A patient with autism and severe depression: medical and ethical challenges for an adolescent medicine unit

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ABSTRACT

- An adolescent with autism and intellectual disability presented with severe depression related to menstruation.
- Because of the complex medical, psychiatric and ethical issues involved, her care was coordinated by a hospital-based adolescent medicine unit.
- After trials of other therapies over an extended period and interdisciplinary and intersectoral case conferencing, it was decided that hysterectomy was the most appropriate management.
- This case highlights the complexity of adolescent health care in a tertiary hospital, the importance of intersectoral cooperation between hospital and community, and the integral role of interdisciplinary care of adolescent patients with chronic conditions.

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An 18-year-old woman with autism and mild to moderate intellectual disability presented in 2004 to a tertiary paediatric hospital with a history of refusing all oral intake over the previous 24 hours. She had stated to her mother on several occasions during this time that she would not eat or drink because she wished to die. She had prior ongoing involvement with the paediatric hospital as an outpatient, but no previous admissions. Transition to adult services had not yet occurred.

The patient lived with her parents. She was able to verbally express basic needs, wants and emotions but was not capable of independent living. She was under the care of a private child and adolescent psychiatrist. Her medications at presentation were a high-dose selective serotonin reuptake inhibitor (paroxetine, 50 mg) for management of obsessive–compulsive behaviour, and a benzodiazepine (temazepam, 20 mg) for night-time agitation.

History: Over several months before presentation, the patient's mother had noted that menstruation triggered severe distress in her daughter, with sadness and a desire to die. This decreased when menses ceased, but, with increasing frequency of menses (now every 2 weeks), her mood had become more persistently depressed. Her menses-related distress also exacerbated her chronic obsessive–compulsive behaviour related to menstrual hygiene. This included repeated menstrual pad and underwear changes, frequent visits to the toilet during the day and night, and use of up to 10 rolls of toilet paper and 50 hand towels every day.

Menarche had occurred when the patient was aged 9 years, and she had been under the care of the hospital child and adolescent gynaecologist for several years for management of menses, which were irregular and heavy and had always caused her great distress. Various options for control of menses had been tried with limited success. The continuous combined oral contraceptive pill (30 μg and 50 μg ethinyloestradiol doses) and then oral progestogen (medroxyprogesterone acetate, 10 mg twice daily) provided only temporary cessation of menses, with subsequent frequent and heavy breakthrough bleeding. The higher oestrogen dose caused heavy vaginal mucus discharge which she tolerated poorly, while the oral progestogen appeared to be associated with greater oppositional behaviour.

In mid-2002, a subdermal implant of etonogestrel was inserted under general anaesthaesia, in the hope of reducing the frequency and amount of bleeding. Menses were suppressed for several months, but gradually resumed with increasing frequency and flow. In late 2003, the gynaecologist considered a levonorgestrel intrauterine device as it was likely to reduce menstrual flow,[1] while recognising that insertion would be technically difficult because of the patient's small stature. The device was refused by the patient and subsequently by the mother because of concern that its insertion, even under general anaesthesia, would cause severe distress and greater behavioural disturbance. The mother was also concerned about the possibility of expulsion of the device,[2] and continuous bleeding, which she herself had experienced.

In addition to compulsive behaviours related to menstruation, the patient had episodes of agitation during the day and night, aggressive outbursts, head-banging and self-mutilation, which worsened during menstrual bleeding and when routine was disrupted. Her behaviour had resulted in damage to the family's property and possessions, and necessitated near 24-hour supervision. Over the 5 years before presentation, many psychotropic medications (antidepressants and atypical antipsychotics) had been trialled in an effort to contain her difficult behaviour, but failed due to the development of intolerable side effects. Her family consistently expended much time, effort and money in the care of their daughter, to the limit of their resources. The Western Australian Government Disability Services Commission could provide only minimal respite support, due to the lack of availability of very experienced carers.

Management: The patient was admitted to the medical ward under the admitting general paediatrician, but was referred to the adolescent medicine unit after initial fluid replacement, as it became clear that the inter-related medical, psychological, social, behavioural, ethical and transition issues required coordination.

