and pain-related mood changes.

Interestingly, although participants from this study were not parents of a clinical sample of adolescents, the findings of this study bear similarities to parents of clinical samples of paediatric chronic pain patients (Bennett et al., 2000). For example, chronic headache, arthritis, and musculoskeletal pain had a negative impact on mothers' ability to sleep, complete household chores, engage in family activities, and increased emotional distress (Bennett et al., 2000). In the current study, several daughters were reported to have a disturbed night's sleep due to menstrual pain and soiling bed sheets with menstrual flow. Several mothers reported being woken up in the night to help daughters relieve their pain by providing hot water bottles, analgesics, and changing bed wear when necessary. Family activities including birthdays, Christmases, weddings and holidays were negatively affected by menstrual pain and accompanying symptoms. Specifically, many mothers reported that their daughters would prefer not to leave the home when menstruating. This meant that parents often had to decipher whether or not to leave their daughter at home alone or miss activities altogether. Three mothers and their partners alternated staying at home with their daughter so that they could both attend family events. However, several mothers felt that if their daughter was in a lot of pain then they preferred their husbands to attend family events alone so that they could stay with their daughter. One mother explained that this was because she was more affectionate than her husband who may not pick up on cues from their daughter that she needed sympathy.

This study expands on the conclusions drawn from the systematic review (Chapter 3) and the first empirical study of this thesis (Chapter 5). These findings, along with those from the systematic review and Chapter 5, support key aspects of the biopsychosocial models of chronic pain outlines in Chapter 2. Specifically, these findings emphasise the importance of the family in relation to adolescents' experience of, and response to pain. As outlined in Palermo and Chamber's (2005) integrative model of parent and family factors in paediatric chronic pain and associated disability, these interactions can occur at individual, dyadic and family levels. Adolescent dysmenorrhea can have a significant impact on family functioning and communication. This relationship however, can be bidirectional as poor family functioning can be associated with increased disability and increased likelihood that chronic pain would continue throughout childhood and adolescence, and into adulthood (Wickrama, Conger, Wallace, & Elder Jr, 2003). Family functioning is thought to negatively influence paediatric chronic pain outcomes, over and above pain intensity (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). A key finding from this study was also that there are clear differences between the way in which mothers respond to their daughters pain. Mothers who reported feeling distressed when their child experienced menstrual pain also reported instances of pain catastrophizing. Parental pain catastrophizing is often associated with paediatric pain catastrophizing and there is a bidirectional relationship between pain catastrophizing, pain and disability, and health-related quality of life outcomes (Tran et al., 2015). The findings from this study have informed further development of a working model by emphasising the importance of family functioning. See Figure 3 presenting a map of the main findings from Chapter 6 and how this expands on the main findings from chapter 5.

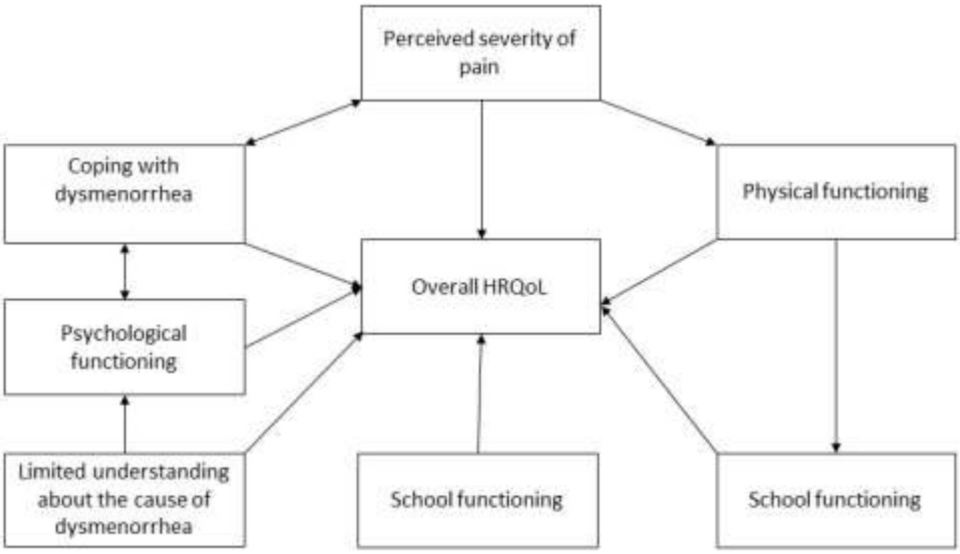


Figure 3 Map of Findings from Chapter 3 and 5 with the Addition of Family Functioning as a Factor Impacting on Daughters' HRQoL and Psychological Functioning from the Mothers' Perspective

6.4.5 Strengths and limitations

Use of qualitative research has allowed mothers to express important information about parenting a daughter with dysmenorrhea that had previously not been considered by researchers. Although parent perspectives of adolescent dysmenorrhea have been similar in many ways to the previous qualitative paediatric chronic pain literature, there are several issues that are specific to dysmenorrhea. For example, menstrual-related pelvic pain is considered a 'normal' phenomenon by most individuals including health-care professionals and school staff. As a result, mothers reported feeling unsure about where to turn to for help with their daughters' pain. As previously mentioned, several mothers had been unsure whether to attend the hospital when their daughter's pain had been so severe. Many mothers also felt that they did not want to be sympathetic or give daughters analgesics because they would have to experience this monthly pain for the rest of their fertile lives. In this case, mothers felt that the least reliant their daughters were, the better they would cope with increased age. Additionally, the most common treatment for primary dysmenorrhea is the OCP. As previously discussed, many mothers expressed concerns about the use of the term ‘contraceptive’ when the OCP was being used for dysmenorrhea or other menstrual issues. Finally, quite often mothers reported that female family members’ menstrual cycles would occur at the same time (described as ‘syc-ing by the participants) resulting in synchronised pain and accompanying symptoms causing a great deal of tension within households. Alternatively, several mothers were experiencing the menopause which caused considerable tension when combined with family discord resulting from daughters’ hormonal fluctuations and pelvic pain.

A limitation of the current study was that, although the aim was to explore the impact of dysmenorrhea on family functioning, maternal perspectives alone were explored. This is in contrast to Britton and Moore’s (2002) study investigating JCA from the perspectives of all family members including mothers, fathers, siblings, and grandparents. However, in previous studies investigating fathers perspectives of the impact of JCA on family functioning (McNeill, 2004; Waite-Jones & Madill, 2008); fathers described their wives as their children’s primary caregiver. The current study supports this previous research as, within this population of mothers of adolescent girls with dysmenorrhea, mothers described themselves as the primary caregiver and source of support for menstrual-related issues. These findings also support findings presented in chapter five where adolescents described feeling embarrassed when discussing menstruation with their fathers. Reasons provided by adolescents were that they felt as though their fathers were unable to understand because they had never experienced menstruation. Mothers described male family members (their fathers, husbands, and sons) as naive regarding menstruation, with many reporting instances where male family members would hide when female household members were menstruating. This could be explained by father’s inability to relate (as was discussed by several mothers) or their unwillingness to burden their wives. Fathers of children with JCA (McNeill, 2004) reported a reluctance to express emotion because they did not want to burden their wives with their concerns.

The use of qualitative methods is a particular benefit of this research. Semi-structured interviews and a data-driven approach to thematic analysis allowed mothers to describe, from their perspectives, how adolescent dysmenorrhea impacts on all aspects of family functioning. This research addresses a gap in the current literature by exploring in-depth and analysing rich interview data of maternal experiences of adolescent dysmenorrhea. However, considering the critical-realist perspective to qualitative analysis adopted, it should be noted that thematic analysis involves some level of interpretation. Addressing the potential researcher influence on these findings, verbatim quotes have been used liberally throughout the findings. The participants own words have provided the shape and structure of the findings, allowing the context of the mothers' worlds to be embedded and embraced as important to the research outcomes.

6.4.6 Implications and future research

As the data has produced many novel and interesting findings, several implications of this report are suggested in terms of future research and application. As stated above, adolescent dysmenorrhea had a negative impact on maternal psychological functioning, particularly when mothers perceived their daughters to not be coping adequately with their pain. Future research could aim to identify ways of improving adolescent period-pain related coping and future interventions could target adolescent menstrual pain-related coping to help improve the psychological functioning of both adolescents and their mothers. A key finding from this research is that, although all mothers wanted to support their adolescents to effectively cope with dysmenorrhea, there were clear differences in the way that they responded to their daugters' pain. Operent-behavioural theories suggest that parental catastrophizing over their child's pain and 'over-protective' responses can result in maladaptive coping strategies adopted by the child (Walker & Zeman, 1992). Future research could benefit from exploring this further in relation to adolescent dysmenorrhea. Future interventions aimed towards supporting adolescents to cope effectively with dysmenorrhea could benefit from considering the potential impact of maternal responses. From the SDT perspective, encouraging parents to engage their adolescents with dysmenorrhea-related problem solving could help to support adolescents cope with and manage their pain (Caruso et al., 2019). Interventions could also benefit from targeting maternal catastrophsing. From a SLT perspective, reductions in maternal catastrophsing might also improve adolescent pain-catastrophizing (Levy et al., 2012). In addition, family-based interventions could serve to reduce the practical and psychological burden that mothers reported as a result of being the primary caregiver for issues related to menstruation. Finally, improved education about the OCP among adolescents and parents regarding its use in relieving menstrual symptoms may help to reduce the stigma which was a cause of concern for many mothers.

In sum, this qualitative study provides an in-depth exploration of the impact of dysmenorrhea on family functioning from mothers' perspectives. This study was conducted to address the gap in the previous literature as no qualitative studies had explored adolescent dysmenorrhea from mothers' perspectives. Suggestions were made for future research and interventions which should aim to expand on these initial findings and address issues that are cause for concern in mothers of girls experiencing dysmenorrhea. The next chapter outlines a study that has built upon the findings from the systematic review and two empirical studies of this thesis. The findings so far have informed the development of the questionnaire used to investigate predictors of HRQoL in chapter seven.

Chapter 7 Psychosocial Predictors of Quality of Life Outcomes among Adolescents Experiencing Dysmenorrhea

7.1 Introduction

It is widely accepted that the experience of pain is related to, not only tissue damage and physical illness, but also to psychological phenomena (Birket-Smith, 2001). Psychosocial factors play critical roles in the development and maintenance of chronic pain (Edwards, Dworkin et al. 2016). Therefore, understanding these psychosocial factors and how they influence pain and pain-related outcomes is important in understanding how to develop effective interventions to improve pain-related outcomes. Findings from the first three studies of this thesis have demonstrated that dysmenorrhea can have a profound, negative impact on all aspects of adolescents' lives. The systematic review of 42 studies investigating the impact of adolescent dysmenorrhea on health related quality of life (HRQoL) and its constituent parts identified the need for further, methodologically rigorous research investigating the complex relationship between adolescent dysmenorrhea and HRQoL. This chapter will begin by summarising the current literature investigating the relationship between adolescent dysmenorrhea and HRQoL, followed by a summary of evidence, from both the first three studies of this thesis and the wider chronic pain literature, of how psychosocial factors including pain catastrophizing, levels of anxiety and depression, family functioning, somatization, and how the interaction between these variables may predict HRQoL, above and beyond the severity of the pain. Finally, the final empirical study of this PhD thesis will be presented including a detailed description of the hypotheses, study design, data collection procedures, data analysis, results, and discussion of the implications of the findings in terms of the current literature, real-world application (to educators, academics, health care professionals, adolescents and their families), and future research.

Adolescent Dysmenorrhea and HRQoL

As the previous chapters demonstrate, dysmenorrhea is consistently associated with limitations to HRQoL (Azurah et al., 2013). The findings in chapter three indicated that overall, girls reported that dysmenorrhea had a negative impact on all domains of HRQoL including physical, social, psychological and school functioning and well-being. The overall evidence indicated that associations between dysmenorrhea and impaired HRQoL often increase with menstrual pain severity (Banikarim et al., 2000; El-Gilany et al., 2005; Eryilmaz et al., 2010; Klein

& Litt, 1981; Pitangui et al., 2013; Teperi & Rimpelä, 1989). Girls reported that dysmenorrhea had a negative impact on psychological functioning, activities of daily living, social relationships and activities, academic performance, and school attendance. A key finding from the systematic review was the profound negative impact of dysmenorrhea on school functioning specifically. A large cross-sectional survey of 1951 adolescents (aged 13-18) found that over half of adolescents felt that their school performance had been impacted by dysmenorrhea (55.7%) including absenteeism (18.6%), focus on school content (50%), missing exams (4.5%), and being able to answer exam questions despite having the knowledge (26.9%)(Eryilmaz et al., 2010). Additionally, dysmenorrhea had a profound impact on girls' social and sporting activities such as completing daily chores (56%), sports participation (51%), and going out with friends (46%) (Banikarim et al., 2000).

In agreement with the limited studies investigating adolescent dysmenorrhea, research from the wider paediatric pain literature has consistently indicated that chronic pain is associated with limitations in HRQoL (e.g., Dhanani, Quenneville, Perron, Abdolell, & Feldman, 2002; Gold, Mahrer, et al., 2009; Hunfeld et al., 2001). For example, Youssef et al (2005) investigated QoL outcomes among children and adolescents with functional abdominal pain (FAP). These children and their families were compared to control groups of healthy children and children with inflammatory bowel disease (IBD) or gastroesophageal reflux disease (GERD). The findings suggested that children with FAD had QoL scores similar to those with GERD and IBD, which were all significantly lower than the healthy children. Specifically, chronic pain in childhood and adolescence is associated with limitations to psychological functioning, functional status, family functioning, peer relationships, and somatisation (Forgeron et al., 2010; Hunfeld et al., 2001). Interestingly, pain intensity and duration only predict a moderate amount of variance in disability among children and adolescents experiencing chronic pain (Claar & Walker, 2006; GauntlettGilbert & Eccleston, 2007), suggesting that there are other factors contributing to HRQoL limitations in this population. Currently, paediatric chronic pain is theorized to be the result of the interplay between biological (i.e., nociception process), psychological (i.e., depression, anxiety), and social (i.e., life stressors, interpersonal relationships) factors (Engle, 1977; Gatchel, Peng, Peters, Fuchs, & Turk, 2007). Though biological factors play an important role, both psychological and social factors have been found to contribute to disability in the paediatric population (Cohen, Vowels, & Eccleston, 2010). Viewing childhood and adolescent chronic pain through a biopsychosocial lens can help us to understand the multiple factors associated with pain, while integrating them and considering the relationships between them (Pillai Riddell et al., 2013). This supports Palermo's (2012) conceptual model for understanding paediatric chronic pain and disability (Palermo, 2012) which posits a complex interrelation between biological (pain severity), psychological (coping, affect, anxiety) and social factors (school environment, social and peer interactions, parental and family factors) influence chronic pain outcomes. This study investigated the impact of a number of biopsychosocial factors that were associated with HRQoL outcomes among girls experiencing dysmenorrhea, based on the notion that a complex interaction between such variables influences outcomes in dysmenorrhea as it does with paediatric chronic pain (see Chapter 2). Specifically, this model indicates that pain coping strategies (e.g., catastrophizing), levels of anxiety and depression, family functioning, and somatisation may be associated with HRQoL outcomes in children and adolescents, beyond pain characteristics (Crombez et al., 2003; Eccleston et al., 2004). Evidence that these psychosocial factors play an important role in predicting HRQoL outcomes, from this thesis and wider paediatric chronic pain literature, will now be summarised.

Pain Catastrophizing

Chapter five of this thesis indicated that the adolescents used a variety of different coping strategies when they experienced menstrual pain. In addition to prescribed and over-the-counter medications and hot water bottles for instance, adolescents described some psychosocial coping mechanisms including social support and their overall ability to psychologically cope with the pain. For example, some girls were unable to cope because they felt their pain tolerance was relatively low:

> *"I find it much harder cause, normally I can't cope with pain and stuff… so I find it much difficult when the like tablets don't work and then… yeah" (pp19, 14 years)*

In addition to this, many girls described a type of 'catastrophizing' thoughts in relation to their pain; many reported that period pain became a major focus in their lives, the anticipation of menstrual pain had a negative impact on aspects of their lives, and some girls had become very concerned about whether or not period pain was 'normal', describing fears of a pathological cause in terms of something abnormal happening to their bodies. Catastrophizing is a pain specific psychosocial construct comprised of negative cognitive and emotional processes such as helplessness, pessimism, rumination about pain-related symptoms, and magnification of pain reports (Edwards, Cahalan et al. 2011). Pain-related cognitions, such as these, are one factor that can influence the development, maintenance, and magnification of chronic pain (Gatchel et al., 2007).

Evidence from the wider paediatric chronic pain literature indicates that pain catastrophizing is one of many psychosocial factors that have been associated with increased somatic complaints, pain severity, disability, anxiety, and depression in clinical and community samples of children (Crombez et al., 2003; Eccleston et al., 2004). It is well established in the literature investigating the paediatric fear avoidance model of chronic pain that anticipation and fear of pain can actually be more disabling than the pain itself, predicting emotional distress and physical disability (Crombez, Vlaeyen et al. 1999, Vlaeyen and Linton 2000). Pain catastrophising in response to a painful injury often leads an individual to experience both fear of pain and pain-related anxiety (Leeuw et al., 2007). This anxiety has the potential to spiral into a self-perpetuating cycle that results in avoidance, functional disability, depression and additional pain and catastrophizing (Asmundson et al., 2012). This has been supported in the paediatric chronic pain literature with greater pain catastrophizing in children being associated with more pain severity and disability, lower pain tolerance (Piira, Taplin et al. 2002, Crombez, Bijttebier et al. 2003), more anxiety and depression (Eccleston, Crombez et al. 2004), and increased analgesic use (Bedard, Reid et al. 1997). Two cross sectional studies, one with a community sample of school children (n=193, Mage=11.1 years) and another of a clinical sample of children experiencing pain such as headache and abdominal pain (mage=11.8 years) showed that pain catastrophizing significantly accounted for the variance of pain, disability, and somatic complaints, beyond the effects of negative affectivity (Vervoort, Goubert et al. 2005).

Levels of Depression and Anxiety

Many studies included in the systematic review (chapter three) found that dysmenorrhea was associated with impaired psychological or emotional functioning. This was described in many ways by authors in a number of ways including feeling ‘mentally affected’ by the pain (Wijesiri & Suresh, 2013), feeling unhappy (Rani et al., 2015), feeling nervous about menstruation (Poureslami & Osati-Ashtiani, 2002), anxiety (Fontana & Rees, 1982; Frisk et al., 1965; Rapkin et al., 2006), depressive symptoms (Dorn et al., 2009; Frisk et al., 1965; Rapkin et al., 2006; Unsal et al., 2012), restlessness (Frisk et al., 1965), mood changes (Santina et al., 2012), negative menstrual experiences (Santina et al., 2012), and depression (Negriff et al., 2009). Participants from chapter five of this thesis also described feeling stressed and anxious before each period was due, related to the anticipation of menstrual pain. Emotional functioning influences pain perception and the perception of pain influences emotional functioning (Saps et al., 2009). Individuals diagnosed with depression or anxiety report higher levels of pain in response to the same pain stimuli than those individuals who do not report an anxiety or depression disorder (Mel'nikova, 1993). Additionally, evidence has shown that individuals with an anxiety or depression disorder are able to tolerate the same pain stimulus for shorter periods of time than their non-anxious/depressed counterparts (Piñerua-Shuhaibar et al., 1999). The effect of emotional functioning on pain perception is not unique to diagnosed psychological disorders.

Short-term negative emotional states have also been found to impact on pain perception (K. Fisher & Johnston, 1996).

Both levels of anxiety (Kashikar-Zuck et al., 2008; Walker & Greene, 1991) and depression (Kashikar-Zuck, Goldschneider et al. 2001, Claar and Walker 2006, Gauntlett-Gilbert and Eccleston 2007) are associated with impaired functioning in paediatric chronic pain patients. Depression and anxiety have been found to predict reports of chronic and recurrent pain (Dooley, Gordon, & Wood, 2005; Egger, Angold, & Costello, 1998), including abdominal pain (Egger, Costello, Erkanli, & Angold, 1999), in children and adolescents. This may be, in part, due to biased attention towards pain-related sensation and stimuli when experiencing high levels of anxiety and depression (Edwards, Dworkin, Sullivan, Turk, & Wasan, 2016). Chronic pain may lead to avoidance of situations that the individual believes will trigger or increase pain, which is reinforced when that avoidance behaviour met with no/ less pain (Fordyce, 1977). This reinforcement of avoidance behaviours and subsequent further anxiety and depression may lead into a cycle of anxiety, depression, and limitations to functioning (Cohen, Vowles, & Eccleston, 2010). This is supported by the fear-avoidance model which posits that both pain-related fear and anxiety influence the development and maintenance of disabling musculoskeletal chronic pain (Asmundson et al., 2012; Leeuw et al., 2007; Vlaeyen & Linton, 2012). This is supported by evidence that pain is consistently related to disability across all components of HRQoL including physical, psychological, social and school functioning, and wellbeing. Additionally, high anxiety was associated with poor functioning, irrespective of pain intensity (Cohen et al., 2010). Levels of anxiety and depression may therefore be important predictors in functional outcomes for adolescents experiencing dysmenorrhea, beyond pain intensity.

Family Functioning

Families, play a critical role in the development, maintenance and experience of chronic pain. They are an important context for understanding, assessing, and managing paediatric chronic pain (Chambers et al., 2002). Family systems theories such as the McMaster model of family functioning (Epstein, Bishop, & Levin, 1978), emphasize an individuals' behaviour within the context of their family environment. For example, these models might investigate the child's response to pain within the context of the overall family environment and functioning (Guite, Russell, Homan, Tepe, & Williams, 2018). The current evidence, summarised in the systematic review (chapter three), indicates that adolescent dysmenorrhea can have a significant negative impact on family relationships (31.8%) including family problems (77.3%), resulting in living apart from families (14.4%), and not fulfilling family responsibilities (8.3%) Eryilmaz et al. (2010). This evidence was supported by both adolescents' (chapter five) and mothers' (chapter six) perspectives. According to mothers' reports in Chapter 6, adolescent dysmenorrhea presented challenges to each of the five areas that the McMaster model assess family functioning in. These include family organisation, cohesion, communication, affective environment, and problem solving (Epstein, Bishop, & Levin, 1978). For example, adolescent girls reported that dysmenorrhea affected their mood and consequently caused some tensions between different family members, particularly with other female family members who may also be experiencing menstrual symptoms (e.g., peri-menopausal and menopausal symptoms). Mothers echoed this, describing a profound impact on theirs and their family's lives including their emotional functioning, relationships between family members, and family daily life.

Family systems theories posit that although pain may have an impact on parental well-being and family functioning, this relationship can be bidirectional. Family functioning has been found to influence a variety of pain-related outcomes (Edwards, Dworkin et al. 2016). For example, recurrent abdominal pain in children and adolescents is significantly associated with negative and stressful life events (e.g., family breakdown and conflict) (Boey & Goh, 2001; Mulvaney, Lambert, Garber, & Walker, 2006). Parents are often the immediate and most prominent form of social environment for children and adolescents and therefore are an important factor in influencing pain-related outcomes (Edwards, Dworkin et al. 2016). Barakat et al., (2008) aimed to investigate the associations between pain, psychological adjustment, and family functioning with HRQoL in a sample of adolescents (12-18 years) with sickle cell disease. They found that disease-related parenting stress were significantly associated with lower HRQoL. Additionally, King et al. (2011) conducted a systematic review of the existing literature investigting the epidemiology of chronic pain in children and adolescents showed that, of the reviewed RAP studies, predictors of RAP and related outcomes included anxiety in children and their mothers, anxiety and depression in children, feelings of sadness. Finally, HRQoL outcome predictors among children and adolescents with chronic pain (aged 2-16 years) showed that psychosocial factors including social support and parental distress explained additional variance in HRQoL outcomes, and that pain-related factors (intensity, duration) could not.

Somatization

Finally, findings from the systematic review (chapter three) indicated that dysmenorrhea was associated with somatisation (Goldstein-Ferber & Granot, 2006; Rapkin et al., 2006). Goldstein-Ferber and Granot (2006) investigated the role of somatization in 160 school girls. They found that girls who experienced dysmenorrhea reported higher scores of pain somatic symptoms than non-pain somatic symptoms, compared to girls without dysmenorrhea. Somatization significantly predicted the intensity of pain. Additionally, adolescents from chapter five described many symptoms other than pain including loose bowels, mood swings, bloating, headaches/migraines, acne, nausea, vomiting, loss of appetite, fatigue, muscle aches, hunger, breast pain, dry hair and skin, body odour, back ache, sweating, dizziness, and feeling generally unwell.

Evidence from the wider chronic pain literature indicates that pain is related to, not only emotional, pain coping, and family functioning factors, but also levels of somatisation (BirketSmith, 2001), which is frequently associated with chronic pain (Fishbain, Lewis, Gao, Cole, & Steele Rosomoff, 2009; McBeth, Macfarlane, Benjamin, & Silman, 2001). For example, children with RAP are more likely to report somatic symptoms compared to healthy patients and other types of pain (Walker, Garber, & Greene, 1991). Research also suggests that somatization is also associated with higher levels of functional disability (Campo, Jansen-McWilliams, Comer, & Kelleher, 1999; Harris, Orav, Bates, & Barsky, 2009; Hyphantis et al., 2009; Walker, Garber, Van Slyke, & Greene, 1995). For example, Campo and colleagues (1999) showed that children with high levels of somatization had poorer health, greater health limitations, and poorer school performance and attendance than children with low levels of somatisation. Moreover, Mahrer (2012) found that, among both children and adolescents, although somatization was significantly and positively related to pain intensity, somatization significantly predicted HRQOL over and above pain.

Interactions between Psychosocial Factors and HRQoL

Adolescents with chronic pain report more negative affectivity such as anxiety than those without chronic pain (Merlijn et al., 2003). The current evidence links levels of anxiety to HRQoL outcomes in paediatric chronic pain, yet the processes that result in this association are uncertain. Pain catastrophizing has been suggested as an important factor in linking anxiety with functional outcomes (Compas et al., 2006; Eccleston, Crombez, Scotford, Clinch, & Connell, 2004). Pain catastrophizing has been suggested as a way of explaining the association between negative affectivity, often measured as trait anxiety (Watson & Clark, 1984), and self-reported health complaints and health-related outcomes in children and adolescents. High levels of negative affectivity have been found to be associated with higher levels of pain catastrophizing (Walker, Garber, Smith, Van Slyke, & Claar, 2001). Negative thinking such as catastrophizing about pain, a passive coping strategy, can develop as a result of anxiety (Garber, Weiss, & Shanley, 1993), and negative thinking in the context of chronic pain results in disruption in daily functioning. Different pain coping strategies have been linked to different outcomes in youth with chronic pain (Walker, Smith, Garber, & Van Slyke, 1997). For example, the use of passive coping strategies, such as self-isolation, catastrophizing, and activity avoidance, has been associated with increased pain, somatic symptoms, depression and anxiety (Kaminsky, Robertson, & Dewey, 2006; Reid, Gillbert, & McGrath, 1998; Walker et al., 1997), and functional disability (Kaminsky et al., 2006). Two cross sectional studies, one with a community sample of school children (n=193, Mage=11.1 years) and another of a clinical sample of children experiencing pain such as headache and abdominal pain (mage=11.8 years) showed that pain catastrophizing mediated the relationship between negative affectivity and functional disability. Both pain catastrophizing and negative affectivity emerged as significant predictors of functional disability (Vervoort, Goubert, Eccleston, Bijttebier, & Crombez, 2005). A further study examined pain coping as a mediator of the relation between anxiety and disability and between anxiety and somatic complaints among a sample of 280, of whom 212 were female, adolescent chronic pain patients (aged 12-17 years) (Kacsynski, 2011). Their findings indicate that the association between anxiety and disability was mediated by passive coping in children and adolescents with a variety of chronic pain symptoms. These results demonstrate that the detrimental impact of anxiety on functional disability can be explained through patients' pain coping strategies, as is consistent with previous research on adolescents' pain coping (e.g., Walker et al., 1997).

Research has also shown that pain catastrophizing may mediate the relationship between pain intensity and HRQoL outcomes in the paediatric chronic pain population. Merlijin, Hunfeld et al. (2006) examined the relationships between pain characteristics, psychosocial factors, and quality of life among 194 adolescents (aged 12-18 years) with chronic and recurrent pain. They found that psychosocial variables (e.g., pain coping) accounted for a significant variance in the adolescents' quality of life, even when controlling for pain characteristics. Pain intensity was a significant predictor of HRQoL outcomes with pain catastrophizing strengthened the negative relationship between pain intensity, indicating that pain intensity influences HQQoL outcomes via pain catastrophizing and further emphasising the importance of psychological functioning with HRQoL outcomes over and above pain characteristics.

Mediating role of levels of anxiety and depression

There is also evidence to support a model whereby levels of anxiety and depression mediate the relationship between somatic complaints and HRQoL outcomes (Walker et al., 2001). Levels of anxiety (Kashikar-Zuck et al., 2008; Walker & Greene, 1991), depression

(Kashikar-Zuck, Goldschneider et al. 2001, Claar and Walker 2006, Gauntlett-Gilbert and Eccleston 2007), and somatisation (Mahrer, 2012; Saps et al., 2009) have been found to predict disability in paediatric chronic pain patients. It may be that those individuals who are more likely to focus attention on bodily sensations may also be more likely to report higher levels of psychological symptoms including anxiety and depression. This increased attention to painful experiences may place a spotlight onto pain and increase pain perception (Morrison & Bennett, 2009). Anxiety and somatisation are also significantly associated in samples of children and adolescents with chronic pain (Tsao et al., 2009). Moreover, research has indicated that levels of somatization and poor psychological functioning (such as levels of anxiety) may be better predictors of HRQOL impairment than pain intensity in children with chronic pain (Mahrer, 2012). Evidence from the wider literature suggests that somatic complaints may negatively impact on HRQoL via negative emotions such as levels of anxiety and depression. This potential pathway may be due to individuals reporting high levels of negative emotions displaying greater hypervigilance towards normal bodily sensations, including minor aches and pains. Anxiety disorders are independently associated with several physical conditions in the community, and this comorbidity is significantly associated with poor quality of life and disability (Sareen et al., 2006).

Overall, dysmenorrhea has a profound, negative impact on adolescents' HRQoL including physical, psychological, social, and school functioning (Parker et al., 2010). Studies from the wider, paediatric chronic pain literature show that psychosocial factors play an important role in the experience of pain, disability, and overall QoL. The existing evidence indicates that psychosocial factors (catastrophizing, anxiety, depression, somatization, and family functioning) are strongly associated with dysmenorrhea and HRQoL. However, no study has yet sought to investigate which psychosocial factors predict HRQoL outcomes in adolescents with dysmenorrhea. There is currently a lack of biopsychosocial, theoretical models of adolescent dysmenorrhea. Development of these models may help to increase awareness among healthcare professionals, parents, and young people about the overall experience of menstrual pain and, in turn, this increased understanding may eventually improve management and care. In addition, Identifying HRQoL correlates in this sample could be used to support the development of interventions to improve QoL for adolescents experiencing dysmenorrhea.

Therefore, the current study will aim to investigate the psychosocial correlates of HRQoL outcomes among adolescents with dysmenorrhea. Based on previous findings and the first three studies of my doctoral thesis, I aim to build and test a working model whereby quality of life outcomes in girls with dysmenorrhea are predicted by levels of anxiety, depression, somatisation, pain catastrophizing, and family functioning. A secondary aim of this study was to explore the mediating role of pain catastrophizing between a) anxiety and HRQoL, and b) pain severity and HRQoL; also to investigating role of anxiety and depression in mediating the relationship between somatisation and HRQoL.

7.1.1 Hypotheses

1. The following biopsychosocial factors: pain severity, pain catastrophizing, somatisation, levels of anxiety and depression, and family functioning will significantly predict Health Related Quality of Life (HRQoL) among adolescent girls experiencing dysmenorrhea.
2. Psychosocial factors (pain catastrophizing, somatisation, levels of anxiety and depression, and family functioning) will predict HRQoL among adolescent girls experiencing dysmenorrhea beyond pain severity (both usual and most recent pain).
3. Pain catastrophizing will mediate the relationship between levels of anxiety, trait anxiety, and pain severity with HRQoL among adolescents experiencing dysmenorrhea.
4. Levels of anxiety and depression will mediate the relationship between somatisation and HRQoL.

7.2 Methods

7.2.1 Ethical Considerations

University of Southampton, School of Psychology Ethics Committee ethics approval was granted (ID: 18838) on 13.04.2016. Head Teachers of the recruited schools, sixth forms and colleges approved the study and appointed a lead teacher or career advisor to liaise with the researcher and organise data collection.

Participants aged 13-16 years were not able to provide informed consent, but were required to read the information sheet (see appendix N) and provide assent to indicate that an adult had explained the research to them, they understood the study procedures, and that they could stop taking part in the study at any point. Additionally, all parents of participants aged below 16 years old were sent a letter from their daughters' school (appendix O) detailing the research aims and procedures, a minimum of seven days before data collection was due to begin. Parents were provided with an 'opt-out' form attached to the letter that they could sign and return to the school before the date of data collection if they did not give permission for their daughter to take part in the survey. Letters clearly stated that if parents did not fill out and return the 'opt out' form, they were giving consent for their daughter to take part in the study. All participants are asked to provide assent/consent before taking part in the survey. If online, participants were required to read the information sheet and sign the online consent/assent form (appendix O) before proceeding to the survey. Participants taking part in the paper copy of the questionnaires were given and asked to read the information sheet and return signed consent/assent forms (appendix P) before being provided with the survey.

Parts of the survey asked about the girls' experiences with period pain, symptoms of anxiety, depression, family functioning, and quality of life. There is always the possibility, when individuals are answering sensitive questions such as these, that they may become distressed. Therefore, all participants were debriefed and provided details about counselling services and information on how to receive help for symptoms of anxiety and depression. In addition, the researchers details were provided at the end of the survey in case of any further questions.

7.2.2 Participants

Five secondary schools, sixth Forms, and colleges from Hampshire and the Isle of White, UK gave permission for the research to be conducted with adolescent girls in grades 9 through to year 13. Schools were sent letters and emails detailing the study aims and procedures, and asking for permission to recruit students for this research. Once written permission from school managers was granted, a lead teacher or career adviser was appointed to liaise with the researcher. Letters were then sent to parents detailing information about the study and explaining that parents of children aged <16 years may choose for their daughter to 'opt out' and not participate in the research. The appointed lead teachers or careers advisors were asked to advertise the study via posters (appendix I) and announcements during year assembly or class. Inclusion criteria for this study include: a) female gender, b) aged 13-18 years old, c) who had experienced dysmenorrhea of any severity d) for a minimum of 3 months (or 3 menstrual cycles) e), be fluent English speakers, and g) provide assent/consent where necessary. Exclusion criteria for this study include: a) male gender, b) aged <13 years or >18 years, c) not fluent English speakers, and d) are unable to provide assent or comply with study procedures. Post Hoc statistical power calculation indicated that the study had sufficient statistical power (r^2=.6, *p*=.05, n=329, effect size= 1).

7.2.3 Measures

Demographic information were collected at the start of the survey. A battery of the following questionnaires will then be used to measure study variables (see full questionnaire in appendix Q):

Menstrual Disorders of Teenagers Questionnaire (MDOT): Fifteen items from the MDOT were selected to obtain information about dysmenorrhea (e.g., pain severity) and menstrual cycles (including duration, regularity, and heaviness, use of analgesia, physical/emotional menstrual symptoms, and school absence) (Parker et al., 2010). The questionnaire was piloted with age appropriate adolescent girls (12-18 years) and questions modified based on their responses (Parker et al., 2010).

Visual Analogue Scale (VAS): An 11-point Visual Analogue Scale (VAS) ranging from 0 (no pain) to 10 (worst possible pain) was used to measure the pain intensity of adolescents' 'usual' and 'most recent' period (McGrath, 1987). Self-report is considered the ‘gold standard’ of pain measurement ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012). The VAS of pain severity has shown good reliability and validity in children aged 9-15 years old and convergent validity with other widely used pain scales (The Numerical Rating Scale of Pain) (r=.87) is excellent (von Baeyer et al., 2009). VAS scores were categorised as 0-3 (mild), 3.5-7 (moderate), 7.5-10 (severe) (Boonstra, Preuper, Balk, & Stewart, 2014).

Paediatric Quality of Life Inventory Version 4 (PedsQL 4.0): The PedsQL 4.0, a 23-item questionnaire measuring the core health dimensions outlined by the World Health Organisation (WHO, 1948) was used to measure QoL. The PedsQL is suitable for participants aged 8-18 years. Core dimensions include: physical functioning (8 items), emotional functioning (5 items), social functioning, and school functioning (5 items) (Varni, Seid, & Kurtin, 2001). A 5-point response scale is used ranging from 0 (never a problem) to 4 (almost always a problem).Use of this generic HRQoL measure allows for benchmarking with both community and clinical samples from the existing literature (Varni, Seid, & Rode, 1999). Internal reliability for self and proxy report scale total scores (.90) and internal reliability for all subscales (>.70) are good (Upton et al., 2005).

The State – Trait Anxiety Inventory (STAIC): The 40-item STAIC measured anxiety (Spielberger, 1983). The STAIC is suitable for participants aged >12 years and is made up of two scales measuring both state (how participants feel at the present time) and trait (how participants generally feel across different situations) anxiety. Both scales contain anxiety present (i.e. “I feel worried”) and anxiety absent (i.e. “I feel secure”) questions. Responses on the S-scale (state anxiety) range from 1- ‘not at all’ to 4-‘very much so’. Responses on the T-scale (trait anxiety) range from 1- ‘almost never’ to 4-‘almost always’. Total scores range from 20-80, with higher scores indicating higher levels of anxiety (Spielberger, 1983). Test–retest reliability coefficients (0.31 to 0.86 and internal consistency (.86 to .95) range from good to excellent (Spielberger, 1983). Negative Affectivity is often measured by the STAIC given that NA and trait anxiety are highly correlated (Watson & Clark, 1984).

Children’s Depression Inventory (CDI) - Short Version: The CDI-short version, a 10-item self-report children’s depression inventory (CDI) (Kovacs, 1978) measured levels of depression in the adolescents. The CDI is suitable for participants aged 7-17 years. Each item, representing a symptom of depression, is scored on a 3-point scale from 0 (no symptom) to 2 (severe form of the symptom). The CDI consists of six subscales including a) sadness, b) self-blame, c) loss of appetite, d) insomnia, e) interpersonal relationships, and f) school adjustment. Higher scores indicate more depressive symptoms. The CDI has shown excellent reliability in community (.82-.84) and clinical samples (.85 -.81) (Masip et al., 2010).

The Children's Somatization Inventory (CSI-24): The CSI-24 (Walker et al., 2009) was used to assess 24 nonspecific somatic symptoms (e.g., "weakness," "dizziness"). Participants report how much they experienced each symptom during the last two weeks using a 5-point scale ranging from 0 (not at all) to 4 (a whole lot). The total score is calculated from the sum of all answers and higher scores indicate higher somatisation levels. The CSI has been found to have good concurrent validity, construct validity, and reliability coefficients (.87) (Walker et al., 2009).

