Med & Health Jun 2019; 14(1): 209-214 https://doi.org/10.17576/MH.2019.1401.19

CASE REPORT

Menstrual Care For Individuals With Disability: A Case Report

NADIA AB[1], LEELAVATHI M[2], NOOR AZIMAH M[2]

[1]Klinik Kesihatan Sibu Jaya, Lorong Sibu Jaya 12D, 96000 Sibu, Sarawak, Malaysia.
[2]Department of Family Medicine, Faculty of Medicine, Universiti Kebangsaan Malaysia Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Cheras, Kuala Lumpur, Malaysia.

ABSTRAK

Orang kelainan upaya mempunyai keperluan yang berbeza pada setiap peringkat kehidupan. Akil baligh merupakan cabaran baru terutama bagi wanita kerana ia memerlukan penjagaan kebersihan diri semasa haid yang melibatkan pesakit dan juga penjaga. Laporan kes ini adalah mengenai seorang gadis berumur 13 tahun dengan sindrom Down yang dijaga oleh ayahnya sejak daripada usia enam tahun. Beliau mengalami kecacatan mental dan mengalami kesukaran dalam pengurusan diri sewaktu haid. Ini menyebabkan bapanya meminta untuk rawatan manipulasi kitaran haid untuknya. Pilihan cara rawatan untuk manipulasi kitaran haid meliputi rawatan secara perubatan dan pembedahan. Rawatan perubatan merangkumi terapi hormonal yang terdiri daripada pil perancang keluarga, depo-provera, implan progestin dan alat IUD. Rawatan secara pembedahan seperti histerektomi atau ablasi endometrium boleh dipertimbangkan sebagai langkah terakhir kerana ia mempunyai risiko pembedahan, kehilangan kesuburan dan melibatkan soal etika dan undang-undang. Pemilihan cara rawatan yang sesuai seharusnya melibatkan perbincangan dua hala di antara penjaga, pesakit dan pengamal perubatan untuk mendapatkan cara rawatan yang optimum dengan mengambil kira kepentingan pesakit. Laporan kes ini juga memaparkan peranan pakar perubatan keluarga dalam menguruskan dan menyelaras penjagaan terhadap isu-isu berkaitan dengan penjagaan haid untuk orang kurang upaya. Diharapkan kajian kes ini dapat dijadikan panduan kepada pengamal perubatan dan keluarga yang mempunyai kanak-kanak berkeperluan istimewa dalam mendalami masalah penjagaan haid.

Kata kunci: haid, intelektual, orang kurang upaya

Address for correspondence and reprint requests: Dr. Nadia Abdul Bari. Klinik Kesihatan Sibu Jaya, Lorong Sibu Jaya 12D, 96000 Sibu, Sarawak, Malaysia. Tel: +6012-2385391 Email: nadia_nini6@hotmail.com

ABSTRACT

Individuals with disabilities have different needs and concerns at different stages of life. The arrival of puberty brings about new challenges especially for females with issues related to menstrual care involving both the patient and their caregivers. This case report is about a 13-year-old girl with Down syndrome who was cared for by her widowed father since the age of six. She was suffering from severe mental disability. Her father was concerned, because she was unable to maintain personal hygiene during menses such as changing sanitary napkins and managing stains, hence requested for menstrual manipulation. Options for menstrual manipulation for individuals with disabilities include both medical and surgical interventions. Hormonal therapy options include oral contraceptive pills, depo-provera, progestin implants and progesterone release intra-uterine contraceptive devices. Surgical options such as hysterectomy or endometrial ablation may be considered as a last resort as it is more invasive and irreversible, involving ethical and legal implications. Selection of the suitable therapy involves shared decision making between health care provider and caregiver taking into consideration the patient's best interest. This case report also highlights the role of family physicians in managing and coordinating care on delicate issues related to menstrual care for people with disabilities. This case report may serve as a guide to physicians and families with special needs children, while approaching issues on menstrual care.

Keywords: disability, intellectual, menstruation

INTRODUCTION

Caregivers of People With Disabilities (PWD) face different care related issues at different stages of life. One of the most challenging issues is regarding the menstrual care for people with disabilities. The onset of menarche, cycle length and duration of bleeding among adolescents with Down syndrome are similar to other young women (Paransky & Zurawin 2003). Caregivers of PWD are usually concerned regarding menstrual hygiene, pre-menstrual syndrome, contraception and risk of sexual abuse (Albanese & Hopper 2007). Common requests encountered during consultation include assistance for bleeding control, timing of menstrual cycles or induction of amenorrhea. The request for menstrual suppression requires a detailed assessment for caregiver burden, patient suitability and implication of the request. The PWD should also be assessed for risk of possible sexual abuse or undiagnosed sexually transmitted infections as they may not be able to express this concern (Stacey 2016).