Examination revealed a withdrawn adolescent with severe psychomotor retardation and evidence of mild dehydration. She refused to interact verbally with general medical staff, but repeatedly expressed suicidal ideation to her mother. She had evidence of recent weight loss and poor nutritional status (weight, 45.8 kg;

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body mass index, 19.5 kg/m^2). Her whole-body bone mineral density was in the osteopenic range (z score, –2.08; reference range [RR], –2.0 to 2.0), and she had vitamin D deficiency (serum vitamin D level, 24 nmol/L; RR, 40–169 nmol/L).

As the patient refused any oral intake, she was treated with intravenous rehydration followed by nasogastric feeding. Treatment with calcium carbonate and vitamin D was subsequently started, in consultation with the endocrinology unit.

The hospital consultation–liaison psychiatrist was consulted and diagnosed a severe depressive disorder with active suicidal intent. The patient was able to communicate adequately to indicate that she no longer wished to live, attributing the reasons directly to menstruation. Despite these statements, she was considered safe in an open adolescent medical ward, because of her limited ability to enact her suicidality beyond her current actions. She was treated with occasional low-dose benzodiazepine to contain episodic agitation and a second antidepressant (mirtazapine) to augment continuing paroxetine treatment.

Case conferencing: The adolescent physician led a case conference at which the hospital gynaecologist reviewed the options for management of menses, along with the hospital psychiatrist, hospital general paediatrician, private psychiatrist, general practitioner, and the patient's case coordinator from the Disability Services Commission. Decisions about management were made in consultation with the family immediately after this meeting.

Injectable medroxyprogesterone acetate was considered unsuitable because of the likelihood of irregular bleeding, at least in the short to medium term; the previous behaviour problems with oral progestins; and the adverse effects on bone mineral density.[3-5]

A levonorgestrel intrauterine device was again strongly opposed by the family. They asserted that any genital intervention would cause their daughter further distress, and that, within the limits of her decision-making capabilities, she would not accept an intervention that did not guarantee cessation of menses.[6] The family could not tolerate any worsening of their daughter's disturbed behaviour; the emotional and physical resources they expended in managing her behaviour meant they were at breaking point. Without guardian consent, insertion of an intrauterine device would have required an application to the State Administrative Tribunal by the treating medical team. The resulting implication that the parents were not acting in their daughter's interests, their disempowerment, and the likely breakdown of the doctor–family relationship were viewed as a very negative outcome for the patient.

Hysterectomy was considered as a last option, but the only certain way to ensure that menstrual bleeding would cease.[7] Endometrial ablation was considered an inferior option, as it would also affect fertility but would not guarantee amenorrhoea.[8] The family agreed that hysterectomy was an intervention they were prepared to accept, if necessary.

As an interim measure, a new subdermal etonogestrel implant was inserted, in the hope of achieving a reduction in menstrual bleeding similar to the initial reduction achieved after insertion of a previous implant.

Clinical course: After 2 weeks of hospitalisation, the patient's nutritional status and mood had improved, and suicidal ideation had lessened, possibly related to improved nutrition and the addition of mirtazapine treatment. She was eating and drinking voluntarily. She was discharged home, and a definitive procedure to prevent menses was deferred.

A month after discharge, mirtazapine therapy was stopped because of the side effect of severe hyperphagia, resulting in distressing choking.[9] A trial of reboxetine (a selective noradrenaline reuptake inhibitor antidepressant) was also unsuccessful, because of excessive agitation. Review of the patient's history of sensitivity to side effects precluded the use of other psychotropic treatments.

At 6 months after discharge, the patient was experiencing continuous light menstrual bleeding. She continued to be depressed with intermittent suicidal ideation and to have very challenging compulsive behaviour related to menstrual hygiene. Her oral intake was poor, and she had lost a further 10% of her initial body weight. The family continued to demonstrate evidence of chronic exhaustion.

Further management: The adolescent medicine unit coordinated further case conferencing between hospital and community providers to achieve consensus on the need for definitive surgery, and to develop a plan for transition of care from paediatric to adult services. The case was also presented at a hospital meeting, where consensus was achieved between the treating interdisciplinary team and hospital medical staff that hysterectomy was appropriate in this particular case.