Children's Pain Catastrophizing Scale (PCS-C): The PCS-C, an adaption of the adult version, assessed catastrophic thinking about pain (Crombez et al., 2003). The PCS-C consists of 13 items describing different thoughts and feelings that children might experience when they are in pain. Children rate how frequently they experience each of the thoughts and feelings using a 5-point Likert scale (0-not at all, to 4- extremely). The PCS-C yields a total score ranging from 0 to 52. Each item is categorised into three domains including helplessness (items 1, 2, 3, 4, 5, and 12), magnification (items 6, 7, and 13), and rumination (items 8, 9, 10, and 11). Responses range from 'not at all' to 'extremely'. The PCS-C has shown excellent validity (.87) and reliability (.88-.90) in both clinical and community samples of children and adolescents (Crombez et al., 2003).

Family Assessment Device (FAD-SF): The 'general functioning' domain of the FAD was used to measure family functioning. The 12 item general functioning scale is a well-established paediatric self-report measure of family functioning. Participant responses will range from 1- strongly agree to 4- strongly disagree. The FAD can be completed by participants aged >12 years (Epstein, Baldwin, & Bishop, 1983). The FAD has shown good test-retest (.66-.76) and internal reliability (.72-.92) (Epstein, Baldwin, & Bishop, 1983).

7.2.4 Procedures

Once informed consent/assent was provided, participants were asked to complete either an online (University of Southampton Isurvey) or hard copy version of the survey (see appendix Q for survey details). Questionnaires measured menstrual characteristics, menstrual pain severity, levels of anxiety and depression, somatisation, family functioning, and pain catastrophizing, taking no longer than 60 minutes to complete. Based on the convenience of the school, girls with parental consent were either a) asked to fill out the online survey, or b) provided with paper copies of the survey and asked to return at the end of the school day. Four of the five recruited schools asked for paper copies of the questionnaires rather than online versions. The primary researcher therefore took the necessary resources into the schools to distribute, with the lead teacher present, the questionnaires. At the end of the survey, participants were presented with a debriefing statement and given the researchers details for any follow up questions they may have. Finally, participants were asked if they would like to be entered into a raffle (top prize was worth £50).

7.2.5 Analyses

Critical Realism and this research

The development of this quantitative study has been informed by the previous two empirical qualitative studies of this thesis. A critical realist approach (Bhaskar, 2013) has guided this process. This approach acts as a compromise between the positivist and constructivist positions and is compatible with both qualitative and quantitative research methodologies, facilitating cooperation between the two (Greene, 2000; Mark & Henry). This perspective acknowledges that, although it is possible to know the ‘truth’ about a phenomena, we can only understand that truth through available discourses (Sayer, 1999). From this perspective, the researcher assumes that ‘truth’ is knowable (positivist perspective) while acknowledging the subjective and socially-constructed nature of that truth (constructivist perspective) (Braun & Clarke, 2013). The critical realist approach does not favour quantitative or qualitative approaches, serving as an ideal framework to guide mixed-methods research (McEvoy & Richards, 2006).

Missing Data Analysis

The exact number and percentage of missing values and cases were identified through missing data analysis in SPSS. Missing values were replaced using the Expectation Maximisation (EM) Algorithm. An assumption of this method is that the data are missing randomly. Little’s missing completely at random (MCAR) test tests the hypothesis that the data values are missing at random or a non-random way. If the test is non-significant, then we fail to reject the null hypothesis that data are missing in a completely random way. EM techniques work by forming a missing data correlation following a distribution (e.g., normal) for the partially missing data (Carter, 2006). EM then makes inferences about the missing values on the likelihood that they would be there on the distribution. There are two steps to this method: 1) the expectation of the missing data are found given the observed values and estimates of the parameters. These expectations are substituted for the missing data and 2) SPSS then performs the maximum likelihood estimations as though the missing data had been filled in. SPSS looks for the most appropriate model to fit the data until this has been reached (Schafer & Graham, 2002). Finally, the new data will be imputed into the missing values of the data set. *Statistical Analysis*

Data analysis of the EM imputed data set was conducted using IBM SPSS Version 24. Descriptive statistics were calculated for both categorical (frequencies and percentage) and continuous variables (mean and standard deviation). The following assumptions were checked before continuing with multiple linear regression analysis:

Normality

The assumption of normality was assessed both visually, via frequency distributions, and statistically, skew and kurtosis calculations. Probability- probability plots (P-P plots) plot the cumulative probability of a variable against the cumulative probability of a particular distribution. Skew and kurtosis statistics were then calculated as visually scanning frequency distributions is subjective and vulnerable to researcher bias. The values of skewness should be 0 in a normal distribution. Positive skew values indicate a pile up on the right; negative skew value indicates a pile up on the left. Positive kurtosis values indicate pointy and heavy tailed distributions. Negative kurtosis indicates flat and light tailed distributions. Typically, values >1.96 (p<.05) are considered cause for concern. In large samples, values >2.58 (p<.01) are considered indicative of a non-normal distribution.

Outliers

Boxplots were created to assess whether there were problematic outliers present in the data. Boxplots are used to show outliers outside of the box, the values next to each represent case number. SPSS makes a distinction between outliers that are more than 1.5 box lengths from one hinge of the box (represented using a circle) and outliers that are more than 3 box lengths from a box hinge (represented using an asterisk).

Collinearity

The variables entered into the regression model were tested for multicollinearity by scanning for tolerance values less than .1 and variation inflation factor (VIF) values greater than 10 which indicate problematic multicollinearity.

Questionnaire Reliability

Cronbach α coefficients were calculated for measures of levels of anxiety and depression, somatisation, pain catastrophizing, family functioning, and HRQoL.

Multiple linear regression

The following variables were entered into a multiple regression model to predict the value of HRQoL outcomes among adolescents experiencing dysmenorrhea: Levels of anxiety and depression, pain catastrophizing, somatisation, family functioning, and pain severity (of both a usual and most recent period). A correlation matrix will be presented first, detailing the correlations between all variables entered into the model. Finally, the model fit will be presented, along with the standardised β, t value, and p values for each predictor value.

Mediation analysis

Mediation analysis is increasingly applied to study psychosocial contributors to the experience of pain (Edwards et al., 2016). Hypothesis 3 and 4 were tested using PROCESS (Model 4, Hayes, 2013), a MACRO of SPSS. The Preacher and Hayes' Bootstrapping method was chosen to investigate mediation. This method was chosen over Baron and Kenny's method of investigating mediation. This is because the Baron and Kenny methods is sensitivive to sample size, assumptions of normality necessary, the sobel test relies on normal distribution, and the relationship between the IV and DV needs to be significant. The Preacher and Hayes (2013) bootstrapping method is a non-parametric test which is ideally suited for small sample sizes. This method has been used because it does not violate the assumptions of normality, rather it acknowledges the skew of the distribution. Additionally, a significant total effect of the independent variable (IV) on the dependent variable (DV) is not necessary to run the analysis and for mediation to occur. Bootstrapping gives an approximation of the sampling distribution. Using this method, each participants' data can be analysed multiple times (Hayes, 2013). Mediation was investigated using a 95% confidence interval and significance set to $p \leq .05$. The unstandardized *b* and standard error, standardised, *p* values, and confidence intervals for total, direct, and indirect effects are reported. Also, a diagram of the mediation model containing the bootstrapped regression coefficients is also presented.

7.2.6 Results

Missing Data

Overall, just 1.3% of items were missing (n=521) throughout the data set. Little's Missing Completely at Random (MCAR) test was non-significant (Chi^2 =8642.666, *df* =8764, *p*=.820). Therefore, as there was no pattern to how the values were missing, imputation of missing values was conducted. Missing data were replaced using the Expectation Maximisation (EM) Algorithm (Schafer & Graham, 2002).

Assumptions

As can be seen in Table 7, no skew and kurtosis values fall above 2.58 indicating that normality can be assumed. Additionally, outliers were identified and considered not a cause for concern. Internal consistency reliability analysis indicated that measures of HRQoL (α=.92), anxiety (α=.95), depressive symptoms (α=.87), family functioning (α=.90), catastrophizing (α=.93), and somatisation (α=.93) were reliable.

Histograms and normal PP-plots show that the residuals are normally distributed. Scatterplot indicates that the residuals are both linear and that heteroscedasticity is not a concern. Examination of the collinearity statistics produced by the regression calculation indicates that multicollinearity is not a problem. None of the variance inflation factors (VIF) for the predictor variables exceeded 10 and no tolerance statistics fell below .02. The strongest correlations between predictor variables are between the anxiety and depression symptom scores (r=.782; *p*=.000) and between usual and most recent pain severity (r=.798; .000).

Table 7 Linearity and Reliability Calculations for Pain Severity, HRQoL, Levels of Anxiety and Depression, Family Functioning, Catastrophizing, and Somatisation

Psychosocial Factors (n=329)	Skew	Kurtosis	Cronbach alpha (α) of measure
VAS: Usual Pain Severity	-.659	-.246	
VAS: Most recent Pain Severity	-.280	-.893	
PedsQL: Physical Functioning	-.336	-.617	.88
Peds QL: Emotional Functioning	-.143	-.475	.79
Peds QL: Social Functioning	-.691	-.163	.80
PedsQL: School Functioning	-.221	-.329	.78
PedsQL: HRQoL- Total Score	-.140	-.708	.92
STAIC: State Anxiety	-.117	-.707	.93
STAIC: Trait Anxiety	.457	-.319	.92
STAIC: Anxiety- Total Score	.169	-.633	.95
CDI: Depressive Symptoms	.525	-.399	.87
FAD: Family Functioning	-.201	.059	.90
PCS: Catastrophizing	.273	-.656	.93
CSI: Somatization	.830	.246	.93
Linearity and Reliability Statistics			

Descriptive Statistics

Data from 333 adolescent girls were collected. The majority of data (n=304) were collected via hard-copies of surveys and inputted manually into an excel spreadsheet. Data from a further 29 participants were collected online via the University of Southampton's Isurvey. Overall, after removing four participants who reported that their last menstruation was 120-365 days ago, data from N=329 participants were included in the final analysis. A heterogeneous sample was recruited with participants ranging in age from early to late adolescence (13 to 18 years; *M*age=15.19, *SD*=1.49) (See Table 8). None of the 21 participants gave more information when responding to 'other' when asked about school year.

Participant Characteristics

Table 8 Participant Characteristics

Variable		Frequency (%)
Age (years) (n=329)		
	13	53 (16.2)
	14	72 (22.0)
	15	56 (17.1)
	16	68 (20.7)
	17	64 (19.5)
	18	15 (4.6)
School year (n=327)		
	Year 9	121 (37.0)
	Year 10	44 (13.4)
	Year 11	35 (10.7)
	Year 12	79 (24.2)
	College	27 (8.3)
	Other	21 (6.4)

Participant Age and School Year

Menstrual Characteristics

Age of menarche ranged from 9 to 15 years (*M*age=11.93, *SD*= 1.37). Days since most recent menstruation ranged from participants who were currently menstruating to those who had not menstruated for 75 days (*M*=13.92, *SD*=12.00).

Adolescents reported taking several different medications to relieve their menstrual symptoms including Nurofen (n=87), the contraceptive pill (n=44), Asprin (n=40), Paracetamol (n=31), Panadol (n=15), ibuprofen (n=11), Ponstan (n=9), tranexamic acid (n=2), Naproxen (n=1), Cocodemol (n=1), the contraceptive implant (n=1), Feminax (n=1), Naprosyn (1), Calpol (n=1), and the Depo injection (n=1). The effectiveness of analgesics used for menstrual pain ranged from 0 (not at all effective) to 11 (completely effective) (*M*=6.54, *SD*=2.82).

Of those adolescents who reported how many days of school were missed (n=94), absence during each menstrual period (M=1.35 days, SD= 1.15) ranged from 0 to 7 days. The majority (n=72, 79.1%) of adolescents were absent for between 1 and 2.5 days. 91 (27.7% of total sample) girls reported missing school because their periods were too painful.

When asked to report any other symptoms not identified in the survey, adolescents reported difficulty walking, anxiety, not ‘wanting to be touched’, mood swings, trouble sleeping, feeling easily agitated, wanting to fidget, and food cravings.

Menstrual Characteristics (MDoT Items)

Table 9 Menstrual Characteristics

Variable	Frequency	%
Age at menarche (years) (n=328)		
	8	8 (2.5)
	10	34 (10.5)
	11	62 (19.1)
	12	113 (34.8)
	13	81 (24.9)
	14	18 (5.5)
	15	8 (2.5)
Days since most recent menstruation (n=302)		
	Participants who were menstruating at the time of the survey	29(9.6)
	1-28	241(79.8)
	29-40	25 (8.3)
	41-75	7 (2.3)
Regularity of periods (n=326)		
	Regular	185 (56.6)
	Irregular	119 (36.4)
	Don’t know	22 (6.7)
Heaviness of bleeding (n=329)		
	Light	36 (11.0)
	Medium	191 (58.6)
	Heavy	99 (30.4)
Do you take medications for period pain? (n=324)		
	No	86 (26.5)
	Yes	237 (73.1)
Perceived Effectiveness of medications (n=300)		
	0	4 (1.3)

	1	2 (.7)
	2	14 (4.7)
	3	26 (8.7)
	4	25 (8.3)
	5	44 (14.7)
	6	40 (13.3)
	7	47 (15.7)
	8	29 (9.7)
	9	11 (3.7)
	10	3 (1.0)
	11	55 (18.3)
Menstrual-related school absences (n=325)		
	No	251 (77.0)
	Yes-every period	3 (0.9)
	Yes-with some periods	71 (21.8)
Days of menstrual-related school absence (n=91)		
	0	11 (12.1)
	1-1.5	59 (64.8)
	2-2.5	13 (14.3)
	3-3.5	2 (2.2)
	4-4.5	3 (3.3)
	5-5.5	2 (2.2)
	6-6.5	0 (0)
	7	1 (1.1)
Most common menstrual symptoms (experienced ‘sometimes’ or ‘all the time’)		
	Feeling really tired (n=325)	300 (92.3)
	Pelvic pain (cramping) (n=322)	291 (90.3)
	Headaches (n=322)	276 (85.7)
	Feeling down or depressed (n=323)	275 (85.1)
	Pelvic pain (aching) (n=322)	248 (77.0)
	Bloating (n=319)	244 (76.5)
	Lower back pain (n=319)	216 (67.8)

	Pelvic Pain (stabbing) (n=319)	214 (67.1)
	Need to pass urine often (n=320)	173 (54.1)

Menstrual Characteristics (MDoT Items)

Note. One participant answered ‘1 years’ when asked age at menarche and was therefore deleted.

The majority of adolescents had not been diagnosed with PCOS (87.7%), endometriosis (89.2%) or PID (88.3%), indicating that most adolescents were experiencing primary dysmenorrhea. Many adolescents did not know whether their mum or sister had been diagnosed with PCOS (46.9%), endometriosis (49.2%) or PID (47.8%).

Medical Characteristics (MDoT Items)

Table 10 Medical Characteristics

Variable	Response	Frequency (%)
Diagnosed with PCOS (n=325)		
	Yes	13 (4.0)
	No	285 (87.7)
	Don’t know	26 (8.0)
Diagnosed with endometriosis (n=325)		
	Yes	7 (2.2)
	No	290 (89.2)
	Don’t know	28 (8.6)
Diagnosed with PID (n=326)		
	Yes	12 (3.7)
	No	288 (88.3)
	Don’t know	26 (8.0)

Mum or sister with period problems (n=323)		
	Yes	94 (29.1)
	No	90 (27.9)
	Don't know	139 (43.0)
Mum or sister with severe period pain (n=324)		
	Yes	106 (32.7)
	No	84 (25.9)
	Don't know	134 (41.4)
Mum or sister with PID (n=320)		
	Yes	3 (.9)
	No	164 (51.3)
	Don't know	153 (47.8)
Mum or sister with PCOS (n=322)		
	Yes	13 (4.0)
	No	158 (49.1)
	Don't know	151 (46.9)
Mum or sister with endometriosis (n=323)		
	Yes	5 (1.5)
	No	159 (49.2)
	Don't know	159 (49.2)

Pain Severity

Adolescents reported the severity of their usual menstrual pain (*M*=5.75, *SD*=2.53) and most recent menstrual pain (*M*=5.10, *SD*=2.78). Approximately half of the adolescent girls reported that their usual (80.5%) and most recent (71.1%) menstrual pains were moderate or severe (VAS rating ≥3.5).

Table 11 Pain Severity

Self- Reported Pain Severity		
		Frequency (%)
VAS: *usual* menstrual pain severity (n=329)		
	0-3	64(19.5)
	3.5-7	184 (55.9)
	7.5-10	81 (24.6)
VAS: *most recent* menstrual pain severity (n=329)		
	0-3	95 (28.9)
	3.5-7	162 (49.2)
	7.5-10	72 (21.9)

Table 12 Desciptive Statistics for Study Variables

Psychosocial Factors (n=329)	Mean (standard deviation)
Usual Pain Severity	5.76 (2.53)
Most recent Pain Severity	5.132 (2.78)
Physical Functioning	20.00 (6.69)
Emotional Functioning	11.41 (4.47)
Social Functioning	15.70 (3.60)
School Functioning	12.53 (4.11)
HRQoL- Total Score	59.92 (15.33)
State Anxiety	20.89 (9.58)

Trait Anxiety	17.79 (7.48)
Anxiety- Total Score	38.68 (15.81)
Depressive Symptoms	6.29 (4.32)
Family Functioning	34.27 (2.85)
Catastrophizing	21.12 (12.19)
Somatization	23.90 (16.72)

Mean Scores

Descriptive Statistics for Pain Severity, HRQoL, Levels of Anxiety and Depression, Family Functioning, Catastrophizing, and Somatisation

All predictor variables were significantly correlated with total HRQoL scores. There were significant negative correlations between HRQoL and levels of anxiety and depression, pain catastrophizing, somatization, usual pain severity and most recent pain severity and a positive correlations between HRQoL and family functioning. Furthermore, the strongest correlation between predictor and outcome variable is for somatization (*r*=-.673; .000) and so, it is likely that this will best predict HRQoL.

Table 13 Correlation Matrix

	HRQoL	Depression	Anxiety	Family Functioning	Catastrophising	Somatisation	VAS Usual	VAS Recent
HRQoL		-.551***	-.633***	.293***	-.556***	-.656***	-.508***	-.482**
Depression			.782***	-.428***	.431***	.479***	.248***	.212***
Anxiety				-.448***	.531***	.616***	.337***	.323***
Family Functioning					-.210***	-.345***	-.192***	-.184***
Catastrophising						.531***	.520***	.479***
Somatisation							.429***	.431***
VAS Usual								.792***
VAS Recent								

Correlation Matrix: Pain Severity, HRQoL, Levels of Anxiety and Depression, Family Functioning, Catastrophising, and Somatisation

Note. **p<.05, **p<.01, ***p<.001*

Multiple Regression

A multiple linear regression was calculated to predict HRQoL based on levels of anxiety and depression, family functioning, pain catastrophizing, and somatization predictors and pain severity. A significant regression model was found (F (7, 321) =64.382, p<.000) with R^2 of .584. Overall, 58.4% of HRQoL scores among adolescent girls experiencing dysmenorrhea were explained by depressive and anxiety symptoms, family functioning, pain severity, pain catastrophizing, and somatization.

Table 14 Multiple Regression

Predictor	**HRQoL**				
	Standardised B	***t***	***p* value**	**Tolerance**	**VIF**
Somatisation	-.314	-6.333	.000 ***	.528	1.895
Anxiety	-.194	-2.914	.004 **	.293	3.418
Depression	-.165	-2.819	.005**	.376	2.658
Pain Severity: Usual	-.152	-2.486	.013*	.345	2.902
Catastrophizing	-.103	-2.119	.035*	.553	1.808
Pain Severity: Recent	-.086	-1.437	.152	.358	2.795
Family Functioning	-.040	-.971	-.332	.769	1.301

Multiple Regression Analyses

Multiple Regression Analyses: Somatisation, Anxiety, Depression, Pain Severity: Usual, Catastrophizing, Pain Severity: Recent, Age, Age at Menarche, and Family Functioning.

Note. *p<.05, **p<.01, **p<.001

As shown in Table 14, somatisation, levels of anxiety and depression, usual pain severity, and pain catastrophizing significantly predicted HRQoL. HRQoL was negatively associated with somatisation, levels of anxiety and depression, usual pain severity, and pain catastrophizing. HRQoL decreased by 0.314 for each increase in somatisation, 0.194 for each increase in anxiety, 0.165 for each increase in depressive symptoms, 0.152 for each increase in usual pain severity, and 0.103 for each increase in pain catastrophizing. Most recent pain severity and family functioning did not significantly predict changes in HRQoL.

Mediation analysis

Pain Catastrophizing as a Mediator

A mediation model tested whether pain catastrophizing mediated the effect of anxiety on HRQoL. As expected, the total effect of anxiety on HRQoL was significant and negative (*b*=-.21, *SE*=.06, 95% CI [-.33, -.08]). Higher levels of anxiety predicted lower HRQoL scores. The direct effect was also significant and negative (*b*=.19, *SE*=.06, 95%CI [.08, .30]). The indirect effect was also significant, confirming that anxiety can effect HRQoL scores via pain catastrophizing among this sample of adolescent girls experiencing dysmenorrhea (*b*=-.03, *β*= -.02, bootstrapped SE= .01, bootstrapped 95% CI [-.06, -.00]). The same model was run to test whether catastrophizing mediated the relationship between trait anxiety alone and HRQoL, however this model was nonsignificant indicating that catastrophizing did not mediate the effect of trait anxiety on HRQoL.

Pain catastrophizing was investigated as a mediator between the effect of usual pain severity on HRQoL. As expected, the total effect of usual pain severity on HRQoL was significant and negative (b= -1.51, SE=.24, 95% CI [-2.00, -1.03]). Higher levels of usual pain severity predicted lower HRQoL scores. The direct effect was also significant and negative (b=-1.30, SE=.26, 95%CI [-1.80, -.77]). The indirect effect was also significant, confirming that usual pain severity can effect HRQoL scores via pain catastrophizing among this sample of adolescent girls experiencing dysmenorrhea (b=-.23, β= -.05, bootstrapped SE= .02, bootstrapped 95% CI [-.10 -.01]).

Levels of Anxiety and Depression as mediators

A mediation model was used to test whether levels of anxiety mediated the effect of somatisation on HRQoL. As expected, the total effect of somatisation on HRQoL was significant and negative (b= -.33, SE=.04, 95% CI [-.42, -.25]). Higher levels of somatisation predicted lower HRQoL scores. The direct effect was also significant and negative (b=.29, SE=.05, 95%CI [-.38, .20]). The indirect effect was also significant, confirming that somatisation can effect HRQoL scores via anxiety among this sample of adolescent girls experiencing dysmenorrhea (b=-.04, β= .05, bootstrapped SE= .02, bootstrapped 95% CI [-.10, -.01]). The same model was used to test whether levels of depression mediated the relationship between somatisation and HRQoL, however this model was non-significant.

7.2.7 Discussion

This study aimed to investigate the psychosocial correlates of HRQoL outcomes among adolescents with dysmenorrhea. Based on the first three studies of this doctoral thesis, the aim was to explore the impact of dysmmneorrhea on the HRQoL of adolescents living in the UK. The aim of this particular study was to test the hypothesis that the HRQoL of girls experiencing dysmenorrhea would be predicted by pain severity, levels of anxiety, depression, somatisation, pain catastrophizing, and family functioning. A secondary aim of this study was to explore the mediating role of pain catastrophizing between a) anxiety and HRQoL, and b) pain severity and HRQoL; also to investigating role of anxiety and depression in mediating the relationship between somatisation and HRQoL. Overall, 54.4% of the variance in HRQoL scores among adolescent girls experiencing dysmenorrhea were explained by levels of depression and anxiety, pain severity, family functioning, pain catastrophizing, and somatization. Somatisation, levels of anxiety and depression, usual pain severity, and pain catastrophizing significantly predicted HRQoL.

Dysmenorrhea Characteristics

The age of menarche ranged from 9 to 15 years (*M*age=11.93, *SD*= 1.37), falling within the range identified in the systematic review (8-19 years) from previous studies of adolescents. Adolescents reported a mean usual pain severity score of 5.75 (*SD*=2.53) on the VAS and 5.10 (*SD*=2.78) for the most recent menstrual pain. 80.5% and 71.1% of the adolescents reported moderate to severe levels of pain for their usual and most recent menstrual pain experience, respectively. Specifically, 55.9% of adolescents reported moderate, and 24.6% reported severe usual pain severity. This is comparable with studies included in the systematic review (chapter three) which showed that moderate pain ranged from 30% to 62.3%, and severe pain ranged from 14% to 51.97%. Also, in concordance with the previous literature identified in the systematic review, adolescents reported a wide range of accompanying symptoms including fatigue, headaches, bloating, needing to frequently pass urine, nausea, and mood swings (Parker et al., 2010). Adolescents who reported being absent from school due to menstruation, had missed between half of a school day and 7 days per menstrual period, supporting the findings of previous studies that found girls missed between a range of individual classes (Banikarim et al., 2000) to 7 full school days (Poureslami & Osati-Ashtiani, 2002). Just under a quarter (22.7%) of adolescents reported missing school because of menstruation, slightly less than that found in Parker et al.'s (2010) study of Australian adolescents, of whom over a quarter (26%) reported missing school because of menstruation. Similarly, the majority of adolescents in this study reported missing 11.5 days of school while menstruating (64.8%), comparable to the 70% of adolescents missing 1 day of school in Parker et al.'s (2010) study.

HRQoL

Overall, previous research has indicated that dysmenorrhea has a profound, negative impact on adolescents' HRQoL including physical, psychological, social, and school functioning (Parker et al., 2010). Chapters' three to six of this thesis have demonstrated that dysmenorrhea is consistently associated with limitations to health-related quality of life (HRQoL) (Nur Azurah, Sanci, Moore, & Grover, 2013). The findings in chapter three of this thesis indicated that overall, girls reported that dysmenorrhea had a negative impact on all domains of HRQoL including physical, social, psychological and school functioning and well-being. From a biopsychosocial perspective, this relationship may be bi-directional and, although dysmenorrhea can affect HRQoL, psychological and social factors can also influence the overall experience of menstrual pain (Gatchel et al., 2007; Walker, 2008).The overall evidence indicated that associations between dysmenorrhea and impaired HRQoL often increase with menstrual pain severity (Banikarim et al., 2000; El-Gilany et al., 2005; Eryilmaz et al., 2010; Klein & Litt, 1981; Pitangui et al., 2013; Teperi & Rimpelä, 1989). Findings from the current study, that pain severity and HRQoL are significantly and inversely correlated, support this. These findings support empirical research investigating paediatric chronic pain and HRQoL which have found that lower levels of pain were associated with higher HRQoL scores (Gold et al., 2009). The current sample of adolescents reported a mean PedsQL score of 59.92 (SD=15.33), which is lower than the PedsQL scores of the 184 adolescents aged 13-18 years attending a gynaecological clinic for menstrual disorders (including dysmenorrhea) in Australia (M= 70.40; SD= 16.36) (Azurah et al., 2013) which, in turn, is lower than adolescents with cystic fibrosis and community samples of adolescents from the 'health of young Victorian' study used as comparisons in Azurah et al.'s (2013) report. However, this finding should be cautiously. The prevalence of adolescent mental health disorders is high in the UK. One study found that 40% adolescents in England are living with either a mental health disorder or hyperactivity (Corner et al., 2016). However, as this research was not conducted with a case control design, it is not possible to compare these scores with adolescent girls in the UK who are not experiencing dysmenorrhea.

Psychosocial Predictors

Evidence from the systematic review (chapter three) indicated that dysmenorrhea was associated with somatisation (Goldstein-Ferber & Granot, 2006; Rapkin et al., 2006). Adolescents from chapter five described many symptoms other than pain including loose bowels, mood swings, bloating, headaches/migraines, acne, nausea, vomiting, loss of appetite, fatigue, muscle aches, hunger, breast pain, dry hair and skin, body odour, back ache, sweating, dizziness, and feeling generally unwell. Somatization was the strongest predictor of HRQoL when controlling for the other psychosocial variables. A significant, negative correlation was found between somatization and HRQoL. This supports findings from the literature that somatization is associated with higher levels of functional disability (Campo, Jansen-McWilliams, Comer, & Kelleher, 1999; Harris, Orav, Bates, & Barsky, 2009; Hyphantis et al., 2009; Walker, Garber, Van Slyke, & Greene, 1995). For example, Campo and colleagues (1999) showed that children with high levels of somatization had poorer health, greater health limitations, and poorer school performance and attendance than children with low levels of somatisation. Moreover, Mahrer (2012) found that, among both children and adolescents, although somatization was significantly and positively related to pain intensity, somatization significantly predicted HRQOL over and above pain.

Many studies included in the systematic review (chapter three) found that dysmenorrhea was associated with impaired psychological or emotional functioning. This was also a key finding from both qualitative empirical studies of the thesis. Both adolescents and mothers described negative emotions associated with adolescent dysmenorrhea. This adds to this finding by showing that, among this sample of adolescent girls, levels of anxiety and depression were both independent, significant predictors of HRQoL. These findings support those from the wider paediatric chronic pain literature that levels of anxiety (Kashikar-Zuck et al., 2008; Walker & Greene, 1991) and depression (Kashikar-Zuck, Goldschneider et al. 2001, Claar and Walker 2006, Gauntlett-Gilbert and Eccleston 2007) are associated with impaired functioning.

The current study found that pain catastrophizing was a significant predictor of HRQoL, independent of anxiety, depression, and family functioning, somatization among the sample. This finding supports findings from chapter five of this thesis where many girls described catastrophizing thoughts in relation to their pain; many reported that period pain became a major focus in their lives, the anticipation of menstrual pain had a negative impact on aspects of their lives, and some girls had become very concerned about whether or not period pain was 'normal', describing fears of a pathological cause in terms of something abnormal happening to their bodies. These findings indicated that, when entered into the regression model together, levels of anxiety and depression were stronger predictors of HRQoL among participants than pain catastrophizing. This contradicts previous findings from a community sample of school children (n=193, Mage=11.1 years) and a clinical sample of children experiencing pain such as headache and abdominal pain (mage=11.8 years) that pain catastrophizing significantly accounted for the variance of pain, disability, and somatic complaints, beyond the effects of negative affectivity (Vervoort, Goubert et al. 2005).This suggests that, unlike with other forms of chronic pain, emotional functioning is a greater predictor of HRQoL outcomes than pain catastrophizing in samples of girls experiencing dysmenorrhea. Negative affectivity and pain catastrophizing develop early in life and are often maintained throughout the lifespan (Brown, O'Keeffe et al. 1986). Previous research has shown that pain catastrophizing is a less stable characteristic than other traits (e.g., levels of anxiety and depression) (Sullivan, Bishop et al. 1995). Therefore, pain coping strategies are more easily changeable, indicating that pain catastrophizing is a potentially important factor to target in future interventions.

In chapter five of this thesis, girls reported that dysmenorrhea caused some tensions between different family members, particularly with other female family members who may also be experiencing menstrual symptoms (e.g., peri-menopausal and menopausal symptoms). Mothers echoed this, describing a profound impact on theirs and their family’s lives including their emotional functioning, relationships between family members, and family daily life. These findings added to this by investigating the impact of family functioning on overall HRQoL outcomes. When correlated alone with HRQoL, there was a significant positive correlation between family and HRQoL. However, when entered into the regression model, and therefore controlling for levels of anxiety and depression, catastrophizing, and pain severity, family functioning was no longer significantly correlated with HRQoL. This indicates that, among this sample, family functioning was not independently associated with variance in HRQoL. Therefore, although parents are often the immediate and most prominent form of social environment for children and adolescents, these findings did not support evidence that family functioning is an important factor in influencing pain-related outcomes, when controlling for other psychosocial factors (Edwards, Dworkin et al. 2016; Barakat et al., 2008; King et al., 2011). As the general functioning domain only of the Family Assessment Device (FAD-SF) was used to measure family functioning, it may be beneficial for future research to investigate whether other domains of family functioning are independently associated with HRQoL.

Interactions between Dysmenorrhea, Psychosocial Factors and HRQoL

Mediation analysis indicated that overall anxiety can effect HRQoL scores via pain catastrophizing among this sample of adolescent girls experiencing dysmenorrhea. These findings support that from the previous literature that pain coping strategies mediate the relationship between anxiety and functioning (Kacsynski, 2011). However, my mediation model with trait anxiety alone was not significant. These results are in contrast with those which have shown that pain catastrophizing could mediate the relationship between negative affectivity and HRQoL (Vervoort et al., 2005).

When examining pain catastrophizing as a mediator between pain severity and HRQoL, usual pain severity, but not most recent pain severity, was a significant predictor of HRQoL when entered into the regression model with the other psychosocial predictor variables. Therefore, mediation analyses were conducted with usual pain severity rather than most recent pain severity. The findings from this study showed that, usual pain severity can effect HRQoL scores via pain catastrophizing among this sample of adolescent girls experiencing dysmenorrhea. This finding supports that of previous research showing that pain catastrophizing may mediate the relationship between pain intensity and HRQoL outcomes in the paediatric chronic pain population (Merlijin, Hunfeld et al., 2006). Finally, levels of anxiety, but not depression, mediated the relationship between somatization and HRQoL within this sample. This supports evidence that high levels of anxiety have been independently associated with several physical conditions within paediatric community samples, and this comorbidity is significantly associated with poor quality of life and disability (Sareen et al., 2006).

Family functioning, measured by the ‘general functioning’ subscale of the FAD, was not significantly associated with HRQoL outcomes in this sample. However, the family-based biopsychosocial models of paediatric chronic pain introduced in Chapter 2 posit that parental and family factors play a key role in predicting paediatric pain outcomes (Campo et al., 2007; Connely et al., 2017; Guite et al., 2018; Turk et al., 1987). This finding is also in contrast with findings from the systematic review (Chapter 3) and two qualtaitive studies (Chapter 5 and Chapter 6). Therefore, future research should explore the association between adolescent dysmenorrhea and family functioning further. For example, using different methodologies and measures for various aspects of family functioning, including parental responses.

Strengths and limitations

The systematic review showed that very few previous studies reported whether participants had any underlying pelvic pathology (Frisk et al., 1965; Parker et al., 2010; Pitangui et al., 2013; Santina et al., 2012; Sanyal & Ray, 2008). Although this study aimed to address this limitation by obtaining information about pelvic pathology, there were not enough instances of secondary dysmenorrhea to make a statistical comparison between primary and secondary dysmenorrhea. In addition, a case-control design was not employed. Therefore, no comparison could be made between adolescent girls who had, and who had not experienced dysmenorrhea. A recommendation for future research is therefore that purposeful sampling be used to recruit adolescents a) without ever having experienced dysmenorrhea, and with b) primary and c) secondary dysmenorrhea so that a comparison of subgroups could be made.

Strengths of the current study is that it addresses limitations of previous research identified from chapter three, the systematic review. Firstly, this study addresses the need for up-to-date research investigating adolescent dysmenorrhea and HRQoL here in England. Over half of studies identified in the systematic review were conducted in non-western cultural settings. This study, in combination with the two qualitative studies of this thesis, provides a detailed exploration of how dysmenorrhea impacts on all aspects of adolescents' and their families' lives, and which psychosocial factors predict HRQoL outcomes within this sample. This study updates previous, outdated, research that has been conducted here in the UK (Fontana & Rees, 1982; Frisk et al., 1965; Hillen et al., 1999; Johnson, 1988; Klein & Litt, 1981; Teperi & Rimpelä, 1989; Widholm, 1979; Wilson & Keye, 1989).

Additionally, this research employed the use of validated measures of pain severity, HRQoL, somatisation, pain catastrophizing, and levels of anxiety and depression. The systematic review showed that very few studies reported the use of validated tools to measure all primary outcomes (Chaudhuri & Singh, 2012; Dorn et al., 2009; Goldstein-Ferber & Granot, 2006; Negriff et al., 2009; Nur Azurah et al., 2013; Rapkin et al., 2006; Santina et al., 2012; Unsal et al., 2012; Wong, 2011; Wong & Khoo, 2010).

Finally, there are currently a lack of biopsychosocial, theoretical models of adolescent dysmenorrhea available. Despite the fact that biopsychosocial models of chronic pain are well established, just one of the reviewed studies developed a theoretical model of menstrual pain in their report (Wijesiri & Suresh, 2013). This study provides a working model of dysmenorrhea where somatisation, pain catastrophizing, usual pain severity, and levels of anxiety and depression predict HRQoL outcomes among adolescents in England experiencing dysmenorrhea. Development of models such as these may help to increase awareness among healthcare professionals, parents, and young people about the overall experience of menstrual pain and, in turn, this increased understanding may eventually improve management and care.

In sum, this study addresses many limitations identified in the systematic review, and builds on the previous work of this thesis to develop a working model of adolescent dysmenorrhea and HRQoL. Suggestions for future research have been made, which include the testing of this working biopsychosocial model of dysmenorrhea for adolescent girls in the UK.

Chapter 8 General Discussion

8.1.1 Introduction to the Chapter

This chapter begins with an overview of the aims of this thesis followed by the main findings, presented for the systematic review and each empirical study seperately. A discussion around what the findings add to the existing literature is then presented. This is followed by a discussion of the main findings in relation to some of the biopsychosocial theories presented in Chapter 2. The order of this is as follows: Dysmenorrhea and HRQoL, Dysmenorrhea and emotion, Dysmenorrhea and pain-catastrophising, Dysmenorrhea and somatisation, and Dysmenorrhea and family functioning. Finally, the key strengths and limitations of the research, along with ideas for future research and interventions will be presented.

8.1.2 Overview of main findings

The overarching aim of this thesis was to explore the experience of dysmenorrhea and its impact on the health-related quality of life (HRQoL) of adolescent girls living in the UK. The specifc aims, as presented in Chaper 1, were as follows:

1. To identify and review the existing literature investigating adolescent dysmenorrhea and health-related quality of life; to identify gaps in the existing literature and make recommendations for research (chapter three).
2. To use qualitative methods to explore adolescent dysmenorrhea and its impact on all aspects of life, from the perspectives of adolescents themselves (chapter five).
3. To explore maternal perceptions of adolescent dysmenorrhea, its impact on their daughters' lives, and its impact on family functioning (chapter six).
4. To develop a working model of the psychosocial predictors of health-related quality of life among adolescents experiencing dysmenorrhea (chapter seven)
5. To consider the implications of the working model developed in chapter seven for future work and interventions (chapter eight).

Main findings from Chapter 3

The aim of chapter three was to conduct a systematic literature review of the existing literature investigating the impact of adolescent dysmenorrhea (both primary and secondary dysmenorrhea) on HRQoL, or its constituent parts including physical, psychological, social and school functioning, and well-being. The fidings from this review highlighted the fact that research investigating adolescent dysmenorrhea and HRQoL is in its infancy. This is particularly true for research in England, the UK where, until now, there has been no research investigating the impact of adolescent dysmehorrhea and HRQoL. The systematic review resulted in the identification of 42 included studies which showed that adolescent dysmenorrhea can have a profound, negative impact on all aspects of HRQoL. Specifically, adolescent dysmenorrhea was associated with reduced school functioning. This included findings of both increased school absenteeism and girls' self-reported limitations to academic performance due to dysmenorrhea. Studies also found that girls reported a negative impact on their psychological functioning as a result of dysmenorrhea including reduced concentration and increased levels of emotional distress. The studies also indicated that dysmenorrhea restricted girls' ability to engage in their usual activities of daily living. In addition, their relationships with friends and engagement with social activities were negatively impacted. The existing evidence suggests that dysmenorrhea has a negative impact on all aspects of HRQoL and that this impact is amplified by increased reported pain severity.