Menstrual manipulation options include medical or surgical intervention to either decrease the flow, regulate cycles or complete suppression.

However, suppression of puberty itself, before the onset of menarche should be discouraged as it impairs the full growth potential due to premature closure of the long bones epiphysis (Albanese & Hopper 2007).

CASE REPORT

A 13-year-old girl with Down syndrome was under the care of her 63-year-old father since the age of six after the death of her mother due to breast cancer. She had no other immediate or extended family support and attended school for children with special needs. She was suffering from severe mental disability with inconsistent bowel and bladder management issues. She did not have any other medical problems and was not on any medication. She attained menarche one year ago and had regular cycles. Menses related behaviour or mood changes were absent. Her father's main concern was regarding her inability to maintain hygiene care during menstrual cycles such as changing sanitary napkins and managing stains. His request for a hysterectomy as a measure of menstrual care was the starting point of this case report.

The patient and her father were assessed and given explanation on the available options for menstrual manipulation. Risks and benefits of each option were discussed. However, the patient was unable to understand or provide consent due to her limited cognitive ability. Using a shared care approach between the family physician, gynaecologist and the caregiver, a decision was made for Levonorgestrel intra-uterine contraceptive device (Mirena IUCD) as the suitable method of menstrual suppression for this patient. Following successful insertion of the device, the patient achieved satisfactory menstrual suppression and was followed-up regularly for review and caregiver support.

DISCUSSION

Requests for mentrual care require detailed initial evaluation which includes history of menstrual cycle to rule out any underlying menstrual pathology and the validity of the request in an effort to assess burden of care. Generally, adolescents with disabilities can be trained to use sanitary napkins and maintain personal hygiene during menses (Altundağ & Çalbayram 2016). PWD who are toilet-trained, can achieve independent menstrual care successfully and this can be done using guided educational tools and repetitive exposure involving caregivers and teachers (Tracy et al. 2016). Such living skills training including special care during menses are provided at training centers for women with disabilities. In Malaysia, assistance may be sought from designated centers in the community (Department of Social Welfare Malaysia, Ministry of Women, Family and Community Development 2018). Qualified special needs teachers are trained using structured modules to address problems with reproductive health issues among PWD (Training Module 'Live Life Stay Safe' 2009). In other parts of the world, support and assistance are also widely available

and can be easily accessed. For instance the Centre for Developmental Disability Health (CDDH), provides training to both caregivers and PWD (Centre for Developmental Disability Health 2017).

Menstrual manipulation may be considered for those with severe disability after discussing with the caregiver and the patient, keeping in mind, the possible cognitive limitations of the PWD. Non-medical management and supportive therapy such as counseling, sexual education and sexual abuse avoidance training should also be incorporated.

The decision for treatment requires detailed counseling and weighing of risk and benefit, approached in a shared care manner for the best interest of the patient and their caregiver. Once treatment is initiated, the PWD must be regularly reviewed for any side effects of medication, whether target outcome is achieved or if treatment revision is necessary. Continuous support for the caregiver and regular review of the patient are essential components of long term care. Any request for suppression of menses before the onset of puberty should not be entertained, as estrogen is an important hormone for growth. Menstrual suppression for PWD can be managed using medical or surgical methods.

Medical options such as hormone-based therapy may be of benefit to eliminate or diminish menstrual flow. These include the oral and the injectable hormonal therapy. Progesterone Only Pill (POP), taken orally three times a day in a continuous manner, may inhibit menstruation. However, there are high chances of irregular and breakthrough bleeding. The use of Combined Oral Contraceptive pills (COC) may be considered on a monthly basis for a more predictable bleed or used in an extended manner for up to 9 weeks followed by a 1 week break for a planned withdrawal bleed (Albanese & Hopper 2007). This controls the bleeding time resuting in fewer cycles of every 3 to 4 months and may reduce menstrual symptoms. However, breakthrough bleeding may occur and it is associated with a risk of breast and cervical cancer. Hence, it may not be suitable for patients at risk (Albanese & Hopper 2007; Quint et al. 2016). PWD who are on medication for seizure require special precautions when considering hormonal treatment as it may render antiepileptic medications less effective. Another medical option is anti-prostaglandins such as NSAIDs. It is a suitable option to reduce bleeding especially when associated with dysmenorrhea (Stacey 2016; Klein et al. 2015).

Intramuscular injection of Depo-Provera every 12 weeks is an effective treatment for menstrual suppression although it is associated with breakthrough bleeding or spotting in about 50% of cases (Albanese & Hopper 2007). Complete amenorrhea may be achieved by the fourth dose (Stacey 2016). However, Depo-Provera may decrease bone mineral density (BMD) leading to osteoporosis hence limiting its use to about 2 years. Another injectable option is GnRH analog, which can be given every 4 weeks. Long acting preparations may be given up to 12 weekly intervals although

the cost is higher. Concomitant use of tibolone (synthetic steroid) or an oestrogen-progesterone combined HRT reduces the risk of BMD depletion and breakthrough bleeding in patients using GnRH. Supplements such as calcium and vitamin D are recommended, if the patient is treated with GnRH and DMPA (Albanese & Hopper 2007; Quint et al. 2016). Once treatment is started, regular monitoring is required to assess the success of medical management which may take a few cycles before switching to another treatment modality.

