DOI: 10.1111/tog.12008
The Obstetrician & Gynaecologist
http://onlinetog.org
2013;15:106–12

Review

Management of menstrual problems in adolescents with learning and physical disabilities

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Accepted on 25 November 2012

Key content
- The onset of menarche in adolescents with disabilities can cause significant disruption to their lives.
- Menstruation has an impact on the symptom control of various medical conditions.
- Signs and symptoms of dysmenorrhoea, menorrhagia and cyclical behavioural disturbances are frequent and distressing.
- There are parental and carer concerns regarding menstrual management and hygiene, vulnerability to sexual abuse and pregnancy, as well as inappropriate behaviour.
- Research on managing the menstrual problems of adolescents with disabilities is limited; consequently there is little guidance to best practice.

Learning objectives
- To recognise the behavioural and emotional changes associated with menstruation.
- To be aware of the pros and cons of the different management options available for adolescents with disabilities.
- To understand the legislature and the legal issues of consent.

Ethical issues
- The role of surgical options for management of menstruation in the adolescent girl.
- Informed counselling includes the short and long-term effects of the disability on menstruation and vice versa, which influence decision-making.
- The contribution of multidisciplinary team in the decision-making process involving the health and wellbeing of the adolescent.

Keywords: adolescent / disabilities / dysmenorrhoea / menorrhagia

Please cite this paper as: Jeffery E, Kayani S, Garden A. Management of menstrual problems in adolescents with learning and physical disabilities. *The Obstetrician & Gynaecologist* 2013;15:106–12.

Introduction

The onset of menarche in adolescents with disabilities can cause significant disruption to their lives.[1,2] Distressing symptoms such as dysmenorrhoea, menorrhagia, increased seizures, cyclical behaviour disturbances and an inability to cope with emotional surges of sex hormones are frequently reported.[1,3] There are also parental and carer concerns regarding menstrual management and hygiene, vulnerability to sexual abuse and pregnancy, or inappropriate behaviour.[2,4–7] These concerns become even more significant if the adolescent is in residential care.

The menstrual problems experienced by this population are often unique and management is restricted due to significant co-morbidities. Therefore treatment principles for the general population cannot always be followed, yet few studies exist to guide the practitioner. This review aims to evaluate the different management options.

Effect of menstruation on the adolescent with disability

Menstrual problems in girls with disabilities are often unique to the population. For instance, a common reason behind a consultation is regarding parental and carer anxiety around menstrual hygiene which can be exacerbated in girls with decreased mobility, contractures, bladder and bowel incontinence and behaviour problems.[4,6] Additionally, girls with severe disabilities may be unable to cooperate with daily hygiene routines.[6]

Another reason for a parent or caregiver to access paediatric and adolescent gynaecology services is concern over cyclical behavioural changes. Restlessness, aggression, hyperactivity, increased agitation and self-mutilation are commonly cited to occur more frequently.[6,8] Studies have shown that up to 18% of adult women with disabilities have premenstrual syndrome compared with only 5% of the

general population.[6] This figure is significantly higher in women with autism compared to matched controls (92% compared to 11%).[8] Behavioural issues related to menstrual pain are also frequently reported but may be difficult to ascertain if the girl is nonverbal or has limited understanding.[5] This is because the coping mechanism is a learnt and acquired behaviour which these girls are unable to attain. On the other hand, when the disability is physical there is understanding of the need for hygiene and symptom control but inability to achieve that or reliance on others. This leads to significant distress and deterioration of quality of life for patient and the carer. Literature also points to an increase in seizure frequency at certain stages of the menstrual cycle and is referred to as catamenial seizure exacerbation.[6] Women with epilepsy also have a higher incidence of reproductive endocrine disorders (such as polycystic ovary syndrome [PCOS] and hyperprolactinaemia) than the general population.[9] This may be related both to the epilepsy itself and to the antiepileptic medications.[9] For instance, sodium valproate has been linked to PCOS[9] which may cause irregular menstruation. Irregular bleeding is also more common in girls with Down syndrome as they have a higher incidence of thyroid disease.[1,2]