Main findings from Chapter 5

Chapter 5, the first empirical study of this thesis, was designed based on the need for up-to-date, methodologically rigorous research investigating the impact of dysmenorrhea on the lives of adolescents living in the UK (Chapter 3). Qualitative in-depth interviews were used to explore the experiences of 20 adolescent girls living with dysmenorrhea. This study found that dysmenorrhea had a profound impact on all aspects of the girls' lives. Four themes (and 17 subthemes) were identified from a thematic analysis of the transcribed interviews including 1) Managing period pain, 2) Period pain is restrictive, 3) Negative emotions associated with dysmenorrhea and accompanying symptoms, and 4) The complexities of managing relationships while experiencing period pain. The girls in this study described the factors that influenced the way in which they managed their pain. For example, their help-seeking behaviours were heavily influenced by gender. For many of the girls, menstruation was considerd an 'embarrassing' or a 'taboo' topic and as a result they were only willing to discuss it with, or seek help from, women. This is strongly associated with another key finding that the girls relied heavily on their mothers while they were experiencing menstrual pain. The restrictive nature of dysmenorrhea was emphasised by many of the adolescents. In particular, the girls reported a negative impact on their physical functioning (e.g., walking, eating, sleeping) and ability to engage in their usual activities. The impact that dysmenorrhea had on their schooling was important to them. Girls weighed up the potential consequences of attending school (and risking being sent home or not being able to concentrate) versus not attending. There was a sense of anxiety and concern about the impact of regular limitations to their school functioning. Dysmenorrhea was associated with negative emotions including resentment that they were experiencing pain when others weren’t. This extended to other girls their age who didn’t experience the same severity of pain when menstruating. There was also a profound sense of anxiety and helplessness surrounding menstruation. Girls struggled to manage their pain and often had trialled a number of non-effective strategies to relieve it. Some girls reported feeling anxious about the pain before they had even begun menstruating. Others described pain catastropising thoughts such as concerns that their pain was not ‘normal’ and actually a result of some sinister undiagnosed pathology. Finally, the difficulties in navigating relationships with family, peers and school staff due to dyemnrorhea and accompanying symptoms were emphasised by all of the girls.

Main findings from Chapter 6

Chapter 6, the second empirical study of this thesis used a similar methodology to that in Chapter 5. Qualitative in-depth interviews with 20 mothers of adolescent girls were used to explore the maternal perceptions of adolescent dysmenorrhea. Overall, dysmenorrhea had a profound, negative impact on many aspects of family functioning including mothers’ emotional functioning, relationships between family members, and family daily life. Three themes (and 10 subthemes) were identified from a thematic analysis of the transcribed interviews including: 1) Differences in maternal responses to adolescent dysmenorrhea, 2) The importance of family functioning, and 3) The primary caregiver for issues related to menstruation. Mothers were often aware of the negative impact of dysmenorrhea on their daughters’ lives and functioning and all wanted to support their daughters to cope with their pain. Although they shared the same goal, there were clear differences in the way in which mothers responded to ther daughters’ pain. These responses often fell into two categories: 1) mothers who encouraged their daughters to ‘get on with it’ and continue with their daily activities despite pain and 2) mothers who were very sympathetic and protective in their responses and would often permit avoidance of activities (e.g., school absence). The importance of family communication was clear in the mothers’ reports although gender did have an influence on how members of the family communicated about dysmenorrhea. Some daughters were described as ‘shy’ and unwilling to talk about menstruation even with women in the family. Adolescent dysmenorrhea had a profound impact on daughters’ mood and, in turn, on family functioning. Girls were described as ‘unsociable’ and ‘moody’ while menstruating which caused tensions and conflict among family members. Generally, mothers were heavily relied upon to support their daughters through the pain, sometimes sacrificing their sleep and taking absence from work to care for their daughters. This seemed to be a heavy burden on mothers, resulting in a profound negative emotional impact.

Main findings from Chapter 7

The final empirical study of this thesis was a quantitative study, using a battery of questionnaires to investigate the psychosocial correlates of HRQoL outcomes among 333 adolescent girls who experience dysmenorrhea. The specific hypotheses of this study were developed based on biopsychosocial models relevant to paediatric chronic pain (Chapter 2), the findings from the systematic review (Chapter 3), the first empirical qualitative study (Chapter 5), and the second empirical qualitative study (Chapter 6).The hypotheses were as follows:

1. The following biopsychosocial factors: pain severity, pain catastrophizing, somatisation, levels of anxiety and depression, and family functioning will significantly predict Health Related Quality of Life (HRQoL) among adolescent girls experiencing dysmenorrhea.
2. Psychosocial factors (pain catastrophizing, somatisation, levels of anxiety and depression, and family functioning) will predict HRQoL among adolescent girls experiencing dysmenorrhea beyond pain severity (both usual and most recent pain).
3. Pain catastrophizing will mediate the relationship between levels of anxiety, trait anxiety, and pain severity with HRQoL among adolescents experiencing dysmenorrhea.
4. Levels of anxiety and depression will mediate the relationship between somatisation and HRQoL.

When entered into a multiple regression model, somatisation, levels of anxiety, levels of depression, catastrophizing thoughts, and usual pain severity of dysmenorrhea significantly predicted HRQoL outcomes among adolescent girls experiencing dysmenorrhea. Overall, 54.4% of the variance in HRQoL scores among adolescent girls experiencing dysmenorrhea were explained by levels of depression and anxiety, usual pain severity, pain catastrophizing, and somatization. Interestingly, family functioning and most recent pain severity did not significantly predict HRQoL outcomes among adolescents experiencing dysmenorrhea. Mediation models indicated that pain catastrophizing mediated the relationship between usual pain severity and HRQoL outcomes. Also, levels of anxiety mediated the relationship between somatisation and HRQoL.

8.1.3 What do these findings add to the existing literature?

There were a number of limitations in the existing literature identified in Chapter three. Importantly, the systematic review indicated that research investigating adolescent dysmenorrhea and HRQoL is particularly sparse in Western cultural settings, with just one, outdated study having been conducted in the UK (Fontana & Rees, 1982). Over half of the data investigating adolescent dysmenorrhea and HRQoL has been collected in non-western cultural settings. Until now, there has been very little academic interest in how dysmenorrhea can impact on the psychological, social, and school functioning of adolescent girls in England, UK. Menstrual attitudes and beliefs have been found to be culturally and socially constructed (Anson, 1999; Marván et al., 2003; McMaster et al., 1997). Therefore, the experiences of adolescent, menstruating girls in England may be unique in comparison to those growing up in other areas of the world. These findings informed the development of the two qualitative studies exploring adolescent dysmenorrhea. Qualitative methods were chosen as the best method for exploring an un-researched area and in capturing the voice of the adolescent. Explorative in-depth interviews conducted from a critical realist epistemological standpoint allows for the perspectives of the adolescents and their mothers to take precedent above researchers' preconceptions and guide any further research development. The use of qualitative methods influenced some novel outcomes of dysmenorrhea that were unexpected. For example, girls reported that dysmenorrhea had some positive influences on family functioning. Some of the girls felt that having dysmenorrhea actually had a positive influence on communication and that, as a result of having to discuss menstruation, their families had become a lot more open about discussing other personal issues. Girls with younger female siblings felt that their sisters would benefit from this improved family communication and their parents' improved ability to help and support their sisters based on their experiences.

Chapter three identified several important limitations in methodological rigour of the current evidence which were likely to have a significant impact on the outcomes obtained. For example, just 10 of the 42 studies included in the systematic review reported the use of validated tools to measure all primary outcomes. Even fewer (n=7) reported the use of validated pain severity measures. Often, there was very little information about how the questionnaires were developed, whether or not piloting had taken place, and whether internal and external validity had been tested. To address this limitation, measures that had been validated among populations of adolescents were used for all outcomes in chapter seven. In addition, measures were chosen based on preliminary findings from the two qualitative studies which showed that dysmenorrhea had a profound impact on levels of anxiety and depression and family functioning, and that the way in which girls thought about and coped with pain (e.g., *'I have a high pain tolerance so I know I'll get through it'* vs *'I can't cope with it at all'*) varied. Not only does the use of validated measures ensure the credibility of results, but also allows for replicability and comparison of findings with future research. The systematic review showed that the majority of empirical research so far has focussed on the impact of adolescent dysmenorrhea on school functioning. The first two empirical studies of this thesis showed that, although an important potential impact of dysmenorrhea, there are many other psychological, social and well-being factors associated with adolescent dysmenorrhea that should not be overlooked. This research has fed into the development of a working model whereby levels of anxiety and depression, pain catastrophizing, usual pain severity, and somatisation predict HRQoL outcomes among adolescents with dysmenorrhea (see Figure 4). The model shows that each predictor has a direct, negative influence on HRQoL. In addition, i) levels of anxiety predicts HRQoL through pain catastrophizing, ii) usual pain severity predicts HRQoL through pain catastrophizing, and iii) somatisation predicts HRQoL through levels of anxiety.

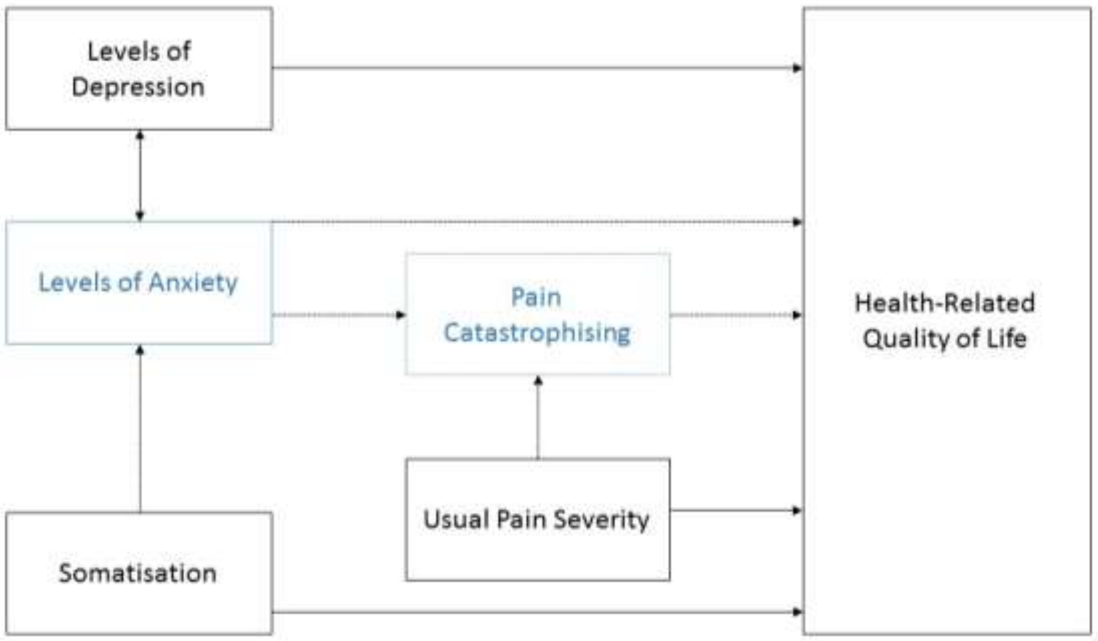


Figure 4 Predictors of HRQoL among adolescents (aged 13-18 years) experiencing dysmenorrhea: A working model.

8.1.4 Dysmenorrhea and Health-Related Quality of Life (HRQoL)

Findings from the systematic review (Chapter 3) and all three empirical studies in this thesis (Chapters 5, 6 and 7) have indicated that dysmenorrhea and its accompanying symptoms can have a profound, negative impact on all aspects of an adolescent girls' HRQoL. Previous research identified in the systematic review indicated that dysmenorrhea had a profound, negative impact on adolescents' physical, psychological, social, and school functioning (Parker et al., 2010). Throughout the thesis, dysmenorrhea has been consistently associated with limitations in health-related quality of life (HRQoL) (Nur Azurah, Sanci, Moore, & Grover, 2013). Findings from the systematic review indicated that associations between dysmenorrhea and impaired HRQoL often increase with menstrual pain severity (Banikarim et al., 2000; El-Gilany et al., 2005; Eryilmaz et al., 2010; Klein & Litt, 1981; Pitangui et al., 2013; Teperi & Rimpelä, 1989). The final empirical study of this thesis indicated that HRQoL outcomes among adolescent girls experiencing dysmenorrhea was predicted by somatisation, usual pain severity, levels of anxiety and depression, pain-catastrophising, and usual pain severity. In addition, although the relationship between usual pain severity of dysmenorrhea and HRQoL was significant, this relationship was mediated by pain-catastrophising. These findings reflect the biopsychosocial models of chronic pain (Gatchel et al., 2007) introduced in Chapter 2 which posits that the relationship between psychological, social and biological factors are interraled and that it is this interrelation that results in an individual's pain experience (Pillai Riddell et al., 2013).

Interestingly, the findings from Chapter 7 suggest that the average HRQoL scores of adolescents experiencing dysmenorrhea may be lower than that of adolescents experiencing other gynaecological conditions. The adolescent girls reported a mean PedsQL (HRQoL) score of 59.92 (SD=15.33), which is lower than the PedsQL scores of the 184 adolescents aged 13-18 years attending a gynaecological clinic for menstrual disorders (including dysmenorrhea) in Australia (M= 70.40; SD= 16.36) (Azurah et al., 2013). However, this should be interpreted with caution as there are a number of reasons why this may be the case. For example, it should be noted that the prevalence of adolescent mental health disorders is high in the UK. One study found that 40% of adolescents in England scored above the threshold for mental health disorders or hyperactivity (Corner et al., 2016). Without a case-control descign, is not possible to ascertain whether these HRQoL scores are low compared to adolescent girls who do not experience dysmenorrhea.

Adolescent dysmenorrhea impacted adolescents psychological, social, physical and school functioning. Both menstrual-related pelvic pain and unpleasant accompanying symptoms were responsible for feelings of emotional distress, anxiety and helplessness. In addition, some reported that the pain felt more severe when they had already felt upset or anxious before its onset. This reflects a biopsychosocial model of chronic pain in which pain can lead to negative emotions, while negative affect can also exacerbate existing pain (Gatchel et al., 2007). The restrictive nature of dysmenorrhea was highlighted by the adolescent girls in Chapter 5 who perceived dysmenorrhea to have an often profound negative impact on their physical functioning (e.g., standing, walking) and ability to engage with their usual daily activities. The girls' frustrations with the restrictive nature of their monthly pain is unsurprising considering that a major developmental change in adolescence is increasing autonomy and independence (Patton et al., 2016; Palermo et al., 2014). For many of the girls in this study, they relied heavily on their mothers' support while experiencing period pain. Parental support is often required by adolescents experiencing chronic pain. Previous research and paediatric chronic pain models have documented the complexity of balancing parental support and adolescents' need for autonomy (Evans et al., 2010; Palermo et al., 2014).

Limitations to school functioning were also a common finding in this thesis research. School of significant importance during adolescence because this is a key time when adolescents engage with their peers andwhen the foundations for an individual's future career are being formed (Lloyd, 2007; Patton et al., 2016). Many of the girls in this study were regularly required to weigh up the possible consequences of attending school in pain or being absent. As adolescents develop autonomy and an identity that is separate from their parents, peer influence becomes increasingly important. Adolescents display a far greater sensitivity to the presence of their peers, viewing the impact of their behaviours to their social reputation as highly important (Patton et al., 2016; Somerville, 2013). Research has shown that adolescents value their relationships and time with their peers over and above that of their family (Patton et al., 2016). The salience of peer relationships was reflected throughout this thesis, particularly in the qualitative adolescent study (Chapter 5). Missing out on sleepovers, having to cancel plans with peers, and difficult peer interactions were of key importance to the adolescents that caused them a significant amont of emotional distress.

8.1.5 Dysmenorrhea and Emotion

Psychological factors, inicluding emotion, are one of the three key interrelated components of pain that are included within the biopsychosocial models of chronic pain (Chapter 2). These models suggest that emotions including levels of depression and anxiety can interact with pain in various ways. Gatchel et al (2007) summarised the various ways in which emotions can interact with pain including: 1) by predisposing an individual to pain, 2) commencing a painful experience, 3) amplifying or inhibiting pain, and 4) emotions being experienced as a result of pain (Gatchel et al., 2007). The findings in this thesis reflect research that has indicated that both anxiety and depression can influence pain severity and disability and the HRQoL outcomes of adolescents experiencing dysmenorrhea (Sullivan et al., 2005; Gatchel et al., 2007). Levels of anxiety in Chapter 7 were independently and significantly invertly associated with HRQoL, in addition to mediating the association between levels of somatisation and HRQoL. It is well established in the literature investigating the paediatric fear avoidance model of chronic pain that anxiety, anticipation and fear surrounding pain can actually be more disabling than the pain itself, predicting emotional distress and physical disability (Asmundson et al., 2012; Crombez, Vlaeyen et al. 1999, Vlaeyen and Linton 2000). This anxiety and fear can lead to the avoidance of situations that the individual believes will trigger or increase pain, which is reinforced when that avoidance behaviour met with no/ less pain (Fordyce, 1977). This reinforcement of avoidance behaviours and subsequent further anxiety and depression may lead into a cycle of anxiety, depression, and limitations to functioning (Cohen, Vowles, & Eccleston, 2010). This is supported by evidence that pain is consistently related to disability across all components of HRQoL including physical, psychological, social and school functioning, and wellbeing.

A key finding from the systematic review (Chapter 3) and empirical studies (Chapter 5, 6 and 7) was that dysmenorrhea is strongly associated with impaired psychological functioning. The adolescent girls in Chapter 5 described feeling resentful, anxious and helpless. Mothers in Chapter 6 recognised the profound impact that adolescent dysmenorrhea had on their daughters' emotional well-being. The final empirical study showed that, among this sample of adolescent girls, levels of anxiety and depression were both independent, significant predictors of HRQoL. The findings that dysmenorrhea has such a profound impact on an adolescents psychological well-being can potentially be explained from a self-determination theory (SDT) (Deci & Ryan, 2008) perspective. When exploring the experiences of adolescents through qualtaitive interviews (Chapter 5), it was clear that dysmenorrhea, like other chronic pain conditions, posed challenges to adolescents' meeting their three innate psychological needs. These needs, as outlined in Chapter 2, include competence, autonomy, and psychological relatedness. Satisfaction of these key psychological needs has been found to be associated with childhood and adolescent well-being. Being unable to meet any of these individual key psychological needs has been associated with increases in depressive symptoms and decreases in well-being (Veronneau, Koestner, & Abela, 2005).

8.1.6 Dysmenorrhea and Pain Catastrophising

Almost all of the adolescent girls in Chapter 5 reported feeling anxious and helpless in relation to their menstrual pain. Many described having 'catastrophizing' thoughts while experiencing period pain. For example, some girls were concerned that menstrual pain was not 'normal' and were anxious that there might be a more sinister, pathological cause to this pain. Catastrophizing is a pain-specific psychosocial construct comprised of negative cognitive and emotional processes such as helplessness, pessimism, rumination about pain-related symptoms, and magnification of pain reports (Edwards, Cahalan et al. 2011). Previous research suggests that pain catastrophizing can influence the development, maintenance, and magnification of chronic pain (Gatchel et al., 2007). Evidence from the wider paediatric chronic pain literature indicates that pain catastrophizing is one of many psychosocial factors that have been associated with increased somatic complaints, pain severity, disability, anxiety, and depression in clinical and community samples of children (Crombez et al., 2003; Eccleston et al., 2004). It is well established in the literature that anticipation and fear of pain can actually be more disabling than the pain itself, predicting emotional distress and physical disability (Crombez, Vlaeyen et al. 1999, Vlaeyen and Linton 2000). Pain catastrophising in response to a painful injury often leads an individual to experience both fear of pain and pain-related anxiety (Leeuw et al., 2007). This anxiety has the potential to spiral into a self-perpetuating cycle that results in avoidance, functional disability, depression and additional pain and catastrophizing (Asmundson et al., 2012). This has been supported in the paediatric chronic pain literature with greater pain catastrophizing in children being associated with more pain severity and disability, lower pain tolerance (Piira, Taplin et al. 2002, Crombez, Bijttebier et al. 2003), more anxiety and depression (Eccleston, Crombez et al. 2004), and increased analgesic use (Bedard, Reid et al. 1997). The final empirical study of this thesis found that pain catastrophizing was a significant predictor of HRQoL, independent of anxiety, depression, and family functioning, somatization among the sample. The study also found that pain catastrophizing mediated the relationship between usual pain intensity and HRQoL outcomes. However, in Chapter 5, levels of anxiety and depression were stronger predictors of HRQoL among participants than pain catastrophizing. This suggests that, unlike with other forms of chronic pain, emotional functioning is a greater predictor of HRQoL outcomes than pain catastrophizing in samples of girls experiencing dysmenorrhea. Negative affectivity and pain catastrophizing develop early in life and are often maintained throughout the lifespan (Brown, O'Keeffe et al. 1986). Previous research has shown that pain catastrophizing is a less stable characteristic than other traits (e.g., levels of anxiety and depression) (Sullivan, Bishop et al. 1995). Therefore, pain coping strategies are more easily changeable, indicating that pain catastrophizing is a potentially important factor to target in future interventions. The way in which pain catastrophizing can develop though parental responses as posited in family-based theories of pain to pain is discussed in section 8.1.8 below.

8.1.7 Dsymenorrhea and Somatisation

Evidence from the systematic review (chapter three) indicated that dysmenorrhea was associated with somatisation (Goldstein-Ferber & Granot, 2006; Rapkin et al., 2006). Adolescents from chapter five described many symptoms other than pain including loose bowels, mood swings, bloating, headaches/migraines, acne, nausea, vomiting, loss of appetite, fatigue, muscle aches, hunger, breast pain, dry hair and skin, body odour, back ache, sweating, dizziness, and feeling generally unwell. Somatization was the strongest predictor of HRQoL when controlling for the other psychosocial variables. A significant, negative correlation was found between somatization and HRQoL. This supports findings from the literature that somatization is associated with higher levels of functional disability (Campo, Jansen-McWilliams, Comer, & Kelleher, 1999; Harris, Orav, Bates, & Barsky, 2009; Hyphantis et al., 2009; Walker, Garber, Van Slyke, & Greene, 1995). For example, Campo and colleagues (1999) showed that children with high levels of somatization had poorer health, greater health limitations, and poorer school performance and attendance than children with low levels of somatisation. Moreover, Mahrer (2012) found that, among both children and adolescents, although somatization was significantly and positively related to pain intensity, somatization significantly predicted HRQOL over and above pain. A key finding of the final empirical study of this thesis was that anxiety mediated the relationship between somatisation and HRQoL outcomes. This findings reflects the biopsychosocial models of paediatric chronic pain that an individual's pain experience isn't down to just one factor. Instead, pain-related outcomes are a result of an interrelation between biological, social and psychological factors.

8.1.8 Dysmenorrhea and Family functioning

The McMaster model of family functioning (Epstein, Bishop, & Levin, 1978) emphasizes the importance of considering an individuals' behaviour within the context of their family situations. From the perspective of family systems models such as this, an adolescent's response to dysmenorrhea needs to be considered within the context of the family environment. The findings, along with the findings from the systematic review, support key aspects of family-based biopsychosocial models presented in Chapter 2. The findings from Chapter 6 emphasise the importance of the family in relation to adolescents' experience of, and response to pain. As outlined in Palermo and Chamber's (2005) integrative model of parent and family factors in paediatric chronic pain and associated disability, these interactions can occur at individual, dyadic and family levels. This was demonstrated by the findings in this thesis. For example, from an individual level, many adolescents reported feelings of anxiety, low mood and helplessness. At a dyadic level, many adolescents relied heavily upon their mothers as their only source of comfort and support while they were menstruating. This had a profound emotional impact on their mothers at an individual level. Finally, the emotional impact of adolescent dysmenorrhea on girls' mood, and that of their mothers, seemed to have an impact on family functioning as a whole. Reports from both the adolescents and their mothers indicated that tensions and conflict often arose within the family and this was attributed to dysmenorrhea and associated symptoms.

Adolescence is a time of considerable behavioural, cognitive, and physiological development whereby new behaviours which may last into adulthood can easily be learned (Blakemore, 2019; Blakemore & Choudhury, 2006). These are foundational years whereby much of an individuals' health behaviours are decided (Lloyd, 2007; Patton et al., 2016). The way in which adolescents manage their menstrual pain during adolescence may have a long-lasting impact on the way in which they manage dysmenorrhea and any future instances of chronic or recurrent pain. It is therefore crucial to understand how adolescents are managing dysmenorrhea. This study has identified some key influences on how adolescents manage their period-related pain. For example, in the first empirical study of this thesis, help-seeking behaviours for period pain seemed to be heavily influenced by gender and whether or not girls perceived menstruation to be ‘taboo’. Gender played a key role in the girls’ help-seeking behaviours, all of whom preferred to discuss menstrual issues including dysmenorrhea with women rather than men. Many of the girls in this study felt too embarrassed to talk to a man about menstruation, indicating that the topic is still relatively taboo. This finding seems to be specific to dysmenorrhea, as many of the girls reported that they wouldn’t seek help from fathers or male friends because men/boys were unable to relate to this specific type of pain. Another explanation for dysmenorrhea being perceived as am embarrassing topic may be due to key developmental changes during adolescence including dramatic changes in identity, self-consciousness, and cognitive flexibility (Rutter & Rutter, 1993).

Adolescent dysmenorrhea can have a significant impact on family functioning and communication. This relationship however, can be bidirectional as poor family functioning can be associated with increased disability and increased likelihood that chronic pain would continue throughout childhood and adolescence, and into adulthood (Wickrama, Conger, Wallace, & Elder Jr, 2003). Family functioning is thought to negatively influence paediatric chronic pain outcomes, over and above pain intensity (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). Lower levels of family functioning (e.g., high levels of conflict and lower levels of adolescent autonomy have been associated with limitations in functioning and increased levels of depression (Lewandowski & Palermo, 2009; Palermo, Putnam, Armstrong, & Daily, 2007). A key finding from the second empirical study in this thesis was also that there are clear differences between mothers in how they responded to their daughters’ pain. Mothers who reported feeling distressed when their child experienced menstrual pain also reported instances of pain catastrophizing. Parental pain catastrophizing is often associated with paediatric pain catastrophizing and there is a bidirectional relationship between pain catastrophizing, pain and disability, and health-related quality of life outcomes (Tran et al., 2015). Mothers’ in Chapter 6 seemed to respond to their daughter’s pain two distinct ways. Some would encourage their daughters to engage in their usual daily activities, despite pain. In contrast, others would take a more sympathetic and protective approach, permitting, and possibly reinforcing, the avoidance of activities such as school. Previous research into the operant model of pain posits that parental responses to a child’s pain can either negatively or positively reinforce increased pain behaviours (e.g., taking time off of school) (Turk et al., 1987). These mothers expressed distress at seeing their daughter in pain, which may have elicited what could be seen as ‘over protective’ responses (Caruso, Grolnick, Rabner, & Lebel, 2019). Parental responses to pain have been shown to influence children’s pain responses and pain-related disability. Social reinforcement includes parental behaviours (e.g., over protective responses) that may inadvertently reinforce maladaptive pain behaviours and coping mechanisms. These can include avoidance of activities (e.g., avoiding school) and pain catastrophizing (Walker, Baber, Garber, & Smith, 2008).

From a social learning theory perspective, through observation and modelling, children can learn to catastrophise about pain from their parents. Paediatric pain catastrophising is also related to maladaptive coping strategies, including the avoidance of activities such as school (Simons, Sieberg, Carpino, Logan, & Berde, 2011). This may be because adolescent girls may then adopt these pain-related catastrophic thoughts as their own. Some mothers in Chapter 6 who were more sympathetic also reported instances of pain catastrophizing. This included concerns that their daughters' period-related pain and accompanying symptoms (e.g., heavy blood flow) had a sinister underlying pathological cause. Previous research has suggested that both positive (provision of emotional support) and negative (punishing) parental responses (Vervoort, Eccleston, Goubert, Buysse, & Crombez, 2010) to their children's pain has been associated with children pain catastrophizing themselves which is associated with greater pain and disability (Sullivan et al., 1995). Pain catastrophizing was not unique to the mothers' reports, this was also found in the adolescent interviews in chapter 5. Both mothers and adolescents reported concern and confusion about certain menstrual-related issues including whether or not severe dysmenorrhea indicated underlying pathological cause.

Self-determination theory (SDT) (Deci & Ryan, 2008) can also provide a biopsychosocial perspecive on adolescent pain behaviours and how family responses could support adolescents to cope with dysmenorrhea. From an SDT perspective (Deci & Ryan, 2008), there are various types of motivation for engaging in health behaviours such as effective pain management including the most autonomous form of self-regulation, identified regulation whereby individuals engage in behaviour out of personal value or perceived importance. This theory posits that individuals' behaviours become increasingly self-regulated through the process of internalisation, during which individuals move from regulating their behaviour due to external factors to more autonomous regulation. Internalisation can be facilitated by parental responses to pain but they can also be discouraged by with parental protectiveness. Parental responses to adolescent dysmenorrhea can therefore be an important influence towards effective self-management.

Although the qualitative studies found that family functioning was perceived as a key factor associated with adolescent dysmenorrhea, this was not supported by the findings of the final empirical study of the thesis. When controlling for levels of anxiety and depression, catastrophizing, and pain severity, family functioning was not significantly correlated with HRQoL. Family functioning was therefore not found to be independently associated with variance in

HRQoL. This is consistent with the finidings from study conducted last year (Cordts et al., 2019) which assessed a unified family-based biopsychosocial model of paediatric chronic pain. They found that parental factors were not associated with paediatric pain outcomes (chronic pain severity, disability, and psychological functioning. Therefore, although parents are often the immediate and most prominent form of social environment for children and adolescents, these findings did not support the hypothesis that family functioning is an important factor in influencing pain-related outcomes, when controlling for other psychosocial factors (Edwards, Dworkin et al. 2016; Barakat et al., 2008; King et al., 2011). However, it should be noted that as the 'general functioning' domain only of the Family Assessment Device (FAD-SF) was used to measure family functioning, it may be beneficial for future research to investigate whether other domains of family functioning are independently associated with HRQoL.

8.1.9 Limitations and Implications for Future Research

Not all limitations identified in the systematic review (Chapter 3) were addressed by the methodologies adopted in the three empirical studies of this research. For example, the systematic review showed that very few researchers had reported whether their participants had any underlying pelvic pathology. Of those that did (Frisk et al., 1965; Parker et al., 2010; Pitangui et al., 2013; Santina et al., 2012; Sanyal & Ray, 2008), there was no investigation into whether primary or secondary dysmenorrhea impacted on HRQoL differently. It was intended for this empirical study to address this. A subgroups analysis was to be conducted, comparing results between adolescents with primary and secondary dysmenorrhea. However, the sample size of participants in chapter seven who indicated a possible pelvic pathology were too few to conduct any subgroups analyses and we did not have sufficient power to compare adolescents with primary and secondary dysmenorrhea. Another limitation of the final empirical study is the observational, cross-sectional nature of the study design. Longitudinal analyses of adolescent girls before menarche through puberty would allow researchers to identify change in the psychosocial predictors over time, and how this change is associated with dysmenorrhea. In addition, a case control design would have allowed for a comparison between adolescents who experience no pain with those who experience pain. A case-control design could not be feasibly conducted at this time due to the limited number of adolescents who experienced no dysmenorrhea at all, and no accompanying menstrual symptoms.

Due to the findings in Chapter 5 and Chapter 6 that there was some secrey and stigma surrounding both menstruation and use of the contraceptive pill, future interventions could consider developing ways of helping all adolescents to feel comfortable discussing dysmenorrhea and the OCP. Information aimed towards for parents and daughters about the OCP could aim to reduce the stigma attached to taking the pill and its association with sexual activity. Increasing the proportion of girls and parents aware that OCP can be used to regulate periods and relieve menstrual pain could give girls and their mothers the opportunity to make an educated decision about its use. In addition, from the SDT perspective, the need for competence, relatedness and autonomy are key psychological needs (Deci & Ryan, 2008) appeared to be greatly challenged by adolescent dysmenorrhea. Therefore, future research could benefit from investigating ways in which the negative impact of dysmenorrhea on these key psychological needs might be improved. Possible approaches might be to engage both parents and adolescents in dysmenorrhea-related problem solving and decision making (Caruso et al., 2019).

Among the sample of adolescents in chapter seven, levels of anxiety influenced HRQoL outcomes via pain catastrophizing (see Figure 4). This supports the notion that psychological functioning can predict pain perception by influencing the way in which an individual thinks about their pain (Morrison & Bennett, 2009). Both pain catastrophizing (Vervoort, Goubert et al. 2005) and poor emotional functioning (Gauntlett-Gilbert & Eccleston, 2007; Walker & Greene, 1991) are associated with poor outcomes in relation to pain in children and adolescents. Therefore, future interventions should aim to improve emotional functioning and reduce pain catastrophizing among adolescents experiencing dysmenorrhea. A potential avenue for future interventions to reduce pain-related anxiety and pain catastrophizing would be to improve knowledge and understanding about adolescent dysmenorrhea. Another potential avenue could be to target maternal catastrophizing and maternal responses to adolescent dysmenorrhea. Although family functioning was not significantly associated with HRQoL outcomes in Chapter 7, family-based biopsychosocial models of paediatric chronic pain (see Chapter 2) posit that parental factors are an important influence on paediatric pain outcomes (Guite et al., 2018). Future research could benefit from using longitudinal methods to understand the bi-directional relationship between parental, family factors and adolescent dysmenorrhea over the course of adolescence (Palermo et al., 2014).

The research presented in this thesis is the first of its kind to identify that adolescent girls here in the UK are not prepared for, or expecting period-related pain, which often results in misconceptions about the causes of pain, limited knowledge about appropriate treatment, and in some cases anxiety about a potential pathological cause of pain. For example, almost all of the girls interviewed in chapter five did not know the cause of dysmenorrhea. One adolescent discussed her previous belief that there might be a sinister reason behind her pain. The majority of adolescents, although experiencing sometimes debilitating pain, did not know that the oral contraceptive pill could be used to reduce pain severity and menstrual flow. In addition, many mothers expressed concerns about the use of the term ‘contraceptive’ when the OCP was being used for dysmenorrhea or other menstrual issues. Another key finding from the qualitative data collected (chapter five and chapter six) was how much importance girls and mothers placed on their interactions with school staff about dysmenorrhea. Many girls reported feeling disbelieved and misunderstood as there was an assumption that they were lying about menstrual pain simply to get out of lessons. This has the potential to influence school performance as student-teacher relationships are associated with both student engagement and achievement. In addition, in six, mothers reported feeling frustrated that their daughters were disbelieved by their teachers. This fostered a lot of negative feelings between the school staff, girls and their mothers, resulting in some mothers taking their daughters out of school without permission. It is possible that structured education about dysmenorrhea may be useful in: i) reducing the occurrence of difficult encounters with school staff, ii) limiting misconceptions about dysmenorrhea, iii) improving communication between girls, their parents and school staff, and (iv) better prepare adolescents for menstruation. In addition, the findings indicated that parental responses were potentially important in adolescent pain outcomes. Interventions using the self-determination theory as a framework might target paretnal responses to adolescent menstrual related pelvic pain. In particular, these interventions might encourage engaging the adolescents in problem-solving and decision making in relation to their pain.

Not surprisingly, the qualitative data showed that many girls avoided engaging in physical education at school while menstruating. Other aspects of physical functioning, apart from PE, were also negatively impacted by dysmenorrhea including sleep disturbances and movement restrictions. Adolescence is a key time during which long-term health can be influenced due to physical (including pubertal) development, and as cognitive functioning is changing (due to increased neuroplasticity) and developing at a quick rate (Patton et al., 2016). Adolescents’ psychosocial worlds are also changing and becoming more complex. This is therefore a time of transition whereby lifelong health behaviours are consolidated (Patton et al., 2016). Despite effecting up to 92% of adolescent girls and having a negative impact on physical functioning, interventions aimed at improving physical activity in adolescence has not taken dysmenorrhea into consideration. Therefore, this is a potential area for intervention, particularly at a time when adolescent obesity is at global epidemic status (Lobstein et al., 2015). Adolescents reported a variety of reasons for avoiding exercise during menstruation including: i) not knowing that exercise can help reduce pain symptoms, ii) fears of increasing flow through movement and leaking menstrual period, and iii) feeling unclean when unable to wash after PE lessons at school. Interventions that improve knowledge and understanding among adolescents, parents and school staff about dysmenorrhea, girls' reasons for avoiding exercise during menstruation and the potential benefits of exercise for relieving pain may improve physical functioning among adolescents with dysmenorrhea.

In addition to an educational intervention, distraction and relaxation techniques may work by targeting the psychosocial predictors of HRQoL among adolescents in chapter seven. Somatisation predicts HRQoL among the adolescents in our sample. This may be because increased focus on pain sensations tends to increase pain perception. Distraction techniques may be a simple and feasible way of improving pain severity and pain-related distress (Birnie et al., 2014). One systematic review of twenty-six randomized controlled trials examining the effects of distraction (e.g., watching television or playing video games) in 2,548 children aged 2–19 years found that distraction is a highly used and investigated psychological intervention for managing pain and distress during a variety of medical procedures, including needles, across a range of health care settings (Birnie, Noel et al. 2014). The use of distraction techniques may significantly reduce an individual's perception of painful experiences. In one study, using the cold pressor test, participants were asked to focus on either the pain sensations or a computer task (James & Hardardottir, 2002). Those who were focussing on the computer task were able to tolerate the cold pressor test for significantly longer than those who were asked to focus on the pain. Several adolescents in chapter five reported already using distraction techniques to reduce pain severity. Distraction could therefore be a simple and effective way of improving pain-related outcomes. Relaxation is another relatively simple way of reducing stress, anxiety, and maladaptive (e.g., catastrophising) thoughts among adolescents experiencing pain. Relaxation techniques include teaching individuals to relax muscles throughout the body by tensing and relaxing each individual muscle group. Sometimes relaxation techniques also include guided imagery, which may also serve as a distraction (Fisher et al., 2014). Relaxation techniques may address levels of anxiety and depression, and pain catastrophizing predictors of HRQoL among our sample.

A multicomponent, school-based intervention targeting adolescents, parents, and school staff could address each of the psychosocial predictors of HRQoL in adolescent dysmenorrhea (somatisation, levels of anxiety and depression, and pain catastrophizing) as well as issues raised in the qualitative studies (e.g., misconceptions and lack of knowledge about dysmenorrhea, difficult interactions with school staff). Further formative work could also be conducted to explore adolescents' perceptions of different types of interventions and to identify the ways in which we could engage (and sustain engagement) them in a participating in an intervention about dysmenorrhea. Adolescents are notoriously difficult to engage in research (Barker & Weller, 2003); a key example of which being that the recruitment was particularly slow for this thesis.

Future researchers may benefit from using creative methods such as vignettes, photographs, games, and Photovoice to enhance youth engagement (Barker & Weller, 2003; Wilson et al., 2007). In addition, including adolescents in each stage of the intervention design and development via online surveys, focus groups, and interviews may also facilitate engagement with the intervention (Wilson et al., 2015). Successful interventions will to aim to improve knowledge and understanding of the aetiology, characteristics and management of dysmenorrhea, teach skills and techniques to reduce levels of anxiety and depression, and support adolescents to cope with dysmenorrhea. The overarching goal of intervention development must be to reduce the negative impact of adolescent dysmenorrhea on HRQoL.

