Menstrual and contraceptive management in women with an intellectual disability

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ABSTRACT

Objective: To review the clinical management of young women with intellectual disabilities with menstrual and contraceptive concerns.

Design: Prospective cohort study of all girls and young women with a significant intellectual disability and moderate to high support needs who presented at my gynaecology clinic for management of menstrual and contraception-related issues in the period 1990–1999.

Setting: Gynaecology clinic at the Centre for Adolescent Health, Royal Children's Hospital, Melbourne, and my private consulting rooms.

Outcome measures: The clinical management options considered most appropriate for these women, including advice, reassurance, medication (oral contraceptive pill, non-steroidal anti-inflammatory drugs, depo-medroxyprogesterone acetate, hormone replacement therapy) and surgical options.

Results: For 2 of 107 young women, surgical approaches were required to manage their menstrual problems or contraception-related issues. For the remainder of the women, information, advice or medical management were sufficient.

Conclusions: Management of the menstrual and contraceptive needs of young women with an intellectual disability is similar in most cases to the management of non-disabled women. Surgical management is required infrequently.

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IN THE PAST, the approach to healthcare in women with intellectual disabilities was primarily determined by the presence of the disability. In the 1970s, the standard management for all institutionalised women with an intellectual disability was to induce amenorrhoea by the almost universal use of continuous progestagens[1,2] or by surgical approaches.

But since 1992 it has been unlawful to conduct a procedure that results in the sterilisation of a person who is unable to give informed consent without the legal authorisation of the Family Court of Australia (if the woman is under 18 years), or the Office of the Public Advocate and the Guardianship and Administration Board (if the woman is 18 years or over). (The appropriate authority varies in different States and Territories in Australia.)

It is essential that the general health needs of women with intellectual disabilities be viewed from the perspective of current standards of care and management,[3,4] while making adjustments to match individuals' needs, abilities and other medical conditions.

The families of these young women are understandably concerned about their daughters' ability to cope with menstruation and the fact that they will be at risk of sexual abuse and possibly become pregnant.[5] Research in Victoria has shown that pregnancy is not a substantial risk, especially for women with high support needs.[6] Contraception can prevent pregnancy, but does not replace the need for a safe environment for these women.[7]

There is little information on the frequency of surgical management of menstrual or contraceptive problems in young women with an intellectual disability. Endometrial ablation has been reported as an option for managing menstrual problems,[8] but with no indication of how often it may be required. My aim was to determine the frequency of requirement for surgical management, compared with other forms of management, among young women with intellectual disabilities who were referred to me for management of menstrual and contraceptive problems.

METHODS

Patient population and setting

All young women with intellectual disabilities who attended my gynaecology clinic and private consulting rooms over a nine-year period (1990–1999) formed the cohort for my prospective study. The gynaecology clinic at the Centre for Adolescent Health of the Royal Children's Hospital (a tertiary paediatric hospital) provides all gynaecology services to the hospital. The hospital has a Child Development and Rehabilitation Service, as well as other specialist services for young people with intellectual disabilities.

My case series includes only those young women with significant intellectual disabilities and moderate to high support needs who have had menstrual or contraceptive problems that could not be managed confidently or satisfactorily by the young woman, her immediate carers or general practitioner and had required referral to a specialist.

Patient data

Information on age, clinical presentation, level of support needs and man-

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agement of each patient was collected for audit purposes.

Choice of management options

Management included the provision of information and discussion about menstrual hygiene training. A variety of approaches to this were taken, including encouragement for instruction at home, written information,[9] further education and supervision at school with the involvement and support of teachers' aides. Family supports were identified, and an effort was made to ensure that adequate resources and the opportunity for respite care were in place for the young woman and her family.

Medical options were initiated as indicated by the clinical problem:

- Dysmenorrhoea or behaviour changes thought to reflect pain, in the absence of a need for contraception, were initially managed with non-steroidal anti-inflammatory drugs (NSAIDs).
- Contraceptive need was identified when the young woman was currently or potentially sexually active or was felt to be at risk due to lack of "stranger awareness" or self-protection skills or due to behaviours that could place her at risk of abuse.
- Hormone replacement therapy for amenorrhoea (associated with delayed puberty or secondary to low weight, when other conditions had been excluded, and when there was no requirement for contraception) was offered to prevent osteoporosis. Other risk factors for osteoporosis were also identified and corrected where possible.
- Menorrhagia was managed with NSAIDs or hormonal treatments (the oral contraceptive pill [OCP] or depomedroxyprogesterone acetate [DMPA]).
- Cyclic exacerbation of epilepsy (ie, increased seizures occurring on a menstrual cyclic pattern) was managed with hormonal treatment (OCP or DMPA).