Management choices and challenges

One of the increasingly experienced challenges is that of weight and degree of mobility. Girls in this cohort may have extremes of weight and variations in mobility. In girls under 20 years of age, body mass index (BMI) percentiles are used instead of set thresholds for identification of being over or underweight as it allows the comparison with children/adolescents of the same gender and age. A BMI less than the 5th percentile is considered underweight and above the 95th percentile is considered obese.[10]

Research on managing the menstrual problems of adolescents with disabilities is limited and consequently there is a lack of evidence of best practice to guide clinicians in this area.[4,6,7,11–13] Clinicians must extrapolate management practices from trials in other populations and apply these practices to girls with disabilities. Therefore, addressing and managing menstrual problems in girls with disabilities represents a challenge which is both clinical and ethical. Clinicians may refer to the UK medical eligibility criteria for contraceptive use (UKMEC) for evidence-based recommendations in the presence of different medical and social factors.[14]

The following section reviews the therapeutic options to be considered to help ease the menstrual problems in this population. The list of indications is only for guidance and is neither exhaustive nor prescriptive.

Medical options

Combined oral contraceptive pill (COCP)

Indications:

- Patient choice (if applicable).
- Method of choice agreed by multidisciplinary team in best interest of the adolescent.
- Physical disability requiring more control of menstruation.
- Gastrostomy tube due to problem with swallowing.

The combined oral contraceptives are widely used in girls with disabilities as compliance requires taking only one tablet regularly, resulting in reduction in menstrual flow, dysmenorrhoea and control over the timing of menstruation.[6] The extended use (greater than 21 days of active pills) of monophasic low-dose estrogen/progestogen pills produces fewer menstrual periods which is achieved by tricycling the COCP and then allowing for a 7-day withdrawal bleed. Alternatively, the COCP may be used continuously until breakthrough bleeding which is then followed by a 7-day withdrawal period.[4] Both approaches have been found to be as safe as the 28-day cycle use in women, although there has been no research into its long-term safety in girls who started taking it just after menarche.[4]

Girls with disabilities often have additional and complex health needs which lead to inherent problems with this modality of treatment. If the girl is confined to a wheelchair and relatively immobile, there is a higher risk of deep venous thrombosis (DVT), although this risk has yet to be quantified.[2,5,6] The dose may also be excessive if the girl has a low BMI which will further increase the risk of DVT. In these girls, the lowest available dose of estrogen should be used and if there is any personal history of DVT, or increased risk of embolus, then the COCP is contraindicated.[5]

Seizure disorders are more common in girls with learning disabilities and antiepileptic drugs (AEDs) may compromise the efficacy of the COCP.[9] Enzyme inducing AEDs (such as phenytoin and phenobarbitone) lead to estrogen being metabolised faster. Consequently normal COCP doses may cause breakthrough bleeding and an increase in the estrogen dose may be needed to control bleeding. Conversely, enzyme inhibiting AEDs (such as valproate and clonazepam) cause the COCP to be metabolised at a slower rate and a lower dose of estrogen is needed. Equally, the COCP also affects the AEDs and causes an increase in seizures and dose adjustments will have to be made (for instance, plasma concentrations of lamotrigine are reduced by estrogen). However there have been no studies to date on this and so the risks cannot be known for sure.

On a practical note, some girls may not be able to take oral medication due to an inability to swallow and therefore this would not be a suitable option.[1] In addition, it must be taken daily and may not represent the best choice, if compliance is

a concern. For girls with gastric feeding tubes, requiring long-term enteral nutrition, the COCP can be administered via this route.

Combined transdermal patch

Indications:

- Patient choice (if applicable)/compliance issue.
- Inability to swallow.
- Malabsorption.
- Need to bypass hepatic metabolism.