In conclusion, dysmenorrhea had a profound, negative impact on all aspects of life for adolescents and their families, living in England, the UK. The three empirical studies presented in this thesis are the first to investigate the impact of dysmenorrhea on the HRQoL of adolescent girls living in England. Two qualitative studies were conducted with 20 adolescents experiencing dysmenorrhea and 20 mothers of a daughter experiencing dysmenorrhea. These empirical studies found that dysmenorrhea had a negative impact on all aspects on the lives of the adolescent girls and their mothers. The final empirical study collected data from 333 adolescent girls and found that somatisation, anxiety, depressive symptoms, usual pain severity and pain-catastrophizing significantly predict HRQoL outcomes among adolescent experiencing dysmenorrhea. A working model (see Figure 4) has been developed whereby psychological functioning (levels of anxiety and depression), somatisation, pain coping (pain catastrophizing), and usual pain severity predict HRQoL outcomes among adolescents experiencing dysmenorrhea. Future research may benefit from further testing of the working model including comparisons with other biopsychosocial models of paediatric chronic pain; which can then be used to develop effective interventions to improve the quality of life for adolescents experiencing dysmenorrhea. Although family functioning was not significantly associated with adolescent HRQoL in Chapter 7, the qualtaitive findings in Chapter 5 and Chapter 6 indicate that the family play an important role in adolescents' management of dysmenorrhea. Family-based biopsychosocial models of paediatric chronic pain also highlight the importance of interations between family (at three levels: individual, dyadic and family), biological, psychological and social factors, and paediatric pain (Palermo & Chambers, 2005). Finally, future research projects could consider further exploration or investigation of several other key findings: 1) The ‘secrey’ surrounding menstruation due to embarrassment and the adolescents’ clear preference for discussing menstruation and the OCP with girls or women; and 2) Maternal responses to adolescent dysmenorrhea and how that influences adolescents’ responses and pain coping and/or management.

Appendix A Search terms

Population	Adolescent(s); adolescence; paediatric; pediatric, young females; school girls
Condition	Dysmenorrhea; endometriosis; menstrual disorders; pelvic pain; chronic pelvic pain; menstrual cycle; period pain; painful menstruation
Outcome	Quality of life; health-related quality of life; QoL; HRQoL; well-being; family functioning; school functioning; school absence; school attendance; academic performance; social isolation; social functioning; emotional functioning; depression; anxiety; affect; mood; disability; peer relationships

Appendix B Search strategy

Search: CINAHL (via EBSCO), filtered by English Language and Date (1960-2014)

S1: adolescen* S2: child

S3: paediatric*

S4: pediatric*

S5: “young females”

S6: “school girls”

S7: S1 OR S2 OR S3 OR S4 OR S5 OR S6

S8: dysmenorrh*

S9: endometriosis

S10: “menst* disorders”

S11: “pelvic pain”

S12: “chronic pelvic pain”

S13: “menstrual cycle”

S14: “period pain”

S15: “painful mens*”

S16: S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

S17: “quality of life”

S18: “health-related quality of life”

S19: “QoL”

S20: “HRQoL”

S21: “well-being”

S22: “family function*”

S23: “school function*

S24: “school absen*”

S26: “school attendance”

S27: “academic performance”

S28: “social isolation”

S29: “social function*”

S30: “emotional function*”

S31: “physical function*”

S32: “psychological function*”

S33: depress*

S34: anxiety

S35: affect

S36: mood

S37: disab*

S38: “peer relationships”

S39: S17 OR S18 OR S19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30

OR 31 OR 32 OR 33 OR 34 OR 35 O5 36 OR 37 OR 38

S39: S7 AND S16 AND S39

Search: MEDLINE (via EBSCO) filtered by English language and date (1960-2014) S1: child

S2: adolescen*

S3: paediatric*

S4: pediatric*

S5: “young females”

S6: “school girls”

S7: S1 OR S2 OR S3 OR S4 OR S5 OR S6

S8: dysmenorrh*

S9: endometriosis

S10: “menst* disorders”

S11: “pelvic pain”

S12: “chronic pelvic pain”

S13: “menstrual cycle”

S14: “period pain”

S15: S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14

S16: “quality of life”

S17: “health-related quality of life”

S18: “QoL”

S19: “HRQoL”

S20: “well-being”

S21: “family function*”

S22: “school function*”

S23: “school absen*”

S24: “school attendance”

S25: “academic performance”

S26:“social isolation”

S27: “social function*”

S28: “emotional function*”

S29: “physical function*”

S30: “psychological function*”

S31: depress*

Appendix B

S32: anxiety

S33: affect

S34: mood

S35: disab*

S36: “peer relationships”

S37: S16 OR S17 ORS18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36

S38: S7 AND S15 AND S37

Search: EMBASE (via ovid) filtered by English language and Date (1960-2014).

1. Adolescen*.mp.
2. Child.mp.
3. Paediatric*.mp.
4. Paediatric*.mp.
5. (young adj females).ti,ab.
6. (school adj girls).ti,ab.
7. 1 or 2 or 3 or 4 or 5 or 6
8. Dysmenorrh*.mp.
9. Endometriosis.mp.
10. (menst* adj disorders).ti,ab.
11. (pelvic adj pain).ti,ab.
12. (chronic adj pelvic adj pain).ti,ab.
13. (menstrual adj cycle).ti,ab.
14. (Period adj pain).ti,ab.
15. (painful adj mens*).ti,ab.

16. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15

17. (quality adj of adj life).ti, ab.

18. (health adj related adj quality adj of adj life).ti, ab

19. QoL.mp.

20. HRQoL.mp.

21. (well adj being).ti,ab.

22. (family adj function*).ti,ab

23. (academic adj achievement).ti,ab 24. (school adj function*).ti,ab

25. Absenteeism.mp.

26. (school adj absen*).ti,ab

27. (school adj attendance).ti,ab

28. (academic adj performance).ti,ab

29. (social adj isolation).ti,ab

30. (social adj function*).ti,ab

31. (emotional adj function*).ti,ab

32. (physical adj function*).ti, ab 33. (psychological adj function*).ti,ab

34. Depress*.mp.

35. Anxiety.mp.

36. Mood.mp. 37. Affect.mp.

38. Disab*.mp.

39. (peer adj relationships).ti,ab

40. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39

41. 7 and 16 and 40

Search: PsychINFO (via EBSCO) filtered by English language and date (1960-2014)

Appendix B

S1: adolescen* S2: child

S3: paediatric*

S4: pediatric*

S5: “young females”

S6: “school girls”

S7: S1 OR S2 OR S3 OR S4 OR S5 OR S6

S8: dysmenorrh*

S9: endometriosis

S10: “menst* disorders”

S11: “pelvic pain”

S12: “chronic pelvic pain”

S13: “menstrual cycle”

S14: “period pain”

S15: “painful menst*”

S16: S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

S17: “quality of life”

S18: “health-related quality of life”

S19: QoL

S20: HRQoL

S21: “well-being”

S22: “family function*”

S23: “school function*”

S24: “school absen*”

S25: “school attendance”

S26: “academic achievement”

S27: “social isolation”

S28: “emotional function*”

S29: “social function*”

S30: “physical function*”

S31: “psychological function*”

S32: depress*

S33: anxiety

S34: mood

S35: affect

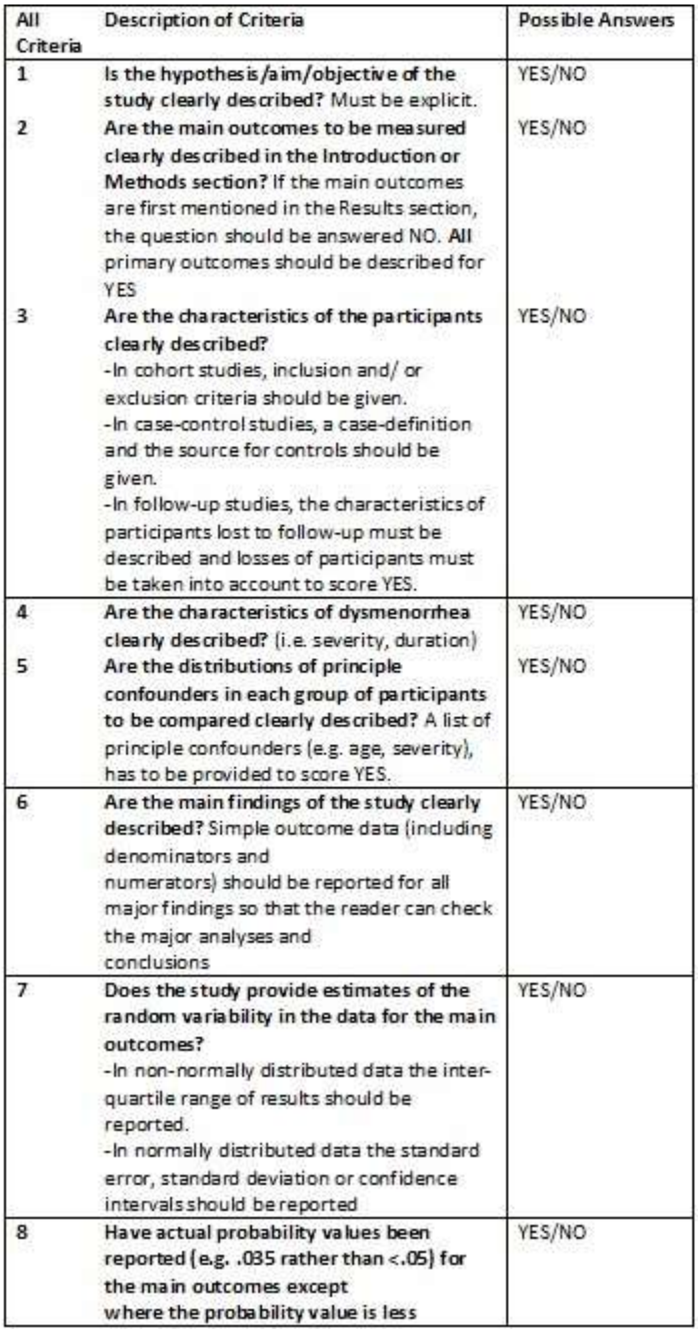
S36: disab*

S37: “peer relationships”

S38: S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37

S39: S7 AND S16 AND S38

Appendix C Quality Assessment Checklist



All Criteria	Description of Criteria	Possible Answers
1	**Is the hypothesis/aim/objective of the study clearly described?** Must be explicit.	YES/NO
2	**Are the main outcomes to be measured clearly described in the Introduction or Methods section?** If the main outcomes are first mentioned in the Results section, the question should be answered NO. **All** primary outcomes should be described for YES	YES/NO
3	**Are the characteristics of the participants clearly described?** -In cohort studies, inclusion and/ or exclusion criteria should be given. -In case-control studies, a case-definition and the source for controls should be given. -In follow-up studies, the characteristics of participants lost to follow-up must be described and losses of participants must be taken into account to score YES.	YES/NO
4	**Are the characteristics of dysmenorrhea clearly described?** (i.e. severity, duration)	YES/NO
5	**Are the distributions of principle confounders in each group of participants to be compared clearly described?** A list of principle confounders (e.g. age, severity), has to be provided to score YES.	YES/NO
6	**Are the main findings of the study clearly described?** Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions	YES/NO
7	**Does the study provide estimates of the random variability in the data for the main outcomes?** -In non-normally distributed data the inter-quartile range of results should be reported. -In normally distributed data the standard error, standard deviation or confidence intervals should be reported	YES/NO
8	**Have actual probability values been reported (e.g. .035 rather than <.05) for the main outcomes except where the probability value is less**	YES/NO

Scoring: Scores will be separated into three categories.

Scores:

YES=1

NO DATA DREDGING=1

NOT APPLICABLE=0

Appendix C

NO=0

UTD=0

Reporting: Scores from questions 1-8

External validity and bias: Scores from questions 9-15

Appendix D Descriptive Tables

Appendix D

Study	**Aims/Objectives**	**Participant characteristics**	**Measures**	**Results**
Pitangui et al. (2013)	To: a) Identify the prevalence and characteristics of adolescent menstrual disturbances. b) Determine the effect of adolescent menstrual disturbances on activities of daily living (ADLs).	205 adolescent school girls (12-17years) from one school in Brazil. Mean age: 13.65 years (+/- 1.45 years).	Menstrual and dysmenorrhea characteristics: specifically developed questionnaire administered by trained interviewer. Menstrual pain severity: 11-point numeric rating scale (NRS) 0=no pain, 10 the worst pain one can imagine (Ana Carolina Rodarti Pitangui, de Sousa, Gomes, Ferreira, & Nakano, 2012). Effect of menstruation disturbances on ADLs: 11-point NRS, 0= does not affect-7-10, clearly inhibiting ADLs.	174 girls had begun menarche. Dysmenorrhea: n=127 (72.99%). Pain intensity: Mild: n=13 (10.24%). Moderate: n=48 (37.80%). Severe: n=66 (51.97%). *Absenteeism* 39 (30.71%) school absenteeism due to menstrual pain. *Interference in ADLs* 43 (33.86%) reported no interference. 66% reported some interference. Specifically: 47 (37.01) low interference. 21 (16.53%) significant interference. 16 (12.60%) incapacitating interference. Associations between variables: Pain severity was significantly associated to : School absenteeism (X^2= 11.38, *p*=.003), interference with ADLs (X^2= 37.85, *p* <.001), seeking medical care (X^2= 7.60, *p*=.02), and use of medications (X^2= 8.65, *p*=.013). Affected ADL were significantly associated to school absenteeism (X^2= 30.56, *p*<.001.
Eryilmaz et al. (2010)	To determine: a) The prevalence of dysmenorrhea in adolescents	1951 adolescent girls (13-18 years) who had begun menarche, from one school in Turkey.	Characteristics of dysmenorrhea: Self-administered 20- item questionnaire.	Dysmenorrhea: n= 1408. *Pain severity* A little bit: n=191 (13.6%).

b)	The effect of dysmenorrhea on school performance and relationships with family and friends.	Mean age: 16.0 years (±1.1 years).	Severity of dysmenorrhea: Facial Pain Rating Scale (Hicks et al., 2001).	A little bit more: n=532 (37.8%). Even more: n=400 (28.4%). A whole lot more: n=130 (9.2%). The worst: n=155 (11%). *Impact of dysmenorrhea on HRQoL* *<u>School performance:</u>* 784 (55.7%) reported that school performance was affected by menstrual pain. Specifically: 210 (18.6%) school absenteeism. 564 (50%) lack of focus on the content of the courses. 51 (4.5%) missing exams. 304 (26.9%) not being able to answer questions in exams despite having the knowledge. *<u>Relationships with family:</u>* 448 (31.8%) relationships with family had been affected by menstrual pain. Specifically: 354 (77.3%) problems with family. 66 (14.4%) living apart from family. 38 (8.3%) not fulfilling family responsibilities. *<u>Relationships with friends:</u>* 452 (21.1%) reported effects of menstrual pain on relationships with friends. Specifically: 176 (37.2%) unwilling to talk. 262 (55.4%) irritable. 35 (7.4%) not comfortable. Associations: Pain duration was significantly positively associated with education (X^2=28.6, *p*<0.0001), relationships with family (X^2=

				15.7, *p*<0.001), and relationships with friends (X^2= 21.5, *p*<0.0001). Pain severity was significantly positively associated education (X^2= 221.3, *p*<0.001), relationships with family (X^2= 78.6, *p*= 0.0001), and relationships with friends (X^2= 87.9, *p*= <0.0001).
Banikarim et al. (2000)	To determine the prevalence, management and impact of dysmenorrhea on school attendance, academic performance, and social and sport activities.	Conflicting reports of participant numbers (760, 706, 740). Hispanic girls from one School in America. Mean age: 16 years (±1.4 years).	Severity and impact of dysmenorrhea on academic performance, school attendance, and sports and social activities: 31-item questionnaire designed specifically for the purposes of the study. Menstrual pain: Visual Analogue Scale dividing pain into mild, moderate and severe (McDowell & Newell, 1996).	Dysmenorrhea: 85% Pain intensity: Mild: n=138 (25%). Moderate: n=183 (33%). Severe: n=234 (42%). *Impact of Dysmenorrhea* *Dysmenorrhea had a negative impact on:* Class concentration (59%), daily chores (56%), sports participation (51%), class participation (50%), going out with friends (46%), taking tests (36%), homework (35%), grades (29%), missing school days (38%), missing individual school classes (in past 3 months) (33%). *Of those reporting school absence:* 46% missed ½ - 1 day, 36% missed 2-3 days, 18% missed >4 days. *The impact of mild, moderate and severe menstrual pain* 52% of girls with severe pain reported absenteeism compared to 20% with mild pain, 67% of those reporting vomiting and 60% of those reporting diarrhoea. Girls with mild pain reported that dysmenorrhea impacted on school absence (20%), homework (20%), class participation (35%), class concentration (41%), taking tests (20%), sports participation (40%), and going out with friends (28%). Compared to those with mild menstrual pain, those with moderate pain reported:

				Significantly greater: school absence (%=33, OD=1.9, CI=0.97-3.8, *p*=.01) and impact on going out with friends (%=44, OD= 2.0, CI= 1.1-3.8, *p*=.003). No significant difference in homework (%=31, OR=1.8, CI=0.91-3.6, *p*=0.03), class participation (%=44, OR= 1.5, CI=0.80-2.7, *p*=.11), class concentration (%=54, OR= 1.7, CI= 0.93-3.0, *p*=.02), in taking tests (%=31, OR= 1.9, CI= 0.93-3.7, *p*=0.02), in sports participation (%= 48, OR= 1.4, CI= 0.78-2.5, *p*=.14). Compared to those with mild pain, those with severe pain reported: Significantly greater: school absence (%=52, OR=4.3, CI= 2.3-8.1, *p*=.001), impact on homework (%=48, OR= 3.6, CI= 2.0-6.4, *p*=.001), impact on class participation (%=65, OR= 3.4, CI= 1.9-6.1, *p*=.001), impact on class concentration (%=76, OR= 3.9, CI= 2.2, 7.1, *p*=.001), impact on taking tests (%=49, OR= 4.0, CI= 2.1-7.6, *p*=.001), and impact on sports participation (%= 60, OR= 2.2, CI= 1.3-4.0, *p*=.001).
Nur Azurah et al. (2013)	To examine the impact of menstrual problems on adolescents QoL, and to identify factors that have an impact on their QoL.	184 post-menarchal adolescents (12-18 years) attending a gynaecology clinic in Australia for menstrual disorders. Mean age: 15.10 years (+/- 1.49 years).	Quality of life (QoL): Pediatric Quality of life-Teen Report 13-18 (PedsQL-Teen Report) (Varni et al., 2003). Parental bonding: The parental bonding instrument (PBI) (Parker, 1988). Presence of Menorrhagia: Menorrhagia questionnaire. Parents answered questionnaires from the SSF 12v2 health survey and the	*Menstrual disorders* *Heavy menstrual bleeding: n=62* *Amenorrhea: n=15* *Oligomenorrhea: n=36* *Dysmenorrhea: n=71* *Impact of different menstrual disorders on HRQoL* *PedsQL scores:* No significant differences between different menstrual problems within all 4 domains. Dysmenorrheic girls reported lower: Physical (70.79) and school functioning (56.41) (This was not significant). *Overall PedsQL scores for girl's with menstrual problems:*

			Kessler Psychological distress scale.	Lower than adolescents with cystic fibrosis and adolescents from the ‘health of young Victorian study’.
Teperi and Rimpelä (1989)	To: a) Study the occurrence of menstrual pain and its effect on the everyday life in a representative sample of Finnish adolescents. b) A comprehensive set of factors (physiological phenomena, socio-economic status, other socio-demographic factors, self-rated health, various health practices) were viewed in relation to menstrual pain in 16 year old girls.	3370 post menarchal, Finnish adolescents (12-18 years). *Age Cohorts:* 12 years: n=486 14 years: n=559 16 years: n=1155 18 years: n=1170	Health, menstrual pain intensity, physical maturation, menstrual characteristics, health practices, demographic information: Postal questionnaire as part of larger study.	*Pain intensity:* Mild pain: 5% (age 12), 12% (age 14), 23% (age 16), and 23% (age 18). Severe pain: 43% (age 12), 49% (age 14), 54% (age 16), 56% (age 18). No pain: 52% (age 12), 39% (age 14), 23% (age 16), 21% (age 18). *Impact of dysmenorrhea on school absenteeism* *Absent ‘often’:* 1% of 12 year olds, 3% of 14 year olds, 5% of 16 year olds, and 4% of 18 year olds. *Absent ‘once’:* 5% of 12 year olds, 9% of 14 year olds, 16% of 16 year olds, and13% of 18 year olds. *Pain severity and absenteeism (16 year olds):* 54% with severe pain had stayed at home due to pain compared with 15% with mild pain. *Associations:* Poor physical condition (X2=17.83, *p*<0.001), several colds in the last 6 months (X2=9.06, *p*<.05), and rarely or never feeling active in the morning (X2=11.30, *p*<.05) was significantly positively associated with severe menstrual pain. Satisfactory/ poor physical health and sleeping disorders were non-significantly associated with severe menstrual pain. *Predictors of severe menstrual pain:* Gynaecological age, consumption of alcohol and duration of menstrual flow followed by physical condition, number of common colds, and physical activity.

Wijesiri and Suresh (2013)	To assess knowledge and attitudes toward dysmenorrhea among adolescent girls in an urban school in Sri Lanka.	200 year 12 students (17-18 years) from one Urban school in Sri Lanka in the following study streams: Bioscience, combined mathematics, arts, and commerce.	Demographic information, menstrual characteristics, menstruation-associated problems, and attitudes towards menstrual pain: Specifically developed, 20-item questionnaire using conceptual framework developed by the authors.	Dysmenorrhea: n= 168 (84%). *Pain intensity:* Moderate: 59% Severe: 14% *Impact of menstrual pain* School absence due to menstrual pain= 44% 'Frequent' absence= 17% 96 (66.2%) felt 'mentally affected'. Social status affected in 44%. *Associations* Statistically significant association between menstrual pain and mental status (X2=5.132, *p*<0.03). No significant association between menstrual pain and physical status (*P* = 0.887), and social status (no value given).
Hillen et al. (1999)	To explore the prevalence of dysmenorrhea in girls in their final 2 years of secondary school, to assess its impact, and determine their knowledge and use of effective treatment.	388 girls (15-17 years) in grades 11 and 12 from three Australian secondary schools.	Frequency and severity of symptoms, symptom management, impact on school, sport and social activities, and treatment/ medication knowledge: Specifically designed questionnaire.	384 girls had begun menarche. Dysmenorrhea: n=309 (80%). *Impact of dysmenorrhea on HRQoL* *Limited activities:* 162 (52%) reported limited activities. Specifically: School activities (45%), sporting activities (48%), and social limitations (46%). *Duration of activity limitations:* <24 hours=48% 48 hours=18%

Poureslami and Osati-Ashtiani (2002)	To assess the knowledge, attitudes and behaviour pattern of young female students in suburban districts of Tehran about dysmenorrhea and menstrual hygiene.	250 female students (15-18 years) from 20 high schools in Tehran, Iran.	Pain management knowledge and impact of pain on daily activities and school absenteeism: 44-item questionnaire specifically designed for the study.	Dysmenorrhea: n=178 (71%). *Impact of dysmenorrhea on HRQoL* 38 (15%) school/activity absenteeism due to menstrual pain (duration=1-7 days in past school year). Girls reported: Becoming a recluse (49%), suffering nervousness (52.5%), becoming shy (52%), and avoiding physical activity during their period (33%).
Strinić et al. (2003)	To examine the prevalence of dysmenorrhea in female adolescents and the influence of anthropological characteristic and lifestyle factors on menstrual pain.	297 girls from ‘several’ schools in Croatia (11-18 years).	Menstrual pain, demographic and clinical characteristics, menstrual characteristics, smoking, sexual activity, and missing activities and treatments related to pain: Questionnaire administered by an interviewer.	Dysmenorrhea: n=164 (55%). *Impact of dysmenorrhea on HRQoL* 9% reported missing ‘any activity’, 22% had missed school and 4% had stayed in bed because of pain.
El-Gilany et al. (2005)	To estimate the prevalence of dysmenorrhea and to study its determinants and impact as well as treatment practices among adolescent students in Mansoura, Egypt.	664 adolescent students from ‘several schools’ in Egypt (14-18 years). Mean age: 15.5 years (+/- 0.99 years).	Demographic information, menstrual characteristics, dysmenorrhea characteristics, impact of menstrual pain on daily activities, and treatments used: self-administered questionnaire.	Prevalence of dysmenorrhea= 74.6%. Pain intensity: Mild: n=265 (55.3%). Moderate: n=143 (30%). Severe: n=71 (14.8%). *Impact of dysmenorrhea on HRQoL* *Daily home chores:* 205 (42.8%) girls reported that it impacted on daily chores. Specifically: 73 (27.5%) with mild, 72 (50.3%) with moderate, and 60 (84.5%) with severe pain. X2=79.0 *Going out of the home:*

199 (41.5%) girls reported impact on whether they went out of the home including:

60 (22.6%) with mild, 71 (49.7%) with moderate, and 68 (95.8%) with severe pain.

X2=128.6

Social events:

187 (39%) of girls reported it affected participation in social events.

Specifically:

51 (19.2%) with mild, 66 (46.2%) with moderate, and 70 (98.6%) with severe pain.

X2=152.5

Sports:

165 (34.4%) girls reported that it affected their participation in sports.

Specifically:

47 (17.7%) with mild, 49 (34.3%) with moderate, and 69 (97.2%) with severe pain

X2=156.5

Class concentration:

117 (24.4%) of girls reported an impact on their class concentration.

Specifically:

28 (10.6%) with mild, 32 (22.4%) with moderate, and 57 (80.3%) with severe pain.

X2=147.9

Homework tasks:

103 (21.5%) girls reported that their homework tasks were affected.

				Specifically: 16 (6%) with mild, 38 (26.6%) with moderate, and 49 (69%) with severe pain. X2=134.7 School attendance: 97 (20.3%) girls reported that their school attendance was affected. Specifically: 13 (4.9%) with mild, 41 (28.7%) with moderate, and 43 (60.6%) with severe pain. X2=116.4 Association Limitations to activities were significantly more frequently reported by student with severe dysmenorrhea.
Goldstein-Ferber and Granot (2006)	To: a) Characterise dysmenorrhea in three subgroups of Israeli Arab adolescents b) Evaluate the role of both somatisation and attitudes toward menstruation in these ethnic groups.	160 high school students in Israel (grades 10 and 11). Mean age: 15.7 years (+/-0.8 years). 3 subgroups: Muslims (*n* =50), Christians (*n* = 50), and Druze (*n* =60).	Menstruation and dysmenorrhea characteristics: Questionnaire using both closed questions and a 5-point Likert scale. Pain severity: The visual analogue scale (VAS). Menstrual attitudes: The Attitudes Toward Menstruation Instrument (ATMI). 20-item questionnaire using 5-point scale rating agreement level from 1= do not agree at all, to 5=very much agree. Domains= impurity and perceived ability. Somatization: 13-item Brief Symptom Inventory (BSI)	Dysmenorrhea: n=68 (45%). *Impact of dysmenorrhea on HRQoL* Associations: No difference in somatization found between dysmenorrheic (mean=13.16, +/- 7.1) and non-dysmenorrheic (mean=13.24 +/- 7.5) girls ($p > .05$). However, when questions assessing pain symptoms alone were included, dysmenorrheic girls reported higher scores of pain symptoms (p=.035). Level of somatization (p= <.0001) and perceived ability (p= <.0001) significantly predicted pain intensity. Lower perceived ability during menstruation was associated with a higher prevalence of dysmenorrhea (X^2=5.0518). Druze Arab adolescents reported the lowest level of perceived ability.

			from the Brief Symptom Check List (SCL-90).	Muslim Arab adolescents reported the highest levels of somatization. This suggests that these two sub populations are at more risk of dysmenorrhea than the Christian subgroup.
Dorn et al. (2009)	To: a) Describe differences in self-reported menstrual symptoms in adolescents in relation to smoking behaviour. b) Examine the relationship of depressive symptoms and anxiety with menstrual symptoms. c) Examine whether smoking moderates the relationship between depressive symptoms/ anxiety and menstrual symptoms.	154 post menarchal girls recruited from an urban teen health centre and the community. Girls were in age cohorts of 11, 13, 15 and 17 years. Mean age: 15.4 years (± 1.9 years).	Smoking experience: Smoking behaviour questionnaire ranging from ‘never’ to ‘daily smokers’. Categorised as ‘never’ or ‘ever’ smokers. Tanner stage, and breast and pubic hair development: Physical examination. Medication and menstrual histories. Obtained at the same time as physical examination. Blood samples taken. Menstrual symptoms: Menstrual Symptom Questionnaire (MSQ) (Chesney & Tasto, 1975). 24-item rated from 1-‘never’ to 5- ‘always’. 5 factors: menstrual pain, premenstrual negative affect, premenstrual water retention, premenstrual pain, menstrual back pain. Depressive symptoms: 27-item Children’s Depression	*Impact of dysmenorrhea on HRQoL:* *Anxiety:* The following were significantly correlated with trait anxiety: Menstrual pain (*p*≤.01) Premenstrual negative affect t (*p*≤.001) Premenstrual water retention (*p*≤.05) Premenstrual pain (*p*≤.01) Menstrual back pain (*p*≤.01) Spasmodic dysmenorrhea (*p*≤.001) Congestive dysmenorrhea (*p*≤.001) *Interaction of smoking:* Ever smokers had significantly higher scores on the MSQ than never smokers (*p*≤.01). This remained significant after adjusting for depression, anxiety and covariates. There were significant depressive symptoms by smoking interaction (beta = 0.52, p<.05). The effect of depressive symptoms on MSQ sum score was significantly stronger for never smokers. In the trait anxiety model there was a significant anxiety-by-smoking interaction where the MSQ sum score was stronger in the never smoked (beta = 0.59, *p*≤.05). In the two factor MSQ model: Congestive factor: no significant depressive symptoms-by-smoking interaction or trait anxiety-by-smoking interactions found.

			Inventory (CDI) (Kovacs, 1981). Trait anxiety: State-Trait Anxiety Inventory (STAI) (Speilberger et al., 1970) for adolescents aged above 12 years and the STAIC for children under 12 years old (Spielberger & Edwards, 1973). 20- items.	Spasmodic factor: Ever smokers had significantly higher scores than never smokers which remained significant after adjusting for anxiety, depression, and covariates. Spasmodic factor: Significant depressive symptoms-by-smoking interaction (beta=0.35, $p \leq .01$) effect as well as trait anxiety-by-smoking (beta=0.37, $p \leq .05$). Post hoc tests= the effects of depressive symptoms and trait anxiety on menstrual symptoms were stronger in the never smoked compared to the ever smoked group. The five factor model for the MSQ: Significant interaction effect of smoking status by depressive symptoms for menstrual pain ($p \leq .05$) and pre-menstrual pain ($p \leq .05$). Effect of depressive symptoms on menstrual pain and premenstrual pain was stronger in never group compared with the ever group Significant interaction of smoking status- by-trait anxiety for menstrual pain ($p \leq .05$) where the effect of trait anxiety on menstrual pain was stronger in the never smoker group. No other significant interactions found. More depressive symptoms/anxiety were related to higher numbers of menstrual symptoms ($r = 0.23–0.44$, $p < .05$)
Johnson (1988)	To establish (within the study population): A The prevalence of dysmenorrhea, school/ work absence due to dysmenorrhea, how many girls had consulted a health care professional (HCP), and knowledge of treatment. B Knowledge and attitudes regarding the	182 girls (14-18 years) from two school settings in the USA. Mean age: 15.8 years.	Demographic information, menstrual characteristics, dysmenorrhea characteristics, school/ work absenteeism, medical consultation, treatments used, and dysmenorrhea knowledge and understanding: a 31-item multiple choice questionnaire, specifically designed for the study, was administered by a physician or nurse. One open-ended question was included.	93.9% of girls had begun menarche. Dysmenorrhea: n=136 (72%). *Impact of dysmenorrhea on HRQoL* *<u>Due to menstrual pain:</u>* 80 (58.9%) were less active. 62 (45.6%) had 'ever' missed school or work. 0.4% missed classes or school days during the previous school year. 19% missed >3 days of school in the previous year.

	aetiology and treatment of dysmenorrhea.		Socioeconomic status: Holingshead two-factor index. Highest= 1.	
Fontana and Rees (1982)	To establish the nature of links, if any, between dysmenorrhea and a range of affective, cognitive, and academic variables in adolescent girls, focussing on personality variables, intelligence, school attendance and attainment.	102 girls from one school in Wales, UK. Mean age of dysmenorrheic girls= 15.56 years. Mean age of non-dysmenorrheic girls = 15.50 years. Participant groups were matched on second-year attendance, and mathematics and English exam results.	School attendance: over two school terms. Academic performance: results in English and Mathematics from summer and Christmas term exams. Verbal, numerical, and perceptual reasoning: The AH2 Test of General Reasoning (Heim et al., 1974). Covert and overt anxiety: The IPAT anxiety scale (Cattell & Scheier, 1963). Extraversion and Neuroticism scores: The New Junior Maudsley Inventory (participants <15 years). Clinical personality scales: The Minesota Multiphasic Personality Inventory (MMPI) (participants >15 years). All conducted over a 3 month period.	*Impact of dysmenorrhea on* 51 with primary dysmenorrhea. 51 without primary dysmenorrhea. *HRQoL* *School absenteeism:* No significant difference was found between groups for school attendance. *Academic performance:* No significant differences found between groups for examination results. No group differences found when participants were split into year groups or by examination and non-examination sets. *One difference was found:* Non-dysmenorrheic girls in the 4th and 5th year exam groups showed a significant improvement in scores ($p<0.05$) between summer and Christmas exams in English language and English literature. Dysmenorrheic girls showed a lesser and an insignificant gain in scores between examinations. *General reasoning:* No significant differences for general reasoning, although the dysmenorrheic girls had a higher total mean score (m=43.57) than the control group (m=40.00). *Trait anxiety:* 13 out of 15 scores were higher for the dysmenorrhea group and only two higher for the control group ($p \leq .01$).

				More differences found between younger students, which was more apparent for overt, than covert anxiety. __Personality variables:__ *The Junior Maudsley Inventory:* Significant difference in neuroticism scores between groups ($p<.01$). There was a higher mean incidence of extroversion among the control group (13.56) compared to the dysmenorrheic group (12.06) (who were more introverted) although, this was not significant. *The MMPI:* Significant differences in hysteria ($p\leq.05$) between dysmenorrheic girls (m=52.54) and the control group (46.41). (The authors note that as there were 12 scales and the significance level was set to .05, this may be due to chance).
Chaudhuri and Singh (2012)	To estimate prevalence of primary dysmenorrhea among school girls, to determine its impact on their routine life and to ascertain the practices adopted by them for the management of primary dysmenorrhea.	224 girls (13-17 years) from two schools in India. Mean age: 14.2 years (+/- 0.864 years).	Demographic information, menstrual history, family history of menstrual pain, impact of dysmenorrhea, and management practices: Interview using a pre-tested and piloted interview schedule. Menstrual experiences: Menstrual Distress Questionnaire (MDQ) (Moos, 1968). Symptoms from participants last menstruation were rated as 1=no experience of symptom, to 4= severe or partially disabling.	Dysmenorrhea: n=128 (59.82%). __Pain intensity:__ Mild: n=37 (28.91%). Moderate: n=70 (54.68%). Severe: n=21 (16.41%). __Impact of dysmenorrhea on HRQoL:__ Poor school performance: n=82 (64.1%) Take naps/staying in bed: n=65 (50.8%) Stay at home: n=68 (53.1%) Difficulty in concentrating: n=95 (74.2%) Avoid social activities: n=69 (53.5%) Decreased physical activity: 38.2%

			Pain severity: 10cm Visual Analogue Scale Pain (VASP) (Langley & Sheppeard, 1985). 0- ‘no pain’, to 10- ‘worst pain imaginable’.	
Parker et al. (2010)	To establish: a) The typical experience of menstruation for senior high school girls. b) How many girls experience considerable menstrual problems that might even require further investigation for pathology (i.e. endometriosis).	1051 girls (14 years, 9 months to 19 years, 3 months) from four schools in Australia. Mean age: 16 years, 10 months (+/- 8 months)	Menstrual characteristics/symptoms, dysmenorrhea, school absence due to menses, use and effectiveness of analgesia, menstrual interference with life activities, perceptions of menstruation: The menstrual disorder of teenagers (MDOT) questionnaire, designed specifically for the purpose of the study and piloted (Parker et al., 2010). Pain intensity: Categorised into none/mild pain (0-3), moderate pain (4-7) or severe pain (8-10). No reports of name or further description of the scale used.	Dysmenorrhea: 93%. *Pain intensity:* None/ mild (0-3 on rating scale): n=317 (31%). Moderate pain (4-7): n=505 (48%). Severe pain (8-10): n=217 (21%). *School absenteeism:* 26% reported missing school because of menses. Of those: 2% reported time off school with every period. Duration of absences: 1 day (70%), <2days (29%), <4 days (1%). Of the girls who missed school, pain was the most common reason (94%). 50% (n=106) of girls with severe pain missed school. When menses were associated with pain, school attendance was the most highly affected of the 9 life activities (x^2=116.2, p<.001). Highly significant associations were found between pain severity, number of menstrual symptoms, interference with life activities and school absence (p<.001). Significant, positive associations were found between pain severity and median interference scores for: Attending school (X^2=116.2, p<.001), completing school work (X^2=100.8, p<.001), social activities (X^2=88.2, p<.001), sport and exercise (X^2=55.4, p<.001), relationship with friends (X^2= 48.2, p<.001), casual paid work (X^2= 46.7, p<.001),

				relationship with family (X^2=45.4, p<.001), sexual activity (X^2= 23.7, p<.001), and relationship with partner (X^2=14.5, p<.001).
Unsal et al. (2012)	To determine: a) The prevalence of dysmenorrhea and, b) the connection between painful menstruation and depression in a group of Turkish female students.	Mean age and range is not reported. 390 girls from two vocational high schools in Turkey.	Socio demographic information, school features, menstrual characteristics, habits, medical history: Questionnaire. Pain severity: Visual analogue scale (VAS) (Larroy, 2002) and the multidimensional scoring system (MSS) (Andersch & Milsom, 1982). Depression: The Beck Depression Scale (BDS) (Beck et al., 1961).	Dysmenorrhea: 279 (71.5%). *Pain Intensity:* Mild: n=106 (38%) Moderate: n=108 (38.7%) Severe: n=65 (23.3%) *Depression:* 144 (51.6%) of girls with dysmenorrhea reported depression compared to 25 (22.5%) girls without dysmenorrhea. As pain severity increased, BDS score increased (F=6.639; p>.05). BDS mean scores for: Girls with mild pain: 17.93±9.38. Girls with moderate pain: 20.29±10.71. Girls with severe pain: 24.11±12.75.
Amu and Bamidele (2014)	To determine: a) The patterns of menstruation, and b) The prevalence of menstrual disorders and their consequences among adolescent girls in Osogbo, South Western Nigeria.	400 adolescent girls (10-19 years) from six schools in Osogbo, Nigeria. 232 (58%) were aged between 10-14 years 168 (42%) were aged between 15-19 years 316 (79%) were Christian, 83 (20.8%) Muslim, and 360 (90%) were Yorubas.	Sociodemographic information, menstrual awareness, and prevalence and effects of menstrual disorders: A pre-tested, semi-structured questionnaire.	397 girls had begun menarche. Dysmenorrhea: n=309 (77.8%). *Impact of dysmenorrhea on HRQoL* n=239 (77.3%) reported effects on daily activities. Specifically: Inability to sleep (n=123, 50.6%), disturbance of reading (n=48, 19.8%), poor class performance (n= 36, 14.8), school absenteeism (n=24, 9.9%), and 'others' (n=12, 4.9%).