Transition to adult care progressed, with the GP taking over the central role, supported by the adolescent medicine unit, and future hospitalisations planned to occur through the adult health care system, as recommended by the GP.

Discussion

This case of severe affective disorder in an adolescent with intellectual disability and autism was clearly related to menstruation. Management involved resolving complex medical, psychiatric and ethical issues, and demonstrates the role of an adolescent medicine unit in coordinating such cases.

Medical and psychiatric issues

There are few reports in the medical literature of menstrual-related mood disorders in individuals with autism. Two cases of premenstrual dysphoric disorder with self-injurious behaviour in adolescents with autism were reported recently.[10] The lack of reports may be due to decreased awareness of depression in individuals with autism, their inability to report symptoms because of cognitive and language delays, and the lack of reliable assessment tools. In addition, any associations between menstruation and affective dysfunction may be overlooked by health care professionals, and viewed as secondary to the primary diagnosis of autism or intellectual disability.[11]

Ethical issues

Although the management of menstrual problems in individuals with intellectual disability rarely requires hysterectomy, in our patient the depression associated with menstruation was so severe that permanent cessation of menses by hysterectomy was considered.[12] This raised important ethical and legal considerations. Concerns were raised about the suitability of performing a definitive procedure such as hysterectomy on a young patient. However, this was discussed in the context of the severity of the patient's depression, the limitations of pharmacological management, the failure of medical management of menstrual bleeding, the impact of her compulsive behaviour on her care givers, and the likelihood

that pregnancy and a family would never be a feasible life course in a patient with established severe autism[13] — a different context from that of intellectual disability without autism.

In Western Australia, when an adult is unable to give consent, it is illegal to conduct a procedure that results in sterilisation without consent from the State Administrative Tribunal under the *Guardianship and Administration Act 1990* (WA), except in unusual circumstances.[14] The Tribunal requires documentation from all parties involved in the person's care to make an informed decision. It may give consent if satisfied that the procedure is in the best interests of the person. Alternatively, the Tribunal may refuse consent or may recommend a less invasive course of action (such as a trial of a levonorgestrel intrauterine device) if that is believed appropriate. All Australian states and territories follow national guidelines[15] and have similar legislation with regard to sterilisation of individuals unable to give their own consent, although specific wording varies.

Adolescent health care in the tertiary hospital

Before this hospitalisation, the patient had been cared for as an outpatient by a GP, a variety of paediatric generalists and specialists, a private child and adolescent psychiatrist, and the WA Government Disabilities Services Commission. Despite the patient's age, her care had not yet been transferred to adult health care services. The process was no doubt hampered by the lack of a defined transition path for adolescents with developmental disability in WA, as well as the fact that no single health professional or organisation had assumed responsibility for coordinating her health and related issues. During this hospitalisation, she was referred to the adolescent medicine unit because of her age, the cross-disciplinary nature of her health care concerns, the need for cross-sectoral coordination between health care providers in the hospital and the community, and also the compelling need for transition to adult services.

Management was decided, and plans for future care formulated, through regular interdisciplinary and intersectoral case-conferencing, both during and after hospital admission. Communication was facilitated by teleconferencing, coordinated by the adolescent medicine unit. Transition of adolescent patients to GPs is recognised as a "primary care" model of transition.[16] However, the complexity of coordinating care of such an adolescent patient presents challenges to the average busy GP and requires a high degree of expertise, which may not be acquired in general practitioner training.[17] In this case, the hospital-based adolescent medicine unit is providing ongoing support to the transition process.

While the specific health issues presented here are familiar to GPs, it is the combination of issues, and their complexity, in a patient of this age that presents the particular challenge. Given the growing number of patients surviving and living in the community with developmental, neurological and chronic physical illnesses, cases of similar complexity are becoming commonplace. Adolescent medicine services in Australian tertiary hospitals usually comprise a range of professionals with expertise in adolescent health and welfare who support and coordinate the care of adolescent patients with complex medical, psychosocial and developmental needs, facilitating interaction between specialist medical care providers and the private and community sectors. Adolescent medicine services also provide training opportunities for health professionals from all disciplines involved in the care of adolescents with chronic illness and complex disorders. This case is an excellent example of one role of a specialist adolescent medicine service.

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Competing interests

None identified.

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