The transdermal patch contains low-dose estrogen and progestogen and therefore raises the same concerns as those discussed above. However, if swallowing or compliance is problematic, it may be a suitable alternative in controlling the signs and symptoms of menstruation. The patches are changed weekly, however, the same effect as continuous OCP can be achieved by applying patches serially for 9 weeks followed by a 7-day withdrawal period, or used continuously until breakthrough bleeding.[4] For girls with low body weight or those on enzyme inhibiting AEDs, the patches can be divided to reduce the dose and tailored to the need of the patient.

Data are available regarding the side effects of combined pill and patch from observational studies only. A Cochrane review noted that overall – compared to COCP users – combined transdermal patch users experienced more breast discomfort, dysmenorrhoea, nausea and vomiting.[15]

Progestogen only pill (POP)

The POP contains a low dose of progestogen, however, its main use is for contraception and not control of periods. Similar to the COCP, its efficacy is reduced when used with certain AEDs and vice versa. The newer POP (Cerazette® [Merck Sharp & Dohme Limited, Hoddesdon, Herts] – 75 micrograms of desogestrel) works by inhibiting ovulation as opposed to thickening cervical mucus caused by the traditional minipills e.g. norethisterone, etynodiol diacetate, levenorgestrel. It therefore has a better side-effect profile with fewer episodes of breakthrough bleeding and better control of dysmenorrhoea. Cerazette® would be more suitable for this group of patients, if estrogen is contraindicated or not tolerated. It may take up to 6 months for adequate menstrual control. The overall amenorrhoea rate is 20%; 40% will have regular periods and 40% will have erratic bleeding.[16] Although periods lighten and become less frequent over time, the bleeding may still be unpredictable, which may not be acceptable to some patients/carers.

Depot medroxyprogesterone acetate (DMPA)

Indication:

- As for transdermal route.

DMPA is a progestogen-only hormonal contraceptive that can bring about amenorrhoea and is given via intramuscular injection every 12 weeks, eliminating the need for daily compliance and swallowing. Complete cessation of menstruation is normally achieved after 1 year in 50% of users although breakthrough bleeding can be a problem in the short-term.[4] It is commonly used in girls with disabilities.[5,6,12,17,18]

The main concern about DMPA is well-established and regards its effect on bone mineral density (BMD). DMPA reduces BMD due to the suppression of the hypothalamic-pituitary-ovarian axis which causes low circulating levels of oestrogen.[19] The impact of this is greatest when it is used during adolescence as this is a critical period of BMD accrual.[17,19] The Committee on Safety of Medicines (CSM) in the UK have advised that in adolescents 'DMPA should only be used when other methods of contraception are inappropriate',[12] while the Food and Drug Administration (FDA) in the USA have stated that it causes a significant reduction in BMD when used in adolescents and therefore should not be used for more than 2 years.[12] This is particularly pertinent to girls with disabilities who are already more likely to have a sub-optimal BMD.[5] However, these studies did not include girls with disabilities.

As these effects are well known, where there is a potential that BMD may be suboptimal, girls should have a dual energy absorptiometry (DXA) scan before commencing DMPA and their BMD monitored annually throughout treatment and 2 years after discontinuation[19] although, this may not always be achievable in adolescents with physical or learning disabilities as it requires cooperation to lie still. If there are concerns regarding adequate dietary intake then supplementation with calcium and vitamin D may be taken (a suspension form is available for girls who are unable to swallow tablets) and concurrent low-dose estrogen given.[4,6,12,19,20] Although there is no clear evidence that this will offset any loss in BMD.

For girls with complex health needs and a reduced life expectancy, the advantage brought about by controlling distressing menstruation may significantly outweigh the potential risk of osteopenia. The DMPA remains the most widely prescribed and accepted method of menstrual suppression within this population and this benefit should not be overridden by concerns regarding BMD.

According to the Society for Adolescent Health and Medicine (SAHM) clinical guidelines[21] for treating adolescents who do well on DMPA for contraception, the physicians should:

- continue prescribing DMPA to adolescent girls needing contraception, while providing adequate explanation of benefits and potential risks;
- consider ordering a DXA scan to evaluate a patient's risk;
- keep in mind that duration of use need *not* be restricted to 2 years;

- recommend 1300 mg calcium plus 400 IU vitamin D and daily exercise to all adolescents receiving DMPA;
- consider estrogen supplementation in those girls with osteopenia (or those at high risk of osteopenia who have not had a DXA scan) who are otherwise doing well on DMPA and have no contraindication to estrogen.