Liliwati et al. (2007)	To determine: a) The prevalence of dysmenorrhea among adolescent girls in a secondary school in Huli Langat district, Selangor. b) The dysmenorrhea association with menstrual characteristics. c) The effect of dysmenorrhea on school activities.	300 menarchal adolescents (12-17 years) from one school in Malaysia. Early adolescence (12-14 years): n=169 (56.3%) Middle adolescence (15-17 years): n=131 (43.7%). Ages of dysmenorrheic girls: Early adolescence (12-14): n=93 (55%). Middle adolescence (15-17): n=94 (71.8%). Ages of non-dysmenorrheic girls: Early adolescence (12-14): n= 76 (45.0%). Middle adolescence (15-17): n=37 (28.2%).	Sociodemographic characteristics, menstrual characteristics, school activities affected by pain: Pretested, 20-item questionnaire designed for the purpose of the study. Pain intensity: Numerical rating scale (NRS) categorised intensity into mild pain (1-3), moderate pain (4-6) and severe pain (7-10).	Dysmenorrhea: n=187 (62.3%). *<u>School absenteeism:</u>* Mild pain: mean=1.02 (+/- 0.13). Moderate pain: mean=1.35 (+/- 0.67). Severe pain: mean=2.82 (+/- 1.24). ANOVA: F=80.266 Pearson Correlation: r=0.690 P<.0005 *<u>Class absenteeism:</u>* Mild pain: mean=1.05 (+/- 0.40) Moderate pain: mean=1.47 (+/- 0.96) Severe pain: mean=2.60 (+/- 1.31) ANOVA: F=38.205 Pearson Correlation: r=0.582 P= <.0005 Students with higher mean pain score also reported impaired concentration in class (p<0.05) and inability to participate in sports activities (p<0.05). *<u>Mean pain score with perceived concentration and sports participation:</u>* Girls with dysmenorrhoea: <u>Concentration Perceived:</u>

				Normal activity: 3.94 (1.92) Reduced activity: 5.95 (2.31) Sports Participation: Normal activity: 4.58 (1.91) Reduced activity: 5.93 (2.36)
Wong (2011)	To determine the prevalence of dysmenorrhea, its impact, and treatment seeking behaviour of rural adolescent girls in Malaysia.	1295 post-menarchal adolescent girls (13-19 years) from 16 schools in rural districts of Malaysia. Mean age: 15.28 years (±1.45 years).	Attitudes toward dysmenorrhea, impact of menstrual pain, and treatment and information sought: Questionnaire in three parts. Similar to that used in another study by the same authors (Wong & Khoo, 2010). Questionnaire reviewed by experts to assess both the face and content validity.	Dysmenorrhea: n=984 (76%). *Impact of dysmenorrhea on HRQoL:* Class concentration limitations (59.9%), restriction to social and recreational activities (58.6%), frequent school absenteeism (18.1%), poor school performance and low grades (16%) *Predictors of dysmenorrhea leading to poor concentration:* Being in upper secondary level (OR = 2.97; 95% CI, 2.32–3.79; P < 0.001), household income above MYR 4000 (OR = 1.79; 95% CI, 1.10–2.93; P < 0.05), and divorced or separated family type (OR = 2.39; 95% CI, 1.07–5.34; P < 0.05). *Predictors of dysmenorrhea leading to absenteeism:* School absenteeism was higher among upper secondary (OR = 1.37; 95% CI, 1.02–1.83; P < 0.05) school students. School absenteeism was lower among households where the income was above MYR 4000 (OR = 0.45; 95% CI, 0.21–0.93; P < 0.05). *Predictors of dysmenorrhea leading to restriction of social activities:* Restriction of social activities was higher in the upper secondary level (OR = 2.44; 95% CI, 1.92–3.10; P < 0.001), and the high household income (OR = 1.37; 95% CI, 0.87–0.94

				MYR 2000–4000; P < 0.05 versus OR = 3.01; 95% CI, 1.76–5.12 above MYR 4000; P < 0.001). *Predictors of dysmenorrhea leading to low grades:* Low grades were higher in upper secondary (OR=1.49; 95% CI, 1.10-2.01; p<0.05) school students. Being in upper secondary was the strongest predictor for poor concentration, absenteeism, and poor school grades due to dysmenorrhea.
Wong and Khoo (2010)	To determine the prevalence of dysmenorrhea, its impact, and the treatment-seeking behaviour of adolescent Asian girls.	1092 girls (13-19 years) from 16 schools in rural districts of Malaysia. Mean age: 15.19 years (± 1.39 years). 2% were 6th form students.	Attitudes toward dysmenorrhea, impact of menstrual pain, and treatment and information sought: Semi-structured questionnaire.	Dysmenorrhea: n=801 (74.5%). 1075 girls had begun menarche. *Impact of dysmenorrhea on HRQoL* Dysmenorrhea: Affected concentration in classroom (51.7%), restricted social and recreational activities (50.2%), and affected school performance and caused girls to receive lower grades (16.4%). *Absenteeism:* 21.5% reported it as a leading reason for school absenteeism *Predictors of factors being affected by dysmenorrhea:* Malays had significantly higher odds of experiencing (due to dysmenorrhea) : Poor concentration (OR, 1.82 95% CI, 1.38-2.40, p=<.001), missing school (OR, 2.13, 95%CI, 1.55-2.92, p<.001), and missing out on social and recreational activities (OR, 1.60, 95%CI, 1.22-2.11, p<.01) Those in upper secondary school levels had significantly higher odds of experiencing (due to dysmenorrhea): Poor concentration (OR, 0.45 95% CI, 0.35-0.59, p=<.0001), missing school (OR, 0.50, 95%CI, 0.37-0.68, p<.001), and

				missing out on social and recreational activities (OR, 0.45, 95%CI, 0.35-0.58, p<.001). Being in upper secondary level (OR0.71, 95%CI, 0.51-0.99, p<.05) and being from a low income household (OR 2.38, 95%CI, 1.47-3.85, p<.001) were predictors of poor school performance or low school grade.
Chongpensuklert et al. (2008)	To determine the prevalence of dysmenorrhea among Thai secondary school students and its impact on educational activities and the methods of pain relief.	575 Thai adolescent girls from three schools in grades 10, 11 or 12. Mean age of dysmenorrheic girls: 16.93 years (±1.05 years). Mean age of girls without dysmenorrhea: 16.55 years (±1.12 years).	Baseline characteristics, menstrual characteristics, menstrual symptoms, pain severity, impact on educational activities, and treatment: Questionnaire. Pain intensity: Categorised as mild, moderate or severe using the following definitions: Mild dysmenorrhea: perception of pain or discomfort associated with menstrual period without any need for treatment. Moderate dysmenorrhea: pain that needed any treatment for pain relief but did not affect daily activity. Severe dysmenorrhea: If dysmenorrheic girl needed any treatment for pain relief and the pain limited activities. No other information is provided.	Dysmenorrhea: n=488, 84.9% (95%CI, 81-88%). *Pain intensity:* Moderate: n=304 (62.3%). Severe: n=126 (25.8%). Mild: n=58 (11.9%). *Impact of dysmenorrhea on HRQoL:* *Poor class concentration:* 361 (73.9%) reported poor concentration. Specifically: 22 (37.9%) girls with mild, 226 (74.3%), and 113 (89.7%) with severe dysmenorrhea. *Limited sports activities:* n=292 (59.8%) reported limited sporting activities. Specifically: 21 (36.2%) with mild, 169 (55.6%) with moderate, and 102 (80.9%) with severe dysmenorrhea. *Limited social activities:* 137 (28.1%) reported limited social activities. Specifically: 8 (13.8%) with mild, 77 (25.3%) with moderate, and 52 (41.3%) with severe dysmenorrhea.

				Absences from school: 89 (18.2%) reported absences from school. Specifically: 0 (0%) with mild, 26 (8.5%) with moderate, and 63 (50%) with severe dysmenorrhea.
Svanberg and Ulmsten (1981)	To investigate the frequency of primary dysmenorrhea.	502 adolescent school girls (10-19 years) were recruited in connection with the introduction of a medical programme in Sweden. Mean age: 15 years Dysmenorrhea: 43% 57 (approx.) girls reported painless menstruation. Prevalence of dysmenorrhea increased with age.	Menstrual characteristics, dysmenorrhea characteristics, and treatments received: Questionnaire. Replies were entered by putting a cross in answer boxes.	Data for 19 year old participants is not reported. *The percentage occurrence of severe dysmenorrhea by age* *Unable to perform normal activities:* 13 years: - 14 years: 12% 15 years: 24% 16 years: 18.3% 17 years: 18.8% 18 years: 25.3% *Absence from School:* 13 years: 8.3% 14 years: 10% 15 years: 11.4% 16 years: 10.2% 17 years: 18.2% 18 years: 12.6% *Stay in bed:*

				13 years: - 14 years:4% 15 years: 5.2% 16 years: 2% 17 years: 8.3% 18 years: 8.5%
Frisk et al. (1965)	No aim or objective of this study was reported.	116 post-menarchal secondary-school girls visiting an outpatient clinic for teenagers. Most girls=16-17 years. Mean age: 16.2 years.	Hyperoestrogenesis: Vaginal smears. Gynaecological findings, other somatic symptoms, family background, “psychic symptoms and mechanisms”, and “pathological findings”: No measurement tool was reported.	Dysmenorrhea: 57 (49%) 56% had gynaecological symptoms. Specifically: Leucorrhoea: 77% Premenstrual tension: 39% Irregular menstruation: 26% Hyperoestrogenous reaction: 21% Relative hyperoestrogenous reaction: 14% Hyperoestrogenous effect (total): 35% **Pathological findings:** Endometriosis: n=1 Follicular cyst: n=1 Suspected salpingo-oophoritis: n=1 *“Psychic symptoms” of girls with dysmenorrhea:* Insomnia (42%), impaired concentration (33%), “emotional instability” (28%), depression (28%), anxiety (26%), conflict with parents (19%), restlessness (14%), “hysteroid reactions” (11%). *School problems:*

				“Considerably impaired results” (39%), “aversion to school” (19%), “truancy” (9%), “school tension” (16%), and “problems connected with adaption to gymnastics” (7%).
Mohamed (2012)	To examine the prevalence, determinants, impact and treatment practices of dysmenorrhea among adolescent secondary school girl students in Assiut City (Egypt).	854 adolescent girls from four schools in Egypt, who had begun menarche a minimum of 3 months previous. Mean age: 16.0 years (± 1.5 years).	Sociodemographic information, drug use, menstrual characteristics, dysmenorrhea characteristics, impact of dysmenorrhea, treatment, and consultation sought: Self-administered, semi-structured questionnaire designed specifically for the study. Pain severity: Visual Analogue Scale (VAS) categorised pain as mild, moderate and severe (McDowell & Newell, 1996).	Dysmenorrhea: 643 (76.1%). *Pain Intensity:* Mild: n=171 (26.6%) Moderate: n=206 (32.0%) Severe: n=266 (41.4%) *Impact of Dysmenorrhea on HRQoL:* *Dysmenorrhea limited:* Class concentration (53.5%), sports participation (50.9%), class participation (45.3%), going out with friends (35.6%), test-taking skills (35.6%), and homework task performance (35.6%). *Absenteeism:* 39% reported missing school days, and 30% individual classes. Specifically: 45% missed half-1 day of school, 38% missed 2-3 days, and 17% missed more than 4 days. *Association between pain severity and limited activities:* *School absence:* Mild pain:22.2% Moderate pain: 34.5% Severe pain: 53.0%

Class participation:

Mild pain:33.9%

Moderate pain: 43.7%

Severe pain: 65.0%

Class concentration:

Mild pain:31.0%

Moderate pain: 53.9%

Severe pain: 67.7%

Test taking skills:

Mild pain:20.5%

Moderate pain: 31.1%

Severe pain: 48.9%

Sports participation:

Mild pain:39.2%

Moderate pain: 47.6%

Severe pain: 60.9%

Homework tasks:

Mild pain:21.1%

Moderate pain: 30.6%

Severe pain: 48.9%

				Going out with friends: Mild pain:26.9% Moderate pain: 44.2% Severe pain: 57.9% A significantly greater proportion of participants with severe pain reported limitations to: School absenteeism (OR3.9, 95%CI, 2.4-8.1; p=.001), class participation (OR, 3.6, 95%CI, 1.9-6.1;p=.001), class concentration(OR, 4.6, 95%CI, 2.2-6.9; p=.001), test taking skills (OR,3.7,95%CI, 2.1-7.6;p=.001), sports participation (OR, 2.4, 95%CI, 1.4-4.0; p=.001), homework tasks(OR, 3.5, 95%CI, 2.0-6.3; p=.001), and going out with friends(OR, 3.7, 95%CI, 2.1-6.5; p=.001). No significant differences in mild and moderate pain scores.
Santina et al. (2012)	To assess the prevalence of dysmenorrhea among school girls in Sidon City and its suburbs and to explore the relationship between menstrual experiences and dysmenorrhea.	389 in grades 8-12 (13-19 years) from five Lebanese secondary schools. Mean age: 15.8 years (±1.4 years).	Sociodemographic infomormation, age of menarche, school grade: Self-administered, structured questionnaire (approx. 25 minutes to complete). Menstrual experiences: Questions from the Menstrual Experience and Behaviour Questionnaire (MEBQ) (McPherson & Korfine, 2004) were also included. Questions related to sexual behaviour were deleted (14,18,19,20) due to cultural preferences. The authors re-organised 3 questions based on two stages of pre-testing on 33 girls.	Dysmenorrhea: 289 (74%). *Dysmenorrhea by age group:* 13-15 years: 80.7% 16-19 years: 70.3%. *Absenteeism:* School absenteeism due to menstruation (p=.031): 48 regularly missed school (1st day of period). Specifically: 42 (87.5%) dysmenorrheic girls, and 6 (12.5%) non-dysmenorrheic girls. 19 regularly missed school (1st and 2nd day of period). Specifically:

			Menstrual characteristics and experiences: Two parts of the MEBQ were used. 1. Menstrual cycle characteristics (5 topics). 2. Menstrual experiences (6 questions).	16 (84.2%) dysmenorrheic girls, and 3 (15.8%) non-dysmenorrheic girls. 94 sometimes missed school. Specifically: 73 (77.7%) dysmenorrheic girls, and 21 (22.3%) girls without dysmenorrhea. 228 never missed school. Specifically: 158 (69.3%) dysmenorrheic girls, and 70 (30.7%) non-dysmenorrheic girls. *Mood changes during menstruation (<.001):* 314 experienced mood changes. Specifically: 246 (78.3%) dysmenorrheic girls, and 68 (21.7%) non-dysmenorrheic girls. 75 did not experience mood changes. Specifically: 43 (57.3%) dysmenorrheic girls, and 32 (42.7%) non-dysmmenorrheic girls. *Menstrual experience (p<.001):* 287 reported negative menstrual experiences. Specifically: 255 (88.2%) dysmenorrheic, and 32 (32.1%) non-dysmenorrheic girls. 102 reported positive menstrual experiences. Specifically: 34 (11.8%) dysmenorrheic, and 68 (68%) non-dysmenrorheic girls.
Negriff et al. (2009)	T a) Examine the factor structure	210 girls (11-17 years) enrolled onto a longitudinal	Menstrual pain and symptoms: Menstrual Symptom Questionnaire (MSQ) (Chesney & Tasto,	*Associations with depressive symptoms:* MSQ factor 1: abdominal pain= 0.19 (p<.05).

and the utility of the MSQ to assess menstrual symptoms in a sample of adolescent girls. b) Correlate depressive symptoms and anxiety with the MSQ factors to provide validity for the interpretations of the factors.	study on smoking, mood and metabolic complications. Mean age: 15.69 years (±1.74 years). Age cohorts: 11, 13, 15, and 17 years old.	1975) : 24-item questionnaire with scores from 1 (never) to 5 (always). Higher scores indicate more menstrual symptoms. A three factor version (as a result of factor analysis) was used: Factor 1= abdominal pain, factor 2= negative affect/ somatic symptoms, and factor 3= back pain. Depressive symptoms: Children's Depression Inventory (CDI) (Kovacs, 1981). 27-items, each with 3 answer options. A composite T score was provided based on a mean of 50 and standard deviation of 10. Higher scores indicate more depressive symptoms. Trait anxiety: State Trait Anxiety Scale (STAI) (Speilberger et al., 1970) for girls <12 years and the State Trait Anxiety Scale for Children (STAIC) (Spielberger & Edwards, 1973) for girls aged 11 years: 20-item measure of trait anxiety (how the girls generally feel). Responses range from 1 (not at all) to 4 (very much so). Participants also reported age, race, SES, use of hormonal	MSQ factor 2: negative affect/ somaptic complaints= 0.37 (p<.01) MSQ factor 3: back pain= 0.18 (p<.05) *Associations with trait anxiety:* MSQ factor 1: abdominal pain= 0.07 (NS) MSQ factor 2: negative affect/ somaptic complaints= 0.22 (p<.01) MSQ factor 3: back pain= 0.07 (NS) Abdominal pain during menstruation was significantly, positively correlated with depressive symptoms but not trait anxiety.

			contraceptives and gynaecological age.	
Rapkin et al. (2006)	To: a) Examine the relationships among hormone concentrations and self-rated tanner staging and the effects of psychosocial factors that may modulate these relationships in an ethnically diverse sample of healthy, adolescent girls. b) Examine the relationships between dysmenorrhea, anxiety, somatization, and depression with tanner stage and hormonal markers of puberty.	106 girls (8-18 years) recruited from a larger study. Mean age: 13 years (±3 years).	Pubertal stage: Self-report instrument (Morris & Udry, 1980). This included schematic drawings and written descriptions of 5 stages of secondary sexual characteristics on two dimensions (female breasts and pubic hair) based on Tanner's sexual maturity scale (Tanner, 1962). Menarche: For girls who had started menarche, response to "how long have you been having periods?" (Years and months) measured menarchal age. This was then subtracted from age. Dysmenorrhea: A dichotomous measure of dysmenorrhea derived from a series of items on period cramping and use of medications to relieve symptoms. Girls were divided into 2 groups (with and without dysmenorrhea) based on responses to 1. "do you get period cramps" –answer= yes/no and 2. "Do you take	54 girls had begun menarche. Dysmenorrhea: n=28 Without dysmenorrhea: n=27 *Associations:* MASC, CSI, and CDI did not moderate the relationship between tanner stage and dysmenorrhea. Dysmenorrhea was not associated with increased MASC (anxiety), CDI (depression) or CSI (somatization) scores. *Correlations of dysmenorrhea with depression, anxiety and somatization scores:* MASC: .207 (*p*=.133) CDI: .234 (*p*=.086) CSI: .177 (*p*=.196)

medicines for your period cramps?” – answer= yes/no.

Dysmenorrhea was defined as menstrual cramps sufficient enough to require medications.

Hormonal measures: 2 finger prick blood spot procedures (Worthman & Stallings, 1994, 1997) at 20 minute intervals to quantify levels of follicule stimulating hormone (FSH) and estradiol (E2).

Anxiety: The Multidimensional Anxiety Scale for Children (MASC) (March, Parker, Sullivan, Stallings, & Conners, 1997). 39-item measure. Higher scores indicate higher levels of anxiety.

Depressive symptoms: Children’s Depression Inventory (CDI) (Kovacs, 1981). A 27-item questionnaire. Higher scores indicate higher levels of depressive symptoms.

Somatization: Children’s somatization inventory (CSI) (Garber et al., 1991).Measures children’s perceptions of 35 non-specific somatic symptoms. Higher

			scores indicate higher levels of somatisation.	
Klein and Litt (1981)	To determine the prevalence and possible correlates of dysmenorrhea.	2699 non-institutionalised, menarchal adolescents (12-17). Participant data retrieved from the National Center for Health Statitics in America.	Data collected from the national health examination survey cycle III (1966-1970) in the United States of America. Specifically: History questionnaire. Physical examination. Laboratory and psychological test data. Absenteeism: Interviews with school personnel.	Dysmenorrhea: n=1611 (59.7%). *Pain intensity:* Mild: (49%). Moderate: (37%). Severe: (14%). *Impact of dysmenorrhea* *Menstrual pain accounted for:* 25% of all excessive school absences. 14% frequently missing school. 50% with severe pain missed school compared to 17% with mild cramps. Despite similar rates of dysmenorrhea, school absence due to cramps differed between African American (23.6%) and white American adolescents (12.3%). No association between preparation for menarche and school absence.
Vicdan et al. (1996)	To determine the average menarchal age and menstrual cycle pattern, prevalence of dysmenorrhea, frequency of smoking, alcohol and drug use, sexual education level, and gynaecologic problems in female adolescents in Turkey.	13,665 girls (13-18 years) from 32 schools in Turkey. Mean age: 15.9 years	Demographic information, menstrual characteristics, dysmenorrhea characteristics, smoking, alcohol consumption, drug use, sexual education and knowledge, and gynaecological problems: 43-item questionnaire including 116 parameters, specifically designed.	Dysmenorrhea: n=10,688 (78.1%). Mild dysmenorrhea: 74.4% *Impact of dysmenorrhea on school absenteeism* 25.6% frequent absenteeism due to moderate or severe pain.
Wilson and Keye (1989)	To assess the prevalence and symptoms of	88 adolescent girls (14-18 years) from one school (two	Dysmenorrhea characteristics, premenstrual symptoms,	Dysmenorrhea: n=80 (90%).

	dysmenorrhea and PMS among adolescent girls and their perceptions of its impact on academic performance, ability to concentrate, study, or take tests, and classes missed, and their course of treatment.	education classes) in the USA. Mean age: 15 years.	perceived impact on academic performance, and medical treatments: 11-item questionnaire.	*Pain intensity:* Mild: n=24 (27%). Moderate: n=36 (41%). Severe: n=20 (23%). *Impact of dysmenorrhea on HRQoL:* *Academic performance:* Dysmenorrhea had a larger perceived impact on academic performance (n=48, 55%) than PMS (n=39, 44%). *Class absenteeism:* Dysmenorrhea had a larger perceived impact on class absenteeism (n=23, 26%) than PMS (n=15, 17%).
Boyle (1997)	To assess the impact of menstrual-cycle moods and symptoms on academic school learning.	427 post-pubescent students were recruited from years 10, 11, and 12 from ‘several’ Australian secondary schools. (The mean age, age range, and dysmenorrhea prevalence was not reported.)	Menstrual experiences: The 47-item trait version (Form C) of the Menstrual Distress Questionnaire (MDQ) (Moos, 1985). Three phases (premenstrual, menstrual and intermenstrual) were explicitly measured. Each item is responded to 3 times (for each phase). A 5-point likert scale measured 8 symptoms: pain, water retention, autonomic reactions, negative affect, impaired concentration, behaviour change, arousal, arid control. Academic grades: 18 school subjects obtained from school records.	*Correlations between pain and academic performance* *Significant correlations were found between premenstrual pain and grades in the following subjects:* Business Studies (-.13), Secretarial Studies (-.16), Home Economics (- .16), Physical Education (- .15), Geography (- .15), Mathematics II (- .17), and Physics (- .11). *Significant correlations were found between menstrual pain and grades in the following subjects:* Business Studies (-.11), Science (-.10), Home Economics (-.13), Physical Education (-.11), Religious Education (-.13), Mathematics I (-.17), and Physics (-.17). *Significant correlations were found between intermenstrual pain and grades in the following subjects:* English Literature (- .19), Mathematics (- .15), Business Studies (- .19), History (- .11), Home Economics (- .27), Physical Education (- .19), Geography (- .13), and Mathematics II (- .23).

				Non-significant correlations (no data given) were found between premenstrual pain and the following subject grades: English Literature, Mathematics, Foreign Language, Art and Craft, History, Science, Religious Education, Mathematics I, Biology, Chemistry, and Study of Society. *Non-significant correlations (no data given) were found between menstrual pain and the following subjects:* English literature, Mathematics, Foreign Language, Secretarial Studies, Art and Craft, History, Geography, Mathematics I, Biology, Chemistry, and Study of society. *Non-significant correlations (no data given) were found between intermenstrual pain and the following subjects:* Foreign language, Secretarial studies, Art and Craft, Science, Religious Education, Mathematics I, Biology, Chemistry, Physics, and Study of Society.
Sule and Ukwenya (2007)	To determine the menstrual abnormalities experienced by adolescents and the health seeking behaviour adopted in response.	385 students (12-18 years) from one secondary school in Kaduna (Nigeria). Mean age: 15.64 years (+/- 1.26 years) Mean age of girls with dysmenorrhea: 15.83 years Mean age of girls without dysmenorrhea: 15.35 years	Demographic information, biosocial characteristics, menstrual characteristics, self-medication, medical attention for menstrual problems, perceptions of menstrual problems: 19-item questionnaire. Most answers consisting of "yes", "no", and "I don't know".	Dysmenorrhea: n=212 (61.27%). No dysmenorrhea: n=134 (38.73%). *Impact of dysmenorrhea on HRQoL* *School absenteeism:* 52 (15.03%) reported that dysmenorrhea had caused school absence. Specifically: 69.23% every month, 23.08% every 2 to 3 months, and 7.69% every 4 months or more. School absenteeism due to dysmenorrhea was significantly higher among girls who: Had seen a doctor ($p<.001$), practiced self-medication ($p<.001$), bled with clots ($p=.001$), felt weak during menses ($p<.001$), and discussed menstrual problems with an aunt ($p<.001$), a male cousin ($p=.001$), or a female friend ($p=.001$). *Associations*

				Significant associations between absenteeism, and attitudes that menstrual pain of any kind (p=.03 after Bonferroni correction) and heavy menstrual bleeding p=.02 after Bonferonni correction) are problems requiring treatment. Non-significant associations between school absenteeism due to pain and: discussing pain with others (X^2=0.347, *p*=0.556), and duration of menses (X^2=1.641, p=.440).
Nwankwo et al. (2010)	To determine the prevalence, pattern of menstrual disorders, treatment practices, and the effect of menstrual disorders on school attendance in adolescent school girls in Enugu, Nigeria.	500 adolescent girls (10-19 years) from three schools in Nigeria. Mean age: 14.9 years (± 1.7 years). 197 (39.8%) of girls were between 10-14 years old. 298 (60.2%) of girls were between 15-19 years old.	Demographic information, family background, menstrual characteristics, and menstrual problems: Self-administered, pretested, semi-structured questionnaire administered by trained students.	495 girls completed the questionnaires. Dysmenorrhea: n= 124 (25%). School absenteeism: 147(9.4%) reported that menstrual disorders led to school absenteeism. Mean duration of absenteeism: 1.8 days (± 1.2 days). 10 (2.2%) girls did not attend school throughout the period of menses (average of 4 days). Dysmenorrhea was responsible for the highest rate of school absenteeism (*P* = 0.002). 30 (24.2%) girls with dysmenorrhea reported school absenteeism due to pain.
Alam et al. (2011)	To compare school performance in pubertal adolescent girls with and without dysmenorrhea.	116 adolescent girls (12-18 years) from one school. Dysmenorrhea: Mean age= 15.14 years (+/- 11.65 years). Without dysmenorrhea: Mean age=15.30 years (+/- 12.60 years).	Demographic information, menstrual characteristics, and school absenteeism: Questionnaire. Academic performance: School reports from two consecutive semesters in one year.	With dysmenorrhea: n=58. Without dysmenorrhea: n=58. School absence: Dysmenorrheic girls: Mean= 3.2 days (+/- 0.88 days). Non-dysmenorrheic girls: Mean: 2.2 days (+/- 0.62 days). It was not reported whether this difference was significant. School performance: Semester 1:

				- Dysmenorrheic girls: mean=7.4 (+/- 0.34). - Non-dysmenorrheic girls: mean=7.4 (+/-0.37). Semester 2: - Dysmenorrheic girls: mean=7.4 (+/- 0.33). - Non-dysmenorrheic girls: mean=7.5 (+/-0.35). No statistically significant difference in each semester between the groups (p=0.176, 95%CI -0.009 to -0.048; p=0.08, 95%CI - 0.052 to 0.024).
Rostami (2007)	To study dysmenorrhoea in the high school girls in Masjed Solayman Khzestan Province in Iran.	500 school girls (15-18 years) living in Iran. Community sample.	Dysmenorrhea characteristics, medical consultation, ability to work during menses, menstrual characteristics, medical requirements, and absenteeism: Postal questionnaire. Pain severity: Verbal multidimensional scoring system. Takes into account the impact of pain on daily activities, systemic symptoms and analgesic requirements (no reference provided). Pain severity: Visual Analogue Scale (VAS): a 10cm line on a sheet of paper. Scores were based on a continuum from one end of the line to the other from 'no pain at all' to 'unbearable pain'.	Dysmenorrhea severity: Grad 0: n=170 (28.80%) Grad 1: n=202 (34.23%) Grad2: n=133 (22.54%) Grad 3: n=85 (14.4%) Dysmenorrhea: 71.20% 85 (14.4%) of girls experienced dysmenorrhea that disturbed daily activities and was not *Absenteeism* 51% had been absent from work or school because of dysmenorrhea. Specifically: Every menstruation (n=62, 10.5%), alternate menstruations (n=54, 9.15%), occasionally (n=184, 31.32%), never (n=290, 49%).

Sanyal and Ray (2008)	To determine variation in the menstrual characteristics among adolescent s of different age groups, and the significant predictors of a menstrual outcome.	280 unmarried adolescent girls from four educational institutes. . Age groups (only the youngest 2 of 3 are included in this summary). <u>Group I (early adolescence):</u> N=108. Range: 14-15 years. Mean age: 14.57 years (±0.05 years). <u>Group II (middle adolescence):</u> N=112. Range: 16-18 years. Mean age: 17.37 years (±0.07 years).	Menstrual characteristics, Pretested, hygiene practices, sociodemographic information, menstrual problems, and gynaecological problems: structured questionnaire.	Dysmenorrhea: Group I: n=74 (68.52%) Group II: n=92 (82.14%) *School absenteeism due to menstrual discomfort:* *<u>Yes:</u>* Group I: n=27 (36.49%). Group II: n=18 (19.35%). *<u>No:</u>* Group I: n=47 (63.51%) Group II: n=75 (80.65%).
Dambhare et al. (2012)	To determine the age at menarche and menstrual patterns among adolescent school girls and to explore its variation across socio-economic and demographic factors.	471 girls (10-19 years) from urban (n=300), and rural (n=171) schools. Girls were recruited from six schools. Mean age: 15.45 years (±1.75 years).	Sociodemographic information, menstrual characteristics, premenstrual symptoms, and dysmenorrhea characteristics: Pre-designed, pre-tested questionnaire administered by a doctor, teacher, nurse, and social worker. Age at menarche was determined by questioning the	Dysmenorrhea: 56.15%. Dysmenorrhea (urban girls): n=237 (60.77%). Dysmenorrhea (rural girls): n=78 (45.61%). *School absenteeism:* All dysmenorrheic girls: n=78 (24.76%). Urban girls: n= 47 (12.05%).

			school about if menarche had taken place and, if it had, when.	Rural girls: n=31 (18.13%). (p>.05). Significant association between pain intensity and duration of menstrual flow (no data reported.
Lee et al. (2006)	To provide information on menstruation and factors associated with it among adolescent girls in Negeri Sembilan, Malaysia	2411 adolescent girls (12-19 years) from 14 schools in Malaysia. Mean age: 15.4 years (±1.8 years).	Sociodemographic information, menstrual characteristics, premenstrual syndrome and its severity, dysmenorrhea and its severity, and physician consultation: Pretested questionnaire.	164 (6.1%) had not reached menarche and were excluded from analysis. Dysmenorrhea= 67.7%. *Pain intensity:* Mild: n=1,406 (62.6%). Moderate to severe: n=152 (6.8%). No response: n=9 (0.4%). *Absenteeism:* The mean no. of days school absence for those with moderate or severe dysmenorrhea= 3.15 days. *Associations:* School absenteeism was more common with increased pain severity (no value provided).
Widholm (1979)	To obtain a picture of the need for drugs for pain relief and absence from school due to menstrual pain.	331 adolescent girls (13-20 years). Age distributions: - 13-14: n=97 - 15: n=91 - 16: n=79 This review will not include data obtained from the last age group (17-20 years).	Dysmenorrhea characteristics, duration of dysmenorrhea, school absence, premenstrual tension syndrome: Questionnaire.	*Prevalence of dysmenorrhea in different age groups:* 13-14 years: n=35 (36.1%). 15 years: n=41 (46.6%). 16 years: n=42 (53.8%). *School absenteeism:*

				1 (1%) 13-14 year old, 1 (1.1%) 15 year old, and 4 (5.1%) 16 year olds were ‘frequently’ absent due to dysmenorrhea. 8 (8.2%) 13-14 year olds, 21 (23.6%) 15 year olds, and 15 (19.2%) 16 year olds were absent ‘sometimes’ due to dysmenorrhea. 88 (90.7%) 13-14 year olds, 67 (75.3%) 15 year olds, and 59 (75.6%) 16 year olds were ‘never’ absent from school due to dysmenorrhea.
Deo and Ghattargi (2007)	To assess adolescent school girls with special reference to menstruation and its disorders.	158 girls (10-18 years) from two schools in India. 88 urban girls. 70 rural girls. Most girls were 13 years old.	Measures are not reported. Girls reported the following information: menstrual history, premenstrual symptoms, menstrual symptoms, and school absenteeism due to menstrual problems (in the previous 3 menstrual cycles).	*Dysmenorrhea* Overall: n=50 (31.64%). Urban girls: n=30 (34.09%). Rural girls: n=20 (28.57%). *School absenteeism due to dysmenorrhea:* 10 (6.33%) girls reported absence. Specifically: 7 (7.95%) urban, and 3 (4.29%) rural girls. 14 (8.86%) girls had been absent from school due to a menstrual disorder. 10 (6.33%) reported dysmenorrhea- related absence in the previous 3 cycles which was the most common menstrual disorder-related absenteeism reason. Days absent from school ranged from 1-3.
Rani et al. (2014)	This study aimed to investigate the prevalence of dysmenorrhea among adolescent girls in Chandigarh, compare the impact of dysmenorrhea on the life of girls from urban, rural, and slum	300 adolescent girls aged 11-18 years from urban (n=100), rural (n=100), and slum (n=100) areas of Chandigarh, India.	Questionnaire designed specifically for the purposes of the study measuring demographic information, family characteristics, menstrual characteristics, dysmenorrhea symptoms and it’s impact on the lives of the	Prevalence of dysmenorrhea was 61.33% (n=184). Dysmenorrhea had a negative impact on girls ability to lift heavy objects (38%; n=70), personal care (26%, n=48), sitting on a chair (20%, n=38), standing for long periods of time (27%, n=50), sleep (17.93%, n=33), social life (17.39%, n=32), and school attendance (24.45%, n=45).

	areas, and compare practices and perceptions among the girls.		girls, and beliefs about menstruation. Visual Analogue Faces Scale ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012) was used to measure dysmenorrhea intensity.	Pain intensity was categorised as 'no hurt' (3.67%), 'little bit' (9.67%), 'little more' (26.67%), 'even more' (9.67%), 'whole lot' (3.67%), and 'hurts worse' (2%). Girls who believed that menstrual pain is a natural process, menstrual blood is impure, one can visit family and friends when menstruating, and should bath daily during menstruation were significantly more likely to report dysmenorrhea (p=.0005, p=.0093, p=.039, and p=.014, respectively).

Appendix E Risk of Bias

Study	Overall Risk of Bias Index	Quality of Reporting	External Validity and Bias	Selection Bias and Power
Pitangui. et al. (2013)	15	8	5	2
Eryilmaz et al. (2010)	14	7	5	2
Banikarim et al. (2000)	14	7	5	2
Nur Azurah et al. (2013)	13	6	6	1
Teperi and Rimpelä (1989)	11	6	3	2
Wijesiri and Suresh (2013)	12	5	5	2
Hillen et al. (1999)	10	4	4	2
Poureslami and Osati-Ashtiani (2002)	6	2	4	0
Strinić et al. (2003)	14	7	5	2
El-Gilany et al. (2005)	14	7	5	2
Goldstein-Ferber and Granot (2006)	14	6	6	2
Dorn et al. (2009)	15	7	6	2
Johnson (1988)	10	4	4	2
Fontana and Rees (1982)	13	5	6	2
Chaudhuri and Singh (2012)	12	6	5	1
Parker et al. (2010)	14	7	5	2
Unsal et al. (2012)	14	6	6	2
Amu and Bamidele (2014)	10	4	5	1
Liliwati et al. (2007)	14	7	5	2
Wong (2011)	14	6	6	2
Wong and Khoo (2010)	12	6	4	2
Chongpensuklert et al. (2008)	11	6	4	1
Svanberg and Ulmsten (1981)	5	2	3	0
Frisk et al. (1965)	2	0	2	0

Mohamed (2012)	15	8	5	2
Santina et al. (2012)	15	7	6	2
Negriff et al. (2009)	13	5	6	2
Rapkin et al. (2006)	15	7	6	2
Klein and Litt (1981)	10	4	4	2
Vicdan et al. (1996)	6	2	4	0
Wilson and Keye (1989)	8	4	4	0
Boyle (1997)	12	4	6	2
Sule and Ukwenya (2007)	13	6	5	2
Nwankwo et al. (2010)	14	7	5	2
Alam et al. (2011)	14	7	5	2
Rostami (2007)	13	6	5	2
Sanyal and Ray (2008)	14	7	5	2
Dambhare et al. (2012)	13	6	5	2
Lee et al. (2006)	13	6	5	2
Widholm (1979)	3	2	1	0
Deo and Ghattargi (2007)	9	2	5	2
Rani et al. (2014)	11	5	5	1

Appendix F Description of Each Included Study

Pitangui et al. (2013) recruited 205 adolescent school girls (12-17 years) from a school in Brazil to complete a questionnaire measuring girl's menstrual characteristics, dysmenorrhea, and the impact of dysmenorrhea on activities of daily living (ADL). An 11-point numeric rating scale (NRS) ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012), consisting of a line between 0 and 10, measured pain intensity. The NRS ranged from 'no pain' (0) to 'the worst pain one can imagine' (10) and participants were asked to choose which number represented their pain. Pain intensity scores were categorised into mild (1-3), moderate (4-7), and severe (8-10). The same scale was used to measure the impact of dysmenorrhea on activities of daily living (ADL) (including self- care, physical activity, sleep and social activity) which were categorised as 'does not affect' (0), 'affects rarely' (1-3), 'affects moderately' (4-6), and 'clearly inhibiting' (7-10). There was a high rate of self-reported school absence as a result of menstrual pain (30.71%). Over half (66%) of girls with dysmenorrhea reported that their menstrual pain had effected their ADLS which many considered significant (16.53%) or incapacitating (12.60%). Specifically, increased pain intensity was significantly associated with more reports of school absenteeism, interference with ADLs, seeking medical care, and the use of medications. Significant associations were also found between affected ADLs and school absenteeism.

Eryilmaz, Ozdemir, and Pasinlioglu (2010) conducted a school-based survey of 1951 adolescent girls (13-18 years) who had begun menarche, from eight schools in Turkey. Participants were asked to report demographic and menstrual characteristics, dysmenorrhea prevalence, and the impact of dysmenorrhea on academic and social functioning. Pain intensity was measured using the facial pain rating scale (FPRS) (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001) which ranged from 1- 'no hurt' to 6- 'the worst (unbearable)' pain. Girls reported that dysmenorrhea had a profound negative impact on the girls school performance (55.7%) including absenteeism (18.6%), focus on school content (50%), missing exams (4.5%), and being able to answer exam questions despite having the knowledge (26.9%). Dysmenorrhea also had negative impacts on family relationships (31.8%) including family problems (77.3%), living apart from families (14.4%), and not fulfilling family responsibilities (8.3%). Girls also reported that relationships with friends had been impacted by dysmenorrhea (32.1%) such as being unwilling to talk (37.2%), being irritable (55.4%), and not feeling comfortable (7.4%). Specifically, it was found that these adverse effects of dysmenorrhea on school performance and relationships with family and friends increased as pain duration and intensity increased.