Surgical management (endometrial ablation or hysterectomy) was undertaken when ongoing problems of heavy irregular bleeding occurred, having a significant impact on the quality of life of the young women. Surgical options were considered only after all other approaches, including education, support and medical treatments, had failed. (The newer levonorgestrel intrauterine systems were not available at the time of this case series). Authority from the Family Court of Australia was obtained before undertaking surgical procedures.

Patients were reviewed only as indicated on clinical grounds. Where clinical follow-up had *not* been indicated, efforts to ensure that surgical management approaches had not been undertaken elsewhere were made by reviewing hospital medical records and by checking patient names with the Office of the Public Advocate and the Guardianship and Administration Board of Victoria. The confidentiality of patient data was strictly maintained.

Clinical problems leading to referral to a gynaecologist, and subsequent management, of 107 young women with intellectual disability

Major presenting symptom(s) or need	Number of patients	Management option chosen (number of patients)
Menorrhagia	18	DMPA (11); OCP (6); NSAIDs (1)
Menorrhagia + irregular menses (cycle length < 24 days to > 35 days)	6	OCP (3); surgery (2); DMPA (1)
Menorrhagia + need for contraception	6	DMPA (3); OCP (3)
Irregular menses	6	Cyclic progestagens (5); OCP (1); information (2); HRT (1)
Irregular menses + need for contraception	4	OCP (3); DMPA (1)
Dysmenorrhoea	9	NSAIDs (4); OCP (4); DMPA (1)
Need for contraception	12	OCP (8); DMPA (4)
Cyclical exacerbation of epilepsy	2	DMPA (2)
Amenorrhoea	10	HRT (8); information (2)
Premenstrual mood or behaviour changes	6	OCP (5); DMPA (1)
Need for advice or information	25	Information / resources (25)

DMPA = Depo medroxyprogesterone acetate. HRT = Hormone replacement therapy. NSAID = Non-steroidal anti-inflammatory drug. OCP = Oral contraceptive pill.

RESULTS

Patient population

A total of 107 young women with intellectual disabilities were seen over the nine-year period (mean age at first consultation, 15.9 years; range, 6–34 years). The young women and girls were a heterogeneous group. The intellectual disabilities and special needs ranged from severe intellectual disability with high support needs ($n = 15$) to moderate intellectual disability with lower support needs ($n = 92$). Some had physical disabilities such as cerebral palsy, and there was a wide range of underlying aetiologies for the disabilities. All required some assistance with self-care, and, as adults, were unlikely to be able to live independently in the community and would require ongoing carer support.

Management

The reasons for referral, and the management options chosen, are shown in the Box.

All patients were assessed with regard to family, community and educational supports, as well as access to respite care. A combination of interventions, including information and referral to resources to assist educators, families and carers, was provided.

Two young women, for whom several different medical approaches had been tried and failed, underwent surgery after authorisation had been obtained from the Family Court of Australia. In one case, the Court's approval for endometrial ablation was sought, with the additional authority to proceed to hysterectomy within a six-month interval if the endometrial ablation failed. For the second young woman, who had a longer life expectancy, an abdominal hysterectomy was performed.

Ongoing review or specialist gynaecological care was not indicated in 68% of the young women. The interval since the last consultation varied from one month to six years. For all those women

whose last consultation with me had been more than one year previously, I instigated a review of the records of the Office of the Public Advocate and the Guardianship and Administration Board to ensure that these women had not transferred their care and had a surgical intervention undertaken by another clinician. The review of files was undertaken by staff of these organisations. The Board confirmed that none of the women in my cohort had contacted the Board via another practitioner for consent or authorisation for a sterilisation procedure.

DISCUSSION

My case series confirms that successful management of the contraceptive and menstrual concerns of young women with significant intellectual disability and high support needs can be readily met by the approaches normally taken with non-disabled women.[10,11]

Awareness that behavioural changes at the time of menses may reflect pain needs to be considered. Recognising that the intellectually disabled woman is continuing to gain new adaptive living skills is indicative that she will continue to improve in personal care skills, including menstrual care skills. The ability of women with disabilities, even those with high support needs, to gain additional skills in their personal menstrual management has been demonstrated.[12]

As no applications were made to the Family Court or the Guardianship Board, I assume that none of the women in my study underwent a sterilisation procedure through another practitioner. If unlawful sterilisations had occurred, I considered it unlikely that they would have been revealed by contacting the families directly.

Giving disabled women, their families and carers adequate information enables the least restrictive and least invasive approach to health matters. A positive attitude on behalf of the carers, health professionals and educators assists in achieving this. As surgical interventions are infrequently required, GPs with appropriate resources and support should be able to confidently care for young women with significant intellectual disabilities. Appropriate allowance for the longer consultation time involved in the care of these young women, and access and referral by doctors to appropriate education and resources, are additional requirements.

COMPETING INTERESTS

None declared.

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