The World Health Organization (WHO) similarly published recommendations stating that no restriction should be placed on the use of DMPA due to bone effects.[22]

A further practical issue that must be addressed is the weight gain associated with the DMPA (up to 4.6 kg per year). This additional weight may severely impact on quality of life, particularly if the girls are immobile[2] and represents a major concern for parents or carers if they have to be lifted.

Nexplanon®

Indication:

- As for transdermal route.

Nexplanon® (Merck Sharp & Dohme Limited, Hoddesdon, Herts) is a low-dose progestogen-only sub-dermal device implanted in the upper arm and provides 3 years of associated reduced menstrual flow. The release rate of etonogestrel is 68 mg over 3 years compared to 150 mg over 12–14 weeks from DMPA. The amenorrhoea rate is 20%, while 50% will have infrequent, frequent or prolonged bleeding and bleeding patterns are likely to remain irregular.[16] This may warrant its removal in some cases. Careful consideration must be placed on the individual because they must be compliant and cooperate during its insertion.[5]

In our experience, the main cause of request for removal of Nexplanon® has been severe mood swings. Given that these girls are more prone to premenstrual syndrome (PMS) type symptoms anyway,[6] the authors strongly advise caution in using this method to achieve menstrual control. Moreover, girls with learning disabilities may pick at the Nexplanon® causing infection at the Nexplanon® site.

Gonadotrophin-releasing hormone (GnRH) analogues

Indication:

- As for transdermal route.

The use of injectable GnRH analogues leads to amenorrhoea. The long-acting preparations are administered every 12 weeks and are highly effective but require attention to dosage intervals to avoid intermittent breakthrough bleeding.[12] Limited results taken from studies treating children with precocious puberty indicate that it also has a negative effect on BMD.[12] The mean age in this group was 8.3 years and the mean treatment time 2.7 years.[23] Estrogen suppression is immediate and BMD is reduced during treatment, however, once treatment is stopped, BMD recovers. The side effects associated with GnRH injections include hot flushes, headaches and night sweats; however these can be managed with estrogen supplements. There are no data regarding the effect of GnRH analogues to control the symptoms of menstruation in girls with complex health needs.

Surgical options

Levonorgestrel intrauterine system (LNG-IUS)

The LNG-IUS is a T-shaped plastic device containing levonorgestrel (52 mg) which is inserted directly into the uterus. It works by causing local estrogen insensitivity thereby inhibiting endometrial proliferation.[12] The mean release of LNG is 14 micrograms per day over a period of 5 years. The initial release is 20 micrograms/day which reduces to 11 micrograms/day at the end of 5 years.[24] The device provides up to 5 years of reduced blood loss or amenorrhoea in 90% of women and has also been shown to reduce dysmenorrhoea. Due to these characteristics, it has been successfully used in girls with disabilities.

However, it is advised to insert the LNG-IUS in girls with disabilities during general anaesthesia and therefore can be considered a surgical procedure.[13] Given the complex health needs in this group, this has increased risks. Insertion of the LNG-IUS also requires a minimum uterine cavity of 5 cm and if the girl is proportionally small, there is a chance that she may also have a small uterus.[4] An ultrasound assessment before insertion may be difficult to perform in a girl who is incontinent or catheterised as she will not have a full bladder. Another concern is that they may not always be able to communicate the occasional uterine cramps/period-type pains which may occur in the first few months of IUS insertion.[6] More general problems related with the LNG-IUS include breakthrough bleeding, ovarian cyst formation and weight gain.[12]