Banikarim et al. (2000) recruited post-menarcheal Hispanic students from one school in America. The exact sample size of this study was difficult to determine as there were conflicting numbers of participants reported (760, 740, and 706). Participants completed a 31-item questionnaire measuring the prevalence of dysmenorrhea and its impact on ADL, sports participation, and school and social functioning. Pain intensity was measured using the visual analogue scale (VAS) ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012). Dysmenorrhea had a profound negative impact on many of the girls' academic, social, and sporting activities specifically, class concentration (59%), daily chores (56%), sports participation (51%), class participation (50%), going out with friends (46%), taking tests (36%), homework (35%), grades (29%), and absenteeism (38%). Compared to girls reporting mild pain, those with severe dysmenorrhea reported significantly greater school absence and impact on homework, class concentration, taking tests, sports participation, and going out with friends. Even among girls who were taking medication to relieve their pain, dysmenorrhea continued to impact on many aspects of their lives including school absenteeism (44%), class concentration (68%), exam skills (42%), and socialising with friends (53%). Nur Azurah et al. (2013) recruited 184 adolescents (13-18 years old), attending a gynaecology clinic for menstrual disorders (including dysmenorrhea, heavy menstrual bleeding, amenorrhea, and oligomenorrhea) in Australia, and their parents. The primary outcome, teen HRQoL, was measured by the 23-item Pediatric Quality of Life- Teen Report (PedsQL) (Varni,

Burwinkle, Seid, & Skarr, 2003). Adolescents also completed the parental bonding instrument (PBI) (G. Parker, 1988) consisting of 25 questions about parents and parts of the Menorrhagia questionnaire (Ruta et al., 1995). Parents answered questionnaires from the SF 12v2 Health survey (Ware, Kosinski, & Turner-Bowker, 2001) and the Kessler Psychological Distress Scale (Kessler et al., 2002). There were no significant differences between girls with different menstrual problems within all 4 domains (physical functioning, emotional functioning, social functioning and school function) of the PedsQL. However, girls with dysmenorrhea rated lower in the physical and school functioning domains of the PedsQL than girls with heavy menstrual bleeding, amenorrhea and oligomenorrhea. Overall, for girls with menstrual problems, PedsQL score was lower than adolescents with cystic fibrosis and adolescents from the 'health of young Victorian study'.

Teperi and Rimpelä (1989) conducted a questionnaire study of 3370 post-menarcheal girls (12-18 years), in age cohorts of 12, 14, 16, and 18 years, derived from the 1982 Finnish National population registry. Participants reported aspects of general health, menstrual characteristics, and socio-demographic information. Menstrual pain was categorised as no pain, mild pain, and severe pain. Severe menstrual pain was not related to self-assessed school performance in 16 year olds. There was not a particularly high prevalence of school absenteeism due to menstrual pain. 1% of 12 year old girls reported missing school ‘often’ compared to 4% of 18 year old girls, and 5% of 12 year old girls reported missing school once compared to 13% of 18 year olds. Most girls reported no absenteeism due to dysmenorrhea however; a large proportion (54%) of 16 year olds with severe pain had stayed at home due to pain compared to those with mild pain (15%). School absenteeism correlated with pain severity, showing that girls with severe pain were more likely to miss school.

Wijesiri and Suresh (2013) asked 200 students (17-18 years) to complete a 20-item, selfreport questionnaire consisting of both open and closed-ended questions. Participants reported demographic information, menstrual characteristics and associated problems, attitudes towards menstrual pain, and the impact of menstrual pain on HRQoL. A large proportion (66.2%) of girls experiencing dysmenorrhea felt they had been ‘mentally affected’ (including increased anger, less concentration, impaired decision making) by their pain. Also, almost half (44%) of the sample reported absenteeism due to menstrual pain however, this was only reported as ‘frequent' in 17%, and 44% of girls reported that their social status had been affected. The most profound impact of dysmenorrhea was its effect on the psychological well-being of participants. A statistically significant association was found between menstrual pain and mental status whereas no significant association between menstrual pain and physical status or social status was found.

Hillen et al. (1999) conducted a study with 388 adolescent girls (15-17years), 384 of which had begun menarche, from three Australian secondary schools. Girls were recruited from a private school and two state schools, one in a high socioeconomic status (SES) area and one in a low SES area. Participants completed a questionnaire measuring dysmenorrhea characteristics, management strategies and their effectiveness, the impact on school, sport, and social activities, and understanding of treatments. Most girls (n=309, 80%) reported dysmenorrhea, many of which reported pain with at least every second period (80%) or with every period (47%). The school in the lowest SES had the highest prevalence of dysmenorrhea. In terms of HRQoL, over half (52%) of girls reported that activities were limited including school (45%), sporting (48%) and social activity limitations (46%). Most participants (48%) reported limitations for less than 24 hours although some (18%) reported them lasting more than 48 hours.

Poureslami and Osati-Ashtiani (2002) recruited 250 students (15-18 years) and randomly selected from 20 schools in the suburban districts of Tehran in Iran to complete a 44-item questionnaire. Participants reported their knowledge of dysmenorrhea management and the impact of menstrual pain on daily activities and school absenteeism. Fifteen percent of girls reported that menstrual pain had caused absence from school or other activities for between 1-7 days in the past school year and 33% avoided any kind of physical activity during menstruation.

Dysmenorrhea had a profound impact on the lives of the adolescents in this sample, causing some to become reclusive (49%), suffer nervousness (52.5%), or become shy (52%) during their period.

Strinić et al. (2003) conducted a questionnaire study of 297 adolescent girls (11-18 years) from ‘several’ schools in Croatia. Participants reported the prevalence of dysmenorrhea and the influence of anthropological characteristics (age at menarche, duration of menses, and length of cycle) and lifestyle factors on menstrual pain. No significant anthropological or clinical differences between girls with and without menstrual pain were found. Some girls reported missing ‘any activities’ (9%), missing school (22%) and staying in bed (4%) as a result of menstrual pain.

El-Gilany, Badawi, and El-Fedawy (2005) carried out a study of 664 adolescent girls (14-18 years) from ‘several’ schools in Egypt who completed a self-administered questionnaire. Questions were related to socio demographic, menstrual, and dysmenorrhea characteristics, and the impact of menstrual pain on ADL and treatments. Self-reported menstrual pain severity was categorised as mild, moderate or severe. Almost half of girls who had begun menarche (n=642) reported that dysmenorrhea caused no limitation on their daily activities (47.4%). Activities that were effected by dysmenorrhea included daily home chores (42.8%), going out of the home (41.5%), participation in social events (39%), participation in sports (34.4%), concentration in class (24.4%), homework tasks (21.5%), and school attendance (20.3)%. In all domains measured, girls with severe dysmenorrhea reported significantly more limitations to their daily activities than girls with mild or moderate dysmenorrhea.

Goldstein-Ferber and Granot (2006) aimed to characterize dysmenorrhea and evaluate the role of somatization and menstrual attitudes in three subgroups of Israeli Arab adolescents (Muslims, Christians, Druze). 160 school girls in grades 10 and 11 were asked questions regarding menstrual characteristics and dysmenorrhea. Pain intensity was measured using the Visual Analogue Scale (VAS) ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012). Girls were asked to rate, using a 5-point scale (ranging from 1 ‘no functioning’ to 5 ‘a drastic reduction in regular behaviour’), whether menstrual pain had changed their regular functioning. Dysmenorrhea was defined by a score of two or more for this question and/or if participants reported that they had used medication to relieve menstrual pain. The 20-item, Attitudes Toward Menstruation Instrument (ATMI) measured menstrual attitudes using a 5-point scale ranging from 1- ‘I do not agree at all’ to 5- ‘very much agree’. Somatisation was measured using the short version of the Brief Symptom Check List (SCL-90) (Derogatis & Cleary, 1977), a 13item questionnaire rating the frequency of complaints or symptoms in different areas of the body. No difference between the levels of somatization were found between adolescents with and without dysmenorrhea although, girls that reported menstrual pain also reported higher scores of pain symptoms than non-pain symptoms. It was found that level of somatization and perceived ability to cope with menstrual pain, significantly predicted the intensity of pain and lower perceived ability was associated with higher rates of dysmenorrhea. Druze adolescents reported the lowest perceived ability and Muslim adolescents reported the highest levels of somatization.

Dorn et al. (2009) conducted a study with a community sample (including adolescents visiting a teen health clinic) of 154 post-menarcheal girls in age cohorts of 11, 13, 15, and 17 years. The authors investigated differences in self-reported menstrual symptoms in relation to smoking behaviour and examined the relationships of depressive symptoms and anxiety with menstrual symptoms. It was also examined whether smoking moderates the relationship between depressive symptoms/anxiety and menstrual symptoms. Numerous measures were used including a physical examination to determine reproductive development, medication and menstrual history were obtained, and blood samples were taken. Girls completed the 24-item

Menstrual Symptom Questionnaire (MSQ) (Chesney & Tasto, 1975) using a 5-point scale from 1- ‘never’ to 5 -‘always’. Depressive symptoms were measured using the 27-item self-report Children’s Depression Inventory (CDI)(Kovacs, 1981) with possible scores ranging from 0-54. The State-Trait Anxiety Inventory (STAI) (Speilberger, Gorsuch, & Lushene, 1970) was used to measure trait anxiety in children aged above 12 years and the child version (State-Trait Anxiety Inventory for Children, STAIC) was used for 11 year old participants (Spielberger & Edwards, 1973). Girls were asked questions regarding smoking behaviour and categorised as ‘ever’ versus ‘never’ smokers. The MSQ was used to measure spasmodic (characterised by symptoms similar to labour pains) and congestive dysmenorrhea (characterised by symptoms or moods in the premenstrual phase). Premenstrual and menstrual pain, menstrual back pain, and congestive and spasmodic dysmenorrhea were significantly correlated with trait anxiety. It was also found that smoking moderated the relationship between depressive symptoms/anxiety and menstrual symptoms. Finally, more depressive symptoms/trait anxiety symptoms were found to be related to higher levels of menstrual symptoms.

Johnson (1988) carried out a survey of 182 adolescent girls (14-18 years) from two school settings. A 31-item multiple-choice questionnaire (with one open-ended question) measured socio demographic information, menstrual characteristics, and dysmenorrheic and premenstrual symptoms. Participants who reported menstrual pain were also asked to report dysmenorrhea characteristics, its impact on school functioning, and girl’s knowledge and management of menstrual pain. Many girls reported that dysmenorrhea caused them to be less active (58.9%), missed school or classes at least once in the previous year (45.6%), and 19 % had missed 3 or more days of school in the past year because of dysmenorrhea.

Fontana and Rees (1982) compared personality variables, intelligence, and school functioning variables between girls with and (n=51) without (n=51) primary dysmenorrhea (determined by school medical records), recruited from a single school in Wales. The two groups were matched by age, school attendance and examination results on English and Mathematics (from second school year, when no symptoms of dysmenorrhea had been observed). The AH2 test of general reasoning (Heim, Watts, & Simmonds, 1974) measured verbal, numerical and perceptual reasoning; the IPAT anxiety scale (Cattell & Scheier, 1963) measured covert and overt anxiety; the new Junior Maudsley Inventory assessed children (aged 11 years) on extraversion and neuroticism dimensions, and the 366-item version of the Minnesota Multiphasic Personality Inventory (MMPI) measured personality variables. Between groups, no significant differences were found in school attendance, overall examination scores, or general reasoning. However, girls who had experienced no dysmenorrhea (4th and 5th year exams) showed greater improvement in examination scores between summer and Christmas exams than those who had. Interestingly, girls with dysmenorrhea had a higher mean AH2 test score than girls without. Girls who experienced monthly menstrual pain reported higher mean trait anxiety scores (overt and covert) and significantly higher levels of neuroticism (among <15 year olds), and “hysteria” (among >15 year olds) scores than girls who had not experienced any dysmenorrhea. Although not significant, girls with dysmenorrhea reported higher scores for social introversion, “hypochcondriasis1F2”, hysteria, psychopathic deviation, psychathenia, and paranoia. However, girls who did not experience dysmenorrhea reported higher mean scores of depression, schizophrenia and hypomania.

Chaudhuri and Singh (2012) recruited 224 girls (13-17 years) from two randomly selected schools in India to complete questionnaires measuring socio demographic information, menstrual characteristics, dysmenorrhea characteristics, and the impact of dysmenorrhea. Pain severity was measured using the visual analogue scale of pain (VASP) ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012), which categorised pain as mild, moderate or severe, and the menstrual distress questionnaire (MDQ) (Moos, 1968) which categorised pain as mild, moderate, severe, or strong. Over half of the sample (59.82%) reported dysmenorrhea. Many girls reported poor school performance (64.1%), taking naps or staying in bed (50.8%), staying at home (53.1%), concentration difficulties (74.2%), avoiding social activities (53.5%), and reduced physical activity (38.2%) as a result of menstrual pain.

Parker et al. (2010) aimed to establish the typical experience of menstruation for 1051 girls (14-19 years) from four schools in Australia and to assess how many experience menstrual problems that may require further investigation for an underlying pathology. The authors developed the Menstrual Disorders of Teenagers (MDOT) questionnaire for which girls were asked to report characteristics of a 'usual' period, menstrual pain, and the menstruation on ADL (attending school, school work, social activities, exercise, social relationships, casual paid work, family relationships, sexual activity, and relationship with partner). Menstrual pain severity was categorised into no pain/ mild pain (0-3), moderate pain (4-7), or severe pain (8-10). 1% of girls reported a medical diagnosis for their menstrual pain (polycystic ovary syndrome and endometriosis).Over a quarter (26%) of girls reported missing school because of menstruation, 94% of which was due to menstrual pain. Most girls reported missing one day of school (70%) and 29% reported missing up to two days. Pain severity was associated with school absence as of those reporting severe pain, 106 (50%) had been absent from school as a result. Significant positive associations were found between pain severity and interference in all activities of life.

Unsal, Tozun, Ayranci, and Orsal (2012) conducted a study to determine the prevalence of dysmenorrhea and its connection with depression among 390 Turkish high school students. Participant ages were not reported. Participants answered questions on medical and socio demographic information, and menstrual characteristics. Menstrual pain severity was measured by the Visual Analogue Scale (VAS) ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012) and the Multidimensional Scoring System (MSS) (Andersch & Milsom, 1982). The Beck Depression Scale (BDS) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) measured depressive symptoms. 144 (51.6%) girls who experienced dysmenorrhea reported depression compared to 25 (22.5%) of girls who did not. Finally, menstrual pain severity was positively correlated with depression scores.

Amu and Bamidele (2014) recruited 400 girls (10-19 years) from six private secondary schools in Osogbo, Nigeria. A pretested, semi-structured questionnaire was distributed to participants to assess their socio demographic characteristics, menstrual characteristics, and prevalence of menstrual disorders and their affect. Of the girls who had begun menarche (n=397) and reported dysmenorrhea, many reported it as severe enough to impact on their daily activities (n=239, 77.3%). Specifically, girls reported that dysmenorrhea affected their school performance (14.8%), ability to sleep (50.6%), ability to read (19.8%), and 'other' activities (4.9%). 24 girls (9.9%) reported that dysmenorrhea had caused school absenteeism.

Liliwati, Verna, and Khairani (2007) administered questionnaires to 300 adolescents (1217 years) from one rural Malaysian secondary school, separated into two age categories: early adolescence (12-14 years) (n=169, 56%) and middle adolescence (15-17 years) (n=131, 43.7%). The questionnaire measured socio demographic characteristics, menstrual characteristics, intensity of pain and its impact on school activities. A numerical rating scale (NRS) ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012) measured pain intensity and categorised intensity as mild (scores of 1-3), moderate (scores of 4-6) and severe (scores of 710). Menstrual pain severity was significantly positively correlated with both school (r=0.690; p<.0005) and class absences (r=0.582; p<.0005). Students with higher mean pain scores also reported impaired concentration in class (p<.05) and ability to participate in sports activities (p<.05).

Wong (2011a) conducted a large study of 1295 post-menarchal, rural adolescent girls (1319 years) from 16 public schools in rural areas of Malaysia. A validated questionnaire, used in one of the author's previous studies (Wong & Khoo, 2010), measured attitudes towards, the impact of, and management of dysmenorrhea. Overall, dysmenorrhea had a negative impact on class concentration (59.9%), social and recreational activities (58.6%), school absenteeism (18.1%) and school performance/ grades (16%). The following characteristics predicted that dysmenorrhea would lead to limited concentration: being in the upper secondary school, being in a family with a high income, and being in a divorced/separated family. Being in upper secondary school and in a high income family also predicted more restriction to social activities due to dysmenorrhea. Living in a high income household predicted less school absenteeism due to dysmenorrhea. Also, being in the upper secondary school predicted reports that dysmenorrhea had negative impact on school performance and grades. Being in the upper secondary school was the strongest predictor for poor concentration, school absenteeism, and poor grades due to dysmenorrhea.

Wong and Khoo (2010) recruited 1092 (13-19) Asian girls from 15 public secondary schools in Malaysia. A semi-structured questionnaire was developed by the research team based on previous studies (Chan, Yiu, Yuen, Sahota, & Chung, 2009; El-Gilany et al., 2005; Tangchai, Titapant, & Boriboonhirunsarn, 2004)and face validated by a team of experts. The questionnaire assessed girl's attitudes about dysmenorrhea, its impact on school and social functioning, and management of menstrual pain. Dysmenorrhea had a profound negative impact on the girl's lives. Specifically, limiting their ability to concentrate (51.7%), restricting their social and recreational activities (50.2%), causing school absenteeism (21.5%) and causing low school grades (16.4%). When investigating the predictors of these effects, it was found that Malays and girls in the upper secondary levels had higher odds of experiencing poor concentration, missing school and missing social and recreational activities. Also, being in the upper secondary level and being from a low income household were predictors of poor school performance or low school grades.

Chongpensuklert et al. (2008) carried out a study of 275 post-menarcheal adolescents from three secondary schools in Thailand. Participants completed a questionnaire assessing menstrual characteristics, menstrual symptoms, management of menstrual pain, and its impact on education activities. Pain intensity was categorised as mild (the perception of menstrual pain or discomfort without the need for treatment), moderate (menstrual pain that needed treatment for relief but did not affect ADL), and severe (menstrual pain that required treatment and limited ADL). Girls experiencing menstrual pain reported a profound impact on educational activities including poor class concentration (n=361, 73%), limited sports activities (n=292, 59.8%), limited social activities (n=137, 28.1%) and absences from school (n=89, 18.2%). Girls in the moderate and severe pain groups reported a greater impact to educational activities than those with mild pain.

Svanberg and Ulmsten (1981) administered questionnaires to 502 adolescent girls (10-19 years) from primary and secondary schools in Sweden which assessed menstrual characteristics, dysmenorrhea characteristics, and treatments received for dysmenorrhea. Overall, severe dysmenorrhea impacted on girls' ability to perform daily activities, caused school absenteeism, and made girls stay in bed. The occurrence of severe dysmenorrhea resulting in absence from school ranged between 8-18% with the older girls reported more of an impact that younger girls. This was also seen in reports of not being able to perform normal activities as just 12% of 14 year olds reported this compared to 25.3% of 18 year old girls.

Frisk et al. (1965) conducted a study of 116 post-menarchal secondary school girls (mostly 16 to 17 years) visiting an Outpatient Clinic for Teenagers. Participants reported the following: medical/gynaecological history, socio demographic information, "psychic symptoms", and "psychic mechanisms". Overall, 57 (49%) girls presented dysmenorrhea, many of which reported other gynaecological and psychological symptoms. Three participants reported a pathological cause for menstrual pain including endometriosis (n=1), follicular cyst (n=1) and suspected pingooophoritis (n=1). Several "psychic" symptoms were reported among adolescents who experienced dysmenorrhea including insomnia (42%), impaired concentration (33%), "emotional instability" (28%), depression (28%), anxiety (26%), conflict with parents (19%), restlessness (14%) and "hysteroid reactions2F " (11%). Girls with dysmenorrhea also reported school problems including impaired results (39%), "aversion" to school (19%), "truancy" (9%), school "tension" (16%) and "problems related to the adaption to gymnastics" (7%). Overall, they found that dysmenorrhea was associated with increased "conflict" and psychological factors. However, these factors were discussed in the paper as mechanisms that may predispose girls to menstrual problems rather than factors that may be a result of dysmenorrhea which is a now outdated view of menstrual pain.

Mohamed (2012) recruited 854 post-menarcheal adolescent girls from four secondary schools in Egypt. Participants were given a semi-structured questionnaire measuring demographic information, menstrual and dysmenorrhea characteristics, the impact of dysmenorrhea (school attendance, academic performance, sports participation, socialising, and ADL), and management of menstrual pain. The visual analogue scale ("Good Practice in Postoperative and Procedural Pain Management, 2nd Edition," 2012) measured menstrual pain severity. Overall, dysmenorrhea had a significant impact on class concentration (53.5%), sports participation (50.9%), class participation (45.3%), going out with friends (35.6%), test taking skills (35.6%) and homework performance (35.6%). 39% of girls reported that they had missed school and 30% had missed school classes because of dysmenorrhea. Of those girls who missed school, 45% reported missing between half and a full day, 38% missed 2-3 days and 17% missed more than four days. Girls with severe menstrual pain reported a significantly greater impact on all domains than those with mild pain.

Santina, Wehbe, and Ziade (2012) asked 389 post-menarcheal girls in grades 8-12 (13-19 years) from five Lebanese secondary schools to complete a self-administered questionnaire assessing socio demographic information, and menstrual characteristics regarding girl's 'usual' menstrual cycles. Two parts of the Menstrual Experience and Behaviour Questionnaire (MEBQ) (McPherson & Korfine, 2004) were used to assess girl's menstrual experiences and scores were categorised as positive or negative experiences. The majority of girls who missed school due to menstruation were those who experienced dysmenorrhea. 87.5% of the girls who regularly missed school on the first day of menstruation reported dysmenorrhea. Dysmenorrhea was significantly associated with missing school days, reporting negative menstrual experiences and mood changes during menstruation.

Negriff et al. (2009) aimed to examine the factor structure and the utility of the MSQ to assess menstrual symptoms in a sample of 210 post-menarcheal adolescent girls (11-17 years). MSQ scores were also correlated with depressive and anxiety symptoms to provide validity for the interpretations of the factors. The 24-item Menstrual Symptom Questionnaire (MSQ) (Chesney & Tasto, 1975) assessed menstrual pain and symptoms. Each item is scored on a scale between 1'never' and 5- 'always' with higher scores indicating more menstrual symptoms experienced. The Children's Depression Inventory (CDI)(Kovacs, 1981) measured self-reported depressive symptoms which consisted of 27 items, each with three different answer options. Higher scores indicated more depressive symptoms. The State Trait Anxiety Inventory (STAI) (Speilberger et al., 1970) for girls >12 years and the State Trait Anxiety Inventory for Children (STAIC) (Spielberger &

Edwards, 1973) was used for 11 year old participants. The STAI and STAIC measured trait anxiety (how they generally feel), consisting of 20 items with responses ranging from 1- ‘not at all’ to 4- ‘very much so’. Abdominal pain (consistent with primary dysmenorrhea) during menstruation was significantly positively correlated with depression symptoms (.19; p<.05) but not with trait anxiety (.07; NS), when controlling for age, race, SES, hormonal contraceptive use and gynaecologic age.

Rapkin et al. (2006) aimed to examine the relationships among hormone concentrations and self-rated tanner staging and the effects of psychosocial factors that might modulate these relationships in a sample of 106 adolescent girls (8-18 years). The authors also aimed to examine relationships between dysmenorrhea, anxiety, somatisation, and depression with tanner stage and hormonal markers of puberty. Pubertal stage was measured using a self-report instrument (Morris & Udry, 1980) based on Tanner’s sexual maturity scale (Tanner, 1962). Menarcheal age was measured by responses to “how long have you been having periods?” which was then subtracted by the participant’s chronological age. A dichotomous measure of dysmenorrhea was used based on responses to two questions: “do you get period cramps?” and “do you take medicines for you period cramps?” Dysmenorrhea was defined as menstrual cramps sufficient enough to warrant medication use. Levels of follicle stimulating hormone (FSH) and estradiol (E2) were measured using two finger prick blood spot procedures (Worthman & Stallings, 1994, 1997). The 39-item Multi-Dimensional Anxiety Scale for Children (MASC) measured domains of childhood anxiety (physical symptoms, social anxiety, harm avoidance, separation anxiety) with higher scores indicating higher levels of anxiety. The 21-item Children’s Depression Inventory (CDI) (Kovacs, 1981) measured depressive symptoms and again, higher scores indicated more depressive symptoms. Finally, the Children’s Somatization Inventory (CSI) (Garber, Walker, & Zeman, 1991) measured perceptions of 35 non-specific somatic symptoms. Again, higher scores indicated higher levels of somatization. Only 54 girls in the sample reported having reached menarche. No association was found between anxiety, depression or somatization scores with dysmenorrhea.

Rani, Sharma, and Singh (2015) compared the impact of dysmenorrhea on the lives of 300 adolescent girls (11-18 years) living in urban, rural, and slum parts of Chandigarh, India. Adolescent girls were recruited using multistage stratified sampling to ensure that data from a representative group of girls from urban (n=100), rural (n=100), and slum areas (n=100) was collected. A questionnaire, designed specifically for the purposes of the study, was used to collect information about the girls’ demographic information, family profile, menstruation, dysmenorrhea characteristics, the impact of dysmenorrhea on life, and beliefs about menstruation. The Visual Analogue Faces Scale (VAFS) ("Good Practice in Postoperative and

Procedural Pain Management, 2nd Edition," 2012) was used to obtain information about menstrual pain severity. Sixty-one percent (n=184) of the girls from urban (n=64), rural (n=62), and slum (n=58) areas reported pain with menstruation. Pain intensity was categorised as 'no hurt' (3.67%), 'little bit' (9.67%), 'little more' (26.67%), 'even more' (9.67%), 'whole lot' (3.67%), and 'hurts worse' (2%). Dysmenorrhea had a negative impact on girls ability to lift heavy objects (38%; n=70), personal care (26%, n=48), sitting on a chair (20%, n=38), standing for long periods (27%, n=50), sleep (17.93%, n=33), social life (17.39%, n=32), and school attendance (24.45%, n=45). Girls who believed that menstrual pain is a natural process, menstrual blood is impure, one can visit family and friends when menstruating, and should bath daily during menstruation were significantly more likely to report dysmenorrhea (p=.0005, p=.0093, p=.039, and p=.014, respectively). No report of whether these beliefs differed between adolescents living in urban, rural, or slum areas was presented

Appendix G Protocol for qualitative studies

Study title: An Exploration of the Impact of Paediatric Chronic Pelvic Pain on the Lives of Young Females and their Families

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SYNOPSIS

Research Aims: This research aims to explore the impact of paediatric chronic pelvic pain (CPP) on the lives of young females (<18) and their families.

Study Design: Individual semi-structured interviews with young females (<18 years old) experiencing CPP and their mother will explore the effect of CPP on all aspects of the individual's life including physical and emotional functioning, school, social interactions with peers, experiences with health care professionals (HCPs) and family functioning. Interviews with mothers will focus on the effects of having a child with CPP on the individual's life, her relationship with the child and her partner (if applicable), and the family as a whole.

BACKGROUND AND RATIONALE

The aim of this research is to explore, using semi-structured interviews, the impact of paediatric CPP on the lives of young females and their families. Due to the limited literature available focussing on paediatric CPP, research on paediatric chronic pain of other aetiologies will first be summarised. Following this, the existing literature focussing on paediatric CPP will be outlined and research questions presented.

Paediatric Chronic Pain

The International Association for the Study of Pain (IASP) defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (Merskey, 1979). Paediatric chronic pain, similarly to that of adults, is generally defined as any continuous or recurrent pain lasting more than 12 weeks, or pain that persists beyond the normal expected time for tissue healing; (Johannes, Le, Zhou, Johnston, & Dworkin, 2010), is complex, and can develop spontaneously, after injury or be disease related (Martin, McGrath, Brown, & Katz, 2007b). An estimated quarter of the paediatric population (0-18 years) experiences some form of chronic pain (Huguet & Miró, 2008; Perquin et al., 2000), although age and gender differences have been found. Research from 5242 children and adolescents (<18 years old) found that prevalence increases with age and that females reported more chronic pain (30.4%) than males (19.5%) (Perquin et al., 2000). The most common forms of paediatric chronic pain were lower limb, abdominal and headache pain (Perquin et al., 2000), although Huguet and Miró (2008) found that girls reported more intense pain in multiple sites, and boys reported more limb pain that girls.

Despite paediatric chronic pain being a major health concern, research has focussed on the prevalence, aetiology and impact of adult pain conditions. This has resulted in limited understanding of paediatric chronic pain and many child pain disorders being ignored (Perquin et al., 2000). Findings from selected studies that have investigated the impact of child pain disorders are summarised below.

The Impact of Chronic Pain on the Child

Numerous quantitative studies have investigated the impact of various types of chronic pain including arthritis, headache, musculoskeletal, recurrent abdominal and low back pain, and found paediatric chronic pain to have a profound impact on many aspects of life including education, sleep, peer relations and physical activity (Eccleston & Malleson, 2003; Malleson, Connell, Bennett, & Eccleston, 2001; Palermo, 2000). Compromised emotional functioning, such as increased levels of anxiety and depression, is also commonly reported by paediatric chronic pain patients (Eccleston et al., 2004).

Qualitative studies have also been conducted to obtain a more in-depth insight into the impact of chronic pain from the child’s perspective. Britton and Moore (2002a) used questionnaires, semi-structured interviews and journals to explore the impact of arthritis on the lives of 46 children (13 boys and 33 girls) and their families. Ethnographic analysis of children’s perspectives showed that many were reluctant to disclose their pain to family or peers which, the authors suggested, was due to children viewing pain as a normal part of their lives, especially those who developed arthritis from a young age. Many children reported that arthritis had a negative emotional impact; eliciting feelings of irritation, resentment and isolation due to feeling 'different' from their peers (Britton & Moore, 2002c). Some children reported feeling as though they were neither disabled, nor 'well' which increased their feelings of isolation.

Meldrum et al. (2008)_ENREF_30 used semi-structured interviews to examine the impact of various types of paediatric chronic pain including headache, fibromyalgia and myofascial pain on functioning and coping strategies. They interviewed 45 children aged 10-18, who, when asked about their pain, reported feeling distress, sadness, anger and most commonly frustration. These feelings were often associated with the impact of pain on daily functioning including their ability to attend school or engage in their favourite hobbies. The authors identified three different ways in which the children were functioning with chronic pain. The most highly functioning children were categorised as 'adaptive', many of whom used distraction as a way of trying to reduce how much they focussed on pain. 'Passive' children were more likely to be overcome by the impact of pain, miss school, and report isolation, whereas 'stressed' children were fairly high functioning but reported high levels of pain-related anxiety. In a follow up study, Meldrum et al. (2009) expanded these findings using 53 in-depth interviews with children aged 10-17 (36 female, 17 male) by asking participants to discuss their life history with pain. Five themes emerged from the data including not wanting to disclose pain to others, feeling isolated from peers, pain-associated activity limitations and concerns about how pain will impact life in the future. The authors, using grounded theory, identified several narratives used by children, all of which told different stories of how children live with their pain. These included the 'weary soldier' who coped with pain despite constant pain-related stress, and the 'invalid' who spoke in terms of being defeated by pain. Follow-up interviews indicated that the narratives used by children could change and that some children were able to develop skills in pain and self-management. This suggests that interventions can be used to improve children's pain-related disability, pain perceptions and perspectives on how chronic pain impacts life.

Paediatric chronic pain patients often visit many HCPs, in search of diagnosis and treatment for their condition (Bennett et al., 2000; Dell'Api et al., 2007), although few qualitative studies have sought to explore these encounters from the child's perspective. Dell'Api et al. (2007), conducted five semi-structured interviews with children aged 10-17 experiencing chronic leg, abdominal, chest and non-specific pain. They were asked to discuss their encounters with health care professionals (HCP's), and found that the pain itself was not the only cause of negative emotions. Interpretive descriptions of their transcripts revealed that these encounters often left children feeling misunderstood, abandoned and disbelieved. These findings, along with Meldrum et al.'s (2009) findings that children felt HCPs were not understanding of their pain, suggest that HCP encounters are an important aspect of paediatric chronic pain, not only in terms of diagnosis and treatment, but also in terms of the child's emotional well-being.

Longitudinal studies show that childhood chronic pain disorders such as headache, back pain and abdominal pain often persist into adulthood (Brattberg, 2004; Christensen & Mortensen, 1975; Guidetti et al., 1998; Walker, Dengler-Crish, Rippel, & Bruehl, 2010). Pain persistence, among other reasons, may be associated with negative emotions such as anxiety or fear, which are frequently reported by children with chronic pain (Martin, McGrath, Brown, & Katz, 2007a). The fear-avoidance model of pain explains that acute pain may become chronic due to a cycle of pain-related fear leading to the avoidance of pain-related stimuli such as physical activity (Asmundson, Norton, & Vlaeyen, 2004). Martin et al. (2007a) investigated the relationship between anxiety, fear and chronic pain in a group of 17 children (8-17 years) experiencing continued headache, abdominal, musculoskeletal and chronic regional pain, three years after being discharged from a paediatric chronic pain clinic. They found that children with higher anxiety scores reported increased pain-related fear, which was linked to increased pain-related disability. They concluded that anxiety and fear may play a role in the cognitive-behavioural processes that maintain paediatric chronic pain. Therefore, understanding and addressing these negative emotions associated with paediatric pain may help reduce the risk of continued pain, and therefore reduce the likelihood of paediatric pain persisting into adulthood.

Paediatric Chronic Pelvic Pain

Chronic pelvic pain (CPP), defined as a non-malignant pain in structures related to the pelvis (Fall et al., 2004), below the umbilicus (Nasir & Bope, 2004), is a neglected, under researched paediatric chronic pain disorder, despite being one of the most commonly reported symptoms by adolescents aged 11-19 (Vercellini et al., 1989), accounting for 10% of adolescent visits to gynaecologists, and 20% of laparoscopies (Hewitt & Brown, 2000). There are several types of paediatric CPP, the most common being dysmenorrhea, commonly occurring during adolescence (Nasir & Bope, 2004). Endometriosis is a common cause of both cyclic menstrual-related pain and acyclic pelvic pain in adolescents (Nasir & Bope, 2004; Song & Advincula, 2005). One review found dysmenorrhea to be as prevalent as 90% in adolescents aged 13-19, with 15% describing it as severe (Davis & Westhoff, 2001), and another found that 62% of female adolescents (13-20 years) experiencing CPP were diagnosed with endometriosis (Janssen, Rijkers, Hoppenbrouwers, Meuleman, & D'Hooghe, 2013). CPP in adult women (18-50) however, is often undiagnosed and paediatric CPP can present further diagnostic difficulties as pelvic pain is frequently described by young people as ‘stomach ache’ and is accompanied by gastrointestinal symptoms such as constipation and nausea (Sager & Laufer, 2013). HCPs are often unable to determine a cause for CPP, and in many cases laparoscopic investigations conclude that the pelvis appears normal (Song & Advincula, 2005). The pathology of CPP is therefore often difficult to determine and frustrating for HCP’s to manage (Greco, 2003).

A very limited amount of studies have investigated the impact of paediatric CPP on the lives of children. A Finnish quantitative study (Olof Widholm, 1979) recruited 331 13-20 year old females with dysmenorrhea and found that, despite experiencing pain, many did not seek help from HCPs. They also reported frequent school absences (23.4%) due to pelvic pain. These findings were supported by Wijesiri and Suresh (2013) who conducted a questionnaire study of 200 adolescents from one school in Sri Lanka and found that 44% reported menstrual pain-related school absence, 17% of which was reported as ‘frequent’ absence. Other quantitative studies have found associations between adolescent dysmenorrhea and depression, reduced body satisfaction and lower academic performance, and school concentration (Ambresin, Belanger, Chamay, Berchtold, & Narring, 2012; Chaudhuri & Singh, 2012; Eryilmaz et al., 2010; Ana Carolina R. Pitangui et al., 2013; Unsal et al., 2012). It has also been found that dysmenorrhea has a profound impact on activities of daily living and relationships with family and friends (Banikarim et al., 2000; Eryilmaz et al., 2010). Despite the alarming lack of evidence on the impact of CPP on children’s lives, reviews of paediatric chronic pelvic pain have been conducted based on adult CPP and other paediatric chronic pain conditions. These conclude that children with CPP may experience altered peer and social interactions, depression, anxiety and limitations to daily activities (Greco, 2003; Schroeder & Sanfilippo, 1999). Greco (2003) also suggested that these associations may be bi-directional for example, young people with CPP may experience feelings of depression and fear that may exacerbate their experience of pain.

Very few studies therefore, have investigated paediatric CPP and its impact on the lives of children, despite evidence from the literature that paediatric chronic pain of various aetiologies has a profound effect on all aspects of life. CPP patients of any age often see several HCP’s, including their GP and gynaecologist (F. M. Howard, 2003) . Specifically, for paediatric CPP patients, multiple pelvic examinations are often carried out during the diagnostic phase (Emans, 2005) and are likely to be the young female’s first ever pelvic examination (Song & Advincula, 2005). Although research has evaluated the use of self-hypnosis in reducing anxiety and pain during adolescent pelvic examination (Kohen, Olness, Colwell, & Heimel, 1984), research has yet to explore the young person’s thoughts and feelings related to these invasive procedures, particularly for children and adolescents experiencing chronic pain.

Appendix G

Parenting a child with Chronic Pain

There are no studies investigating the impact of parenting a child with CPP however, we have summarised the existing literature focussing on other forms of paediatric chronic pain and its impact on the young patient's family. The existing literature suggests that paediatric chronic pain spreads out beyond the child who experiences it (Maciver et al., 2010) and quantitative research shows that paediatric chronic pain is associated with maternal distress and depression (Eccleston et al., 2004; Logan & Scharff, 2005). Despite this, few qualitative studies have explored the views of those parenting a child with chronic pain; these are discussed below.

Bennett et al. (2000) used a mixed methods approach to explore the views of 43 parents of children (eight boys, 35 girls) aged 7-16 years with chronic arthritis, musculoskeletal, headache and abdominal pain. Parents completed questionnaires comprising of both open and closed questions based on their child's experience of pain over the past year, its impact on family life, and treatments used to manage pain and reported both personal and economic costs due to their child's chronic pain condition. Another study used questionnaires, in-depth interviews and journals to explore the impact of paediatric arthritis on the lives of the family including mothers, fathers, and siblings (Britton & Moore, 2002a). Only eight of the 46 fathers completed questionnaires and it was found that in nearly all cases, mothers, as opposed to fathers, were responsible for managing their child's daily care. In accordance with other findings that mothers are often the primary caregivers of children experiencing chronic pain (Hunfeld et al., 2001), this suggests that mothers are able to provide a more detailed insight into paediatric chronic pain and its impact on the lives of the child and family. Mothers felt that due to caring for their child with arthritis, they had less energy and time to engage in family leisure activities and many were concerned about having less time with other siblings. Parents reported feelings of helplessness and that difficulty obtaining a diagnosis for their child's pain often evoked negative emotions such as anxiety and frustration with HCP's which was supported in Carter's (2002) study using loosely structured interviews to explore the perspectives of three mothers, three fathers, one grandparent, and one sibling, of children with chronic knee, abdominal and back pain. Thematic analysis showed that family members reported negative feelings about HCP encounters which often resulted in parents feeling judged and disbelieved.

