Management of menstrual difficulties in adolescents with physical and intellectual disabilities at a New Zealand tertiary hospital

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Menstrual difficulties in adolescents with intellectual and physical disabilities represent yet another challenge to be addressed in what is invariably a life-long partnership between the individual, their carers and the health system. Indeed, menarche is often the first signal to caregivers that their child is approaching adulthood, representing the first step in transition to adult services.

Menarche brings with it new challenges, from hygiene and behavioural difficulties, through to exacerbation of pre-existing medical conditions and vulnerability to abuse.1,2 Fortunately, menarche can be anticipated, and ideally counselling should occur pre-menarche. For the clinician, this can be difficult, as there is a paucity of data to inform management, and counsel appropriately.1-4

With this in mind, we share our experience at Counties-Manukau Health (CMH), and present data from a retrospective cohort study conducted within our gynaecology service examining the referral pathway, management, and common complications for these patients which reviewed 40 cases over a period of 2004–2012. It is hoped that this provides others in New Zealand some local context to an important issue.

We advocate a proactive approach to better prepare caregivers to face these issues. Therefore, initial counselling is ideally performed within the familiar confines of a paediatric clinic prior to consultation in the adult world of a gynaecology clinic. Following this, patients or their carers may then contact our gynaecology clinic directly and arrange further follow-up, typically following menarche. At CMH, 21 (50%) adolescents received pre-menarchal counselling via this route.

It is a well-recognised and genuine concern for caregivers that this population is vulnerable to both physical and sexual abuse and menarche often has the effect of crystallising these fears. Contraception, therefore, in part drives the desire for menstrual suppression. Certainly, the issue of reproductive rights is complex, and in some circles taboo,1-6 therefore reversible forms of menstrual suppression address these issues without compromising future fertility. In the study population, sexual abuse was reported in 4 patients, likely an under-estimation, and is an intended component of future research.

Worldwide the most common first line agent for managing menstrual difficulties in adolescents with physical and/or intellectual disabilities is Depo-Provera (DMPA),1,4,6 particularly in those concurrently on anti-epileptic medications where oral contraceptives are less effective. Concerns exist over the (albeit reversible) effects on bone mineral density (BMD) in these patients, where reduced mobility and nutritional compromise are commonplace.5-10 As such,
alternative strategies, like the Mirena IUCD, are becoming more common.6

Long-term Mirena IUCD use has been shown to be safe and highly effective in reducing menstrual bleeding and dysmenorrhea, with minimal impact on BMD and body composition, with a low risk of drug interactions due to its small systemic dose.7-10 Coupled with its long duration of efficacy, it is an attractive alternative to the oral contraceptive pill (OCP) and DMPA.

At CMH, the Mirena IUCD was employed for menstrual suppression in 31 (78%) adolescents, with 50% reporting amenorrhea.

Where DMPA and OCP was used as first-line therapy, we experienced a high rate of failure, with 5 of 8 on DMPA and 3 of 4 on OCP transitioning to the Mirena IUCD as second line. While we cannot comment on patient and carer satisfaction, it is inferred as there were no requests for removal over the 8-year study period.

Previous studies have commented on the need to investigate heavy menstrual bleeding and dysmenorrhea prior to initiating treatment.1-5 We feel this is unnecessary since for many, performing an ultrasound or phlebotomy may require general anaesthesia or sedation and in adolescents the most common cause of menstrual issues are anovulatory cycles, and so investigations are unlikely to change management.

In our experience, the most common menstrual difficulties related to hygiene and behavioural issues (30 patients), while 10 patients reported heavy menstrual bleeding. For those with physical disabilities, improving hygiene is a massive quality-of-life improvement.

Four patients underwent investigations based on history, without positive findings. While 4 Mirena’s were expelled, all uterine cavity lengths were over 6cm, well within the adult range. No other adverse events related to the Mirena or its placement was noted. All insertions were performed under general anaesthetic. While not without risk, insertions are required infrequently and can be combined with other procedures, ie, dental examinations.

Mirena IUCD’s were typically sourced via the DHB rather than on special authority, as the majority of patients do not meet the special authority criteria.

We advocate using the Mirena IUCD for managing menstrual difficulties in this population. While its use is more common at CMH than reported globally,1-6 this variance in practice is supported by its greater efficacy, duration of action and safety profile.

We feel that a proactive approach using the Mirena IUCD forms a safe, effective, long-term solution for what is an important but oft-overlooked problem.

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Nil

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