Endometrial ablation

Endometrial ablation can provide relief from menorrhagia, metrorrhagia and the attendant quality of life worries and where hygiene concerns are an issue. Compared to hysterectomy, there is significantly reduced morbidity and can potentially save 40 or so years of hormonal management. However, studies show that when endometrial ablation is used in women in their 30s, they are more likely to need further ablation than when it is carried out in women in their 40s.[25] The consequences of undertaking this in adolescents are unknown. Need for contraception will need to be addressed if future sexual activity is a possibility. In case of pregnancy, complications such as premature labour and placenta accreta may occur. The risks associated with a general anaesthetic also need to be considered. The roller ball endometrial ablation or transcervical resection of endometrium (TCRE) may be a better option than the standard 2nd and 3rd generation endometrial ablation devices

available in the market. The one exception would be the 3rd generation hydrothermal ablation (HTA) device as it obviates the need for a minimal uterine cavity size, provides direct visualisation of the endometrial cavity during ablation and can be repeated as necessary as it does not cause obliteration of the uterine cavity as other endometrial ablation devices may do. Concomitant or later use of Mirena IUS remains a possibility in difficult cases or for better control.

Hysterectomy

Parents or carers may feel unable to cope with the additional care needs during menstruation or that the symptoms of menstruation are too distressing for their child and may request a hysterectomy. Ethical issues around this are discussed in depth in several articles.[26–31] One high-profile case involved Ashley X, an American girl with static encephalopathy. At the age of 7 Ashley underwent high-dose estrogen therapy to halt her growth and a hysterectomy and mastectomy to stop puberty. Her parents argued that it would not be appropriate or dignified for Ashley to go through puberty as her development was assessed to be aged 6 months.[32] They also insisted halting her growth would allow them to continue dealing with her activities of daily living rather than sending for residential care as they grew older, thus maintaining Ashley's quality of life. In the UK, surgical options are only considered if it benefits the patient and not for the benefit of the caregiver.[1,12] Under most circumstances, menstrual problems can be successfully managed by medical treatment and therefore the request for permanent surgical procedures is approved only in exceptional circumstances.

Table 1. A summary of management options

	Pros	Cons
Medical options		
COCP	Reduced signs and symptoms of menstruation, contraceptive effect. May be taken continuously (e.g. tricycle)	Regular intake, need for high compliance, DVT risk, potential weight gain (fluid retention), need good swallow, headaches, interaction with other medications, contraindicated in some children, may not lead to amenorrhoea
POP	Contraceptive effect, may reduce signs and symptoms of menstruation.	Daily intake, need for high compliance, need good swallow, interaction with other medications, headaches, breakthrough bleeding, may not lead to amenorrhoea
Transdermal patch	Reduced signs and symptoms of menstruation, contraceptive effect, can be used continuously (e.g. tricycle). *Used when inability to swallow, to bypass hepatic metabolism, malabsorption conditions.	Skin irritation, adhesive allergy, headaches, may be removed by adolescent, remembering to remove and replace
DMPA	Once every 12 weeks, can lead to amenorrhoea, reduced signs and symptoms of menstruation, contraceptive effect. *Same as transdermal patch	Weight gain, BMD reduction, pain from injection headaches, breakthrough bleeding
GnRH analogues	Once every 12 weeks, can lead to amenorrhoea, contraceptive effect. *Same as transdermal patch	Pain from injection, menopausal symptoms, headaches, breakthrough bleeding, BMD reduction
Nexplanon®	Inserted every 3 years, reduced signs and symptoms of menstruation, contraceptive effect, releases less hormone than DMPA. *Same as transdermal patch	Insertion under local or general anaesthetic, pain from insertion site, headaches, may pick at implant, may not lead to amenorrhoea, breakthrough bleeding,
Surgical options		
LNG-IGS	Inserted every 5 years, contraceptive effect, amenorrhoea, reduction in signs and symptoms of menstruation, releases less hormone than DMPA and Implanon	Insertion under general anaesthetic, Cavity size 5 cm, requires ultrasound before insertion, breakthrough bleeding,ovarian cyst formation, infection, may not lead to amenorrhoea
Ablation	Amenorrhoea, reduction in menorrhagia and dysmenorrhoea	Procedure under general anaesthetic, ethical considerations, contraceptive needs to be considered if sexual activity a possibility, may lead to complications during pregnancy, may need repeated procedures
Hysterectomy	Definitive treatment	Requires general anaesthetic, ethical considerations, definitive sterility

BMD=bone mineral density; COCP=combined oral contraceptive pill; DMPA=depot medroxyprogesterone acetate; DVT=deep vein thrombosis; GnRH=gonadotrophin-releasing hormone; LNG-IGS=levonorgestrel intrauterine system; POP=progestogen-only pill

Table 1 summarises the management options described above.