Maciver et al. (2010) interviewed 12 parents, ten mothers and two fathers, of children with chronic musculoskeletal and neuropathic pain, asking them to tell the story of their child's pain from the beginning. They used an inductive, thematic and interpretive approach and found that many parents report distress when their child's chronic pain symptoms are first presented, although some develop a more adaptive response, being able to control emotional reactions to their child’s pain. Parents that thought they should be able to stop their child’s pain, and were catastrophizing more, felt more negative emotions such as hopelessness and distress (Maciver et al., 2010). This suggests that parents of children experiencing any type of chronic pain may need support in how to effectively care for their child’s pain and alleviate their own distress. Despite this evidence that paediatric chronic pain affects the family and their importance in managing their child’s pain, parents have been neglected in research (Palermo & Eccleston, 2009).

Recent qualitative and mixed methods research, aiming to explore parent- child pain associations, suggested that parents may influence their child’s experience of pain. Evans, Meldrum, Tsao, Fraynt, and Zeltzer (2010) used mixed methods to study 179 children aged 11-19 experiencing chronic pain and their mothers. A sub-sample of 34 mothers and children also participated in in-depth interviews which suggested that girl’s pain and pain-related disability is related to maternal models of pain and an overly enmeshed mother-daughter relationship. These parent-child pain associations may be explained by operant-behavioural models which posit that parents may reinforce their child’s pain behaviours (Walker & Zeman, 1992). Solicitous responses to child’s pain (e.g. allowing school absenteeism) is associated with increased self -reported pain and pain behaviours (Walker & Zeman, 1992) and parental catastrophizing of child’s pain is associated with avoidance behaviours (Caes, Vervoort, Eccleston, Vandenhende, & Goubert, 2011). This is further supported by experimental studies that maternal pain promoting behaviour is associated with girls responses to the cold pressor test (Chambers, Craig, & Bennett, 2002). Findings of parent-child pain associations indicate that parental behaviours and responses are an important factor in their child’s pain experience, suggesting that parents should not be neglected in paediatric chronic pain research.

In addition to the impact of parenting a child with chronic pain and the parent-child pain associations discussed above, there are specific factors related to parenting a child with CPP that require further exploration. During the diagnostic phase of paediatric CPP, HCPs must speak confidentially with the patient about sexual activity, sexual assault, pregnancy and drug or alcohol abuse (Song & Advincula, 2005). It is suggested that the acknowledgement of sexual assault as a possible cause in these early phases of diagnosis could potentially affect relationships between the parental couple. Mothers are also sometimes present during their child’s pelvic examination (Song & Advincula, 2005), yet no qualitative research has explored the thoughts and feelings of mothers in this situation and the impact of paediatric CPP on family life has yet to be explored.

In sum, chronic pain affects many aspects of young people’s and their family’s lives. Paediatric CPP is complex, difficult to diagnose and manage, highly prevalent, and often involves invasive exploratory procedures. However, unlike other common paediatric chronic pain disorders, there has yet to be any qualitative exploration into how young females experience this pain, what impact it has on their and their families lives, and how they cope with it. Therefore, with the aim of addressing this gap in the existing literature, a qualitative deign has been chosen to obtain an in-depth understanding of the experience of pain of young females (<18) and their mothers, its impact on life, along with experiences of medical procedures and treatments for CPP. Improved understanding of these phenomena will have many positive implications such as helping HCP's, education professionals and family members to understand and improve management of the effects of paediatric CPP and improve quality of life for both the children and their families.

RESEARCH QUESTIONS

This study will explore the following research questions:

How do young females experience chronic pelvic pain and how does it affect all aspects of their lives including physical, psychological, school and social functioning, and well-being?

How do mothers experience parenting a child with chronic pelvic pain and how does chronic pelvic pain impact upon them as individuals, the family unit, and the parental couple where relevant.

OVERALL STUDY DESIGN AND MEASURES

Participants will complete one interview, each lasting approximately 30-60 minutes which will take place at the University of Southampton Pain Research Laboratory or, in the participants' own homes. In exceptional circumstances, mothers' may be interviewed over the telephone. Participants over the age of 16 can come alone to the interview if they prefer. All young participants (<16 years) must have a parent or guardian accompany them to interviews. The Pain Research Laboratory has a sound proof room where the interviews will take place. Young participants (<16 years) will be asked if they would like their parent/ guardian to wait in the waiting area outside the Pain Research Laboratory which is separated from the interview room by a door with a glass panel, so that the child can see her parent/guardian at all times. Younger children will be asked if they would like to have their parent/ guardian present in the interview room for the interview. If participants decide to have the interview take place in their own homes, daughters will be asked where they would like their parent(s) to wait during the interview. Doors of the interview rooms in participants own homes will remain open at all times.

A semi-structured interview design, using open-ended questions will allow participants to discuss issues important to them in detail and broaden the possibility of addressing new, unanticipated topics (Braun & Clarke, 2013; Kortesluoma et al., 2003). Each interview will follow an interview schedule, tailored for each type of participant, developed by the researcher and based on discussions with academic supervisors and previous research (DiCicco-Bloom & Crabtree, 2006). Prompts and probes will also be used to encourage participants to clarify, expand, and provide more detailed answers (Braun & Clarke, 2013). As data collection proceeds, enhanced understanding of important issues may lead to interview guide alterations (DiCicco-Bloom & Crabtree, 2006). When interviewing young people, techniques will be appropriately modified based on their individual and cognitive development stage (Faux et al., 1988).

Finally, interviews with mothers and adolescents will begin with a broad, open-ended question, whereas child (<8 years old) interviewees will first be asked if they would like to draw their pain. This aims to facilitate discussion, particularly for younger children who sometimes find it difficult to describe or locate their pain Britton & Moore, 2002c; Driessnack, 2005). If the child creates a drawing, the researcher will ask the child to explain what they have drawn, what it means, and what it tells us about the pain that they are experiencing. All interviews will be audiotaped and transcribed verbatim.

PARTICIPANT IDENTIFICATION

Study Participants

Overall, approximately 20 participants will be recruited consisting of ten mothers and ten children. Recruitment will stop once data saturation, the point where additional data fails to generate new information (Morse, 1995; as cited in Braun & Clarke, 2013), has been achieved.

Young Females (<18 years old) Experiencing Chronic Pelvic Pain

Inclusion criteria for this study include: a) female gender, b) aged 4-18 years old, c) have experienced some form of CPP severe enough to require medical consultation d) for a minimum of 3 months (or 3 menstrual cycles for dysmenorrheic girls), e) be fluent English speakers, f) provide assent/consent where necessary.

Exclusion criteria for this study include: a) male gender, b) aged <4 years or >18 years, c) not fluent English speakers, d) unable to provide assent or comply with study procedures, e) diagnosed with learning difficulties, f) diagnosed with a major psychiatric disorder, g) another chronic medical condition.

Mothers of Young Females Experiencing Chronic Pain

Inclusion criteria for this study include: a) aged >18 years, b) be a biological or adoptive mother of the CPP patient, c) speak fluent English, d) be able to provide consent for their own and their child's participation in the study, e) be able to comply with all study procedures.

Exclusion criteria for this study include: a) aged <18 years, b) are unable to give consent for either themselves or their child, c) diagnosed with any major cognitive impairments, d) diagnosed with a major psychiatric disorder, e) are foster parent of the CPP patient.

STUDY PROCEDURES

Recruitment

Contact will be made with the head teachers of local primary and secondary schools to ask permission to recruit female students aged 4-18 years. If permission is granted, letters inviting students and parents to take part in the study will be drafted and sent to school personnel for approval. Once approved, the letters will be sent to parents through the schools. The researchers contact details will be provided on the letter and mothers will be asked to contact the researchers directly if they would like themselves and their daughter to participate.

Children and adolescents experiencing CPP and their mothers from the community will also be recruited via advertisements in local newspapers, the Vulval Pain Society (VPS) website, and the University of Southampton 'SUSSED' website. Participants will also be recruited via press announcements (through the University of Southampton), and posters at local youth groups (i.e. girl guiding groups in Southampton), community centres, and the University of Southampton. Potential participants expressing interest in the study will be sent information sheets and a letter by post, inviting them to meet informally with the researchers.

Informed Consent

Potential participants will be provided with an information sheet, tailored to their age, language abilities and participant type. This will detail all aspects of the study, participation requirements, and information regarding right to withdraw and confidentiality. Participants will also be given the opportunity to meet with the researcher if they would like, before the study for any further questions they may have.

Younger participants (<16 years old) will be required to give written informed assent once fully informed parental consent for their participation is provided. Informed consent (adolescents aged 16-18 years, and mothers) and assent (children aged <16 years) will be obtained via a dated signature and kept at the University of Southampton.

If mothers take part in telephone interviews, their information sheet and consent form will be sent to them in the post. Participants will also be sent a stamped, return address envelope. Once participants have read, fully understood the information sheets and sent signed consent forms to the researcher, the interview can take place. Debrief forms will be sent to participants of telephone interviews either by post or email depending on participant preference.

Before each interview, participants will be informed again during the preamble that they are able to withdraw from the study at any time, reminded that their information will remain confidential and asked again if they are happy to participate and begin the study.

Procedure

The interviewer has previous experience in interviewing (n=20) adult women experiencing chronic pelvic pain and will first be trained in paediatric interview techniques by Dr Christina Liossi, experienced Paediatric Psychologist researcher, currently Senior Lecturer in Health Psychology at the University of Southampton and Honorary Consultant Paediatric Psychologist at the Paediatric Chronic Pain Clinic, Great Ormond Street Hospital for Children, NHS Trust, London. Dr Christina Liossi will also guide the researcher in appropriate reading materials, including guidelines for child interviews. Dr Christina Liossi will be nearby during interviews with younger participants (<10 years) and interviews that take place at the University of Southampton. She will also be working closely with the interviewer, listening to transcripts and providing feedback.

Before each interview, the researcher will introduce herself and the study again, participants will be thanked, reminded of their right to withdraw, confidentiality and that the interview will be recorded. All participants will be assured that there are no right or wrong answers and will be asked if it is OK for the researcher to start the recording and the interview. At the end of the interview, once all topics from the interview schedule have been covered, participants will be asked if they would like to add anything, thanked and the recording will be stopped. Participants will then be debriefed. Finally, all participants will be entered into a raffle where the winner will receive a prize worth £20-£30.

Definition of End of Study

The end of study is the date of the last interview.

Analysis

Interviews will be transcribed verbatim by the chief investigator and analysed using thematic analysis, following Braun and Clarke’s (2006) guide, identifying and reporting themes (Braun & Clarke, 2006). A ‘bottom up’ approach will be applied and initial codes will be generated for each transcript and then revised, collated and categorised into potential themes. Regular revision of potential themes will take place until a final thematic map consisting of an overarching theme, themes and subthemes is created and agreed by all researchers. When analysing children's transcripts, care will be taken to keep particularly close to the data set to avoid biasing the results with an adult researchers' perspective.

The final results will describe all themes relating to how CPP affects young women and their families from the mothers and daughters perspectives. Similarities and differences will be noted between adult and child accounts of CPP, and between adolescents experiencing cyclic, menstrual-related pain (dysmenorrhea), and those experiencing non-cyclic CPP.

DATA MANAGEMENT

Data Recording and Record Keeping

Audio recordings and transcripts will be saved on a password only access computer. Any identifying information will be eliminated from the transcripts and replaced with pseudonyms.

ETHICAL AND REGULATORY CONSIDERATIONS

The paediatric CPP participants are classified as a vulnerable group (Kortesluoma et al., 2003). Therefore, procedures will be put in place to ensure their safety at all times. The researcher has been CRB checked and all young participants will be informed that if they indicate that they, or another child are at risk of harm, then confidentiality between researcher and participant can be breached and the appropriate authorities will be contacted such as ChildLine or the NSPCC. All children will be given details of these organisations in the debriefing statement as well.

When recalling experiences related to pain or the effect of CPP on their lives, participants may show signs of distress. If this occurs then the researcher will manage it effectively by acknowledging it, asking participants if they would like to stop the interview, and by reminding participants that support is available to them by their general practitioner (GP) and school (Braun & Clarke, 2013). Mothers will also be nearby to assist with younger children taking part in the interview. Details this will be provided in the Risk Assessment forms and School Ethics forms provided by the University of Southampton.

All participants will be debriefed at the end of the study and young participants (>16 years old) will be asked to discuss the interview during debriefing to monitor for any unforeseen effects (Neill, 2005).

Risk assessment procedures will also be put in place to endure the safety of the researcher and participants.

Lastly, if participants travel to the University of Southampton for interview, any travel costs will be compensated.

FINANCE

Funding

Funding has been granted by the ESRC.

Interview schedule

To begin with, the researcher will provide the participant with the information sheet and consent forms. Once consent is given, the researcher will then introduce the interview with the following:

Preamble

First of all I would like to thank you for taking part in my study and welcoming me into your home. My name is Polly, I am a PhD student from the University of Southampton and this interview is part of my PhD research.

From these interviews, I am interested in finding out how paediatric CPP affects all aspects of young people and their families' lives such as school, friendships, self-esteem, family functioning and parental relationships. The interview will be just like a conversation, there are no right or wrong answers and anything that you can tell me about this during the interview will be interesting and helpful.

Anything you tell me during the interview will be confidential *.

*for children: unless you disclose that you or another child is at risk of harm, in which case, I will have to contact the appropriate authorities to ensure your safety.

You will not be referred to by name but as a participant number allocated to you and any names or locations mentioned during the interview will be edited out of the study and replaced with pseudonyms is this OK?

The interview is going to be recorded, is that OK?

If at any point during the study you would like to stop participating in the research, please let me know and I will stop the interview. *

*for children: If you feel that you would like a break at all during the interview, just let me know and I will stop the interview until you are ready to continue.

Do you have any questions? Are you happy for me to start recording and begin the interview?

Interview Schedule for girls (<18 years old) experiencing CPP

So, if it's OK, can you tell me a bit about yourself please? *Probe: School year, age, favourite school lessons, favourite hobbies, family and living arrangements.*

Would it be OK if I ask you about the (use appropriate term for pain i.e. stomach ache/ pelvic pain/ period pain/ sore tummy) you experience now? *If participant agrees, move on to questions 1, 2 and 3.*

Ice breaker for younger children (<8 years old): Would you like to draw a picture of your (insert child specific term used for pelvic pain)? *Probe: Can you explain to me what this means? How does the pain feel? Do you remember when it started? Has it changed since you first felt your (insert appropriate word for pelvic pain)? What makes the (insert appropriate word for pelvic pain) worse or better?*

For older children/adolescents (>9 years old): Can you tell me a bit about the (insert appropriate work for pelvic pain) that you experience? *When did it start? Has it changed at all? Have you noticed any times when the (insert appropriate word for pelvic pain is worse or better?*

For younger children (<8 years old): Have you been to see a doctor about your (insert appropriate word for pelvic pain)? *If yes, what happened when you went to see them? What did your doctor do? Did it help? What did you think of that (treatments)? What was that like? How did you feel about that?*

For older children/ adolescents (>9 years old): Can you please tell me about any treatment you have had for the pain? *What HCP did you go to first? How did you find that? Where did you go from there? Can you tell me what treatments you have had? What do you think of them? Have you had any examinations? What was that like? How did you feel about that?*

Would it be OK to talk about any effect CPP has had on your life? If participant agrees, go to question 5.

For younger children (<8 years old): Do you think the (insert appropriate word for pelvic pain) affects parts of your life? *How about school? Does it make a difference to the things that you can do? What about (insert hobbies mentioned previously by the interviewee)? What about family type things? Do your friends know about your (insert appropriate word for pelvic pain)? How do* *you feel about having (insert appropriate word for pelvic pain)? Can you tell me some more about that please? How does this make you feel?*

For older children/ adolescents (>9 years old): Do you think that the (insert appropriate word for pelvic pain) affects your life in any way? *(School, physical functioning, hobbies, sports, friendships, social life, family life, self-esteem, social support, future plans) Probe: How does it affect it? Can you tell me more about this? How does this make you feel?*

Is there anything that we haven't talked about today that you would like to talk about in this interview?

Interview Schedule for Mothers of girls experiencing CPP

OK, so to start off, can you please tell me a bit about yourself? *Age, Occupation, family situation and living arrangements, hobbies.*

If it is OK with you, we will now discuss (name of child's) pelvic pain.

So, can you tell me about the pain that (name of child) experiences? *Probe: when did it start? When were you first aware of it? How did she describe it to you? Have you noticed any times when it is worse or better? Has the pain changed at all over time?*

Could you tell me about treatments for (insert the same term for CPP that mother used) that (name of child) has had? *When did she first seek medical help? What HCP's has she seen? Alternative therapies? How do you feel about the treatments? Examinations? How did you feel about that? How do you think (name of child) felt at the time?*

If it's OK, we will now discuss the effect of (insert the same term for CPP that mother used) on (name of child)'s life and family life.

Do you think the (insert the same term for CPP that mother used) affects her life in any way *(School, hobbies, sports, friendships, relationships with siblings, social life, social support, self-esteem, future plans) Probe: How does it affect it? How do you think this makes (name of child) feel? How does this make you feel?*

Do you think the (insert the same term for CPP that mother used) affects your life in any way? (*Social life, family activities, occupation, relationship with other children, relationship with partner, family dynamic, leisure, anxiety)Probe: How does this make you feel? How does it make other family members feel?*

Is there anything that we haven’t covered that you would like to talk about in this interview?

Techniques that will be implemented where appropriate in the interview:

That’s interesting; can you please tell me more about that?

“Yeah”

“mhmm”

Nodding

Appropriate pauses

“Could you please just clarify something for me, what did you mean by?”

Ending the Interview

Thank you very much. What you have said has been very helpful. Is there anything you would like to add before I stop the recording? Thank you for sharing this personal information.

Appendix H Information Sent to Schools

Recruitment Letter

Version: Two, date: 16.09.2014

Researcher: Polly Langdon

ERGO Study ID number: 12099

Dear (insert name of Head Teacher),

We are writing to request permission to ask your female students and their mothers to take part in a study exploring the impact of period-related pain on the lives of young girls and their families. Period pain is usually located in the lower abdomen and pelvis and characterised by a crampy pain during menstruation. In particular, we are interested in understanding how period pain impacts on all aspects of young people's (<18 years) and their family's lives. Period pain is under-researched in adolescents, despite being highly prevalent, causing high rates of school absenteeism, and impacting on academic performance. We hope that the results of this study will help improve understanding of adolescent period pain and that this may, in the future, reduce the negative impact of period pain on all aspects of life for young girls.

This project has received Ethics approval from the School of Psychology, University of Southampton Research Ethics Committee. The PhD student conducting the study, Polly Langdon, and academic supervisors, Dr Christina Liossi, and Dr Cynthia Graham, have been cleared with a criminal records bureau check.

We are recruiting girls who have experienced period pain for a minimum of three months (or three periods) and their mothers to participate in individual, audiotaped interviews. Young people experiencing period pain can take part in this study whether or not they use medication for their pain. The interviews can take place either at the University of Southampton Pain Research Laboratory, or in participants own homes and last approximately 30-60 minutes. Interviews with mothers can take part over the telephone. We will ask girls about their period pain and its impact on all aspects of life including physical, social, psychological, and school functioning. We will ask mothers about their daughter's period pain and its impact on all aspects of their families lives. Only the researchers will have access to the data, and the results will only be used in conjunction with this investigation. All participants will also be entered into a raffle where the winner will receive a prize worth £20-£30.

If you are willing to help us with recruitment for our study, then please let us know what will be easiest for you. We can come and meet with you to discuss the study in further detail, or email you a copy of the participant information sheets.

Should you wish to talk about this study further, please do not hesitate to contact Polly Langdon on 02380 594597 or email: plhj1e12@soton.ac.uk. You can also contact Dr Christina Liossi on 023 8059 4645 or email C.Liossi@soton.ac.uk. We would very much appreciate your support on this important project.

Looking forward to hearing from you soon.

Yours sincerely,

Polly Langdon,

University of Southampton PhD student.

Dr Christina Liossi, CPsychol

Senior Lecturer in Health Psychology

Honorary Consultant Paediatric Psychologist

Appendix I Recruitment Poster

Exploring Period-Related Pain Version ONE: 05.11.2014

Researcher: Polly Langdon

ERGO and RGO Study ID: 12099 (12871 after amendments)

Researchers at the University of Southampton are exploring how period-related pain affects the lives of young girls and their families. If you are a girl who has experienced period-related pain for the last three months (or three periods) in a row, please contact us to take part in this important study. You can participate in this study whether you use medication to relieve your pain or not.

We would like to interview both girls with period-related pain and their mothers. The interviews will last around 30-60 minutes and take place at the University of Southampton Pain Research Laboratory, or your own home. Travel expenses of up to £20 will be reimbursed. Also, participants will be entered into a raffle where the winner will receive a prize worth £20-£30. We hope that our findings will help improve understanding of period-related pain which may, in the future, benefit the care that young people with period-related pain receive.

If you are interested in participating, or would like to receive further information, please contact Polly Langdon by email: plhj1e12@soton.ac.uk or telephone 02380594719

plhj1e12@soton.ac.uk
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plhj1e12@soton.ac.uk

Appendix J Information Sheets and Consent Forms

Participant Information Sheet for Children and Adolescents (11-15 years) (Version no: Two, date: 16.09.2014)

Study Title: How does period pain affect children and their families?

Researcher: Polly Langdon.

ERGO and RGO reference number: 12099 (12871 after amendments)

(To be read with a parent/guardian/the study researcher)

Note: Make sure you read this with your parent/ guardian or the researcher for this study.

We are asking whether you would join in a research project to find out the answer to these questions:

1. How does period pain affect a child’s life?
2. How does period pain affect a child’s family?

If you decide to, you can help us to answer question 1 and your mother can help us answer question 2.

Before you decide if you want to join in, it‘s important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, teacher, doctor or nurse if you want to.

There are 2 parts to this information sheet:

Part 1: We will describe our research; tell you why it is being done, and what you would do if you decide to join in.

Part 2: Go into a little bit more detail about the research

Part One:

<u>Why are we doing this research?</u>

We would like to understand how period pain affects children and their families. We would like to know this so that more people can learn about it. This might help doctors and professionals take care of young people with pelvic pain in the future.

Why have I been invited to take part?

You have been invited because you are a young person who experiences period pain. Because you are living with this pain, you (and other girls with period pain) will be able to tell us about it and help us to answer our research question.

Do I have to take part?

No! It is up to you. We will ask you for your assent (permission) and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

What will happen to me if I take part?

If you would like to take part in this study then we would like to arrange one interview with you. The interview will be audio-recorded and transcribed word-for-word by the researcher.

Your interview will last for around 30-60 minutes and will be similar to a conversation. The researcher will ask you some questions about your pain, experiences and how it affects your life.

You and your mum can decide whether you would like the interview to take place at home or the University of Southampton Pain Research Laboratory. The Pain Research Laboratory has a sound proof room where the interviews will take place. Your mum or dad must come with you to the interview but you will be asked if you would like your parent/ guardian to wait in the waiting area which is separated from the interview room by a door with a glass panel, so that you can see your parent/guardian at all times. Travel expenses, of up to £20 per participant, will be compensated. If you decide to do the interview at home, you will be asked where you would like your mum or dad to wait during the interview. Doors of the interview rooms in participants own homes will remain open at all times.

What will I have to do?

You will be asked to answer as honestly as possible about your experiences and feelings. You will not have to discuss anything that you do not want to.

Also, you won't have to miss any school because we can conduct the interview outside of school hours.

Is there anything to be worried about if I take part?

If you feel upset at all during the interview, you can let the researcher know. The researcher will be understanding and ask if you would like to take a break from the interview. If you feel distressed at all or say that you would like to stop, the researcher will stop the recording and the interview. If this happens, your travel expenses will still be compensated and your standard of care will not be affected. The researchers will understand if you would like to stop taking part at any time.

What are the possible benefits to taking part?

We cannot promise that there will be benefits to taking part. We hope that our findings will improve understanding and help to improve care for children with period pain in the future. If you participate, you will be entered into a raffle where the winner will receive a prize worth £20-£30.

Contact Details:

If you have any questions and would like to contact one of the researchers:

Name of researcher: Polly Langdon

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

Thank you for reading this so far, if you are still interested, please go to **part 2**:

Part 2:

What if there is a problem?

If you do not feel comfortable with the way you have been treated in the study, please tell your parent/ guardian or one of the research team. We will try to solve the problem immediately, listen to any complaints and try to resolve it as best we can.

If you would not like to discuss the complaint with a researcher and would like to make a formal complaint then please contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk.

Will anyone else know I’m doing this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. Wherever possible, we will only send out information that has your name and address removed.

The only time that we won't be able to keep your information in confidence is if you tell us that you or another child is at risk of harm. If this happens then the appropriate authorities will be contacted (i.e. ChildLine or the NSPCC).

What will happen to the results of the research study?

If you would like to find out about the findings of our research, you will be able to contact any member of the research team who will be happy to provide you that information or links to the published report. Your parent/guardian will also be able to help you with this.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee.

They make sure that the research is fair. Your project has been checked by the University of Southampton Research Ethics Committee.

Thank you for reading this – please ask any questions if you need to.

Contact Details:

If you have any questions and would like to contact one of the researchers:

Name of researcher: Polly Langdon

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

Participant Information Sheet for Adolescents (16-18 years) (Version no: Two, date: 16.09.2014)

Study Title: An Exploration of the Impact of Period-Related Pelvic Pain on the Lives of Young Females and their Families

Researcher: Polly Langdon.

ERGO Study ID and RGO reference number: 12099 (12871 after amendments)

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

Invitation:

We would like to invite you to take part in our research. Before you decide whether you would like to take part or not, we would like you to understand why we are carrying out this research and what your help would involve. A member of our research team is going to go through this information with you and will be happy to answer any questions you might have. Please make sure you take as much time as you need to go through this information and talk to others about it (i.e. your clinician, family, teachers, or peers) if you would like.

In our research, we are interviewing young girls who are experiencing chronic pelvic pain and their mothers.

The first part of this information sheet will explain why we are carrying out this research and what your participation would involve. The second part will go into some more details about the conduct of the study. Please ask us if any of the information is not clear or if you have any other questions.

Part One

What is the purpose of the study?

This study is being conducted to help researchers and health care professionals to better understand how your pain affects your life and your family's life. We would like to find this out because so far, there is very little understanding about this. By improving how much people know about it, we may, in the future, be able to help improve the quality of care and management for girls who experience this pain and their families.

Why have I been invited?

You have been invited to help with our research because you experience period pain.

Do I have to take part?

It is up to you whether or not you take part in this study. Once we have described the study and you have understood all of the information in this sheet, you can tell us whether you would like to take part or not. If you would then we will ask you to sign a consent form. You are free to change your mind at any time in the study, even if you have signed the form. If you do decided that you would not like to take part, or you withdraw your consent, you do not have to give a reason and this will not affect any care you receive for your pain.

What will happen to me if I take part?

If you consent to take part in this study then we would like to arrange one interview with you. The interview will be audio-recorded and transcribed word-for-word by the researcher.

Your interview will last for around 30-60 minutes and will be similar to a conversation. The researcher will ask you some questions about your pain, experiences and how it affects your life.

You and your mother can decide whether you would like the interview to take place at home or the University of Southampton Pain Research Laboratory. The Pain Research Laboratory has a sound proof room where the interviews will take place. Travel expenses, of up to £20 per participant, will be compensated. You can either come to the interview on your own or with a parent/ guardian.

What will I have to do?

You will be asked to answer as honestly as possible about your experiences and feelings. If you do not wish to answer anything just let the researcher know. You will not have to discuss anything that you do not want to.

You can decide to have your interview outside of school/work/college hours.

What are the possible disadvantages to taking part?

If you feel upset at all during the interview, you can let the researcher know. The researcher will be understanding and ask if you would like to take a break from the interview. If you feel distressed at all or say that you would like to stop, the researcher will stop the recording and the interview. If this happens there will be no penalty or consequences to you or your mother. Your travel expenses will still be compensated and your standard of care will not be affected.

What are the possible advantages to taking part?

We cannot promise that there will be any advantages to taking part in this research. We hope that our findings will improve understanding about paediatric chronic pelvic pain and help to improve management and care in the future. All participants will be entered into a raffle where the winner will receive a prize worth £20-£30.

What if there is a problem?

Any complaint that you may have about the way that you have been dealt with in the study will be addressed. Detailed information about this is presented in part two.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Details will be provided in part two.

This completes part one. If the information in part one has interested you and you are considering participation in this research, please read part two before making a decision.

Part Two:

What will happen if I do not want to carry on with the study?

If you decide to withdraw from the study then all of the information that you have provided up until that point will be destroyed.

What if there is a problem?

If you have any complaints about the study or the way that you have been treated in the study, then you can contact any members of the research team (details at the end of the information sheet) to let them know. The researcher you contact will try to solve the problem immediately. If you would not like to discuss the complaint with a researcher and would like to make a formal complaint then please contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk.

Will my taking part in the study be kept confidential?

Yes, all information about you will be kept confidential. The information you provide will be safeguarded. The recordings and transcripts will be kept safe on a pass-worded computer. Any names or places (or any other identifying information) will be deleted or replaced with pseudonyms (fake names).

No identifying information will be used in the report.

The only time that confidentiality will be breached is if you tell us that you or another child is at risk of harm. If this happens then the appropriate authorities will be contacted (i.e. ChildLine or the NSPCC).

What will happen to the results of the research study?

It is possible that the final report will be published. If you would like to be informed of the findings you will be able to contact any member of the research team who will be happy to provide you that information or links to the published report.

Who is funding the research?

The Economic and Social Research Council (ESRC) are funding this research.

Who has reviewed this study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Southampton Research Ethics Committee.

Further information and contact details:

If you have any further questions or would like any further details, please contact the primary researcher, Polly Langdon.

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

Participant Information Sheet for Mothers Providing Consent for their Daughter's Participation

(Version no: Two, date: 16.09.2014)

Study Title: An Exploration of the Impact of Period-Related Pelvic Pain on the Lives of Young Females and their Families

Researcher: Polly Langdon

ERGO Study ID and RGO reference number: 12099 (12871 after amendments)

Please read this information carefully before deciding for your daughter to take part in this research. If you are happy for her to participate, you will be asked to sign a consent form, and your daughter will be asked to sign an assent form.

Invitation:

We would like to invite your daughter to take part in our research. Before you decide whether you would like your daughter to take part or not, we would like you to understand why we are carrying out this research and what her participation would involve. A member of our research team is going to go through this information with you and will be happy to go answer any questions you might have. Please make sure you take as much time as you need to go through this information and talk to others about it (i.e. your family or peers) if you would like.

In our research, we are interviewing children and adolescent girls experiencing chronic pelvic pain and their mothers. We will require your consent for your own participation as well as your daughter's participation if she is less than 16 years old. This information sheet is relevant to your child's participation in the research. You will be provided with a separate information sheet that will provide details about your participation.

The first part of this information sheet will explain why we are carrying out this research and what her participation would involve. The second part will go into some more details about the conduct of the study. Please ask us if any of the information is not clear or if you have any other questions.

Part One

What is the purpose of the study?

This study is being conducted to help researchers and health care professionals to better understand how your child's pain affects yours, your child's and your family's lives. We would like to find this out because so far, there is very little understanding about this. By improving how much people know about it, we may, in the future, be able to help improve the quality of care and management for girls experiencing period pain and their families.

Why has my daughter been invited?

Your child has been invited to help with our research because she is currently experiencing period-related pain.

Does she have to take part?

It is up to you and your daughter to decide whether or not you would like to take part in this study. Once we have described the study and you have understood all of the information in this sheet, you can tell us whether you would like your child to take part or not. If you would like her to take part, then we will ask you to sign a consent form. You are free to change your mind at any time in the study, even if you have signed the form. If you do decide that you would not like your child to take part, or you withdraw your consent, you do not have to give a reason and this will not affect any standard of care your daughter receives. We will also provide your child with an information sheet for you to read with her, and will ask for her to provide assent. This means that your child can say whether or not she would like to take part in this study.

What will happen to my daughter if she takes part?

If you consent for your child to take part in this study then we would like to arrange one interview with her. You or another parent/ guardian must accompany your daughter to the interview. The interview will be audio-recorded and transcribed word-for-word by the researcher.

Her interview will last for around 30-60 minutes and will be similar to a conversation. The researcher will ask your daughter questions about her pain, her experiences related to her pain and how it affects her life. If your daughter is under the age of 10, we will begin the interview by asking her is she would like to draw her pain. This will be used as an ice-breaker to start up conversation about her experiences.

You and your daughter can decide whether you would like the interview to take place at home or the University of Southampton Pain Research Laboratory. The Pain Research Laboratory has a sound proof room where the interviews will take place. Your daughter will be asked if she would like her parent/ guardian to wait in the waiting area which is separated from the interview room by a door with a glass panel, so that your child can see her parent/guardian at all times. Younger children will be asked if they would like to have their parent/ guardian present in the interview room for the interview. Travel expenses, of up to £20 per participant, will be compensated for your daughter and yourself. If you decide to have the interview take place in your own home, your daughter will be asked where she would like her parent(s) to wait during the interview. Doors of the interview rooms in participants own homes will remain open at all times.

What will she have to do?

She will be asked to answer as honestly as possible about her experiences and feelings. If she does not wish to answer anything, she can let the researcher know. She will not have to discuss anything that she does not want to.

What are the possible disadvantages to taking part?

If your daughter feels upset at all during the interview, she will be informed that she can let the researcher know who will respond sensitively by reassuring the child that their parent or guardian are nearby, reassuring the child that it is OK to feel upset, and by asking if she would like to take a break from the interview. Your daughter will also be reminded that she can withdraw from the research at any time. If she feels distressed at all and indicates that she would like to stop then the researcher will stop the recording and the interview. If this happens there will be no penalty or consequences to you or your child. Your travel expenses will still be compensated and your child’s standard of care will not be affected. You or another parent/ guardian will also be nearby at all times to comfort your child if they feel upset at all.

What are the possible advantages to taking part?

We cannot promise that there will be any advantages to taking part in this research. We hope that our findings will improve understanding about adolescent period pain and help to improve management and care in the future. All participants will be entered into a raffle where the winner will receive a prize worth approximately £20-£30.

What if there is a problem?

Any complaint that you may have about the way that your child has been dealt with in the study will be addressed. Detailed information about this is presented in part two.

Will her taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about your daughter will be handled in confidence. Details will be provided in part two.

This completes part one. If the information in part one has interested you and you are considering participation in this research, please read part two before making a decision.

Part Two:

What will happen if she doesn't want to carry on with the study?

If she decides to withdraw from the study then all of the information that she has provided up until that point will be destroyed.

What if there is a problem?

If you or your daughter have any complaints about the study or the way that she has been treated in the study, then you can contact any members of the research team (details at the end of the information sheet) to let them know. The researcher you contact will try to solve the problem immediately. If you would not like to discuss the complaint with a researcher and would like to make a formal complaint then please contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk. Your complaint will be taken seriously and addressed accordingly depending on the nature of the complaint.

Will her taking part in the study be kept confidential?

Yes, all information about your daughter will be kept confidential. The information you provide will be safeguarded. The recordings and transcripts will be kept safe on a pass-worded computer. Any names or places (or any other identifying information) will be deleted or replaced with pseudonyms (fake names).

No identifying information will be used in the report.

The only time that confidentiality will be breached is if your child tells us that she, or another child is at risk of harm. If this happens then the appropriate authorities will be contacted (i.e. ChildLine or the NSPCC).

What will happen to the results of the research study?

It is possible that the final report will be published. If you or your daughter would like to be informed of the findings you will be able to contact any member of the research team who will be happy to provide you that information or links to the published report.

Who is funding the research?

The Economic and Social Research Council (ESRC) are funding this research.

Who has reviewed this study?

All research is looked at by independent group of people, called a

Research Ethics Committee, to protect your interests. This study has been reviewed

and given favourable opinion by the University of Southampton Research Ethics Committee.

Further information and contact details:

If you have any further questions or would like any further details, please contact the primary researcher, Polly Langdon.

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

CONSENT FORM for Adolescents (16-18 years)(Version no: TWO, date: 16. 09. 2014)

Study title: Title of Project: An Exploration of the Impact of Period-Related Pelvic Pain on the Lives of Young Females and their Families

Researcher name: Polly Langdon

ERGO and RGO reference number: 12099 (12871 for amendments)

Please initial the box (es) if you agree with the statement(s):

I have read and understood the information sheet (date: 16.09.2014/version no: TWO.) and have had the opportunity to ask questions about the study ☐

Appendix J

I agree to take part in this research project and agree for my data to be used for the purpose of this study ☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected ☐

Name of participant (print name)…………………………………………………

Signature of participant…………………………………………………………..

Date………………………………………………………………………………

Assent Form for Children (aged 11-15 years)

(To be completed by the child and their parent/guardian)

Version: Two, Date: 16.09.2014

Project title: How Does Period Pain Affect Children and their Families?

Name of researcher: Polly Langdon

ERGO and RGO reference number: 12099 (12871 after amendments)

Child (or if unable, parent on their behalf) /young person to circle all they agree with:

Has somebody else explained this project to you? Yes/No

Do you understand what this project is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you had your questions answered in a way you understand? Yes/No

Do you understand it’s OK to stop taking part at any time? Yes/No

Are you happy to take part? Yes/No

If any answers are “no” or you do not want to take part, don’t sign your name!

If you do want to take part, you can write your name below

Your name ……………………………………………………………………………………………

Date ……………………………………………………………………………………………………

The adult who explained this project to you needs to sign too:

Print Name ……………………………………………………………………………………………………….

Sign ………...

Date ………,,

Thank you for your help!

CONSENT FORM for Mother's Providing Consent for their Daughters Participation

(Version no: Two, date: 16.09.2014)

Study title: Title of Project: An Exploration of the Impact of Period-Related Pelvic Pain on the Lives of Young Females and their Families

Researcher name: Polly Langdon

ERGO and RGO reference number: 12099 (12871 after amendments)

Please initial the box (es) if you agree with the statement(s):

I have read and understood the information sheet (Date: 16.09.2014/version no: TWO) and have had the opportunity to ask questions about the study ☐

I agree that my daughter can take part in this research project and agree for my daughter's data to be used for the purpose of this study ☐

I understand my daughter's participation is voluntary and she may withdraw at any time without her legal rights being affected

Name of child/ adolescent participant (print name)…………………………………………………

Name of parent/guardian providing consent (print name)…………………………………………

Signature ……………………………………………………………..