Mirena IUCD and Progestin implants insertion may be considered although these are more invasive options. Mirena IUCD is a slow release progesterone contraceptive device which decreases menstrual flow in about 90% cases and amenorrhea in about 50% cases over 1 year. Complications such as infection, expulsion of device and breakthrough bleeding may be experienced (Albanese & Hopper 2007; Quint et al. 2016). Progestin implant on the other hand may induce amenorrhea up to 13% cases over 1 year, however, about one third users may experience prolonged spotting which may be troublesome (Quint et al. 2016; Tracy et al. 2016). Issues regarding consent for insertion of these devices and the need for patient's cooperation during the procedure must be taken into consideration if this method is selected.

Surgical modality of management should only be considered if all other treatment modalities fail as it causes amenorrhea and irreversible infertility. Procedures such as endometrial ablation or hysterectomy can be used but it is associated with procedure related risks (Stacey 2016). These surgical options are controversial as they have legal and ethical implications based on the fact that reproduction is a basic human right, regardless of the individual's intellectual ability (United Nations Human Rights 2017). Hence surgical options may not be the optimal choice for mentally incompetent patients especially when they are unable to comprehend the risks and consequences of the procedure. If surgical method is chosen, then joint consultation with an experienced gynaecologist and legal advisor may be necessary, especially if the PWD has limited cognitive ability.

CONCLUSION

Family physicians must be proactive to enquire into puberty related issues among caregivers of PWD as a part of long term care. They play an important role to help foster partnership of care between the family and the relevant specialists. Discussion regarding realistic goals of menstrual manipulation must be agreed upon before treatment initiation as complete amenorrhea may not be possible. Treatment needs to be tailored to suit the patient. Extended COC may be considered if fewer cycles are acceptable rather than amenorrhea. If amenorrhea is preferred, then Mirena IUCD may be more suitable. DMPA or oral progesterone can be considered if amenorrhea is desired and the baseline BMD is normal. However, BMD must be monitored and repeated

at 1 to 2 yearly intervals, if this treatment is chosen. If BMD is affected then the need for treatment must be reviewed and allow treatment holiday, if necessary. Concurrent treatment with GnRH agonist or COC along with tibolone may also be considered.

REFERENCES

Albanese, A., Hopper, N.W. 2007. Suppression of menstruation in adolescents with severe learning disabilities. *Arch Dis Child* **92**(7): 629-32.

Altundağ, S., Çalbayram, N.Ç. 2016. Teaching menstrual care skills to intellectually disabled female students. *J Clin Nurs* **25**(13-14): 1962-8.

Centre for Developmental Disability Health (CDDH). 2017. http://cddh.monash.org/assets/supporting-women-carer.pdf [28 August 2018]

Department of Social Welfare Malaysia, Ministry of Women, Family and Community Development https://www.schoolmalaysia.com/resources/govn_social_welfare.php [4 June 2018]

Klein, D.A., Gawrys, B.L., Sylvester, J.E. 2015. Menstrual concerns in an adolescent with disabilities. *Am Fam Physician* **92**(9): 823-31.

Paransky, O.I., Zurawin, R.K. 2003. Management of menstrual problems and contraception in adolescents with mental retardation: A medical, legal and ethical review with new suggested guidelines. *J Pediatr Adolesc Gynecol* **16**(4): 223-35.

Quint, E.H., O'Brien, R.F. 2016. Menstrual management for adolescents with disabilities. *Pediatrics* **138**(1): e1-e9.

Stacey, J.H. 2016. Menstrual manipulation for adolescents with physical and developmental disabilities. *Obstetrics & Gynecology* **128**(2): e20-e25

Tracy, J., Grover, S., Macgibbon, S. 2016. Menstrual issues for women with intellectual disability. *Aust Prescr* **39**(2): 54-7.

Training module 'live life, stay safe'. Reproductive health for children and adolescents with disabilities. 2009. http://fh.moh.gov.my/v3/index.php/component/jdownloads/send/24-sektor-kesihatan-orang-kurang-upaya/360-book-sec-1?option=com_jdownloads [4 June 2018]

United Nations Human Rights Office of the High Commissioner. 2017. Sterilization a form of "systemic violence" against girls with disabilities http://www.ohchr.org/EN/NewsEvents/Pages/SterilizationAgainstGirlsWithDisabilities.aspx [4 June 2018]

Received: 29 June 2018
Accepted: 30 Nov 2018