Ethical considerations

The Mental Capacity Act 2005 (MCA) states that incompetent adults should be treated in a way that serves their best interests. Under this act, doctors have a legal duty to consult a range of people when determining the best interests of a person who lacks capacity.[33] This act does not cover children under 16 years old.

Children are not always capable of participating even minimally in respect of their own treatment and therefore the involvement of parents is crucial and consistent with the MCA. When considering consent to treatment involving children, the Children Act, the Family Law Reform Act and the Gillick/Fraser guidelines, bring about two points which are relevant here.

First, that the requirement for interventions should be the least restrictive of basic rights and freedom, and second, that those with parental responsibility have the legal right to give consent on behalf of minors for medical treatment. But such proxy consent is limited. A child should not be allowed to come to serious harm because the parent refuses consent for the appropriate treatment. Nor can a parent insist on treatment that doctors believe is not in the child's best interests.

The interests of the child must remain paramount, which can be difficult to achieve when the parent or carer have their own agenda. For example, parents can ask for cessation of menstruation because of the effect on their own quality of life when it may have no impact on the quality of life of the child. In the UK, surgical options must only be considered as a last resort when symptoms and signs of menstruation are severe and medical management have failed and not for the benefit of the caregiver.[1,12] Under UK law, approval from a high court judge is necessary before surgery can be carried out.[12]

Conclusion

Managing the menstrual problems of girls with disabilities represents a challenging clinical dilemma and the complexity of their symptoms means there is no one-size fits all solution to managing these girls' problems. This is because the choice of menstrual control is never clear-cut, the presence of concomitant medical problems and the decision is difficult as a significant proportion of patients in this population will not be able to consent to treatment. As such, it should not be assumed that what is appropriate in one case is appropriate in all cases. Thus generalisations for this specific population should not be made and, standard protocols or large randomised control trials in this area may not be practical or insightful. Instead, the decision has to rest on the multi-disciplinary team (MDT), which would include medical practitioners (both hospital specialists and general practitioners), specialist nurse, social worker, occupational therapist, physiotherapist, community specialists, the girl and her parents/caregiver. The girl, within the limits of her understanding, and her parents should be given the opportunity to know available options and the advantages and disadvantages to each and the clinician should rely on their previous experiences.

Adolescents with disabilities are more likely to have menstrual problems than the general female population. However, this is not to say that all adolescents with disabilities will encounter problems and often parental and carer concerns do not transpire. The MDT also has an important role to play in addressing concerns around the onset of menstruation, reassuring and discussing management options prior to menarche.

Disclosure of interests

Prof Anne S Garden is a contributor to and joint editor of *Paediatric and Adolescent Gynaecology for the MRCOG and Beyond*. 2nd ed. RCOG Press; 2008. Dr Elizabeth Jeffery and Dr Salma Kayani have no disclosures of interests to declare.

Supporting information

The following supplementary information is available for this article online:

UN Convention on Children's Rights 1989 [www.unesco.org/education/pdf/CHILD_E.PDF].
Protection of Children Act 1999 [www.legislation.gov.uk/ukpga/1999/14/contents].
Safeguarding Vulnerable Groups Act 2006 [www.legislation.gov.uk/ukpga/2006/47/contents].
Childcare Act 2006 [www.legislation.gov.uk/ukpga/2006/21/contents].
The Children and Young Person Act 2008 [www.legislation.gov.uk/ukpga/2008/23/contents].

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