Date……………………………………………………………………

Appendix K Example of Coding Framework

Age at menarche

Menarche: Year 7 (aged 11)	“Yep, erm I started when I was in my first year of high school…” (pp1, 17 years)
Menarche: 11 years old	“Erm, er well I started having, I started coming on my period when I was 11” (pp2, 17 years)
Menarche: 11 years old	“Um, Yeah. I started when I was… I’ve only been on it for two years, I started when I was 11” (pp3, 13 years)
Menarche: 12	“Erm, I’d say, erm, trying to think hang on, when I was about 12, 12 yeah” (pp4, 16 years)
Menarche: 11 years	“Um, I started my period in year 6 so I was 11.” (pp5, 16 years)
Menarche: 12 years old	“Erm, I think I was 13, well maybe 12.” (pp6, 16 years)
Menarche: 15.5	“They started when I was about 15 and half “ (pp7, 16 years)
I haven’t had periods for very long	“so I haven’t had them for very long, a year and a half maybe.” (pp7, 16 years)
Menarche: 13 years	“Erm I think I was between 13 and 14, I think I was nearly 14, it was like the summer holidays at the end of year 8 or 9, I can’t really remember” (pp8, 17 years)
Menarche: 13.5	“Umm, I think I was like halfway through being, 6 months into being 13 when I started it” (pp9, 15 years)
Menarche: year 8 (12 years)	“Erm it was November, I was in year 8 at school” (pp10, 14 years)
Menarche: 13 years	“I think I was 13.” (pp11, 16 years)
Menarche: 11 years	Pp12, 12 years)
Menarche: 13.5	“Um when I was about 13 and a half.” (pp13, 14 years)
Menarche: 10 years old (primary school)	“Mine started when I was like 10 in primary school” (pp14, 17 years)
Menarche: 11 years	“so I was 11, just turned 11” (pp15, 16 years)
Menarche: 11 years	Pp16, 14 years
Menarche: 11 years	Pp 17, 14 years
Menarche: 12	Pp18, 13 years
Menarche: 13 years	Pp 19, 14 years

Regularity of Periods

Periods irregular at the beginning	“And straight away they were massively irregular” (pp1, 17 years)
Belief that irregular periods are normal at the start	“which of course we thought was normal because they are irregular when you start off a lot of the time” (pp1, 17 years)
At the start my periods were regular and now I have 2 periods per month	“there used to be, I’ve always had regular periods, they’ve never been irregular, they’ve always been in a, a month but then, as I got older they got erm more frequent so I can have 2 a month but they’re never late, they’re just always early and” (pp5, 16 years)
I am on twice a month but the periods in between aren’t that painful	“Yeah, I do, it’s quite common that I’m on twice. Erm no, it’s usually, say it was regular, the ones that would just com in between aren’t that painful.” (pp5, 16 years)
Periods were irregular at the start but have evened out now	“ Well it used to be very irregular at the start but now it’s kind of evened out” (pp6, 16 years)
Irregular periods	“So I’ll go like normally it’ll be like 3 weeks or then like so I’ll have like a chunk where there’s one every 3 weeks and then in there they’ll, there’ll be 6 weeks or where I’ll go without having one and then it’ll go again to every 3 weeks but then again that’s not regular, so I dunno when the 6 week gap is coming and stuff like that.” (pp8, 17 years)
Periods were irregular in the first year and mild but now they’re regular and I get cramps	“Erm it’s fine, it’s pretty much every month now, for the first like year it was only every 3 months I think it came and I never really got any pain, it was really mild and now it’s sort of every month like 28 days, just over a month, like pretty much every month and erm I get a bit of cramp but it’s not severe or anything” (pp10, 14 years)
Mostly regular	“Um, sometimes they’re a bit late or a bit early” (pp13, 14 years)
Regular periods	“me and then I, my periods are like clockwork so always the same day, on time every month no matter what um” (pp15, 16 years)

Appendix L Interview guide for mothers

Interview Schedule for Mothers

OK, so to start off, can you please tell me a bit about yourself? Age, Occupation, family situation and living arrangements, hobbies.

If it is OK with you, we will now discuss (name of child's) period-related pain.

So, can you tell me about the pain that (name of child) experiences? Probe: when did it start? When were you first aware of it? How did she describe it to you? Have you noticed any times when it is worse or better? Has the pain changed at all over time?

Could you tell me about treatments for (insert the same term for CPP that mother used) that (name of child) has had? When did she first seek medical help? What HCP's has she seen? Alternative therapies? How do you feel about the treatments? Examinations? How did you feel about that? How do you think (name of child) felt at the time?

If it's OK, we will now discuss the effect of (insert the same term for CPP that mother used) on (name of child)'s life and family life.

Appendix L: Interview Guide

Do you think the (insert the same term for CPP that mother used) affects her life in any way (School, hobbies, sports, friendships, relationships with siblings, social life, social support, selfesteem, future plans) Probe: How does it affect it? How do you think this makes (name of child) feel? How does this make you feel?

Do you think the (insert the same term for CPP that mother used) affects your life in any way? (Social life, family activities, occupation, relationship with other children, relationship with partner, family dynamic, leisure, anxiety)Probe: How does this make you feel? How does it make other family members feel?

Is there anything that we haven't covered that you would like to talk about in this interview?

Techniques that will be implemented where appropriate in the interview:

That's interesting; can you please tell me more about that?

"Yeah"

“mhmm”

Nodding

Appropriate pauses

“Could you please just clarify something for me, what did you mean by?”

Ending the Interview

Thank you very much. What you have said has been very helpful. Is there anything you would like to add before I stop the recording? Thank you for sharing this personal information.

Appendix M Information Sheet for Mothers

Participant Information Sheet for Mother's Participation (Version no: THREE, date: 31.03.2015)

Study Title: An Exploration of the Impact of Period-Related Pelvic Pain on the Lives of Young Females and their Families

Researcher: Polly Langdon.

ERGO Study ID and RGO reference number: 12099 (12871 after amendments)

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

Invitation:

We would like to invite you to take part in our research. Before you decide whether you would like to take part or not, we would like you to understand why we are carrying out this research and what your participation would involve. A member of our research team is going to go through this information with you and will be happy to answer any questions you might have. Please make sure you take as much time as you need to go through this information and talk to others about it (i.e. your family or peers) if you would like.

In our research, we are interviewing children and adolescents experiencing chronic pelvic pain and their mothers. We will require your consent for your own participation as well as your consent for your daughter's participation if she is less than 16 years old. This information sheet is relevant to your participation in the research. You will be provided with a separate information sheet that will provide details about your daughter's participation.

The first part of this information sheet will explain why we are carrying out this research and what your participation would involve. The second part will go into some more details about the conduct of the study. Please ask us if any of the information is not clear or if you have any other questions.

Part One

What is the purpose of the study?

This study is being conducted to help researchers and health care professionals to better understand how your child's pain affects yours, your child's and your family's lives. We would like to find this out because so far, there is very little understanding about this. By improving how much people know about it, we may, in the future, be able to help improve the quality of care and management for girls experiencing period pain and their families.

Why have I been invited?

You have been invited to help with our research because you are the mother of a child who experiences period pain.

Do I have to take part?

It is up to you whether or not you would like to take part in this study. Once we have described the study and you have understood all of the information in this sheet, you can tell us whether you would like to take part or not. If you would like to take part, then we will ask you to sign a consent form. You are free to stop participating at any time in the study, even if you have signed the form. If you do decided not to take part, or you withdraw your consent, you do not have to give a reason and this will not affect the standard of care your daughter receives.

What will happen to me if I take part?

If you decide that you would like to take part in this study then we would like to arrange one interview with you. The interview will be audio-recorded and transcribed word-for-word by the researcher.

Your interview will last for around 30-60 minutes and will be similar to a conversation. The researcher will ask you questions about your child's pain and how it affects your child, you, and any other family members.

You can decide whether you would like the interview to take place at home, the University of

Southampton Pain Research Laboratory, or the interview can be conducted over the telephone. The Pain Research Laboratory has a sound proof room where the interviews will take place. Travel expenses, of up to £20 per participant, will be compensated.

What will I have to do?

You will be asked to answer as honestly as possible about your experiences and feelings about your child's pain. If you do not wish to answer anything, just let the researcher know. You will not have to discuss anything that you do not want to.

What are the possible disadvantages to taking part?

If you feel upset at all whilst discussing your experiences, let the researcher know and she will ask if you would like to take a break from the interview. If you feel distressed at all and would like to stop then the researcher will stop the recording and the interview. If this happens there will be no penalty or consequences to you or your child. Your travel expenses will still be compensated and your child's standard of care will not be affected.

What are the possible advantages to taking part?

We cannot promise that there will be any advantages to taking part in this research. We hope that our findings will improve understanding about adolescent period pain and help to improve management and care in the future. All participants will be entered into a raffle where the winner will receive a prize worth approximately £20-£30.

What if there is a problem?

Any complaint that you may have about the way you have been dealt with in the study will be addressed. Detailed information about this is presented in part two.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Details will be provided in part two.

This completes part one. If the information in part one has interested you and you are considering participation in this research, please read part two before making a decision.

Part Two:

What will happen if I don't want to carry on with the study?

If you would like to withdraw from the study then all of the information that you have provided up until that point will be destroyed.

What if there is a problem?

If you have any complaints about the study or the way that you have been treated in the study, then you can contact any members of the research team (details at the end of the information sheet) to let them know. The researcher you contact will try to solve the problem immediately. If you would not like to discuss the complaint with a researcher and would like to make a formal complaint then please contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk.

Your complaint will be taken seriously and addressed accordingly depending on the nature of the complaint.

Will my taking part in the study be kept confidential?

Yes, all information about you will be kept confidential. The information you provide will be safeguarded. The recordings and transcripts will be kept safe on a pass-worded computer. Any names or places (or any other identifying information) will be deleted or replaced with pseudonyms (fake names).

No identifying information will be used in the report.

What will happen to the results of the research study?

It is possible that the final report will be published. If you would like to be informed of the findings you will be able to contact any member of the research team who will be happy to provide you that information or links to the published report.

Who is funding the research?

The Economic and Social Research Council (ESRC) are funding this research.

Who has reviewed this study?

All research is looked at by independent group of people, called a

Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Southampton Research Ethics Committee.

Further information and contact details:

If you have any further questions or would like any further details, please contact the primary researcher, Polly Langdon.

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

Appendix N Information Sheet for Final Study

Participant Information Sheet for Children and Adolescents (13-18 years) (Version no: Three, date: 17.03.2016)

Study Title: Predictors of Quality of Life in Adolescents with Dysmenorrhea.

Researcher: Polly Langdon.

ERGO and RGO reference number: 18838

We are asking whether you would join in a research project to find out the answer to this question:

3. *How does period pain affect a teenager's life?*
4. *What factors influence how much period pain affects a teenager's life?*

If you decide to, you can help us to answer these questions.

Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this carefully and discuss with your parents/teacher/nurse/ the researcher if you want to.

There are 2 parts to this information sheet:

Part 1: We will describe our research; tell you why it is being done, and what you would do if you decide to join in.

Part 2: Go into a little bit more detail about the research

Part One:

Why are we doing this research?

We would like to understand how period pain affects teenagers. We also would like to know what type of factors can influence how period pain affects teenagers' lives. We would like to know this so that more people can learn about it. This might help doctors and other healthcare professionals take care of teenagers with period pain in the future.

Why have I been invited to take part?

You have been invited because you are a teenager who experiences period pain. Because you are living with this pain, you (and other girls with period pain) will be able to answer our questions to help us to better understand it.

Do I have to take part?

No! It is up to you. We will ask you for your permission before you start the survey. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect any care you receive.

What will happen to me if I take part?

If you would like to take part in this study then we would like you to take part in an online survey. The survey will last for around 60 minutes and consist of 122 very short questions. During the survey, you will be asked questions about your periods (e.g., how long you have been having periods for), period pain and other period symptoms (e.g., back pain). You will also be asked to fill out questions about your quality of life, depressive feelings (sadness), feelings of anxiety (worry), and family life. Finally, your will be asked questions about you cope with period pain and how you feel about some other bodily symptoms (such as dizziness). Finally, we will ask if you would like to be entered into a raffle. It is up to you if you would like to take part in the raffle.

What will I have to do?

You will be asked to fill out a survey which will ask you questions about your periods, how you cope with period pain, depression, anxiety, and quality of life. You will be asked to answer as honestly as possible about your experiences and feelings. You will not have to answer anything that you do not want to.

Also, you won't have to miss any school because you can fill out the survey anytime.

Is there anything to be worried about if I take part?

If you feel upset at all during the survey, you can take a break from the survey and come back to it later. If you feel distressed at all or would like to stop, you can just stop the survey. If this happens, any care that you receive will not be affected. The researchers will understand if you would like to stop taking part at any time.

What are the possible benefits to taking part?

We cannot promise that there will be benefits to taking part. We hope that our findings will improve understanding and help to improve care for teenagers with period pain in the future. If you participate, you can choose to be entered into a raffle where the winners will receive a prize worth approximately £50 for 1st prize, £25 for 2nd prize, and £10 for 3rd prize.

Contact Details:

If you have any questions and would like to contact one of the researchers:

Name of researcher: Polly Langdon

Telephone: 02380 594719 Email: plhj1e12@soton.ac.uk

Thank you for reading this so far, if you are still interested, please go to part 2:

Part 2:

What if there is a problem?

If you do not feel comfortable with the way you have been treated in the study, please tell your parent/ guardian or one of the research team. We will try to solve the problem immediately, listen to any complaints and try to resolve it as best we can.

If you would not like to discuss the complaint with a researcher and would like to make a formal complaint then please contact the Chair of the Ethics Committee, Psychology, University of

Southampton, Southampton, SO17 1BJ. You can phone on: (023) 8059 3091 or email C.A.Graham@soton.ac.uk.

Will anyone else know I'm doing this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. You will not be asked your name or date of birth during the survey however, if you would like to be entered into the prize draw then we will ask you to enter your personal contact details so that we can contact you if you win.

What will happen to the results of the research study?

If you would like to find out about the findings of our research, you will be able to contact any member of the research team who will be happy to provide you that information or links to the published report. Your parent/guardian will also be able to help you with this.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the University of Southampton Research Ethics Committee.

Thank you for reading this – please ask any questions if you need to.

Contact Details:

If you have any questions and would like to contact one of the researchers:

Name of researcher: Polly Langdon

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

Appendix O Information for Schools (For Final Study)

Researcher: Polly Langdon

ERGO Study ID number: 18838

Dear--,

We are writing to request permission to ask your female students to take part in a study investigating the impact of period-related pain on the lives of young girls. Period pain is usually located in the lower abdomen and pelvis and characterised by a crampy pain during menstruation. In particular, we are interested in understanding how period pain impacts on all aspects of young people's (13-18 years) lives. We are investigating what factors (e.g., anxiety, depression, and coping strategies) influence how period pain affects adolescents' quality of life. Period pain is under-researched in adolescents, despite being highly prevalent, causing high rates of school absenteeism, and impacting on academic performance. We hope that the results of this study will help improve understanding of adolescent period pain and that this may, in the future, reduce the negative impact of period pain on all aspects of life for young girls.

This project has received Ethics approval from the School of Psychology, University of

Southampton Research Ethics Committee. The PhD student conducting the study, Polly Langdon, and academic supervisors, Dr Christina Liossi, and Dr Cynthia Graham, have been cleared with a criminal records bureau check.

We are recruiting girls who have experienced period pain for a minimum of three months (or three periods) to participate in an online survey (approx. 60 minutes). Adolescents experiencing period pain can take part in this study whether or not they use medication for their pain. We will ask adolescents about their period pain, their quality of life, anxiety, depressive symptoms, family functioning, how they cope with period pain, and how distressed they are by general bodily symptoms. The aim of the study is to determine what factors predict quality of life outcomes for girls experiencing period pain. Only the researchers will have access to the data, and the results will only be used in conjunction with this investigation. All participants will also be entered into a raffle where the winners will receive a 1st prize worth £50, 2nd prize worth £25, and a 3rd prize worth £10.

If you are willing to help us with recruitment for our study, then please let us know what will be easiest for you. We can come and meet with you to discuss the study in further detail, or email you a copy of the participant information sheets.

Should you wish to talk about this study further, please do not hesitate to contact Polly Langdon on 02380 594597 or email: plhj1e12@soton.ac.uk. You can also contact Dr Christina Liossi on 023 8059 4645 or email C.Liossi@soton.ac.uk. We would very much appreciate your support on this important project.

Looking forward to hearing from you soon.

Yours sincerely,

Polly Langdon,

University of Southampton PhD student.

Dr Christina Liossi, CPsychol

Senior Lecturer in Health Psychology

Honorary Consultant Paediatric Psychologist

RESEARCH IN PARTNERSHIP SCHEME INFORMATION FOR SCHOOLS	
Project Title.	Predictors of Quality of Life in Adolescents with Dysmenorrhea.
Background.	We are writing to request permission to ask your female students to take part in a study investigating the impact of period-related pain on the lives of young girls. Period pain is usually located in the lower abdomen and pelvis and characterised by a crampy pain during menstruation. Period pain is under researched in adolescents, despite being highly prevalent, causing high rates of school absenteeism, and impacting on academic performance.

Aims of the project.	The aim of the study is to determine what factors predict quality of life outcomes for girls experiencing period pain. Specifically, we are interested in understanding how period pain impacts on all aspects of young people's (aged 13-18 years) lives. We are investigating what factors (e.g., anxiety, depression, and coping strategies) influence how period pain affects adolescents' quality of life
Who is conducting and supervising the project?	This project has received Ethics approval from the School of Psychology, University of Southampton Research Ethics Committee. Polly Louise Langdon, who has been DBS (CRB) checked, is conducting the project. Academic supervisors include: a) Dr Christina Liossi, an experienced Paediatric Psychologist Researcher, currently Senior Lecturer at the University of Southampton, and Honorary Consultant Paediatric Psychologist at the Paediatric Chronic Pain Clinic, Great Ormond Street Hospital for Children, NHS Trust, London, and b) Dr Cynthia Graham, a registered Health Psychologist and Clinical psychologist currently Senior Lecturer in Health Psychology at the university of Southampton.
What is the proposed start date and time frame?	Approximate start date: 25.04.2016 We can continue to recruit participants until schools break up for their summer holidays.

Appendix P Consent Form for Final Study

Study Title: Predictors of Quality of Life in Adolescents with Dysmenorrhea.

Researcher: Polly Langdon; ERGO and RGO reference number: 18838

Dear Parent/Guardian,

I am a PhD student studying Psychology at the University of Southampton. I am writing to you about my study which looks at how period pain affects the lives of adolescent girls. As period pain can affect many aspects of a teenager's life such as school attendance, mood and concentration, it is important to get a better understanding of teenage period pain so that doctors, schools, and researchers can support girls.

I will ask your daughter to fill out a survey that will take about 60 minutes to complete. I will ask her about her periods and how she copes with period pain. I will also ask her questions about how she generally feels including whether she worries or feels depressed. Your daughter will not have to answer anything that she does not want to and she won't have to miss any school. Also, your daughter can choose not to take part in the survey at any time.

This research project has been approved by the Psychology Research Ethics Committee at the University of Southampton (study ID 18838, approved on 14.04.2016)**.** Also, I have contacted the Samuel Whitbread Academy and explained the aims of my study. The Head Teacher, Mr Robson has kindly agreed to distribute these letters to you. If you have any further questions about the research, please contact me, Polly Langdon, on plhj1e12@soton.ac.uk.

If your daughter is below the age of 16 years old, you can choose for her not to take part in the study. If you would prefer that your daughter does not take part in the study, please sign and return the form enclosed within seven days of this letter being sent out. If you do not sign and return the form, you are giving permission for your daughter to take part in this study.

Yours sincerely,

Polly Langdon,

PLangdon

PARENT OPT-OUT FORM

Study Title: Predictors of Quality of Life in Adolescents with Dysmenorrhea.

Researcher: Polly Langdon.

ERGO and RGO reference number: 18838

I have read the information about the study and talked about this with my daughter.

Please tick the box below.

☐

I am not willing for my child to take part in the study.

Name of child: …………………………………

School: …………………………………………….

Class: ……………………………………………..

330

Signature of parent/guardian: ………………………………………………………….

Date: ……………………………………………..

Assent Form for Children (aged 13-15 years) Version: Three; Date: 17.03.2016

Project title: Predictors of Quality of Life in Adolescents with Dysmenorrhea

Name of researcher: Polly Langdon

ERGO and RGO reference number: 18838

Young person to circle all they agree with:

Has somebody else explained this project to you? Yes/No

Do you understand what this project is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you had your questions answered in a way you understand? Yes/No

Do you understand it’s OK to stop taking part at any time? Yes/No

Are you happy to take part? Yes/No

If any answers are “no” or you do not want to take part, don’t sign your name!

If you do want to take part, you can write your name below

Your name

Date

Thank you for your help!

UNIVERSITY OF
Southampton

CONSENT FORM (Version no Three, date 17.03.2016)

Study title: Predictors of Quality of Life in Adolescents with Dysmenorrhea.

Researcher name: Polly Langdon

ERGO Study ID number:18838

Please initial the box (es) if you agree with the statement(s):

I have read and understood the information sheet (17.03.2016/Version Three.) and have had the opportunity to ask questions about the study ☐

I agree to take part in this research project and agree for my data to be used for the purpose of this study ☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected ☐

Name of participant (print name)…………………………………………………

Signature of participant……………………………………………………………..

Date…………………………………………………………………………………

Appendix Q Questionnaire

Researcher: Polly Langdon

ERGO ID number: 18838

Adolescent Period Pain and Quality of Life

Participant Information Sheet for Adolescents (13-18 years) (Version no: Three, date: 17.03.2016)

Study Title: Predictors of Quality of Life in Adolescents with Dysmenorrhea.

Researcher: Polly Langdon.

ERGO and RGO reference number: 18838

We are asking whether you would join in a research project to find out the answer to this question:

1. *How does period pain affect a teenager's life?*
2. *What factors influence how much period pain affects a teenager's life?*

If you decide to, you can help us to answer these questions.

Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this carefully and discuss with your parents/teacher/nurse/ the researcher if you want to.

There are 2 parts to this information sheet:

Part 1: We will describe our research; tell you why it is being done, and what you would do if you decide to join in.

Part 2: Go into a little bit more detail about the research

Part One:

Why are we doing this research?

We would like to understand how period pain affects teenagers. We also would like to know what type of factors can influence how period pain affects teenagers' lives. We would like to know this so that more people can learn about it. This might help doctors and other health-care professionals take care of teenagers with period pain in the future.

Why have I been invited to take part?

You have been invited because you are a teenager who experiences period pain. Because you are living with this pain, you (and other girls with period pain) will be able to answer our questions to help us to better understand it.

Do I have to take part?

No! It is up to you. We will ask you for your permission before you start the survey. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect any care you receive.

What will happen to me if I take part?

If you would like to take part in this study then we would like you to take part in an online survey. The survey will last for around 60 minutes and consist of 133 very short questions. During the survey, you will be asked questions about your periods (e.g., how long you have been having periods for), period pain and other period symptoms (e.g., back pain). You will also be asked to fill out questions about your quality of life, depressive feelings (sadness), feelings of anxiety (worry), and family life. Finally, your will be asked questions about you cope with period pain and how you feel about some other bodily symptoms (such as dizziness). Finally, we will ask if you would like to be entered into a raffle. It is up to you if you would like to take part in the raffle.

What will I have to do?

You will be asked to fill out a survey which will ask you questions about your periods, how you cope with period pain, depression, anxiety, and quality of life. You will be asked to answer as honestly as possible about your experiences and feelings. You will not have to answer anything that you do not want to.

Also, you won't have to miss any school because you can fill out the survey anytime.

Is there anything to be worried about if I take part?

If you feel upset at all during the survey, you can take a break from the survey and come back to it later. If you feel distressed at all or would like to stop, you can just stop the survey. If this happens, any care that you receive will not be affected. The researchers will understand if you would like to stop taking part at any time.

What are the possible benefits to taking part?

We cannot promise that there will be benefits to taking part. We hope that our findings will improve understanding and help to improve care for teenagers with period pain in the future. If you participate, you will be entered into a raffle where the winners will receive a prize worth approximately £50 for 1st prize, £25 for 2nd prize, and £10 for 3rd prize.

Contact Details:

If you have any questions and would like to contact one of the researchers:

Name of researcher: Polly Langdon

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

Thank you for reading this so far, if you are still interested, please go to part 2:

Part 2:

What if there is a problem?

If you do not feel comfortable with the way you have been treated in the study, please tell your parent/ guardian or one of the research team. We will try to solve the problem immediately, listen to any complaints and try to resolve it as best we can.

If you would not like to discuss the complaint with a researcher and would like to make a formal complaint then please contact the Chair of the Ethics Committee, Psychology, University of

Southampton, Southampton, SO17 1BJ. You can phone on: (023) 8059 3091 or email C.A.Graham@soton.ac.uk.

Will anyone else know I'm doing this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. You will not be asked your name or date of birth during the survey.

What will happen to the results of the research study?

If you would like to find out about the findings of our research, you will be able to contact any member of the research team who will be happy to provide you that information or links to the published report. Your parent/guardian will also be able to help you with this.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the University of Southampton Research Ethics Committee.

Thank you for reading this – please ask any questions if you need to.

Contact Details:

If you have any questions and would like to contact one of the researchers:

Name of researcher: Polly Langdon

Telephone: 02380 594719

Email: plhj1e12@soton.ac.uk

☐

Please tick (check) this box to indicate that you consent to taking part in this survey

Adolescent Period Pain and Quality of Life

For participants under the age of 16

If you are under the age of 16, your parent(s) must be happy for you to participate in this research before you continue.

Assent Form for Children (aged 13-15 years)

Version: Three; Date: 17.03.2016

Project title: Predictors of Quality of Life in Adolescents with Dysmenorrhea

Name of researcher: Polly Langdon

ERGO and RGO reference number: 18838

Young person to circle all they agree with:

Has somebody else explained this project to you? Yes/No

Do you understand what this project is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you had your questions answered in a way you understand? Yes/No

Do you understand it's OK to stop taking part at any time? Yes/No

Are you happy to take part? Yes/No

If any answers are "no" or you do not want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name

Date

Thank you for your help

2. Consent for participants aged 16-18

CONSENT FORM (Version no Three, date 17.03.2016)

Study title: Predictors of Quality of Life in Adolescents with Dysmenorrhea.

Researcher name: Polly Langdon

ERGO Study ID number:18838

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (17.03.2016/Version Three.) and have had the opportunity to ask questions about the study ☐

I agree to take part in this research project and agree for my data to ☐ be used for the purpose of this study

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected ☐

Name of participant (print name)…………………………………………………

Signature of participant……………………………………………………………..

Date………………………………………………………………………………

3. About You

Question 1.

Age

○ 13

○ 14

○ 15

○ 16

○ 17

○ 18

Question 2.

School year

○ Year 7

○ Year 8

○ Year 9

○ Year 10

○ Year 11

○ Year 12

○ College

○ Other

4. Menstrual Symptoms

Question 1.

How old were you when you got your first period? (approx years)

____

Question 2.

How many days ago did you finish your last period?

____

Question 3.

Over the past 3 months have your periods been:

(regular = the time between periods is usually about the same length, irregular = if the length of time between periods often changes)

○ Regular

○ irregular

○ don't know

Question 4.

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

○ Light

○ Medium

○ Heavy

Question 5.

Do you miss school because of your periods?

○

○

○

Question 6.

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

☐

Question 7.

What is it about your period that causes you to miss school? (You can choose more than one)

☐

☐

☐

☐

☐ Other

Question 8.

If you have period pain do you take medication?

○ Yes

○ No

Question 9.

If yes, which medication/s do you usually take?

○ [illegible]

○ [illegible]

○ [illegible]

○ [illegible]

○ [illegible]

○ [illegible]

○ [illegible]

○ [illegible]

Question 10.

How effective is the medication in relieving your pain?

Not effective 0 1 2 3 4 5 6 7 8 9 10 Highly effective

○ 0

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10

○ N/A

Question 11.

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)

	Doesn't apply to me	No or never	All the time	Sometimes
Nausea (feel like vomiting)	☐	☐	☐	☐
Vomiting	☐	☐	☐	☐
Bloating (swollen tummy)	☐	☐	☐	☐

Diarrhoea/constipation or both	☐	☐	☐	☐

Indigestion, reflux, heartburn	☐	☐	☐	☐
Changes in appetite	☐	☐	☐	☐
Aching outside your vagina	☐	☐	☐	☐
Aching down the legs	☐	☐	☐	☐
Pelvic pain: aching	☐	☐	☐	☐
Pelvic pain: cramping	☐	☐	☐	☐
Pelvic pain: stabbing	☐	☐	☐	☐
Pelvic pain: other	☐	☐	☐	☐
Lower back pain	☐	☐	☐	☐
Pain during or after passing urine	☐	☐	☐	☐
Pain when your bladder is full	☐	☐	☐	☐
Pain before or when passing wind	☐	☐	☐	☐
Pain when emptying your bowels	☐	☐	☐	☐
Feeling an urgent need to empty your bowels	☐	☐	☐	☐
Bleeding from your bottom (anus)	☐	☐	☐	☐
Pain during or after sexual intercourse	☐	☐	☐	☐
Need to pass urine often	☐	☐	☐	☐
Feeling really tired	☐	☐	☐	☐

Headaches	☐	☐	☐	☐
Thrush (itchy and sore around and outside the vagina)	☐	☐	☐	☐
Dizziness, fainting or passing out	☐	☐	☐	☐
Feeling ‘down’ or depressed	☐	☐	☐	☐

Question 12.

Other symptoms

☐

Question 13.

Have you ever been diagnosed with any of the following?

	Yes	No	Don't know
Polycystic ovarian syndrome / polycystic ovaries (PCOS)	○	○	○
Endometriosis	○	○	○
Pelvic inflammatory disease (PID)	○	○	○

Question 14.

Does your mother or sister have any of the following?

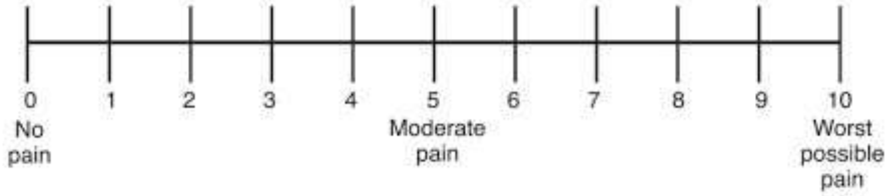
	Yes	No	Don't know	**N/A**

	○	○	○	○	○
	○	○	○	○	○
	○	○	○	○	○
	○	○	○	○	○
	○	○	○	○	○

Question 15.

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)

5. Period Pain



Question 1.

Using the scale above, please indicate using the numbers 0-10 (0 being no pain to 10 being the worst pain possible) how bad your period pain is on average, during most of your periods.

Please select ▾

Question 2.

Using the scale above, please indicate using the numbers 0-10 (0 being no pain to 10 being the worst pain possible) how bad your pain was during your most recent period.

▾

6. Quality of Life

One of the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the past **ONE month** by clicking on:

Never if it is never a problem

Almost never if it is almost never a problem

Sometimes if it is sometimes a problem

Often if it is often a problem

Almost Always if it is almost always a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.

In the past ONE month, how much of a problem has this been for you...

Question 1.

ABOUT MY HEALTH AND ACTIVITIES (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
It is hard for me to walk more than one block	○	○	○	○	○
It is hard for me to run	○	○	○	○	○
It is hard for me to do sports activity or exercise	○	○	○	○	○

It is hard for me to lift something heavy	○	○	○	○	○
It is hard for me to take a bath or shower by myself	○	○	○	○	○
It is hard for me to do chores around	○	○	○	○	○
	○	○	○	○	○
	○	○	○	○	○

Question 2.

ABOUT MY FEELINGS (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
I feel afraid or	○	○	○	○	○

[illegible]	○	○	○	○	○
[illegible]	○	○	○	○	○
[illegible]	○	○	○	○	○
[illegible] what will happen to me	○	○	○	○	○

Question 3.

HOW I GET ALONG WITH OTHERS (problems with)

	Never	Almost Never	Sometimes	Often	Almost Always
I have trouble getting along with other teens	○	○	○	○	○
Other teens do not want	○	○	○	○	○

to be my

	○	○	○	○	○
	○	○	○	○	○

that other teens my age

	○	○	○	○	○

Question 4.

ABOUT SCHOOL (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
It is hard to pay attention in class	○	○	○	○	○
I forget things	○	○	○	○	○
I have trouble keeping up with my school work	○	○	○	○	○
I miss school because of not feeling [illegible]	○	○	○	○	○
[illegible]	○	○	○	○	○

7. Depressive Symptoms

Kids sometimes have different feelings and ideas.

This form lists the feelings and ideas in groups. From each group of three sentances, pick one snetance that describes you *best* for the past two weeks. After you pick a sentance from the first group, go on to the next group.

There is no right or wrong answer. Just pick the sentence that best describes the way you have been recently.

Question 1.

Item 1

○ I am sad once in a while

○ I am sad many times

○ I am sad all the time

Question 2.

Item 2

○ Nothing will ever work out for me

○ I am not sure of things will work out for me

○ Things will work out for me O.K

Question 3.

Item 3

○ [illegible]

○ [illegible]

○ [illegible]

Question 4.

Item 4

○ [illegible]

○ [illegible]

○ I like myself

Question 5.

Item 5

○ I feel like crying every day

○ I feel like crying many days

○ I feel like crying once in a while

Question 6.

Item 6

○ Things bother me all the time

○ Things bother me many times

○ Things bother me once in a while

Question 7.

Item 7

○ I look O.K

○ There are some bad things about my looks

○ I look ugly

Question 8.

Item 8

○ I do not feel alone

○ I feel alone many times

○ I feel alone all the time

Question 9.

Item 9

○

○ I have some friends but I wish I had more

○ I do not have any friends

Question 10.

Item 10

○

○

○

8. Anxiety Symptoms

A member of statements which boys and girls use to describe themselves are given below. Read each statement carefully and decide if it is *hardly-ever*, or *sometimes*, or *often* true for you. Then for each statement, click the answer that seems to describe you best. There are no right or wrong answers. Don't spend too much time on any one statement. Remember, choose the word which seems to describe how you usually feel.

Question 1.

	Hardly-Ever	Sometimes	Often
I worry about making mistakes	○	○	○
I feel like crying	○	○	○
I feel unhappy	○	○	○
I have trouble making up my mind	○	○	○

I worry too much	○	○	○
I get upset at home	○	○	○
I am shy	○	○	○
I feel troubled	○	○	○
Unimportant thoughts run through my mind and bother me	○	○	○
I worry about school	○	○	○
deciding what to do	○	○	○
It is difficult for me to face my problems	○	○	○

I have trouble

[illegible]	○	○	○
[illegible]	○	○	○
[illegible]	○	○	○
[illegible]	○	○	○
[illegible]	○	○	○
that may [illegible]			
[illegible]	○	○	○
[illegible]	○	○	○
[illegible]	○	○	○

[illegible]

I feel...

○ [illegible]

○ [illegible]

○ [illegible]

Question 3.

I feel

○ Very upset

○ Upset

○ Not upset

Question 4.

I feel...

○ Very pleasant

○ Pleasant

○ Not pleasant

Question 5.

I feel...

○ Very nervous

○ Nervous

○ Not nervous

Question 6.

I feel...

○ Very jittery

○ Jittery

○ Not jittery

Question 7.

I feel...

○ Very rested

○ Rested

○ Not rested

Question 8.

I feel...

○ Very scared

○ Scared

○ Not scared

Question 9.

I feel...

○ Very relaxed

○ Relaxed

○ Not relaxed

Question 10.

I feel...

○ Very worried

○ Worried

○ Not worried

Question 11.

I feel...

○ Very satisfied

○ Satisfied

○ Not satisfied

Question 12.

I feel...

○ Very frightened

○ Frightened

○ Not frightened

Question 13.

I feel...

○

○

○

Question 14.

I feel...

○ Very sure

○ Sure

○ Not sure

Question 15.

I feel...

○ Very good

○ Good

○ Not good

Question 16.

I feel...

○ Very troubled

○ Troubled

○ Not troubled

Question 17.

I feel...

○ Very bothered

○ Bothered

○ Not bothered

Question 18.

I feel...

○

○ Nice

○ Not nice

Question 19.

I feel...

○ Very terrified

○ Terrified

○ Not terrified

Question 20.

I feel...

○ Very mixed up

○ Mixed up

○ Not mixed up

Question 21.

I feel...

○

○

○

9. Family Life

Please rate how much you agree or disagree with the statements below

---

Question 1.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Planning family activities is difficult because we misunderstand each other	○	○	○	○
In time of crisis we can turn to each other for support	○	○	○	○
We cannot talk to each other about sadness we feel	○	○	○	○

Individuals are accepted for what they are	○	○	○	○
We avoid discussing our fears and concerns	○	○	○	○
We can express feelings to each other	○	○	○	○
There are lots of bad feelings in the family	○	○	○	○
We feel accepted for what we are	○	○	○	○
Making decisions is a problem for our family	○	○	○	○
We are unable to make decisions about how to solve problems	○	○	○	○
[illegible]	○	○	○	○
[illegible]	○	○	○	○

10. Thoughts and Feelings During Pain

We are interested in what you think and how strong the feelings are when you are in pain. Below are 13 sentences of different thoughts and feelings you can have when you are in pain. Try to show us as clearly as possible what you think and feel by putting a circle around the word under each sentence that best reflects how strongly you have each thought..

Question 1.

When I am in pain, I worry all the time about when the pain will end.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 2.

When I am in pain, I feel I can't go on like this much longer.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 3.

When I am in pain, it's terrible and I think it's never going to get better.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 4.

When I am in pain, it's awful and I feel that it takes over me.

○

○

○

○

○ Extremely

Question 5.

When I am in pain, I can't stand it anymore.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 6.

When I am in pain, I become afraid that the pain will get worse.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 7.

When I am in pain, I keep thinking of other painful events.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 8.

When I am in pain, I want the pain to go away.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 9.

When I am in pain, I can't keep it out of my mind.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 10.

When I am in pain, I keep thinking about how much it hurts.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 11.

When I am in pain, I keep thinking about how much I want the pain to stop.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 12.

When I am in pain, there is nothing I can do to stop the pain.

○ Not at all

○ Mildly

○ Moderately

○ Severely

○ Extremely

Question 13.

When I am in pain, I wonder whether something serious may happen.

○

○

○

○

○

11. Thoughts and Feelings about Bodily Symptoms

Your Symptoms

Below is a list of symptoms that children and teenagers sometimes have. Circle a number telling how much you were bothered by each symptom during the past two weeks.

Question 1.

In the last 2 weeks, how much were you bothered by each symptom?

	Not at all	A little	Some	A lot	A whole lot
Headaches	○	○	○	○	○
Faintness or dizziness(feeling faint or dizzy)	○	○	○	○	○
Pain in your heart or chest	○	○	○	○	○
Feeling low in energy or slowed down	○	○	○	○	○

Pains in your lower back	○	○	○	○	○
Sore muscles	○	○	○	○	○
Trouble getting your breath (when you're not exercising)	○	○	○	○	○
Hot or cold spells (suddenly feeling hot or cold for no reason)	○	○	○	○	○
Numbness or tingling in parts of your body	○	○	○	○	○
Weakness (feeling weak) in parts of your body	○	○	○	○	○
Heavy feelings in your arms or legs (when they feel too heavy to move)	○	○	○	○	○
Nausea or upset stomach (feeling like you might throw up, or having an upset stomach)	○	○	○	○	○
Constipation(when it's hard to have a B.M.or go poop)	○	○	○	○	○

Loose (runny) BM's or diarrhea	○	○	○	○	○
Pain in your stomach or abdomen(stomach aches)	○	○	○	○	○
Your heart beating too fast (even when you're not exercising)	○	○	○	○	○
Difficulty swallowing	○	○	○	○	○
Losing your voice	○	○	○	○	○
Blurred vision (when things look blurry, even with glasses on)	○	○	○	○	○
Vomiting (or throwing up)	○	○	○	○	○
Feeling bloated or gassy	○	○	○	○	○
Food making you sick	○	○	○	○	○
Pain in your knees, elbows or other joints	○	○	○	○	○
Pain in your arms or legs	○	○	○	○	○

Thank you for completing this survey.

Would you like to be entered into a raffle where the winners receive a 1st prize worth £50, a 2nd prize worth £25, and 3rd prize worth £10?

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